The High Cost of Low Wages

The disregarded impact of balancing a budget on the backs of the disabled

Developed by
Pax Ratio, Inc.

on behalf of
Consumer Directed Personal Assistance Association of New York State (CDPAANYS)

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Executive Summary

Consumer Directed Personal Assistance (CDPA) is a vital long-term care service for tens of thousands of people with disabilities and seniors in New York. This program is intended "to permit chronically ill and/or physically disabled individuals receiving home care services…greater flexibility and freedom of choice in obtaining such services."[1] It allows those who utilize it, called consumers, to select, schedule and otherwise supervise their own personal assistants (PAs). In addition to providing consumers with dignity and choice over who assists them with intimate personal care needs, CDPA saves the state hundreds of millions of dollars annually compared to costs of similar services in the community. Institutional services for this population, in addition to violating the Supreme Court's *Olmstead* decision, would cost over a billion dollars more per year. The program, however, remains under attack not only from a national home care industry workforce shortage crisis of which New York is the epicenter; but also, from draconian cuts imposed by the state in an effort to curb Medicaid costs, with the most recent coming during this budget in the midst of the global coronavirus pandemic.

In February 2017, the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) first published results from a statewide survey collecting data from CDPA consumers on the health of the program. The value gained from this data proved useful to advocates and government officials in better understanding the needs of consumers. Given the recent aforementioned cuts, CDPAANYS reissued the survey in Fall 2019 to gather updated data on the landscape of CDPA.

What the survey data shows is remarkable. Not only were data points consistent between the two surveys across all areas of questioning, where differences occur trend equally to what we would expect to see with continued difficulties related to recruitment and retention, and PA wages and benefits.

Consumers reported advertisement rates at near identical levels in the 2017 report. The only changes were to the lower two rates, 1 to 2 times per year and 3 to 5 times per year. Less individuals posted 1 to 2 times per year, yet nearly the same number of individuals posted more 3 to 5 times per year. This indicates an increasing hardship on consumers to fill positions, as they are posting slightly more frequently than just three years ago.

We see a parallel trend in length of time to hire, taking slightly longer than in years past. The data eliminates fiscal intermediary (FI) inefficiencies for any responsibility in the increased hiring length. In fact, consumer experience of FI accountability as the lengthiest part of the hiring process significantly declined from 12% in 2017 to just 2%.

Workers continue to cite low pay and inadequate benefits as the number one cause for

[1] New York Social Services Law § 365-f (1).

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leaving their employment. And, although minimum wage increased across the state in the past three years, six per cent of PAs wages have dropped.

Additionally, this current survey iteration tracked changes occurring during and after the implementation of per member per month (PMPM) administrative reimbursement rate cuts temporarily imposed by the Department of Health (DOH) on September 1, 2019. As advocates had maintained for many months prior, PMPM imposed a direct impact on workers' wages and benefits, and consumers themselves.

Per member per month was directly responsible for wage decreases to at least 5,500 PAs and loss of overtime benefits for 1 in 5 workers. For many, the court's decision to order PMPM null and void did not revert course. A continuation of PMPM, as currently proposed in rulemaking, will see these impacts, which occurred over just a six-week period, expanded. It will decimate CDPA and the very lives of those who depend on it to survive.

Contrary to claims that fiscal intermediaries (FIs) are *just* payroll companies, data indicates that the strong majority of consumers receive tremendous value from their FI. Consumers overwhelmingly link their success in CDPA and the community to the support they receive from their chosen FI. Services outside of the scope of payroll support are highly utilized by consumers. Limiting the total number of FIs in operation will disrupt service for thousands of consumers, as transition processes are not seamless. Consumer selection and choice is crucial to their independence and health outcomes.

