The High Cost of Low Wages

A decade's worth of neglect in Consumer Directed Personal Assistance

A report by the Consumer Directed Personal Assistance Association of New York State

February, 2017

This report was made possible thanks to the work of the Consumer Directed Personal Assistance Association's Consumer Advisory Workgroup, made up of individuals from around the state who utilize CDPA. The members of the group are Kendra Scalia, who drafted the survey and did extensive work helping analyze results, Ed Sperling, Thomas Grimes and John Stucki. Ane Mathieson, a policy fellow from the Center for Women in Government, was responsible for additional data analysis and authoring the report.

CDPAANYS appreciates the efforts made by all of those involved in this effort.

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Executive Summary

Consumer directed personal assistance (CDPA) is a Medicaid program that serves as an alternative to traditional home care services that allows people with disabilities and seniors to take charge of their own services by recruiting, hiring, training, supervising and terminating their own workers, called personal assistants (PAs). The consumers then work with a Fiscal Intermediary (FI), who collects employment records, processes payroll, offers worker's compensation and other insurance for the PA and provides the consumer with support as needed.

CDPA is an extraordinarily successful program that saves Medicaid over $150 million per year, but more importantly, it allows people with disabilities and seniors to stay in their homes and empowers them to direct their own care.

However, due to a decade's worth of neglect, the future of this program is more tenuous than ever. Stagnant or falling reimbursement has led to wages that have not increased in a decade, and in some instances have decreased. Consumers are unable to hire and retain quality workers who are willing and able to work for the low wages paid in CDPA.

The Consumer Directed Personal Assistance Association of New York State (CDPAANYS) conducted a statewide survey to determine the extent of the workforce crisis and its impact on both those who rely on the program and those employed by it. The data confirms that consumers are struggling to recruit and retain PAs because workers are unable to provide for basic living expenses on the wages being offered in this state Medicaid program.

"It is a shame that Governor Cuomo grandstands to give "living wages" to fast food attendants while ignoring the critical service PAs provide to families. I am a 46 year old father of two teenage boys whose wife has ALS. The care of my wife is more important than my service at McDonald's and the Governor should be ashamed of himself for not acknowledging that in their wages."

-Survey Respondent

The findings are telling:

- Twelve percent of respondents said it took longer than six months to hire a worker. Five percent of those indicated it took longer than a year.

- One-quarter of CDPA consumers reported supplementing the wage paid by the Medicaid program because they could not attract or keep workers at the wage offered.
- Over half of the workers who quit did so because of low wages. Two-thirds of those who quit did so because of either low wages or too few hours, indicating that consumers with low hours are particularly impacted by the low wages.
- One-third of respondents indicated that their workers had never received a raise. Another 20% indicated that wages had decreased.
- Nearly three out of every five personal assistants request a pay raise either sometimes or frequently.

Because CDPA is a Medicaid only program, wages are a direct result of reimbursement. FIs traditionally have a 10% administrative rate, meaning $0.90 of every dollar the agency receives goes to wages or legally required expenses such as workers compensation, payroll taxes or unemployment insurance. Traditional home care agencies are allowed administrative costs up to 28%.

Therefore, solving this problem requires additional reimbursement and new rules on managed care plans that require sufficient reimbursement to providers in order to pay adequate wages. To that end, CDPAANYS has joined the Real Lives, Real Jobs campaign, which is looking to solve the workforce crisis in home care and CDPA (www.reallivesrealjobs.com).

To do so, the campaign recommends that the State:

- Raise and fund the wage of personal assistants to at least the fast food minimum wage by October 1, 2017;
- Create a high need community based rate cell to ensure that the rates received by managed care plans is sufficient to pay for those who need the most services and ensure there are standards in place to make sure those funds get to FIs and workers; and
- Create a Stakeholder Workgroup co-chaired by the Department of Health and the Department of Labor to examine the necessary wages and other forms of compensation that will resolve the workforce crisis in CDPA and home care.

Background

As a Medicaid alternative to traditional home health care or visiting nurse programs, consumer directed personal assistance (CDPA) allows people with disabilities and seniors who have stable medical conditions to direct their own home health care and skilled nursing services. Consumers recruit, hire, train, schedule, supervise and, if necessary, terminate their own workers, called personal assistants (PAs). When a person is unwilling or unable to perform their responsibilities as a consumer, a designated representative (DR) performs the consumer's responsibilities. A PA can be anyone who is not a spouse, designated representative, or parent of a minor child.

From the inception of the State's CDPA program in 1997 through November of 2011, program growth was slow. In 2003, the program had 1,645 people.[1] Growing by approximately 500-750 people per year, it had 10,285 in 2011, a year before it became a mandatory benefit in managed care.[2]

As the State has moved forward with the continued redesign of the Medicaid system, first through the Medicaid Redesign Team, and then through other initiatives such as the Delivery System Reform Incentive Payment (DSRIP) program, CDPA has evolved as a benefit. With its demonstrable success in achieving the Triple Aim, the service continues to grow at a rate of over twenty percent per year, making it one of the fastest growing industries in the state. Indeed, since the service's move to managed care (including managed long-term care), it is anticipated that the program has doubled in size.[3]

This growth is likely the result of a number of different factors; however, they are easily distilled to one key principle. CDPA is extremely effective at facilitating the goals of the Triple Aim.

Research undertaken since the program's creation in the mid-eighties as a pilot in New York City, and repeated in several other states since then, has demonstrated its ability to increase satisfaction over services delivered through more traditional home care models.[4]

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[1] New York State Department of Health. "Interim Report: Home Health Care Reimbursement Workgroup." December, 2009. https://www.health.ny.gov/facilities/long_term_care/reimbursement/archive/hhc_workgroup/docs/hcrw_interim_report.pdf. Accessed on September 23, 2015.

