

**ADDITIONAL  
WRITTEN  
TESTIMONY  
(NOT IN ATTENDANCE)**



# Bonnie Watson

This is Adrienne  picture

Adrienne is 27 yo and has a rare condition called Phelan McDermid syndrome, which essentially is a form of Autism with other complications.

Adrienne has been in a self-directed program for the past 6 years. She has a variety of volunteer jobs to build her job skills and address specific goals toward growth and independence. All the volunteer positions have been organized by her parents! Her goal has always been to work, just like all of us, SHE NEEDS A PURPOSE IN LIFE! She is approved for pre-voc, and we have applied to many Project Search programs run by the ARC of Monroe that would suit her. They have repeatedly denied her, always with reasons that are found AFTER we question the denial. In this case, her application was not even read before denying her!

On March 21, 2021, a very contentious meeting was held with Person Centered Services, The ARC of Monroe, OPWDD and us to discuss this recent application to the ARC's SELF program.

The meeting was attended by 9\*\* people, most of whom did not know Adrienne or us.

What we learned and are quite concerned about is:

1. Adrienne is clearly being discriminated against based on issues that are directly related to her disability! This current application and her ISP were not read, or supplemental information considered i.e., documentation from service providers, video tapes and other evidence of growth. Decision was rendered by an Intake person and supported by ARC Administration. The disdain for us was evident during this meeting, "" etc." and they are clearly "cherry picking for their programs.
2. OPWDD supported the ARC and recommended that we could apply to other pre-Vocational programs that may not be as "sexy" as the ARC's (yes that is what was said!).
3. That despite being approved for Pre-Voc through OPWDD and following previous recommendations from the ARC to prepare Adrienne for a successful Pre-voc experience, she was systematically denied.

The ARC of Monroe receives a great deal of money to develop progressive pre-employment day programs. They selectively choose individuals that are fiscally and politically advantages to them. The criterion established for these programs are purposely vague and allow an agency to reject individuals at will. We have been told this is their right! We object to State and Federal money being used to fund OPWDD and ARC programs that our daughter, and probably many others, do not have access to. We object to these discriminatory practices as acceptable in the world of Developmental Disabilities where "behavior" is commonplace and the inability to fully communicate is impaired or there are other neurologic impairments or mental health issues at play. The world of Developmental Disabilities is complicated and complex. Services that taxpayers pay high taxes for should not be predicated on a forced choice instrument like the DDP2, the color of ones' skin, politics, or religion. Current practices allow this to happen.

Quandary #2: A self-directed budget is very misleading i.e., the money is there but the limitations on how it can be spent is determined by so many regulations that it is really NOT self-directed at all!8

It also requires care givers to find Direct Service Personal for very little money and to try to maintain them when they could work in a fast-food restaurant for more. Please support Bill A6329 and A8229 to keep and attract these very valuable people!

In addition, when an instrument like the DDP2 is used to determine budget, and the individual is showing growth toward independence to qualify for said ARC programs, the budget gets reduced, and then the individual is still denied access to the program! It is a Catch 22.

In the next 5-year plan, please review these practices and make appropriate changes.

Thank you



**To: Senator Mannion**

**Date: 09/10/2021**

**The Partnership Coalition Mission:**

***We are a coalition of diverse voices advocating for collaboration that promotes best practices and true inclusion of people with disabilities in all aspects of life.***

The Partnership Coalition is comprised of self-advocates, family members, volunteers, and provider agencies. We are connected to tens of thousands of New York State residents living with disabilities, their loved ones, concerned community members, and human service professionals who work daily to support the lives and wellbeing of people with disabilities.

The staffing crisis we are experiencing today has dramatically intensified; but it is not new. Experts have been warning us for over two decades to plan for this. Instead, over the past twelve years, New York State has steadily reduced the funding that is so desperately needed to support our workforce while accomplishing little in the way of system transformation to contend with today's realities. These dedicated human services professionals—who once earned more than 30% above the minimum wage—are now paid less than fast food workers. This is a disgrace, and it is costly. We are losing our most skilled, experienced, and dedicated workers. The result is not only a severe staffing shortage, but also, a grossly inadequate workforce; one less equipped to support the health and wellbeing of New Yorkers and provide the quality care that can only come from a healthy and thriving system of support.

Every day, people living with disabilities in New York State who need help to use the bathroom or leave their bed for food or drink are left to their own devices; left to suffer alone in their own waste and wonder when, or if, someone is coming to assist them. Countless others endure depleted staff support that struggles to assure even basic safety because they can no longer provide the assistance that New York State rightly insists they deserve but neglects to deliver. Our service system is supposed to support not only people's basic needs but enable a meaningful and fulfilling life. Not only is this not happening, but the current circumstances are traumatizing individuals, families, and workers and are extinguishing trust in the system and hope for the future. The fact is, there has been an appalling lack of respect and concern for people living with disabilities and the dedicated staff who support them living independently or in the most integrated setting possible. The results of this lack of regard are now upon us.

There must now be dramatic and bold action to effectively address this human crisis. The health, freedom, and lives of New Yorkers are at stake.

Band-Aid solutions are simply not enough. Incremental changes such as minute pay increases are not leading to change. We urge the NYS Senate to recognize the gravity of this situation and to take steps to meaningfully address this crisis now. We need strategic investment in technologies that can supplement and enhance our workforce needs now, and in the future.

There must be a substantial investment in wages that reflect the level of work that DSPs and home health aides are responsible for. We must invest in professionalizing the workforce through credentialing and offer true opportunities for a life-long careers with compensation to match. These workers are far more than caretakers; they are habilitation professionals that specialize in supporting quality of life and dignity, decency, and freedom for people with disabilities. First and foremost, they have a profound impact on thousands and thousands of lives that are transformed and sustained for the better. This is a noble profession, and its practitioners deserve our respect, appreciation, and support. This work promotes self-reliance and lessens dependence on far costlier supports such as nursing homes and hospitals. We are not serving anyone's interests by being short-sighted and reactive. This is a human health and human rights issue. Those who need the most support are at ever-increasing risk for re-institutionalization if this situation continues. We must reconcile this reality with our values. Current policy does not reflect that we are prioritizing our basic humanity.

Our human services workforce is the key. They must be valued for the important work they do, and they must be compensated in a manner that reflects our values and attracts them to stay. Yes, for our workers it is a practical matter of earning enough money to live a decent life without needing to work multiple jobs. Our workforce also needs benefits that enable them to keep themselves and their families healthy. There is no alternative, especially in the short-term.

As the New York State legislature, you have the power and the opportunity to take *profound* steps to address this crisis. Our workforce is wholly dependent upon the funding you recommend and authorize. There is nowhere else to turn. We urge you to recognize these unprecedented circumstances and to act accordingly.

The Partnership Coalition is urging the State Senate to act decisively by finding ways to strengthen our system of care and invest—long-term—in technology, strategies to support people living with disabilities, and a first-rate workforce.

We thank you for the opportunity to submit comments.

Sincerely,

The Partnership Coalition



September 10, 2021

Senate Committee on Disabilities

Re: Written Testimony for a Public Hearing to Evaluate the Current Work Force Challenges of I/DD Delivery

I am a parent of a mentally challenged 50 year old who has lived in a group home in Campbell Hall since 2005. Over the years, it has become more and more difficult to keep staff because of the salary. We were promised COLA by the last administration, but it was never included in the budget.

I am advocating for a living wage for our Direct Support Professionals (DSPs). Many are forced to work two jobs to supplement their income. The fast food and state workers will be receiving \$15 minimum wage, but where does that leave our people?

As a member of GROW and the Arc of Greater Hudson Valley, I have written letters, called Politicians, and lobbied in Albany on their behalf. Our DSP workers at Hampton House are Overworked, understaffed, and stressed out. This is a dire situation that can lead to medical Errors and other mistakes that could be tragic for Christopher and his housemates.

Christopher has had chronic hearing problems from multiple infections, scar tissue, and Cholesteotomas. He now wears a cochlear implant called a BAHA (bone-anchored hearing Aid) that required two surgeries in 2012/2013. My ongoing fear is that an untrained or Stressed-out staff member might unintentionally damage or destroy this expensive aid. And, that would surely destroy Christopher's quality of life.

Thank you, Senate Committee, for your support. It is imperative that this be addressed. The Health, safety, and well being of our most vulnerable citizens depend on it. God bless you!

Sincerely Yours,

Julie Ploski, Parent, Advocate, and Legal Guardian  
Of Christopher Ploski





September 7, 2021

Senator John Mannion  
Chairman of Committee on Disabilities  
188 State Street  
Legislative Office Building, Room 814  
Albany, NY 12247

**RE: Workforce Crisis-Member Testimonials**

Senator Mannion,

We are members of the LIFEPlan Member and Family Advisory Council who serve on an Advocacy Committee. Today we are writing on behalf of all individuals with developmental disabilities who receive Care Management services from the CCO/HH delivery system.

Many of us have already written to OPWDD, testified at their spring hearings and taken action via various state-wide campaigns to advocate for a living wage for direct care professionals. Today, we appeal to the Senate to help our community address this crisis in care.

As we are sure you are aware, the current crisis in the workforce has compromised the health, safety and basic human rights of our most vulnerable citizens to access employment, day habilitation, residential supports and community-based programs. The regression on our family members has been tremendous, the toll on their families significant.

We want you to hear some of their stories.