Based on the findings in this report, CDPAANYS recommends the State of New York:

- Undo budget cuts, particularly the $45 million cut to Home Care Workforce Recruitment and Retention, to recognize and emphasize CDPA as a cost savings program and demonstrate that the workforce is valued as healthcare heroes;
- Raise and maintain the wage of personal assistants statewide; and
- Decline the proposed regulatory amendment that would make per member per month a permanent reimbursement rate structure for fiscal intermediaries.

Workers deserve a wage comparable to the critical services they provide. Higher wages alleviate many of the issues consumers face today, including difficulty recruiting new workers, retaining current workers, and ending out-of-pocket wage subsidies.

Survey results overwhelmingly suggested the 6-week implementation of the PMPM reimbursement cut had a significant and lasting negative impact. Wages declined and benefits were lost. As a result, consumers lost PAs.

Moreover, CDPA has led to Medicaid cost savings. Any changes that further underfund or cut the program will impact the Medicaid budget by shifting and increasing health care costs elsewhere. The state legislature and administration must acknowledge and support this fiscally efficient program for what it is, and pledge to save CDPA.

Background

First designed and developed by New Yorkers with disabilities in the 1980s as a pilot program, Consumer Directed Personal Assistance (CDPA) is an alternative to traditional home care services and remains the only service created by and for people with disabilities. Beginning statewide as a fully-fledged Medicaid program in 1995, CDPA centers the recipient of service as the direct employer and supervisor. This unique model, which now operates in some form across all 50 states, offers consumers more choice, flexibility and control over their home care and, ultimately, health outcomes. Consumers recruit, hire, train, schedule, supervise, and, when necessary, terminate their own employees called personal assistants (PAs). A designated representative (DR) performs the consumer's responsibilities if a person is unable or unwilling to fulfill these duties.

Third-party fiscal intermediaries (FIs) provide professional payroll services and offer a range of other programming and services to supplement gaps in community needs. As CDPA evolved through the Medicaid Redesign Team's (MRT) initial effort, Governor Cuomo's Olmstead Plan, and subsequent initiatives, FI sustainability has often been overlooked at best. The impact of these choices is rarely discussed. Varying reimbursement rates aren't the only outcome to adjusting budget structures. Disabled New Yorkers and their workers under the CDPA program also experience demonstrable effects from these decisions.

The State must shift the way it looks at CDPA and regard it as a vital part of Medicaid cost savings and service provision.

Once again, the State is seeking a solution to Medicaid growth - a direct response to their self-imposed "global cap". The FY 2021 budget reconstituted MRT with the goals of accelerating successful cost saving strategies while creating course corrections to restore Medicaid financial sustainability. MRT II was charged with achieving $2.5 billion in Medicaid savings.[2] However, this time CDPA, and its natural growth given demographic changes, was not overlooked, it was actively blamed and targeted for additional cuts.

The MRT II result enacted over $680 million reform to long-term care costs across FY 2021 and FY 2022, largely within CDPA. While about 20% of the cuts were efficiencies proposed by CDPAANYS, the other cuts are primarily achieved through eliminating eligibility for a wide range of individuals including those who require assistance with one or two activities of daily living (ADLs), and instituting an enhanced utilization review for consumers assessed to need more than 12 hours per day of care. Of course, most relevant to the findings here, the budget cut Home Care Workforce Recruitment and Retention money, funds that must go to wages and benefits for PAs, by $45 million, or 25%.

[2] "Redesigning the Medicaid Program." *Medicaid Redesign Team (MRT) II*, New York State Department of Health.

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Those who may no longer qualify for home care programs will certainly find themselves more frequently at their doctor, in a hospital stay, institutionalized or requiring more pharmaceuticals to manage expanding health issues that could have otherwise been avoided or managed through a personal assistant's daily care. With nursing homes not only more expensive, but currently being described as "death pits"[3], the failure to invest in CDPA is not only bad fiscal policy and a potential violation of the state's obligations under *Olmstead*, it is inhumane.