[2] Department of Health. Presentation of Mark Kissinger to the MRT Managed Long Term Care Implementation and Waiver Redesign Work Group. "Long Term Care Waivers and State Plan Services." July 8, 2011.

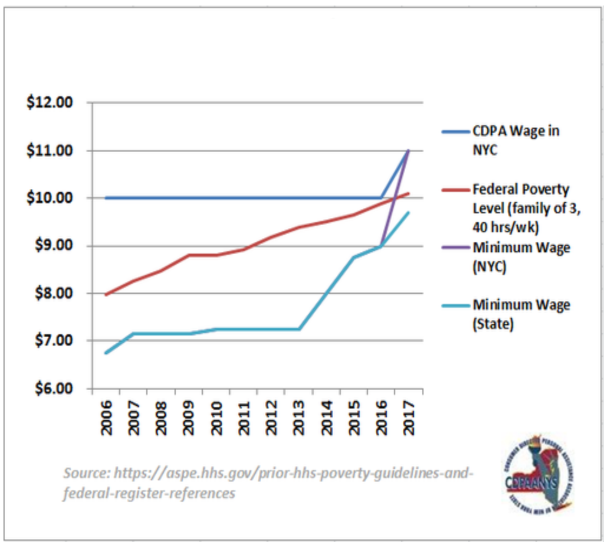
[3] Based on estimates using CDPAANYS members as a percent of the industry as a whole, assuming CDPAANYS members accounted for 75% of services.

[4] Benjamin, A.E., Ruth Matthias, and Todd M. Franke. "Comparing Consumer-directed ad Agency Models for Providing Supportive Services at Home." *Health Services Research*. 35(1), Part II. 351-66. April, 2000.

Studies also report significant reductions in unmet need, increases in patient safety and an improvement in outcomes.[5,6]

Despite the service's rapid growth, its ongoing success is threatened by an ever increasing workforce shortage. PAs in CDPA, who provide critical services to seniors and people with disabilities, used to make over 150% of the minimum wage. Years of neglect by Medicaid and the unwillingness of the Department of Health (DOH) to ensure adequate reimbursements to providers have left fiscal intermediaries (FIs) fighting for scraps just to stay at minimum wage. The increases that came with the 2017 minimum wage increase represented the first raise many workers received in a decade (*see* Fig 1).

Fig 1. CDPA Wages in NYC vs. Federal Poverty Level, Minimum Wage



The stagnant wages paid in CDPA stand in stark contrast against the steady increase not only of the state minimum wage and the wages of what used to be lower wage industries, but also the federal poverty level. In fact, if not for the minimum wage increase, which requires pay of at least $11.00 per hour in New York City, workers would be making less than the federal standard for poverty this year. Throughout Upstate, with its minimum wage of $9.70, thousands of PAs are now making this sub-poverty wage.

Just as many workers received their first raise in a decade, thousands of other PAs have seen their wages go down over the past six months. Cuts of over $1.50 per hour by Fidelis, and over three dollars per hour by GuildNet, NorthShore-LIJ, and most recently, AgeWell, have resulted in PAs on Long Island and in Westchester having their wages reduced from $13.13 per hour to $11 or less.

This problem is only made worse by the fact that fast food workers, who used to be in a lower wage category than PAs, now have a guaranteed wage $1.00 higher than the PAs' wage in New York City and $1.05 higher through the Upstate counties. In Upstate counties, this gap will continue to grow until 2020 when fast food workers will reach $15 per hour and PAs, if nothing changes, will be frozen at $12.70, a difference of almost $5,000 over the course of a year.

[5] Ibid.

[6] Robert Wood Johnson Foundation. "Choosing Independence: A summary of the cash and counseling model of self-directed personal assistance services." Spring, 2007.

It does not have to be this way. According to the Bureau of Labor Statistics, the average wages paid to personal care aides (including PAs in the states' self-directed programs) are higher in neighboring states. Personal care aides working in Connecticut, Massachusetts, and New Jersey were paid better than personal care aides and PAs working in New York State (*see* Fig 2). The lowest of these three states, Connecticut, averages $0.71 per hour more than New York. New Jersey, the most reflective of the New York City Metro market, pays $1.52 more per hour.

Despite the ability of those using the program to use family as members in their workforce, it is becoming increasingly difficult to recruit and retain workers. Some consumers do not have family to use, or do not want to do so in order to maintain boundaries. In many cases, even family cannot afford to perform this work, as they still have financial obligations that need to be met.

Therefore, consumers cannot hire new staff, and they are losing the staff they have. They deserve better than losing their workers - and their ability to live in the community - because fast food and retail pay more. Their workers deserve respect for the important work that they do, which often involves complex nursing services such as ventilator work, suctioning and medication delivery.

In the fastest growing sector of the workforce, people are unwilling to work for the current inadequate wages.

Jensen is in his mid-twenties and lives in an apartment. He is able to do so thanks to CDPA. Prior to enrolling in CDPA, Jensen was forced to live in a nursing home during his teenage years. Jensen notes, "All of my attendants are being forced to get second jobs because they're being paid low wages through CDPA. Without my attendants, I wouldn't be able to live in my own apartment and do my own thing. If I can't keep attendants, there's a possibility I'll end up being forced back into a nursing home. My attendants deserve to be paid higher wages for the hard work they do. I will lose all my freedom and independence without my attendants."