- **Jackie S:** *Most of my son's programs and services have not been able to start up because the agency that provided them cannot find enough DSPs. He is home almost all the time. His friend who lives in a group home is forced to stay there because the agency cannot find staff to take her into the community. **This is a crisis.** The state needs to act immediately to raise reimbursement rates so that DSPs can be paid a living wage, commensurate with the difficult and essential work they do.*
- **Minh N:** *We are a multi-generational family with an adult male sibling on the spectrum who has become very aggressive due to lack of services, especially day programming. We recently had to call the police and have him hospitalized when he attacked my elderly father and threw things at my young children. **The hospital would not admit him and there were no respite houses available due to staff shortages.** He has never been aggressive, but the lack of structure and routine has dramatically impacted him and our whole family.*
- **Kerry S:** *Our 32 year old daughter with autism and seizures still has some of her staff but without her day staff I have her about 75% of the time. **I was still working but now juggle that with my husband who is a full-time researcher and scientist.** I assume I have to just wait until the extra unemployment payments **stop** to be able to hire a new staff. This administration is in full blown denial of this fact when the signs are all around them.*



- **Mary S:** *We are down to 2 staff and 1 is out on medical leave. We have had 4 in the past. We have trouble hiring since the majority of the time they are alone in the house with my sister. I have some supervision, but I also work full time. Background checks only look at paper. Not character. It's hard to find trustworthy staff and be able to retain them at a decent pay rate.*
- **John W:** *At least 3 of our son's friends are directly impacted by the DSP shortage. One lives with parents whose day hab workers were transferred to residential positions or finding other employment. Another friend lives in an apartment but has lost job time. Another lives in a residential house and spends most of his time there after being employed regularly for years.*

These are just a handful of the stories shared with us about the hardship endured. There are many more. People are suffering.

The workforce shortage either directly or indirectly effects every single individual in the system and must be addressed immediately, not next winter when the budget process begins in NYS.

It is imperative that OPWDD and our new Governor not only allocate a significant portion of FMAP funds to address this crisis, but also reinforce that commitment in the 2022 NYS Budget as well as the 5.07 State Plan. ***We need long term solutions, and we need them NOW!***

We appreciate the time and effort of the Senate Committee on Disabilities and hope the attention you bring to this workforce crisis will result in meaningful, long term and sustainable change. Direct Support Professionals are essential workers and the core of the OPWDD service infrastructure.

Sincerely,

Tara Klein, Member Relations Manager and parent of a LIFEPlan member  
Jackie Sauter, Advocacy Committee Chair and parent of a LIFEPlan member

*LIFEPlan Family and Member Advisory Council, 2021 Advocacy Committee:*

Sandi Rosenbaum, parent of a LIFEPlan member  
Tina Fitzgerald, LIFEPlan member  
Amy Watkins, parent of a LIFEPlan member  
Mary Schwanke, sister of a LIFEPlan member  
JP Wanamaker, parent of a LIFEPlan member  
Lori Lemke, MFA Liaison and parent of a LIFEPlan member

***Sent via email***

CC: Nick Cappoletti, Chief Executive Officer  
LIFEPlan CCO NY



# Local 338

# RWDSU/UFCW

JOHN R. DURSO  
*President*

JOSEPH FONTANO  
*Secretary-Treasurer*

NEIL GONZALVO  
*Executive Vice President*

DEBRA BOLLBACH  
*Recorder*

September 14, 2021

***Local 338 RWDSU/UFCW Testimony to Senate Standing Committee on Disabilities in regard to Evaluating the Current Workforce Challenges of the I/DD Service Delivery System***

Local 338 RWDSU/UFCW represents approximately 13,000 women and men employed in a diverse range of industries across New York State, including non-profit agencies that provide services and care to the developmentally disabled. We proudly represent over 1,100 essential workers who are employed as direct support professionals and in other vital non-managerial roles at the Institute of Applied Human Dynamics (IAHD), Community Resources, and Innovative Resources for Independence (IRI). All three organizations receive almost all of their funding through the Office of People with Developmental Disabilities (OPWDD), including for wage increases for the staff that they employ.

In recent years, the industry-wide turnover rate has been over 20% with a vacancy rate of as high as 14%. Statewide agencies statewide estimate that one in every three direct caregivers leaving their jobs in the industry in less than a year. From our perspective, higher industry wide wages would help non-profit agencies keep the costs associated to training staff low, maintain an experienced workforce, and ensure the stability and quality of care for the organization's individuals. Worker retention is critical not only for agencies and the individuals they serve, but also for the mental and physical health of direct caregivers themselves who due to staffing shortages are subject to extensive mandatory overtime.

IAHD, IRI, and Community Resources provide services and educational programs to women and men with developmental disabilities in New York City, Long Island and Westchester County. The direct caregivers and service staff at these organizations are well versed in how to effectively and safely work with those who are developmentally disabled. They are also incredibly dedicated to their individuals and have developed longstanding relationships with the individuals' families due to their long-term employment with their agency. Despite the level of responsibility and sophistication of care expected for direct caregivers to perform, Local 338 RWDSU/UFCW members at OPWDD facilities make an average of about \$16 an hour and many of the dedicated workers in this industry often struggle to care for their own families. These wages are on par with service and retail sector industry positions that do not require the same degree of knowledge nor state oversight that workers in direct care positions do.

In recent years New York State has allocated funding or wage increases for direct caregivers, as well as a cost-of-living adjustments, the issue of wage compression has not been adequately addressed. Historically, Local 338 members in the direct care positions were paid \$3 above minimum wage but due to wage compression this level of compensation to reward seniority is difficult to negotiate in

## **STRONGER TOGETHER**

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collective bargaining agreements. As a result, direct service professionals with decades of experience at agencies make comparable salaries to those just beginning their careers in the industry.

Recent State Budgets have also included language granting non-profit agencies the “flexibility” in how they allocate the funding they receive for wage increases increase for salaries and salary related fringe benefits to their direct support professionals and clinical staff. As a result, agencies have the ability to offer wage increases at under the full allocated percentage as outlined in that year’s Budget. In implementing that funding there has been no mechanism in place to understand how agencies are using the funding to address agency-specific workforce challenges nor to guarantee that funding is being allocated equitably at the agency level unless there is a collective bargaining agreement in place. However, even with the presence of a collective bargaining agreement, agencies have used their ability to be “flexible” as leverage to issue wage increase at their discretion as they know there is little recourse for labor unions to explore.

We often hear from well-meaning advocates that the key to retention is additional training. As a union, we appreciate and encourage opportunities for workforce development and know the value of expanding the knowledge base of those providing critical services to our State’s most vulnerable population. This does not adequately get to the root of challenges workers, especially those who have developed extensive skillsets due to hands on experience face. Much of the strain on their time, emotional and physical health, is due to staffing shortages and low wages, not lack of education.

New York State’s direct service professionals are essential workers and over the last year and a half have found themselves becoming almost live-in care particularly during the height of the pandemic. Yet, despite the risks and sacrifices they made; many did not receive hazard pay. In our experience representing workers in agencies providing direct care, they are passionate about the individuals they care for and go to great personal lengths to show emotional support to those in their care. They put health and physical safety on the line every day, even prior to a global pandemic. However, the common thread we hear when speaking to direct caregivers is that they don’t feel adequately invested in or supported for all that is expected of them when they clock in for their shift.

We have an incredible opportunity to show that as a State we value the workers who provide direct care and serve as stop gaps in the face of a long-term pattern of staffing shortages within the industry. Local 338 RWDSU/ UFCW appreciates the opportunity to provide insight into the challenges workers employed in the I/DD Service Delivery System.

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Senator John Mannion, Chair  
NYS Senate Standing Committee on Disabilities

Dear Members,

Now is the time for the NYS Office for People with Developmental Disabilities to finally recognize that the workforce crisis is now a real emergency. The staff that provide services and supports to the over 130,000 people with intellectual and developmental disabilities are underpaid and undervalued. Called Direct Support Professionals, they are necessary supports to do everything from taking individuals shopping, providing help with everyday living skills, to getting people to the bathroom, and lots more; and done in compassionate and friendly ways.

About 10 years ago these staff members made about 33% above the minimum wage. As NYS moved to increase the minimum wage, OPWDD has not provided the funding necessary for not for profit agencies to keep pace with this increase to keep these positions competitive and commensurate with the human value they contribute. As parents we know just how valuable they are to our son Craig's life. He lives in a semi-independent living situation. What they provide includes supervision and support for everyday living skills for him and his housemates, take them shopping, out for recreation, and so much more. Largely due to the pandemic we lost staff in his house and are having difficulties attracting new ones in part because of the salaries. Certified group homes are experiencing an emergency where there are reportedly more than 3,200 openings in WNY alone. As the remaining staff have to do the overtime to cover these critical openings more stress is on them and their own families.

As the minimum wage goes from the now \$12.50 per hour to \$15, we believe these staff need to be making \$18 or more per hour now, just to be keeping pace as this work is so necessary to the safety, welfare, and quality of life for these citizens. They deserve nothing less. As parents we have been calling attention to our government officials for years and little has been done to stop this emergency from occurring. There needs to be immediate and aggressive action to be taken now so this dangerous situation doesn't get any worse. We ask that NYS OPWDD address this issue now and come up with a solution to deal with this unacceptable situation with a sustainable plan that will protect these deserving citizens and insure their well-being now and in the future.

Max and Joyce Donatelli  
Family Advocates

[REDACTED]  
[REDACTED]  
[REDACTED]



# Sophia Roberts

I have many friends with disabilities. They call on me when they don't have someone to get them out of (or into) bed, or go to the bathroom, or take them somewhere for work or life.

For the past 10 years or so, it's been hard finding staff at times, and I'd fill in every once in a while during transitions between a staff person leaving and a new one coming on. I knew it was helping them to live on their own, have some say in their everyday lives, and to stay out of a group home or nursing home; institutional settings. Moreover, I did it so they could have peace, choice, freedom, work and life in the world. A very worthwhile cause, in my mind.

Since the pandemic, finding staff is impossible. I cannot fill the needs of all of the people I know. Yesterday, two people called- they had no one to help them go to the bathroom. They had called everyone they knew. I was already helping someone and then I had my full time job to go to. I couldn't help. They spent the majority of the day not being able to pee or poop. Or they sat soiled. It's unconscionable.

For me, this is not just a workforce crisis- it is a moral crisis: Will we let our brothers and sisters, our neighbors, suffer in this way? Will we deny them the basic rights that many take for granted: to go to the bathroom, to work, to choose who you live with? Will we continue to disrespect workers expecting them to do physical, intellectual and emotional work for little pay?