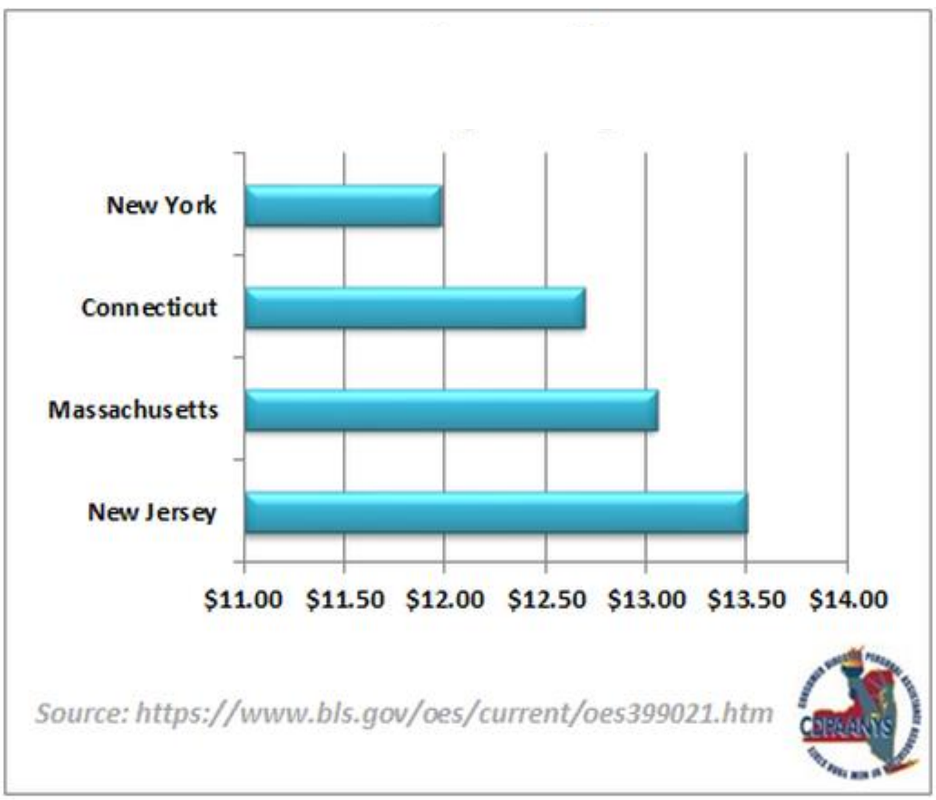
Jensen Caraballo and Wilfredo, who has worked for many years as a PA.

> **"We have lost two fantastic PAs over the last year. Both PAs had families to support and because OT was eliminated, they couldn't make enough to support their families. They got better paying jobs and we have had to hire younger, less experienced PAs."**
>
> -Survey Respondent

To capture the scope of this problem more accurately, the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) surveyed consumers around the state about their experiences with CDPA. In an extensive questionnaire developed by the organization's Consumer Advisory Workgroup, CDPAANYS sought input from those who rely on the program about the impact that wages are having on their ability to utilize it.

The survey was made available from October 20, 2016 through December 1, 2016. It was distributed across the state via e-mail, the Internet, and hard copy mailings, and received 451 valid responses. Surveys were eliminated if the respondent was neither a consumer nor a designated representative within CDPA.

Fig.2 Average Personal Care Aide Wages: New York vs. Neighboring States



Since survey participation was voluntary, different regions of the state had different response rates. The largest number of responses came from Long Island, Westchester and the Capital District. New York City was significantly under-represented as a proportion of the program. This means that the minimum wage increase of 2017, which primarily impacted New York City, had no real impact on the legitimacy of these findings.

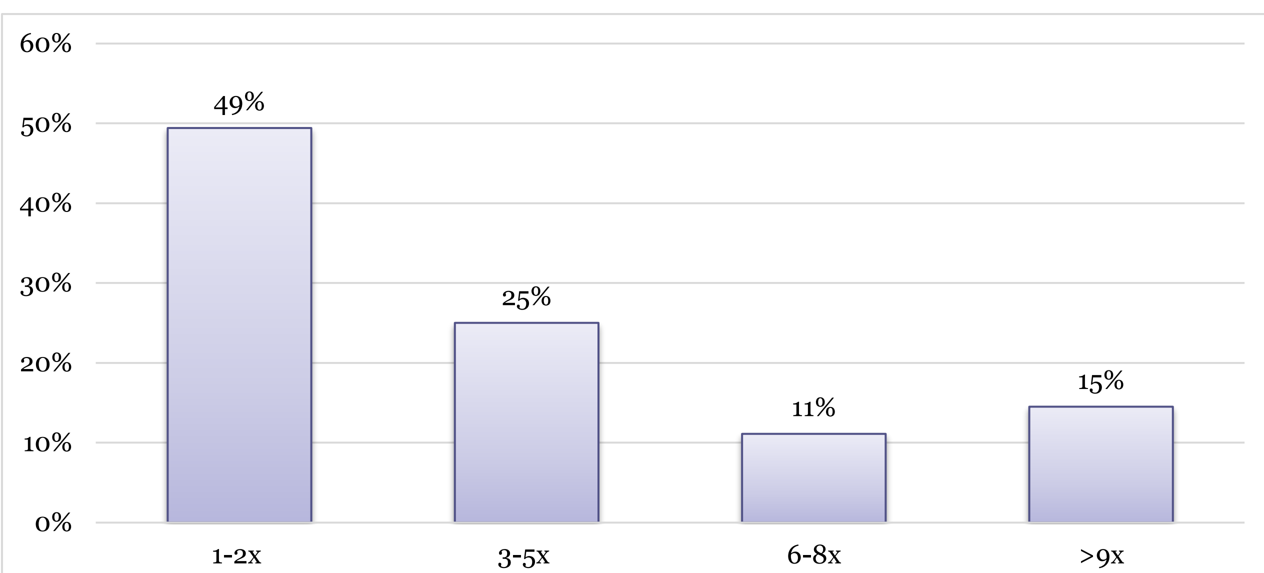
Of the respondents, 285 are female; 161 male; 1 is transgendered; 1 is gender-nonconforming; and 3 did not answer. The racial breakdown of respondents is as follows: 4 Asian American; 49 Black or African American; 349 Caucasian; 1 Pacific Islander; and 12 multiracial. Because the survey was distributed in English only, sampling based on language was statistically invalid. The respondents ranged greatly in age: 29 are under the age of 18; 216 are between the ages of 19 and 59; and 206 are 60 and older.

Findings

Consumers Cannot Recruit or Retain Workers in a Timely Manner

Consumers in CDPA are responsible for recruiting, hiring, training, supervising, and, if necessary, terminating their PAs. For consumers, the length of time from when they begin the recruitment process to when a PA is hired and working can mean the difference between remaining at home and being forced into an institution. Any delay is cause for alarm, and unexpected disruptions in a consumer's workforce can lead to hospitalization, nursing home placement and significant deterioration in the consumer's ability to carry out Activities of Daily Living (ADLs) and Indirect Activities of Daily Living (IADLs).

Fig 3. How Frequently Consumers Advertise Per Year



Recruiting and retaining a high quality workforce is critical for consumers choosing CDPA, and for many consumers the recruitment process begins with advertising for new employees. Of survey respondents that advertised, the majority advertise 1-2 times per year (*see* Fig 3).

A much more disturbing finding, however, is that the remaining consumers are advertising for new attendants much more frequently:

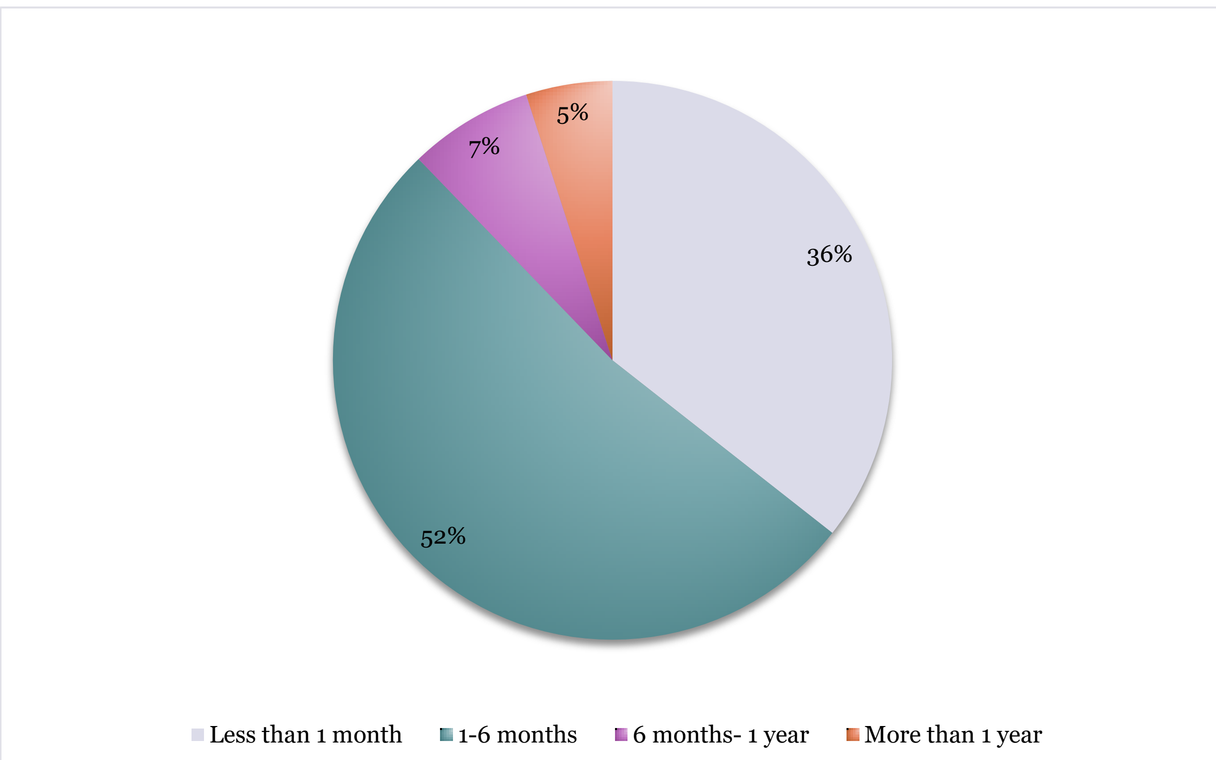
- **25% advertise three to five times per year;**
- **11 % advertise six to eight times per year; and**
- **15 % are advertising nine or more times per year (see Fig 3).**

The strength of CDPA lies in the consistency of the workforce. The relationship built between the consumer and her or his PA grants the PA insight into the consumer's needs. This insight increases the quality of care that only a PA who has been trained by the consumer they work for is able to provide.

"The current pay rate is making it extremely difficult to hire and retain good employees. I have been using the program for 18+years and it is the most difficult it has ever been, directly due to the low pay rate."

-Survey Respondent

Fig 4: Length of Time from Advertisement to Hire



When half of consumers are placing new ads to hire more than five times per year, and one in seven place more than ten ads a year, it indicates that for many PAs, the job is only temporary until they find something that pays more and is less labor-intensive. In some cases, worker quality is so low that consumers are forced to fire them for their own safety. Given the severe implications of interruptions in staff, the decision to terminate a PA is not made lightly.

Consumers are not only forced to hire often; the hiring process is made extremely difficult due to the low wages and difficult nature of the work.