These are only the few people I know. They have a say over their lives, and they will have to decide when they can't take it anymore, when they are done putting up with staff who are abusive or disrespectful because they can't afford to tell them to go home, or when their health is at risk enough to give up their freedom, their home, and living with their spouse or their young children. There are others, many others, who similarly affected.

"What am I supposed to do?" strong, able self-advocates have told me. Will they have to go back after over a decade of living on their own, or for the first time in their whole life, to a group home? Will a group home even be available for them? They too are shutting down because of a lack of staff.

These same advocates, along with all of us in the disability community, which includes people like me, neighbors, friends, families, and self-advocates, have been sounding the alarm to the Governor for over 8 years. It has gone unaddressed in any serious way in all that time, and only recently has there been anything done. We are truly at a crisis point like I have not yet seen, and New York State can no longer afford to keep turning its back on people with disabilities who get both Direct Support services and home health aides. This is no longer a problem that can be solved with only looking at future solutions. An influx of resources is needed now. Yesterday, in fact.





My name is Renee Christian. I am a person with developmental disabilities from Buffalo, NY.

The biggest thing that needs to be addressed is the wage for Personal Care Attendants. I cannot get people to come into the door. They are going for other jobs more than home health care jobs. They look at agencies that pay \$13-15, and with home health aides only making \$12.50, as soon as they can get those higher paying jobs, they are out the door. It leaves people like me in very vulnerable situations.

I think another misunderstanding of our industry is that people like myself should have a lot of natural supports or family to step in to provide the care that is lacking, but when you come from family with drug addiction or abuse issues and trauma, that is not always available. Also, using those supports puts me at risk of being taken advantage of financially and emotionally. I have had to learn to limit my interaction with family for those reasons, but it leaves me in a state of constant insecurity, wondering when is the next time I'm going to be able to pee or eat?

This situation also leaves me in a state of constant limbo and makes me question my value. It makes me feel like I am disposable, that I am not valued by my society. I am proud of being independent- it gives me a sense of having

control over myself. I am very good at being independent and advocating for myself, but at the same time, I need physical supports that are out of my control. To me the solution is to empower that sense of independence, not take it away.

The situation as a whole has people thinking about doing things they normally wouldn't do, because of the severity of the situation and the fear of losing independence. For example, my abusive ex-husband, seeing my struggle with support staff, asked me if I wanted to move in with him and our child. Physically, it would be easier, and I would be assured of living with my daughter, but emotionally, it is not a choice that is safe to make.

I think about it every day- what if they come in here and say "you can't live on your own anymore" or if I get an infection and end up in the hospital? What if they try to take my daughter away? Stress, and continuously high levels of cortisol causes illness. You need to look not only at the physical care that we don't have, but the mental and emotional effects of not having that care.

I have 5 ads out everywhere I can now and no one wants the job. They can work at Tim Horton's for more pay and less responsibility. In the past 3 months, I have had 8 people start the hiring process with my fiscal agency and not finish the process because they found a better paying job. I've had more staff quit in the last year than I have

ever had in 14 years of self-direction. I am not one to have a revolving door. Most of my staff who have worked for me, worked for a minimum of 5 years, and my longest has worked for me for 10 years.

So the way I see it is you have two choices: you can continue to choose to not increase the wage for home health care aids and know that you are causing mental and emotional harm to people like me that get these services, as well as physical neglect when we are unable to find the staffing we need, or you can choose to empower my life and empower my choice for independence by raising the wage and supporting us in getting better support staff in our homes. I didn't get to choose this disability. I didn't get to choose my family. Don't take away my choice of how I want to live my life independently and in my own home. You get to decide: the future of my life is in your hands.





State Sen. John Mannion  
Committee on Disabilities  
188 State Street  
Legislative Office Building, Room 814  
Albany, NY 12247

Dear Senator John Mannion, Chair, and Committee Members:

Please accept this as testimony from Person Centered Services Care Coordination Organization's **Family, Individual, and Caregiver Advisory Board** for this most urgent concern. This Advisory Board represents individuals with intellectual and developmental disabilities, families, and caregivers in the western part of New York State.

Person Centered Services provides care coordination for over 17,000 individuals and their families. We thank you for holding hearings on this workforce crisis, which impacts those we represent. Unfortunately, many of us have been calling attention to the lack of attention to this issue for the past 10 years without necessary results. The Covid pandemic has only made it worse.

Direct Support Professionals provide essential services and supports to individuals in certified group homes, in self-directed environments, and in the community. DSPs provide a variety of support based on person centered needs that can include helping a person living in the community with their budgeting and shopping, et al, to providing people in group homes more intensive help with feeding, going to the bathroom, making dinner and more. These frontline workers are the backbone of the I/DD system and prior to the past 10 years were paid a fair wage, about 35-40 above the minimum wage.

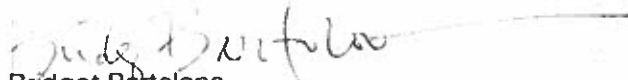
With years of no cost of living increases and budget neutrality, the DSP position has suffered financially despite the growing need for their services. With the increase of the minimum wage going toward \$15 per hour, the DSP wages have not increased proportionately, therefore the voluntary agencies that provide 80% of these services are competing with Burger King, Delta Sonic, and retail for workers. With the general workforce shortage these businesses are increasing their wages and/or cutting hours. This has caused voluntary agencies in Western and Finger Lakes to have an astounding 3200+ openings for DSPs. The system is bordering on collapse, and this is unacceptable.

We recommend that federal Medicaid money be directed to put a down payment to help to end this crisis and OPWDD come up with a plan how to sustain fair and equitable wages for DSPs. DSPs need to be starting out at least \$20 per hour or more because of the value they provide.

The recruitment and retention of DSPs and their managers need to be the top priorities of OPWDD. They need to partner with the voluntary agencies, individuals, and families to come up with a short and long range plan to stop the bleeding of these critical staff members.

Finally, time is of the essence and action needs to be taken now. We appreciate the opportunity to offer our input at this critical juncture. Please consider us a resource as we are willing to offer stories and examples of the desperation that has resulted. We look to you as our representatives to help find lasting solutions to this urgent situation.

Sincerely,

  
Bridget Bartolone  
CEO

To: Senate Standing Committee on Disabilities

Regarding: Written Testimony for Public Hearing to evaluate the current workforce challenges of the I/DD service delivery system

Thank you for taking the opportunity to listen to what people who are severely disabled are presently going through in receiving necessary services through the OPWDD's waiver services.

We are a couple that has been married for over 32 years, living in our own home in Colonie, New York. Mike works at the OPWDD Central Office and Wendy was employed at O. D. Heck until she left because of medical reasons.

Every day of our lives, multiple times a day we should be getting at least 18 hours a day on the weekdays, and at least 12 hours a day on the weekends. We can work with flexibility. But lately our services have substantially diminished. Our manager of our services who worked for a majority of the week recently quit. The director was told by his supervisor (and I have the letter to prove it), that he was not supposed to come and help us in lieu of our absent manager, when he said he would help out. This to us is unbelievable because we have such a disability that we need services on the daily basis. When we used to have services, we were designated as a "must cover". As of 2018 we were notified that our waiver agency no longer considers us a "must cover". How could we no longer be a must cover, because we are supposed to get approximately 114 hours a week? It does not make sense. We also had a system that if we needed assistance in the middle of the night we could call a number. We have been told now that we could only do it in a 911 situation.

A must cover is a designation that says a person (or a couple) must have services in order to survive. This does not mean that services that are provided must be on an equal basis (for when the agency is short of staff) but complete the necessary parts of a person's life multiple times a day. This was a security blanket. Since this security blanket was stripped from us, how can we continue to live the life that we once had? It is not because of our age that we are becoming more disabled, but it is because of ineptness of Medicaid funds to pay for a living wage for people to give essential services. This also includes time deferential pay.

Who decided that individuals with severe disabilities that live in the community (which is the right of everyone) are not a "must cover" case?

We as disabled people are as important as the nondisabled individuals. And we have every right to lives as everyone else with the proper support. But we are finding out that this is not the case in New York. Remember, anybody can become a member of our class at any time. If you are going to rewrite the policies for Direct Support Professionals (DSP), may we ask you to have a group of people that are severely disabled and that use these services on a daily basis to work with the committee to come up with a solution. If you would write new policies without the severe disabled working side by side with you, then it would be another act of useless legislative writing.

Our question is, if this happened to you or a loved one, would they be able to survive and thrive in the conditions that you are putting the severely disabled that live in the community through? We almost guarantee that you would do anything for that person or yourself to live a productive life. We are only asking the same thing.

Thank you. We are looking forward to seeing that you write this wrong and increase the payment for the DSP.

Mr. and Mrs. Orzel

[REDACTED] Albany, NY [REDACTED]

[REDACTED]

[REDACTED]

Page 2 of 2



To: The Senate Standing Committee on Disabilities

Written Testimony for Public Hearing to evaluate the current workforce challenges of the I/DD service delivery system

As a parent of a woman with Down syndrome I am deeply concerned about the staffing crisis. We have been without staff for a year and a half and cannot secure respite staff at this time. We are working to bring a L'Arche (please see L'Archeusa.org) to Buffalo and Western NY and wonder how we will find staff to support the community we hope to establish. What I hear most often from families caring without adequate support is, "We are exhausted". Our circles of care are collapsing. I believe that the devaluation of care work over several years has been so damaging that it has resulted in abandonment of our most vulnerable people.

I support raising the salaries of direct care staff to the level recommended by the Caring Majority-150% of the current minimum wage. In addition to increasing wages, we need to incentivize the critical work of care giving and take steps to professionalize the work force. Student loan forgiveness and tuition assistance attached to taking a job in this field may encourage staff to apply. Care to Own, a housing model suggested by Al-Jen Poo of Caring Across the Generations is an outstanding example of an approach designed to benefit care givers and care receivers. PHI, an agency that works to transform eldercare and disability services is promoting the creation of a Home Care Jobs Innovation Fund that would identify promising practices to address the work force shortages.