Only slightly more than one-third of consumers are able to hire a new worker within a month (35.6%). For over half (52.2%) it takes one to six months to recruit a new PA. Nearly one in ten consumers (7.2%) are without adequate staffing for six months to one year. In perhaps the most telling result, for five percent, or 1 in 20 CDPA consumers, it takes over a year from when they post an advertisement to when they are able to attract and hire a worker (*see* Fig 4).

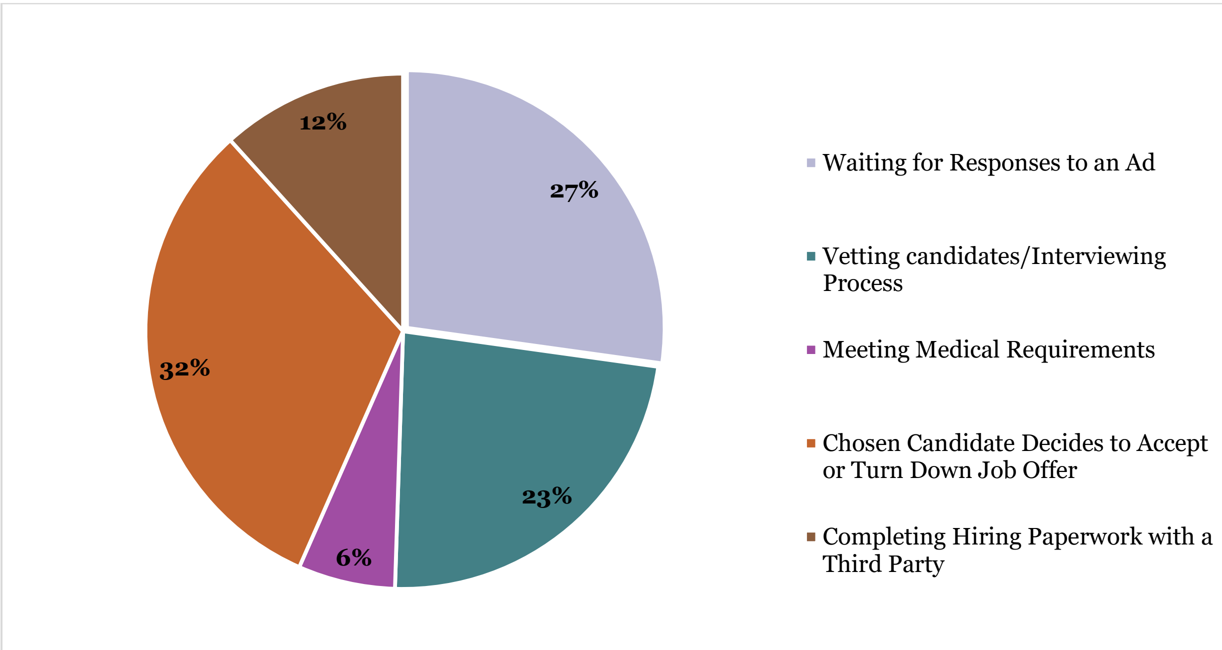
In nearly all industries, being short-staffed places employers in a difficult position. In CDPA, being short-staffed means consumers cannot get out of bed in the morning. It means they do not eat. It means their catheters back up because the bag has not been changed. It also means that other PAs are forced to work longer hours and cover additional shifts, which can lead to a greater potential for injury of both the consumer and the PA – if overtime is allowed.

Many consumers who are short-staffed find themselves in a catch-22 when it comes to overtime. Most fiscal intermediaries (FIs) are not adequately reimbursed to pay time and a half for overtime hours, so PAs must limit the number of overtime hours they work. Consumers who cannot find enough PAs to work without going over the allotted overtime hours are threatened with discontinuation of service by their FI, who cannot sustain operations when too much overtime is worked and therefore cannot afford to jeopardize services for hundreds or thousands of others.

All of these issues are directly linked to the low wages in this industry. When respondents were asked to identify which part of the hiring process took the longest, one-quarter noted that waiting for a response to their advertisement was the longest part of the process (*see* Fig 5). Another quarter indicated that vetting candidates was the most time-consuming process, meaning that the candidates who apply are not qualified or capable of doing the work. One-third indicated that having prospective PAs choose to accept the job took the longest, which means that PAs who are qualified, once offered the job, decide to turn it down.

The need to supplement wages means that one out of every four consumers are unable to attract qualified workers who will accept the job at the wage offered. With such compelling issues caused by low wages, any economist would tell the employer to raise wages. Unfortunately, due to the low reimbursement to FIs, the State and managed care plans are the only ones who can raise wages, and there has been consistent unwillingness to do so. Therefore, consumers continue to struggle to attract quality workers to this field.