Government needs to establish an Ethic of Care more actively by establishing policies that promote equitable care giving practices for both care givers and care receivers. Covid 19 has laid bare the inequities in our system, particularly for the vulnerable that includes an ever-expanding swath of people in America. In fact, Covid 19 has made us all vulnerable, however some of us have the protective resources to minimize vulnerability, while others such as people with disabilities and their families endure fear, isolation and need. We cannot have a true democracy without an Ethic of Care that supports all our citizens.

Thank you for your attention to this truly critical problem.

Maggie Buckley, PhD  
Friends of L'Arche Buffalo and Western NY  




Written testimony to the Senate Standing Committee on Disabilities Re:  
The Evaluation of the Current Workforce Challenges of the I/DD Service Delivery System

September 10, 2021

Dear Senators:

We are writing today to seek your assistance with raising the wages of the Direct Support Professionals (DSPs) who support those people living with intellectual and developmental disabilities. Without such assistance we fear that the people served by DSPs will see a continued decline in their quality of life. That is an outcome we cannot stand by to watch happen.

As you know, the Medicaid program provides the funding for the programs and services provided by the Arc Chapters across New York State as well as other voluntary providers. Unfortunately the Medicaid program has not provided for an increase in the pay for DSPs for ten years, until this year when salaries will increase by one percent. While we deeply appreciated your efforts to fight the Governor's proposal to cut that one percent out of the budget, we think it's fair to say, one percent is not enough.

A DSP's salary amounts to approximately \$29,000 per year. Even in upstate New York where the cost of living is lower than downstate, New York City and Long Island, \$29,000 does not constitute a sufficient salary on which to live. Nor does that salary adequately compensate our staff for the work that they do to help those we serve with the tasks of everyday life not to mention helping them pursue their interests and engagement in their community.

Time and again we see our DSPs having to leave the people and career they love to take a job that will pay the bills for them and their families. And time and again, those we serve, who are feeling the loss of the person who worked with them, are having to establish a relationship with someone new. It's important to note that the DSPs are not just babysitters or cooks or cleaners. They are the helping those people with special needs live their lives to the fullest in every aspect of their lives.

We are sure you would agree that if you had similar needs, you would not want a different person coming into your home everyday to help you bath, dress, engage in interests, etc. We would all want some consistency so that we could establish a working relationship that valued our humanity.

Because of the high turnover in the field of Direct Support Professionals, we as an agency are not able to provide all the services we should to the people we serve and to the people who are waiting to enter our programs. Consequently we fear without intervention, those with intellectual and developmental disabilities will be left behind by society as they were decades ago in places like Willowbrook.

As we hear of proposals to increase pay to home care workers and increase the number of nurses and aides required in nursing homes and hospitals, we see even more competition for the human services workforce we depend upon. But we cannot attract and retain these workers without being able to offer a competitive, living wage. We desperately need your help to do that!

We sincerely thank you for your interest in this matter and the opportunity to share out thoughts with you. And we stand ready to help you in addressing this dire problem!

Sincerely,

Edward Spain, Chair and Kathleen Jimino, Assistant Treasurer  
Board of Directors of the Arc of Rensselaer County.



September 10, 2021

Written testimony to the Senate Standing Committee on Disabilities Re:

To Evaluate the Current Workforce Challenges of the I/DD Service Delivery System

Dear Senators:

I am writing to give you a sense of the importance of the Direct Support Professional Role and the impact on people due to the workforce crisis. The effects reach individuals we support, staff, families of both, and the leaders in all providers across the state.

The most significant is the life disruption to the individuals that we support. We have a system that has promised people that they will receive support in various areas of their lives. Whether it is day services, employment service, respite for the family, or someone's home, every aspect of that support, is essential to the person being supported. We even built a system telling people that they would be given choices in living, support options, working, and even staying home. We even told them they would live in supportive settings where they would be healthy and safe. Currently, the situations are dire in we have such a staff crisis maintaining health and safety is challenging. In some cases, it is getting almost scary. I fear the impacts on people; 100% of the people involved in these services and providing these services are people.

Please remember that at the end of this workforce crisis is someone's son, daughter, sister, brother, or friend. Would you please take a second to think about that statement? Also, please remember that the staff person is someone's daughter, son, brother, sister, parent, or friend. Would you please take another second to think about that statement?

We are asking these staff who do not make a living wage to be the lifeline for a fellow human being. Economically, we are saying that we value product over you, both the individual and the staff. We are willing to push the Fast Food Workers rate of pay higher because we value the economic activity over someone's life. Does that sound right to you?

The Direct Support Professional is asked to wear many hats and possess many skills that are hard to define. They need to manage all of these roles interchangeably some at the same time in the community:


- **Life Coach** aid a person in improving their relationships, careers, and day-to-day lives
- **Mentor** walks alongside someone to guide the person in doing for themselves.

*Administrative Offices*

79 102nd Street • 3rd Floor • Troy, New York • 12180-1125

P 518 274 3110 • F 518 272 1522 • [www.renarc.org](http://www.renarc.org)

*Supporting individuals with intellectual disabilities and their families*



*A chapter of* **The Arc.**  
New York

- **Medical Assistant**- Some of their responsibilities include: Turning or moving patients, overseeing prescription administration, gathering medical supplies, changing any bandages, apply ointments, Feeding Tubes, reporting on conditions of residents, Assisting with some medical procedures, Safety procedures
- **A Documentation Specialist** responsible for writing, distributing, collecting, storing, and maintaining a person's medical, support, and life record.
- **Transportation** safely transports a person to their needed location or helping a person learn the ins and outs of bus routes or ridesharing.
- **Assist with Daily Living Skills** are routine, self-care tasks in which most people participate daily without assistance. Basic daily living skills include showering and bathing, dressing, eating, using the toilet, and transferring between beds and chairs.
- **The dietician** helps the individual eat a well-balanced diet with a safety component of having food portions in proper sizes to avoid choking.
- **Support with Emotional Needs**, which help the person feel/deal with being: **Respected.** Treated with courtesy acceptance. **Importance.** · Feeling appreciated. · Feeling useful. **Security.** · Feeling cared for. · Feeling safe and Inclusion. · Feel connected to others. · Be part of something meaningful.
- **Psychological Needs** help and coach the person through varying needs from the need for attachment, self-esteem, anxiety concerns, everything everyone will feel through their day.
- **Teachers** were helping the individual learn to the total ability they have to participate in their life as much as possible. The DSP is to work with a person in doing for themselves, not doing for the person. The skill to do this and understand this is in itself one of outstanding achievement.
- **Housekeeping** If the person is unable, they need to do the household chores like laundry, cleaning, dishes, and other tasks needed to maintain a home.

All of these skills are to be delivered with empathy, care, and the ultimate goal of helping elevate a person's life. Do these skills sound like entry-level tasks to you? They do not sound like entry-level skills to me. We need to recognize the skill set we are asking of our staff and pay them accordingly. We need to acknowledge the responsibility we are asking of our staff and pay them accordingly. My ask is we do this now. It cannot wait as the lives of people receiving supports and the staff providing it are in danger. You can be the hero who rights this injustice to both the people supported and the people working in this support system.

The result of lack of staffing and low wages is forcing staff to work long hours in stressful situations that are highly regulated and impactful on a person's life. Staff is missing valuable work-life balance as they care so much for the people they support they want to be there. They realize that if they are not working, the person cannot participate in life and can even die from the lack of care. They work long hours because they are mandated to stay if the next staff person does not show up for work. The mandated occurrences increase as there are more and more vacant positions. I want to make sure you know that the pandemic did not cause this; it has existed before the pandemic. The pandemic has only increased the staffing situation. But it is a real issue that needs to be addressed now.

I also want to make sure you know that the number one issue is wages. We hear it could be engagement, appreciation, and training. However, please realize that DSP is making \$13 to 15 dollars per hour and that wage cannot provide a sustained living.

The Federal Government has the funding being worked out; we must act fast to help foster that funding. We then must act promptly to distribute as the lives of so many people are really at stake. We need the funding to be committed long term, we cannot cut any more from our supports, and we must act quickly.

I thank you for your time and can be reached at ~~XXXXXXXXXX~~ or via email at ~~XXXXXXXXXX~~

Sincerely,

A handwritten signature in black ink, appearing to read "Don Mullin". The signature is fluid and cursive, with the first name "Don" and last name "Mullin" clearly distinguishable.

Donald J. Mullin  
Chief Executive Officer





September 10, 2021

To: Senate Standing Committee on Disabilities  
C/o Senator John Mannion, Chair  
188 State Street  
Legislative Office Building, Room 814  
Albany, NY 12247

Re: Written Testimony for Public Hearing to evaluate the current workforce challenges of the I/DD service delivery system

Dear Chair Mannion and Honorable Members of the Senate Standing Committee on Disabilities:

My husband and I are blessed with four amazing children with varying levels of need. Three of them have IEPs and one has a 504 plan. Our daughter Devyn faces some of the more difficult challenges given her need for 24/7 care. She was born with a rare genetic condition and has life threatening seizures. While the school provides a 1:1 nurse while she is there, we do not qualify for nursing at home. We rely on the Consumer Directed Personal Attendant Program (CDPAP) and Respite Hours through our self-direction budget to provide Devyn with caregivers who can help keep her happy, healthy, and safe. We are no strangers to challenges. With the support of wonderfully dedicated DSPs we had the strength to face adversity before ((and WIN)) ... You may recognize my daughter's name (Devyn Pereira) because the United States Department of Justice brought our previous school district to federal court because they refused to provide her with reasonable accommodations to utilize her service dog. Our case set a legal precedent for the entire country! It was hard work, but worth the blood, sweat, and tears. We always knew that we were fighting for more than just us. Now, we are battling a new challenge and we are definitely not alone.