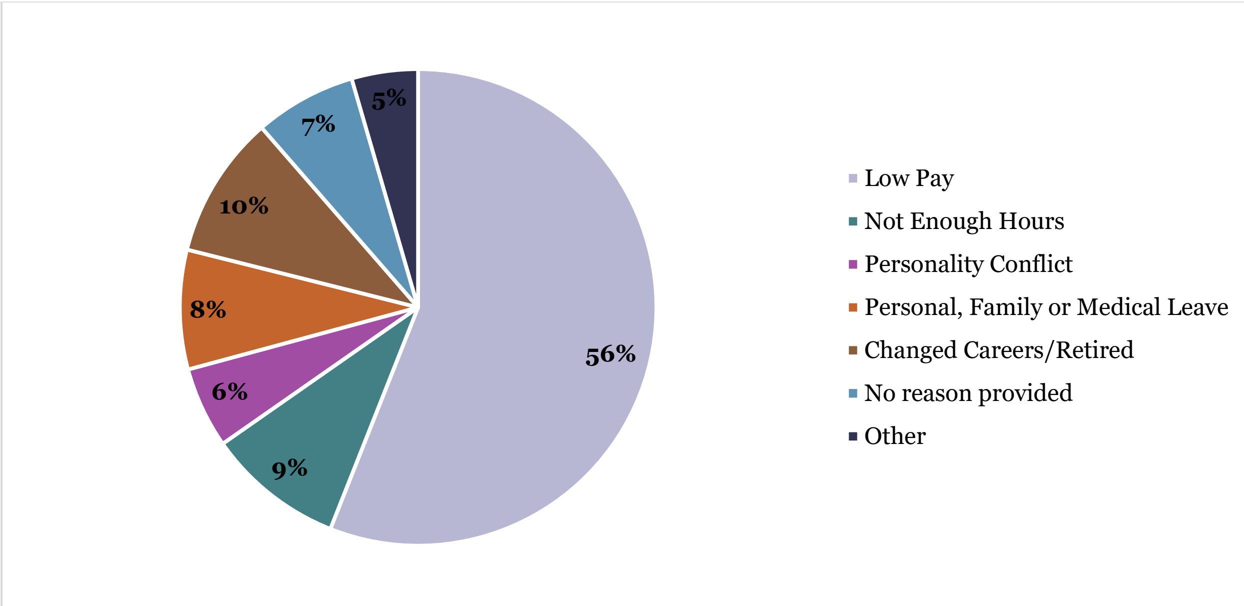
Fig 5. Hiring Process: What Takes the Longest?



Of PAs that quit, over half (56%) do so because the pay is too low. This in and of itself demonstrates that the wages offered are inadequate for the work that is expected. Furthermore, an additional one in ten quit because they do not receive enough hours (*see* Fig 6). It is clear that low pay is a major, if not the single greatest, factor impacting the ability of consumers to hire and retain workers.

If PAs are quitting because the wage is insufficient to work low hours, then those consumers who do not need forty hours a week from a PA will have a particularly difficult time hiring. Consumers' health and abilities degrade rapidly without adequate care, which ultimately leads to the need for significantly higher hours more rapidly than would otherwise be necessary. As the state pursues Value Based Purchasing and DSRIP, raising costs due to insufficient reimbursement and wages is counterproductive.

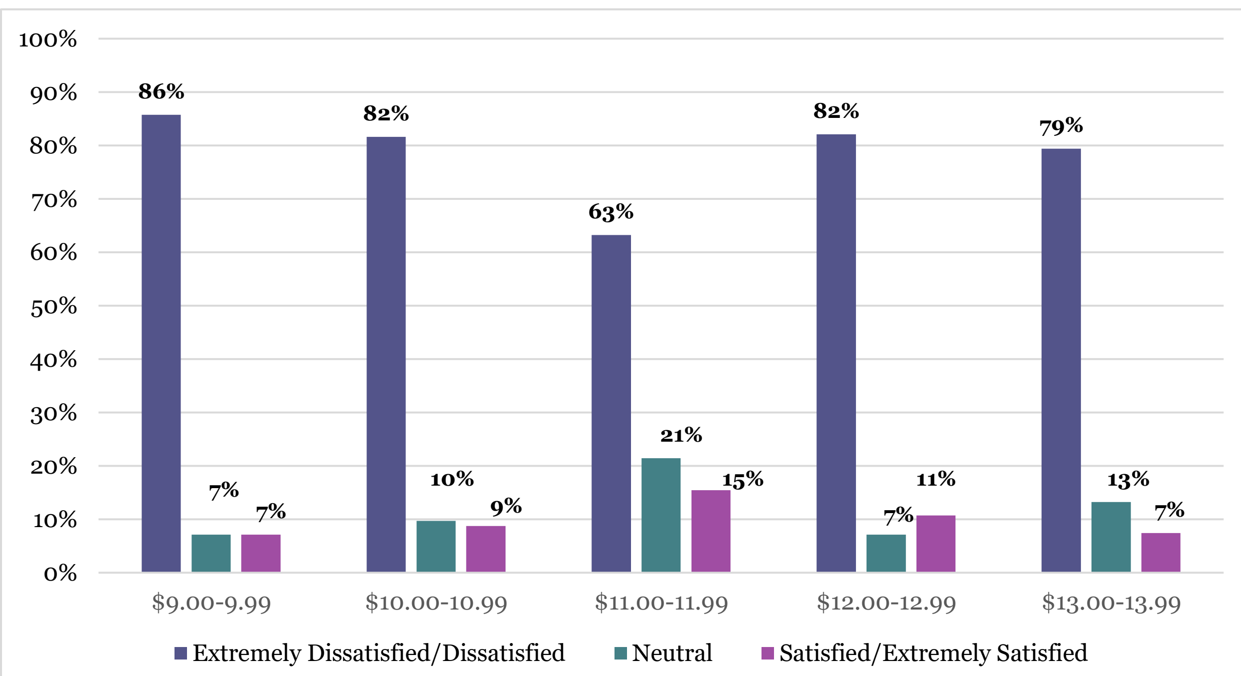
Fig 6. Of Those PAs that Quit, Reasons Given for Quitting