My husband and I are often working more than one job each to make ends meet. He is a military veteran and a mason. I am a psychologist that worked in education for years and am now in healthcare serving the nursing home population. For the first time in Devyn's 14 years of life we are unable to secure and keep enough caregivers to watch her while we are at work and sleeping. The pandemic has had devastating ripple effects on so many... For us, it has meant that I needed to step down to a part-time position at work to stay at home with Devyn. This will have an obvious financial impact on our family, but the 400+ residents at the community nursing home are also greatly impacted by all of this.

I know we are not alone, even though this can feel very lonely to be in this position. Our children will not "grow out of needing this support" and as parents, we must always be planning on how they will be cared for when we are gone. It keeps us up at night thinking about how broken this system is right now and worrying how proposed cuts will further devastate such a vulnerable group of people.

What would help?

- RAISE THE WAGES for our indispensable DSPs
- Immediately pass and implement Assembly Bill A.6329 requires a minimum a base wage for home care workers at 150% of the regional minimum wage.
- Fully funding our institutions providing vital services to our I/DD community

- Fully fund our residential habilitation services. Immediately pass and implement Assembly Bill A.8091 would sustain reimbursements for residential habilitation services and prevent proposed cuts by the OPWDD.
- Fully fund 853 and 4410 schools. In the FY 2022 Enacted Budget, public schools received a 7% Foundation Aid increase and despite vigorous advocacy from the Assembly, special needs education only received a 4% increase.
- Institute an annual 2% COLA increase.
- Support programs that help develop and retain the DSP work force
- Pass and fund Assembly Bill A.8229, which directs the Department of Health to create a grant program non-profit organizations and home care providers to support peer-mentoring programs for home care workers.

Thank you for your continued advocacy & hard work!

Best,

Heather Burroughs

~~603.225.0111 ext 111~~

~~@heatherburroughs~~

~~heatherburroughs@opwdd.nh.gov~~

Care Design NY  
Individual & Family Advisory Board

Testimony to NY State Senate Hearing on IDD Workforce Emergency  
9/14/2021

Care Design NY is a Care Coordination Organization representing 110,000 individuals with Intellectual and Developmental Disabilities (IDD) and their families. Our Advisory Board is composed of people with IDD and family members across the State. No matter what part of the State we live in, we have all been affected by the ongoing Direct Support Professional labor shortage, which deteriorated from a chronic shortage to an acute emergency over the last year.

No matter what types of services our members use, the workforce emergency has led to a severe inability to meet the goals established in their life plans, often limiting access to any services at all. We know that many providers, DSP's and individuals will testify today to the anguishing details of what we have all been experiencing.

We would like to take this opportunity to reflect on the root causes of this emergency. Most fundamentally, we believe that the State has achieved "budget neutrality" over the last decade by devaluing the needs of the IDD community. The minimal wage increases provided to our DSP's after the aggressive campaign of Be Fair to Direct Care were accompanied by budget "offsets" which included no Cost of Living increases to IDD providers until this year and additional budget cuts disguised as "rate rationalization" as well as outright reimbursement reductions to certified residential providers in the most recent HCBS Waiver. Additional cuts in Comm Hab and other services are anticipated in the near future. The shamefully inadequate ISS housing subsidy is another consequence of this budgetary shell game.

We believe that the Executive has already acknowledged the necessity to provide a substantial wage increase to stabilize the DSP workforce. There may well be differences on pace and timing and regional implementation to iron out. But our biggest fear is that any money allocated to this wage increase will then be withdrawn from the IDD system through additional budget cuts.

We ask the legislature to ensure that the continued erosion of funding for IDD services and providers does not continue. It would be a terrible shame for the State to grant the much-needed DSP wage increase, only to jeopardize the agencies they work for and the very services they are there to provide. Please mandate that all Medicaid revenue generated through the Federal share of IDD funding be used to fund IDD services instead of being diverted to other uses in the General Fund. This is the best long term plan to fiscally stabilize the IDD sector and allow providers and people in Self-Direction to continue to provide good salaries and benefits to our essential DSP's.



During the 12 years my son has had Direct Service Professional, we have had high turnover due to the low wages allowed for these critical workers. Expressing regret and frustration, these dedicated individuals have universally cited low pay as the reason for their departure. They have left my son's employ to take unskilled positions such as warehouse work, because a few additional dollars per hour can make the difference in paying their rent and other bills.

DSP staff are trained, experienced, intuitive and highly needed. They help the individuals they work with attain goals of increased independence, contribute to the work force or volunteer world and add significantly to their quality of life.

For most people with disabilities, losing a staff person is an emergency situation. We must do more to ensure a living wage and encourage long-term careers for these important members of our society. Paying higher wages is a money-saver in the long term, because it will mean less turnover and higher continuity of care.

Marilyn Jeffery, Parent

~~XXXXXXXXXX~~

~~XXXXXXXXXX~~

~~XXXXXXXXXX~~

~~XXXXXXXXXX~~



**Dear Senate Standing Committee on Disabilities:**

I am very pleased to be addressing this vital committee. I understand that the purpose of this hearing is to evaluate the workforce crisis within the I/DD service delivery system. What you have termed a challenge, people within that system no longer hesitate to call a crisis. Let us not forget that the well-being of individuals with disabilities is directly impacted by this crisis. This includes myself, a thirty-year-old constituent with cerebral palsy. I live in a group home on Long Island, which was very well-run prior to the pandemic, while state funding did not allow its workers to be properly compensated. This home and others like it have been greatly impacted during the pandemic, worsening a problem of many years with workers coming and going in a revolving door effect. Some workers who do not leave are constantly working double shifts of fifteen hours or more per day, leaving them tired and often ineffective with only a little more money to show for it. Worse yet, I am often forced to worry that the training and supervision of new workers is rushed with the accelerated need to provide staffing that is only superficially adequate. This leaves me at times fearing not only for the future of the field but my own personal safety and that of others with disabilities. It is impossible to make our field attractive when there are so many others that are less demanding but so much better compensated. I keep hearing talk of legislation designed to fix these issues. I shudder to think what catastrophes await if this doesn't happen. As I thank you for your time, I must ask you for your prompt service in regard to these pressing matters.

Respectively,

Kevin Christman





**From:** Susan Becker

**To:** Senate Standing Committee on Disabilities

**Re:** Written Testimony for Public Hearing to evaluate the current workforce challenges of the I/DD service delivery system

**Date:** September 8, 2021

**Cc:** [REDACTED]

As a parent of an adult son with disabilities, I know the staff crisis firsthand

I am not an HR director, yet I'm expected to find, train and manage staff to deliver services to my son. This model is broken. It is failing our citizens with disabilities and it is crushing their families.

Please help.

Best,  
Susan

Susan Becker

[REDACTED]



To Senate Standing Committee on Disabilities:

I have been working in the field since August 2016 and I am currently employed there in the Department of Quality Assurance. In 2010, I worked as a Direct Support Professional in a residential program operated by an agency in the Capital Region. There has always been a high rate of staff turnover, especially among Direct Support Professionals (DSPs), but since I re-entered the field in 2016, the problem has become so severe that it is now referred to as a crisis. As a Medicaid funded service we are depend on reimbursements from the government to generate income to pay the staff that support individuals with developmental disabilities. This makes it difficult for a not-for-profit agency to offer competitive wages and raises. When the pay is low and there is no prospect of a raise, morale suffers. We cannot compete with other industries like fast food or the service where companies can afford to pay more and can utilize more technology and automation. Human Service Professionals are essential employees. Individuals and family members of individuals with disabilities knew this before the Covid-19 pandemic. We provide services 24 hours a day, seven days a week. There is no such thing as a snow day. If the weather is bad and someone cannot make it work, then the employee who is there is mandated to stay. Human Services Professionals often do not have advance degrees yet they are responsible for health, safety, and welfare of humans with complex needs. At minimum, most of the DSPs we employ pass medications, must be able to perform First Aid/CPR, use a computer, have a clean driving record, prepare nutritious meals according to specific dining plans, assist individuals during medical appointments, support individuals to use adaptive equipment, write notes, document behavior tracking, and maintain a germ-free environment. Employees must be aware of fire safety, hazardous chemicals, and maintain HIPAA regulations. Employees must have an understanding of developmental disabilities, mental health diagnoses, human growth and development, trauma informed care, human rights, and strategies for crisis intervention and prevention. In addition to these knowledge, skills, and responsibilities, staff also must develop positive professional relationships with the individuals they support which takes time, experience, and it depends a great deal of personal chemistry. Therefore staff turnover is not just a problem for managers making a schedule; the impact of having inexperienced, unfamiliar, or apathetic staff can be detrimental to individuals who receive services and are vulnerable to abuse, neglect, and exploitation. We need to be able to offer competitive pay to keep the staff who are in the field for the right reasons. Because of the pandemic and being investigated by the Justice Center, staff are resigning and there are no applicants to fill the shifts. Our agency has been forced to temporarily close a residence and relocate individuals from their homes to other programs to pool are resources. Everyone in the office who was previously not providing direct care, including administrators, directors, and the executive director, are now required to cover shifts in the programs just so we can meet the minimum staffing requirements and that is still not enough. For months, staff have told me that when they go to work, they bring a bag of extra clothes and extra food because they do not know when they will be able to leave because they expect that there is no one scheduled to cover the shift after theirs. Staff have said this has created problems in their personal lives, because they are not present for their spouses and children. The staff who do show up for work are increasingly pulled into investigations because of not having enough staff. Staff feel like they are being punished. The individuals they support are left to wonder who will be working and is it someone they know. Our ability to honor the individuals' preference for staff, recreation, and is vanishing because we don't have a big enough pool of staff to pull from. Furthermore, there are a disproportionate amount of women, minorities, and immigrants in this field. If we can raise the rate of pay and more people stay in the field, it will be an investment in our communities and the underserved.

Sincerely,  
Alisa Bielert

Dear Senate Standing Committee on Disabilities,

I am writing to you pleading for assistance with the staffing crisis that has hit an all time high in the world of disabilities. I am currently a manager in the Community Hab and respite programs. I have been in this position for 16 years. Staffing has always been a struggle but now it is so much more than that. Applicants are almost obsolete and those we get are very short term employees. We are faced with the constant cuts to these services every time there is a budget vote. Since the pandemic and the higher amount of unemployment wages other employers are raising wages to a degree that we can not contend with. Most are over \$15 hr and that is not competitive in our world as the reimbursement rates through the medicaid waiver are so low. There are no incentives we can use to entice people into applying for these jobs and currently all staff in disabilities services are working extra days and hours to keep their agencies afloat.

I don't want you to think that I am just a manager as I said I have done that job for 16 years. I am also a CSP when I leave my day job. I worked with 3 ladies for several years until 2 moved into residential settings and could no longer utilize Community Hab, the 3rd young lady I have worked with for 16 years. I have assisted her with school, culinary arts program, getting a job, getting her license, socializing, budgeting, getting into her community and now working with her for independent living. This job is fun, rewarding and can also be very draining and hard. I recently went to work with a young man for he day his grandmother had passed away and he can't be in that type of a setting. He had no staff and his parents were not going to be able to say their last good byes without someone to be with their son. No one should have to face that, Not ever! It is necessary to those approved to receive the supports they are approved for in order to grow their independence. This is what they want, what they strive for. Each person is differently abled and have their own chosen goals they want to become more independent with. From personal hygiene, to shopping, maintaining their home, getting a license, getting a job etc. What they want most is to know someone is coming, that the person coming will be coming for a long time. They don't want a new staff every 30 days they want consistency in their lives, just like you and me.

While I am maintaining 2 jobs now for 16 years recently I was mandated to work additional hours in our agency residences. Now I say mandated but honesty if we don't all step up there will be no agency. Where will all these people go? Is there other options we are not aware of? What about those that don't have family or don't have an advocate? Who will be their voice. This past week I worked 14 hour days and traveled 1 hour each way to get to work. That equates to 80 hours although I don't get paid for the travel time. There are multiple staff working 80+ hours weekly. They haven't used any vacation time in months and can't due to lack of relief staff. People are working weekends, holidays, overnights whatever needs to be done to ensure the safety of those residing in the residences.

I currently have approximately 200 people who are on our roster to receive services with Community Hab and or respite I also have about 60 more waiting for an agency to take them on. On my current list there are about 65 people with no staff and haven't had staff some for years. Their families are aging, getting tired, want time to themselves but can't get it because there no staff to work with their family member that needs assistance. Go back 10 years this was a competitive employment. We filled almost all of our cases and could take on more. We work extremely hard to ensure each person is receiving person centered services but again this is failing since there are so little staff to work with. We were one of the largest provider of Com Hab and Respite in the capital region now I am not sure where we stand. It is imperative that something is done to repair this broken system, ensure quality staff to work with those that need assistance, ensure staff are able to take the time they need for their own mental health, ensure that the correct amount of pay is being presented that would entice people not only to come but to stay and provide long term services to those seeking them. There should never be fear that there is not enough staff to meet the required numbers and with the right reimbursement rate

these services can again rise and meet the needs of those that chose us to ensure they get all they deserve. Without your assistance these services will be obsolete! They are headed in that direction at a high rate of speed. Who is going to explain that to them, their families. Who is going to take care of them when their advocates are gone. Is the government going to stand up and tell these individuals/families what they are facing and why? Or are you going to take a stand and get these services back on a path of righteousness and provide them with the person centered services they have been promised?

Thank you,

Jamie Daniels

Manger, CSP, advocate and friend to all those differently abled that need others to assist them in justly receiving what they deserve.

To whom it may concern:

I work for the ARC of Genesee Orleans as a Direct Support Professional. There are only seven to eight workers total in the house to work that covers three shifts seven days a week with a worker having two days off a week. Our challenge is to find extra help to cover as our workers are over worked and under paid. No one wants to work at the ARC for \$13.00 an hour when they could be working at Subway for \$17.00 an hour. As I always say it would be easier to make twenty subs an hour then listen and deal with behaviors for eight plus hours. This job should be paying over \$20.00 for the care we give the people we serve. Any raise that is given is a measly 0.15 to 0.20 cent raise yes, I said cent raise.

Don't get me wrong I love the people I work with and love to do things with them. However, being over worked and under paid stresses the workers out. We do the same exact work that the state houses do. We follow the same guidelines. We work with the same Justice Center and OPWDD. We should be getting the same pay rate the only difference is a test and physical fitness test that is a joke.

It is getting to the point that our coordinators do not want to help out working and coming up with memos to sign such as no one can leave until the full next shift arrives. What if they never arrive because the house is short and no one wants to pick up those hours? You can only call out three times in six months and it has to be approved or it will be a no call no show on your recorded. Another memo was that the workers had to pick up at least four hours overtime a week.

We cannot even use our paid time off because there are no workers to cover. We can only roll over 40 for the next year and the rest is taken away. We worked hard for that PTO time. I am constantly picking up extra shifts and hours. So I definitely deserve to use my PTO time whenever I want. SO many times I have tried to ask for days off and they all get denied. Also we aren't guaranteed sick time. I tried calling off sick in the past and was told I needed to come in because there are not enough staff. Really that is so wrong to come in and risk getting the residents sick. Why aren't DSP at the Arc required to get the Covid Vaccine? It makes no sense since we are considered health care workers and work in a group home. I have complained about my co workers not being vaccinated and going around the residents without a mask and nobody cares. It is like this agency does not truly care for these residents.

Other workers from other houses are not fully trained and do not know what to do with the people we serve. Fire drills are not preformed when new staff come to help out. Also we do not get any paid breaks or lunches, there is not enough staff to cover for breaks or lunches even though it is in the handbook that we get them.

The Manager and Coordinators act like the workers do not have kids or family that they want to spend time with. There are a lot of functions that we all have missed over the years.





Thank you for allowing our agency, Ability Beyond, to submit written testimony in regards to the topic 'Evaluate the current workforce challenges of the I/DD service delivery system'. I would like to start by saying that that this is more than a workforce challenge, it is a workforce crisis. Ability Beyond provides services in several counties in NY, one of which is Westchester County. Westchester County has a very high cost of living which makes staff who want to work in this field unable to do so at the wages that are paid. Westchester borders the Bronx where the minimum wage is \$15/hr which means few residents from the Bronx are willing to travel to work in Westchester even though it is geographically close. Additionally, Westchester's minimum wage mandates have required the minimum wage increase each December. Our agency, in December 2021, will be paying minimum wage of \$15/hr. This is the same, and sometimes lower, than the wage paid at fast food restaurants and entry level retail jobs. The direct care position requires many high level tasks such as performing cpr, dispensing medication, and transporting individuals. Paying these staff minimum wage is a disservice to them and to the I/DD field. Anyone would agree that the direct care position is not an entry level, minimum wage appropriate job. The high level person needed to fill a direct care role and perform the job well is worthy of much more than minimum wage. Continuing to pay at or near minimum wage will not allow for the quality of services needed to serve the I/DD population. These individuals deserve much more!

In trying to hire for this role in this geographic area, we are finding that low numbers of applicants and low quality applicants are applying for this position. During the months of June and July 2021, we received 1035 applications. Many of those were not qualified, were unresponsive post-application or did not show to a scheduled interview. We completed 170 interviews and offered positions to 105 applicants. Of those 105 applicants that our agency wanted to hire, 31% ghosted us after receiving the offer which meant only 20.5% were hired (equates to 21 new employees). Of these 21 new employees, only 13 of them were full time (working 30 hours or more). The other 8 employees were hired as per diem which means there's no guarantee of how many hours they will work per week. We have spent a considerable amount of money in advertising, recruiting and training costs to result in only 21 new employees.

Our programs have been operating consistently over the last several months at a 25% staff vacancy rate, which means current staff are working many extra shifts. This has directly impacted the significantly increased overtime costs we have been spending while also causing burnout to our current staff. Many staff have left due to this burnout which circles back to increased staff vacancies. Our turnover for direct care staff through June 2021 was 33%.

I thank you again for allowing us to share this information in the hopes that a resolution to this workforce crisis may be found.

Respectfully submitted,

Rachael Kaiser-Levitz

Human Resources Manager

Ability Beyond





Wade and Patricia Marvin

[REDACTED]

[REDACTED]

September 7, 2021

To the Senate Standing Committee on Disabilities-

RE: Public Hearings to Evaluate Current Workforce Challenges for People with Intellectual Disabilities

Dear Committee Members,

We are parents to our daughter Leah, age 23 ½ years. She is the youngest of our three children; her brothers are married with families of their own and live more than 300 miles from our home. Leah was a student at West Genesee CSD for 14 years where she received Special Education services including Speech, Occupational Therapy, and Physical Therapy during her school career. When Leah left high school at age 19 we worked with Advocates, Inc., LifePlan CCO, and OPWDD for two years to develop a Life Plan for her future including a Budget, Safeguards, Goals and Services necessary to support her after school and into the community. The key to this plan is hiring Direct Service Professionals to work with her on her goals. With the Life Plan and Safeguards in place our daughter has thrived in her home community. She takes classes at the local YMCA, takes a cooking class at a local studio, music and drumming classes, participates in Special Olympics bowling and meets with a group of friends and Mentors at a local church for dance and singing. She practices her Faith in the community and with her church family each week.