Current Wage and Benefits Packages

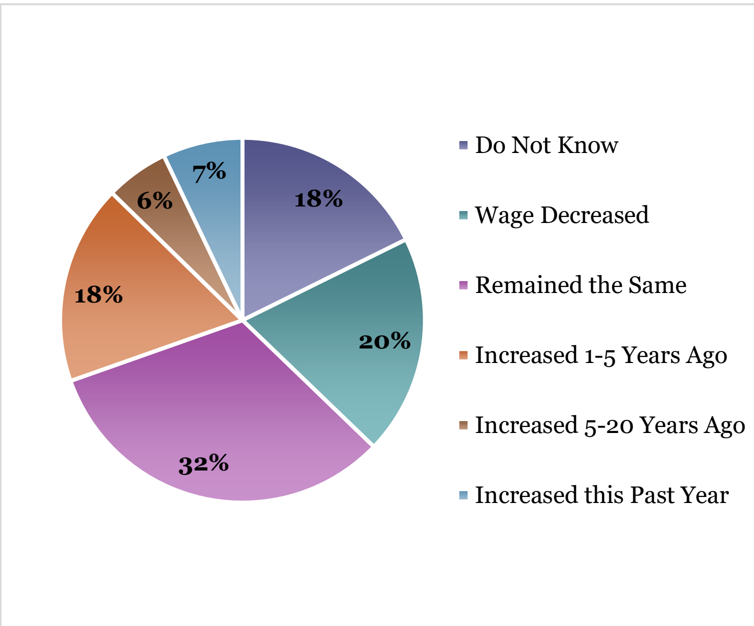
Unsurprisingly, across pay ranges, consumers indicated high rates of dissatisfaction with the wage and benefits packages provided to their PAs (*see* Fig 7).

Fig 7. Consumer Satisfaction with Current Wage and Benefits Package Provided to PAs, Across Wage Ranges



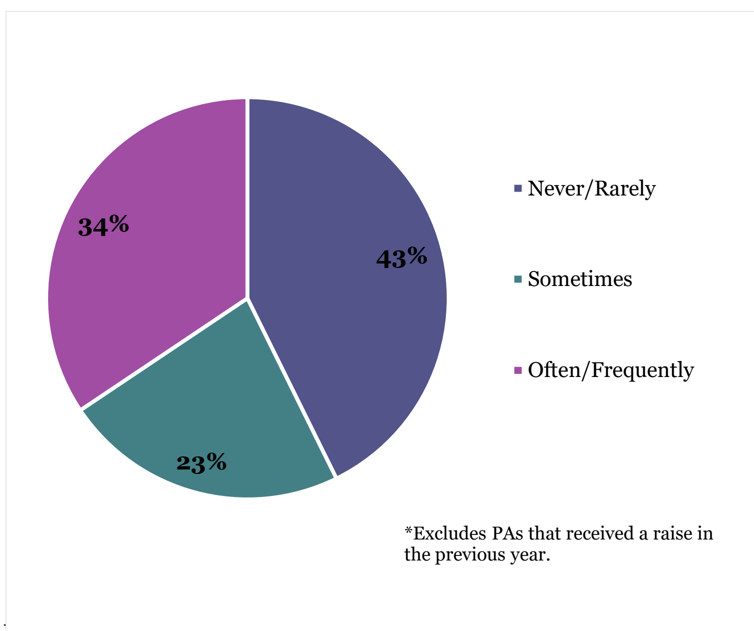
While at first glance it may seem counterintuitive that such a high percentage of people at the $13-$13.99 per hour wage are dissatisfied with their pay, it must be taken into account that individuals in this pay range live in Long Island and Westchester, areas that have some of the highest costs of living in the country. Similarly, when the dissatisfaction rate is compared against the last raise received by the worker, it becomes clear that the lower dissatisfaction rate among those who earn between $11 and $11.99 per hour can be attributed in large part to a modest increase in wages from one FI to workers in the Capital District.

Fig 8. Last Wage Increase Received by PAs



PAs' dissatisfaction with the wage is indicated by the frequency with which they request a raise or more hours. Almost one-third of consumers (34%) reported that their PAs often or frequently request a pay increase or more hours. Another 23 percent sometimes request a pay increase or more hours. In all, over half of PAs ask for a raise or more hours on a consistent basis (see Fig. 9).

Fig 9. Frequency that PA Requests More Hours or Pay Increase



Requests for higher wages reflect only part of the story. In fact, the biggest explanation of why PAs consistently ask for a raise may be that they have never had one.

In response to the question, "When was the last wage increase received by PAs under the consumer's program?" one-third of consumers indicated that wages for their PAs had remained the same. Six percent of consumers indicated that the last time their staff received a raise was over five years ago. Even more appalling is that 20

> "Since the decrease in wages I now must pay $400 a month out of pocket. This has severely impacted my finances. My aide would have left if I didn't supplement her salary…and NO ONE will work for $11/hour."
> -Survey Respondent

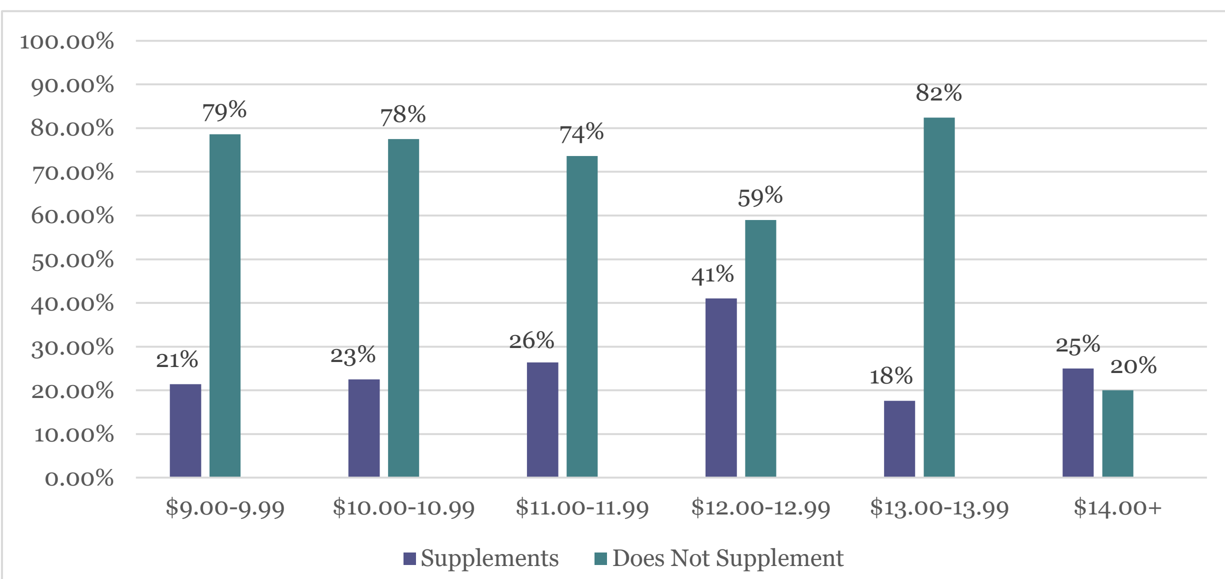
percent of consumers actually saw their workers' wages decrease (see Fig 8).