These activities are all possible due to the support provided by Leah's Direct Service Professional. We hired this young lady on the recommendation of an employee at Advocates and at 19 years of age she has followed the letter of Leah's Life Plan while learning about Leah. She works three days per week with Leah and works with two other families each on Monday and Friday. Two weeks ago she gave us notice that she and her sister were moving to Texas on October 15<sup>th</sup>. We appreciate her candor and giving as much notice as she did and she will be missed. I contacted Leah's Broker to advise her only Mentor was leaving and was informed there was a waiting list of 200+ families looking for a Direct Service Professional to work with their loved ones. How can this occur? The Direct Service

Professional is the key to fulfilling the goals and needs of individuals who cannot speak for themselves. The families of each individual rely upon these professionals each day to provide their critical support in order for the family to pursue their jobs and maintain their households. Right now I do not have much Hope that we can work through replacing Leah's Direct Service Professional this year.

Please advise what you recommend for each of us to do to help solve this critical need for placing Direct Service Professionals with waiting families.

Thank you for your time and consideration,

Patti Marvin

# **BOARD OF VISITORS-Capital District DDSO**

**500 Balltown Road, Schenectady, NY 12304**

Date: September 7, 2021

To: The Senate Standing Committee on Disabilities

Re: Testimony for Sept 14 Hearing to evaluate the current workforce challenges of the I/DD service delivery system

The Board of Visitors (BOV) for the Capital District Developmental Disabilities Services Office (CDDDSO), under the auspices of the NYS Office for People with Developmental Disabilities (OPWDD), has oversight of a nine-county catchment area including Albany, Schenectady, Rensselaer, Schoharie, Fulton, Montgomery, Saratoga, Warren, and Washington counties.

The BOV meets monthly with the Director and Deputy Director to discuss district updates, challenges, and operational strategies. A critical area of focus is the increasing staffing crisis of our Direct Care Professionals due to lack of applicants, high attrition, FMLA, administrative leaves and suspensions, workers compensation, military leaves and medical leaves. The COVID 19 pandemic exacerbated an already burgeoning staffing crisis. During the 2020 pandemic recruitment efforts came to a standstill due to budgetary constraints and limitations on hiring events (i.e.: job fairs) and in person Civil Service testing. Eventually attrition outpaced hiring deepening the staffing crisis. In addition, as minimum wage increased in other industries, the salaries for the DSPs have stagnated. Working conditions have continue to deteriorate due to mandated overtime severely hindering the work/life balance of our hard working, exhausted workforce.

At this time our Direct Care Professional staffing levels have reached a crisis state. As of August 2021, there are 589 DSP/LPN vacancies (which includes administrative leaves and suspensions, medical leaves, worker's comp and COVID-related leaves). Capital District has attrited 114 employees since January 2021. To maintain proper staffing levels at each home, employees must be mandated to work extreme overtime including multiple double shifts and, at times, triple shifts (16 – 24 hours). It is well documented that excessive overtime leads to staff working in a state of exhaustion leading to medication errors, poor quality of care, and increased incidents of abuse and neglect. This is not acceptable and all those with intellectual and developmental disabilities deserve better. Something needs to be done immediately to prevent another tragedy, such as happened in 2007 with the death of Jonathan Carey. Overtime was deemed a contributing factor in this tragedy.

The current staffing shortage means we can no longer provide appropriate or quality care. Those in our care spent much of 2020 at home with minimal habilitation needed to teach skills and provide life-enriching activities. Due to the staffing crisis, day programs have yet to return to full operation impacting the quality of life of those in our care. More than half of the individuals who live in our residences or family care homes as well as those individuals attending voluntary agencies programs, have no program! While at home, the care falls just short of custodial care! Can the traumas of Willowbrook be far behind?

It is incumbent upon the governor and legislators of New York State to implement strategies that will not only help to retain staff, but also to provide incentives that will entice individuals to apply for direct care jobs within OPWDD. We, along with voluntary agencies need immediate help to improve our work force numbers starting with negotiating and instituting new salary rates for our Direct Care Professionals.

Starting direct care workers are now receiving a lower rate than what an employee might receive at any fast food establishment. The responsibilities of the job as a direct care worker (i.e., providing care to individuals, many whom need help with the basic functions of life (feeding, washing, and dressing) far exceeds the tasks performed by a fast food employee. "Band-aid policies" are no longer an acceptable remedy to our lack of staff. In the opinion of this BOV, any monies received by OPWDD through the American Rescue Plan Funding (FMAP) should be directed at raising the salaries of DCP/LPN and putting incentives in place that will help retain our present employees.

Respectively submitted by: Members of the Capital District DDSO BOV

*Susan O'Connor*

Susan O'Connor, President

To whom it may concern:

To start off that line to whom it my concern would cover the majority of the health care field. I work for the ARC of Genesee Orleans as a "Health advocate" but really as a DSP due to the shortage of DSP in my field I have to sacrifice my title until more workers are hired. It has been more than 4 months since I was told that more workers will be hired so I could do my job 6 to 2 or 8 to 4 taking people we serve to their appointments and contacting doctors for medication. At the house I work for there are 7 people we serve. Minimums of workers are at least 3. There is only 7 to 8 workers total in the house to work that covers 3 shifts 7 days a week with a worker having 2 days off a week.

Our challenge is to find extra help to cover as our workers are over worked and under paid. No one wants to work at the ARC for \$13.00 an hour when they could be working at Subway for \$17.00. As I always say I would rather make 20 subs an hour then listens and deal with behaviors for 8 plus hours. This job should be paying over \$20.00 for the care we give the people we serve. Any raise that is given is a measly 0.15 to 0.20 cent raise yes, I said cent raise.

Don't get me wrong I love the people I work with and love to do things with them. However, being over worked and under paid stresses the workers out. We do the same exact work that the state houses do. We follow the same guidelines. We work with the same Justice Center and OPWDD. We should be getting the same pay rate the only difference is a test and physical fitness test that is a joke.

It is getting to the point that our coordinators do not want to help out working and coming up with memos to sign such as no one can leave until the full next shift arrives. What if they never arrive because the house is short and no ones wants to pick up those hours? You can only call out 3 times in 6 months and it has to be approved or it will be a no call no show on your recorded. Another memo was that the workers had to pick up at least 4 hours overtime a week.

We can not even use or PTO because there are no workers to cover. We can only roll over 40 for the next year and the rest is taken away. We worked hard for that PTO.

Other workers from other houses are not fully trained and do not know what to do with the people we serve. Fire drills are not preformed when new staff come to help out.

We do not get any paid breaks or lunches, there is not enough staff to cover for breaks or lunches even though it is in the handbook that we get them.

The Manager and Coordinators act like the workers do not have kids or family that they want to spend time with. There are a lot of functions that we all have missed over the years.

Maintenance or the agency does not fix the issues that is wrong in the houses. The houses look institutionalized they all need paint, floors fixed, heating and air ducts fixed, bug problems, carpet pulled up and holes fixed. The behavior specialist that are hired by the ARC tells staff that they must be causing the behavior for the people we serve and rewards the behavior person with taking them out to dinner and the behavior continues after the specialist drops the person off. The agency sweeps major things under the rug that is very concerning to staff.





To: Senate Standing Committee On Disabilities

re: Written Testimony for Public Hearing to evaluate the current workforce challenges of the I/DD service delivery system.

My Name is Joseph Damiano, I am a person with a disability who receives services, and I am also the peer support specialist at the Arc of Allegany Steuben.

What I have been hearing from the people I support is the services they receive are needed to reach their goals and live the life they want to live.

Many people expressed they do not have enough supports at this time to reach these goals. They feel like their services could be improved if they had more of them if more transportation was available and if they had less regulatory barriers.

These needs have been made more emerging since the COVID-19 Pandemic.

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In general staffing has gotten way worse. I know at our agency we currently have multiple positions open for employment. A lot of programs have to use staff that might already was supposed to be on a service with someone else but because of staffing had to go with the other person. I also can say that residential at least at our organization is always to looking for people to take shifts and sometimes employees who normally don't work in the houses are picking up shifts because of the crisis.



Senate Standing Committee on Disabilities  
c/o Senator John Mannion, Chair  
188 State Street  
Legislative Office Building, Room 814  
Albany, NY 12247

Re: Written Testimony for Public Hearing to evaluate the current workforce challenges of the I/DD service delivery system

Dear Chair Mannion and Honorable Members of the Senate Standing:

For almost 40 years, our work at Heritage Christian Service has supported initiatives that enhance the opportunity for people to have diverse, inclusive and equitable community experiences rich with meaningful relationships. We partner with thousands of people throughout Rochester and Buffalo to ensure people with intellectual and developmental disabilities feel valued and respected. We serve our community with programs that promote housing options like certified residential services – and the support within them – along with programs that create relevant employment and day habilitation, and embrace self-direction.

For more than a decade, agencies like ours have not been able to count on a Cost of Living Adjustment (COLA) from New York State. The number of years that we have not received a COLA have far outnumbered the years that we have, making it difficult for us to plan and budget as we provide essential services for people with intellectual and developmental disabilities. **We are asking that NYS institute an annual 3% annual COLA – the same type of increase that the state gives to other sectors- and to codify it so that it cannot be deferred. We ask that the commitment be made for the next five years, so that agencies can plan and budget accordingly.** The COLA will allow agencies like Heritage Christian to continue to provide supports and services and raise wages for the direct support workforce.

Direct support professionals work with people with intellectual and developmental disabilities to support them as they live and work in their communities. These care professionals perform critical work, and they are required to be skilled professionals with specific training and education. People who choose a career that directly supports the health and well-being of others deserve to earn a wage that allows them self-sufficiency. Currently, many of them cannot financially take care of their own families because of the low wages associated with their jobs. Lower wages than are paid by other industries have also made it more difficult for agencies like Heritage Christian to recruit and retain staff. In their Sept. 2021 report [\*Direct Care Workers in the United States: Key Facts\*](#), New York think tank PHI states, “Despite high demand for direct care workers, their wages remain low—the median hourly wage for this workforce was \$13.56 in 2020 (US Bureau of Labor Statistics). Low wages combined with high rate of part time work make it challenging for direct care workers to financially support themselves and their

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families. Median annual earnings are just \$20,200, 44 percent of direct care workers live in low-income households and 45 percent rely on some form of public assistance such as Medicaid, nutrition assistance or cash assistance. These trends both reflect and perpetuate the racial and gender inequalities faced by direct care workers, who are largely women of color.”

Increased funding for wages will help human services organizations keep pace with other sectors, and to recruit and retain top talent to these critical positions. The New York State Office for People with Developmental Disabilities (OPWDD) has received a one-time allotment of Federal Medicare Assistance Percentage (FMAP) funding as a result of the COVID-19 pandemic, estimated to be around \$740 million. **We are requesting that these funds be released to agencies like Heritage Christian to be used for staff wages and bonuses, and to invest in the infrastructure of residential homes and physical properties for people with intellectual and developmental disabilities so that they are fully accessible and can continue to meet the needs of an aging population.**

**In addition, we are calling on New York State to immediately pass and implement Assembly Bill A.8109 which would sustain reimbursements for residential habilitation services and prevent cuts proposed by OPWDD.** These cuts will be retroactive to May 1, 2021, and their impact will be devastating. In the midst of a workforce crisis, these cuts will further limit our ability to pay a competitive and self-sustaining wage. For Heritage Christian Services, the will cuts hit our budget to the tune of more than \$1.6-million annually. In addition to the significant impact these cuts would have on direct support wages, the would also impact our overall service delivery.

First is the reimbursement we receive when a person is hospitalized. It is Heritage Christian Services’ commitment to provide staffing for a person throughout their hospitalization, unless otherwise restricted by government mandates or hospital policies. When staff members are by someone’s side through their period of hospitalization, we find that the length of their stay is often shortened, and their transition plan home allows them a better chance at staying home and not returning to the hospital quickly. Should these cuts go into effect, there will be a 50% decrease in reimbursement. Our commitment to support someone through their hospitalization will not change; in the event that someone who we provide residential services to is hospitalized, we will continue to have a staff member at their side. The annual impact, based on our historical hospitalization rates, is projected to be a \$500,000 loss. While hospital coverage costs more with one-on-one staffing and increased overtime, we believe this is an essential support. The government has said that hospitals are paid to provide the appropriate oversight, but we have not found this to be the case.

The second cut involves reimbursement when a person leaves their residential home overnight. Where the person sleeps is the key determinant. Should these cuts go into place, the rate of reimbursement will be reduced by 50% for every night a person is gone from their home. Given trends for overnight visits, we project a net loss of at least \$1.1-million annually. In order to sustain this loss, we would need to ask family members to decrease the number of nights their loved one sleeps away from their home. Asking people to spend less time with their families in the name of budget cuts is inhumane. We should be encouraging people to spend time with their family and friends and not be concerned with the negative impact on the organization that supports them. Current governance stipulates that an

organization cannot ask someone to not go visit their family, and we absolutely support that. However, both the people who live in the home and their families will be aware that the organization will receive a drastic cut in revenue when a person spends a night away from their home, which will create unintentional challenges for families who feel guilty hurting the organization that supports their loved one. It will have real life, day-to-day impacts that are not in line with OPWDD's people first philosophy. Perhaps most importantly, OPWDD misrepresented to CMS that these cuts will go into place when a person is not receiving services because they are away from home, implying that organizations like Heritage Christian Services are being paid when services are not being delivered. This is not accurate, as most of our costs are fixed, so even when a person is away with their families, our costs do not go down.

The third cut is related to home vacancies, which often follows when a person passes away. Should these cuts go into effect we will not be reimbursed when there is a residential opening. The annual impact to Heritage Christian Services is expected to be \$125,000. To limit this loss, we will need to match new people to home settings with a different kind of immediacy. We will do so with sensitivity and care. However, New York State controls who the organization can consider for these openings, and the process is time consuming. Organizations like Heritage Christian Services will lose precious funding that should be used to provide services each day that the opening remains, and we believe that this will cause organizations to make rushed decisions on who should live together, which may cause additional challenges in the future.

Finally, we ask that you would advocate at the federal level for direct support staff to have their own Department of Labor occupational code. They currently do not, and this makes it difficult for us to gather the data necessary to make informed decisions about the future of our valued staff members and their wages, when they are included with home health aides, personal care aids and other types of human services workers.

Thank you for your time, attention and consideration. We appreciate your advocacy and support.

Sincerely,

A handwritten signature in black ink, appearing to read 'D. Bielemeier', with a stylized flourish at the end.

Drew Bielemeier  
Senior Vice President of Operations  
Heritage Christian Services



September 14, 2021

Senator John Mannion

Standing Committee on Disabilities

Dear Senator Mannion:

Starbridge has been serving individuals with disabilities and their families for 40 years. I write to you today in support of services for individuals with I/DD in particular. I hope that your committee will advocate for continued and enhanced support for these services.

Well before COVID, our service systems was struggling. Continued funding cuts over at least ten years have led to tremendous difficulty in recruiting and retaining staff. COVID, of course, has made matters worse. Even a \$15 per/hour pay rate (which Starbridge has implemented) is not enough to attract and retain employees. Now the new vaccine requirements for Medicaid-funded organizations will further challenge agencies like Starbridge to retain employees.

Ultimately, of course, the lack of adequate staffing and supports creates deleterious outcomes for those we serve. Specifically, I urge you and the Standing Committee to advocate for the following:

- Immediately pass and implement Assembly Bill A.6329
- Immediately pass and implement Assembly Bill A.8091
- Fully fund 853 and 4410 schools
- Institute an annual 2% COLA increase
- Pass and fund Assembly Bill A.8229

Thank you for your consideration.

Sincerely,

Colin Garwood

President/CEO Starbridge





To Whom it May Concern:

The incomparable Horace Mann was quoted as saying "be ashamed to die until you have won some victory for humanity". As a young man, still figuring out what I wanted to do with my life some twenty years ago, I came across this quote and it resonated with me on a fundamental level. Since then, I have kept it close to me, looking wherever I can to advance the common cause of my fellows no matter their circumstances. I pursued higher education with the intent of teaching, reasoning that was one of the best ways that I could make a positive influence in the world and help others. Life has its own ideas, and I found myself working as a direct support professional (DSP) in a residential IRA in order to help pay the bills while going through school. It was through this unexpected set of circumstances that I found my mission in life, and my plans to teach high school became instead a passion to help the most vulnerable.

The field to which I have dedicated much of my adult life and indeed all of my professional energy for over a decade is one measured by incremental progress and small victories, ones that are on the most personal level, the very tangible victories of which Mann spoke. I feel pride in the work my colleagues and I do every single day, no matter the challenges we face, because we care about the mission, and we care about the people we help live their most fulfilling lives.

It is also a field that is very much at a crossroads. It is hard to understate the level of crisis that my agency and others, across the state and indeed across the nation, are facing at this moment. Staffing levels, which had been strained prior to the COVID-19 pandemic, have now reached critical levels. Programs are operating with the bare minimum of critical care staff, providing absolutely basic care to citizens in need; nowhere near the level of care that they deserve. New York, decades ago, made a promise to our most vulnerable, that we would not allow their care to be neglected, that they would not be forgotten or left behind. Yet we are in danger of allowing that to happen, not through the efforts of our staff, who work day and night, but simply through a dearth of resources..

Nobody gets into our field to get wealthy. But the work that every one of our staff does, every single day, providing a meaningful life to our fellow citizens, demands a level of responsibility, of foresight, of training, beyond minimum wage jobs. The relative worth of a DSP is far beyond minimum wage work. It requires skills and specifications beyond entry-level qualifications, and as a result the compensation for that work needs to be better. This is not to denigrate minimum wage work-many of us have held retail jobs, worked in restaurants, and the like. That work is important to the function of our economy. But the work that our staff does is equally important economically and arguably far more important *morally*.

We have a collective responsibility as New Yorkers to take care of our own, and we simply cannot do it any more with the resources at hand. Our DSPs deserve better pay for the awesome responsibility that they hold in their hands each and every day. Our staff aren't paid enough to affordably live in their own communities. Long Island is an expensive place to live,

and our individuals rightly want to live near their families-but who will care for them if there are no staff who can afford to work at the wages offered?

We need more funding-simply because *they* need reinforcements. The well is dry. There is no great reservoir of new staff coming as help, to allow us to give the people that we support the quality of care that they richly deserve. Our field is critically understaffed. Our agencies need more resources to attract the kind of generous, hardworking people who could provide the care that the population we serve deserves.

We need the resources to adequately compensate the heroes that have stood by them through the greatest public health crisis in a century. Much ado was made during the pandemic of front-line health care workers and others in positions such as our DSPs, who continued to provide absolutely essential services during the crisis. Our individuals did not "go home". We, for the most part, didn't have the option to simply work from home. Our DSPs were in congregate home settings, caring for the people that were their responsibility, even as we didn't truly understand how COVID-19 spread and guidelines from OPWDD and the CDC changed rapidly. Indeed, early on in the pandemic, when there was a critical shortage of PPE, we went without, as supplies went to hospitals and our staff were forgotten.

While my current role is primarily to provide clinical support to our programs, I provided coverage in our houses to provide support where I could, in some cases covering for front-line workers who had fallen ill. In one case early on, we weren't even aware of the importance of wearing masks indoors yet-but the house had already had several staff fall ill, and we needed all hands on deck to cover. The remaining staff on-site were working double shifts five and six days a week to make sure those under their care stayed safe. They never stopped caring.

It is now the responsibility of us as a people, as a state, to show that we care about them. They are burnt out. They're demoralized. They're criminally underpaid. They need help. Help that Albany can help provide. In the strongest possible terms, I respectfully urge this body to do whatever it can to increase the reimbursement rates agencies receive in order to pay Direct Support Professional and other staff their relative worth, so New York workers doing important work can live comfortable lives and New York citizens can get the care and support they deserve and our code of ethics demands they receive. Let us all win a victory for humanity and do the right thing, as quickly as possible. The alternative is too terrible to contemplate.

Thank you for your time and consideration.

-Garrett Petersen, MS Ed  
Stony Brook '08, Dowling '12