The impact of low wages is most dramatically illustrated in the number of CDPA consumers who are forced to supplement their workers' wages out of their own pocket. One in four consumers reported that, in order to recruit new staff or retain those they already had, they provided their staff with additional pay out of their own pocket.

This occurs despite the fact that most consumers themselves are on very limited incomes. While supplementing is not technically allowed, it is apparent from this survey that many consumers feel obligated to supplement to either recruit or retain their PAs.

In any other sector of Medicaid, the notion of co-pays is considered a Medicaid cut. Policymakers have traditionally been loathe to institute such measures, and they are voluntary where they exist. Yet in CDPA, many consumers must pay an hourly co-pay on their services (see Fig 10). Not only is the notion that Medicaid recipients need to pay money out of their own pockets to hire and keep workers inappropriate; it also results in unreported income. The State, through neglect of this system, has created a grey market that is exempt from taxes, workers compensation, benefits and more.

Fig 10. Consumers Supplementing Wages across Pay Ranges



Recommendations for Achieving Better Long Term Care

CDPAANYS is part of the Real Lives, Real Jobs campaign (**reallivesrealjobs.com**), which recently came together to seek policy initiatives to address the workforce crisis in both home care and personal care. To that end, we advance the recommendations of the campaign, which include the following:

- **Raise and maintain the wage of personal assistants to at least the fast food minimum wage by October 1, 2017**. Everyone deserves a living wage, and CDPAANYS does not begrudge fast food workers the right to earn a wage they can live on. That said, it is unacceptable that the State feels the critical services performed by those who keep our parents and our loved ones at home–living as high a quality of life as possible, in an integrated setting–are paid over a dollar less than those who work in fast food. The State must immediately address this by infusing more money into the system to allow all workers to be paid at least what those in the fast food industry are making by October 1, 2017, and index the wage so that it remains at that level until further reforms are put in place. This proposal will cost $21 million in 2017, but will cost less if the system is restructured properly as outlined below.

- **Create a high need community based rate cell to ensure that the rates received by managed care plans are sufficient to pay for those who need the most services and ensure there are standards in place to make sure those funds get to FIs and workers.** Wages for many PAs have been reduced because of dramatic reimbursement cuts from managed care plans. These cuts were made because the capitation model that the State uses to pay plans is broken. If a plan has a large percentage of individuals who use over 12 hours of services per day, the existing capitation model cannot account for it. This model also allows a plan that keeps its number of high need individuals low to reap a large financial windfall.

  A high need rate cell will restructure capitation in a manner that ensures that the State adequately reimburses plans for the services they deliver. If the State wants to stand by its promise to honor the Supreme Court's *Olmstead* decision, establishing an individual's right to live in the least restrictive setting possible, it must appropriately fund the services that allow it. This proposal would not cost any additional money, and would merely reallocate the funding that is already in the system in a manner that more accurately reflects costs.

- **Create a Stakeholder Workgroup co-chaired by the Department of Health and the Department of Labor, to examine the necessary wages and the necessary minimum reimbursement that will resolve the workforce crisis in CDPA and home care.** The decade of neglect imposed on CDPA and home care has put this industry in a crisis. The workers exist, but they are unwilling to do the job for the inadequate wages offered today. As the Baby Boomer generation continues to age, the need for this workforce will grow at a faster rate. The 20% per year growth rate CDPA is experiencing will not end anytime in the near future. This means that efforts must be undertaken now to resolve this crisis and invest in those who provide critical services to our seniors and people with disabilities.

  The Department of Health and the Department of Labor together hold significant expertise on the issues that must be considered to effectively deal with this crisis. A workgroup chaired by these two agencies and including CDPAANYS and other critical stakeholders will be able to examine the issue in depth and develop further recommendations as to wages and other benefits that are necessary, on a regional basis, to recruit and retain a highly qualified workforce to this field.

Conclusion

CDPA represents a policy victory for the State of New York. This program, created in New York City in 1979, has served as a model for the country and is currently experiencing rapid growth as people with disabilities and seniors in need of long-term care realize the benefits of the flexibility that the program offers. The State also enjoys the program's ability to meet the Triple Aim.

Without immediate action, the future of this program, and that of thousands of people with disabilities and seniors across the state, is threatened. A program without a workforce cannot survive, and a decade of neglect has placed this program in a precarious position. If we do not act now, the time to act may very well pass, and the consequences will be devastating.

> *"…aides are entrusted with the care of our loved ones. To get qualified people for these positions I think you have to pay them a proper wage that reflects responsibilities that are placed on them in their care giving duties. I find it appalling that we are going to pay people $15 an hour to flip hamburgers, but pay a substandard wage to care for the most important people in our lives, our parents, grandparents, spouses, children and loved ones."*
>
> *-Survey Respondent*