The State must shift the way it looks at CDPA and regard it as a vital part of Medicaid cost savings and service provision. The ability of fiscal intermediaries to meet administrative and direct care costs without sacrificing services and programs to consumers is crucial to the success of the program. The reality is that the population is changing. More individuals are becoming disabled and require care in order to remain safely in their homes. The success of the program is critical to the ability of the state to meet the ballooning need for these services, a need that will only continue to grow as the Baby Boomer generation continues to age.

The State maintains that any proposed changes will not impact services to consumers. However, it has been clear over the past year that the State not only lacks vital information and data on CDPA but refuses to acknowledge the direct harm their actions do have on consumers.

After a FY 2020 budget session attempt to limit the total number of operating FIs, the state legislature required the Department of Health (DOH) create a FI Workgroup made up of stakeholders to assist the Department in establishing FI best practices, standardization of services, quality indicators and consumer transition protections. The FI Workgroup met four times over Summer 2019. On July 1, 2019, in the midst of the Workgroup discussions, the Department announced a massive cut to FI administration reimbursement rates, effective September 1.[4] Their per member per month (PMPM) restructuring came with no community input and jeopardized the stability of every FI in the state. Even while Workgroup members brought up the PMPM cut, wrote a letter detailing the harm the rates would cause, and repeatedly tried to present factual data to the DOH, its staff shut down conversations regarding PMPM impact. The DOH maintained their position that PMPM would not impact services to consumers despite clear evidence from FIs themselves that rate changes to this degree would necessarily have a direct effect on both consumers and the workforce.[5] FIs pointed to various secondary services for consumers, overtime and other benefits for PAs that would be

[3] Stockman, F., Matt Richtel, Danielle Ivory, and Mitch Smith. "'They're Death Pits': Virus Claims at Least 7,000 Lives in U.S. Nursing Homes". *The New York Times.* 17 Apr 2020.
[4] Managed Care Policy 19.01: Implementation of *Fiscal Intermediary (FI) Rate Structure Enacted in the SFY 2019-20 NYS Budget*. New York Office of Health Insurance Programs Division of Long Term Care, 1 July 2019.
[5] Young, Shannon. "Advocates Protest CDPAP Rate Structure Changes." *Politico*, 8 Aug 2019.

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eliminated and, given that direct care rates were not distinguishable from administrative rates in contracts between FIs and Managed Long Term Care Plans (MLTCs), wages reduced.

[T]he failure to invest in CDPA is not only bad fiscal policy and a potential violation of the state's obligations under Olmstead, it is inhumane.

In July 2019, the Consumer Directed Personal Assistance Association of New York State (CDPAANYS), the New York Association on Independent Living (NYAIL), New York State Association of Health Care Providers (HCP) and other litigants sued the State alleging that DOH violated state laws and regulations in the development of PMPM. By early October, the State Supreme Court submitted its decision to order the reimbursement rate change null and void, with an immediate order to revert reimbursement rates to the previous methodology.[6] Unfortunately, during the six weeks of PMPM implementation, PAs and consumers had already felt the impact.

Since the court's decision, DOH has moved forward in following reimbursement rate regulations. A Notice of Proposed Rulemaking, published December 31, 2019, recommends the same reimbursement rate cuts. According to estimates by CDPAANYS, over 11,000 comments were submitted in opposition to the rule.

Methodology

In response to the growing workforce shortage, CDPAANYS surveyed consumers around the state about their experience with CDPA in late 2016. Those findings were published February 2017 in a report titled *The High Cost of Low Wages: A decade's worth of neglect in Consumer Directed Personal Assistance*. Three years later, CDPAANYS reissued the survey with slight modifications to capture the brief impact of PMPM on consumers and their workers.

The survey was made available November 7, 2019 through December 1, 2019 via the Internet and received 111 eligible responses. Surveys were eliminated if the respondent was neither a consumer nor a designated representative within CDPA. All responses were anonymous.

Survey participation was voluntary and response rates vary across the state. Representation was largest from Western New York and New York City, followed by the

[6] Consumer Directed Personal Assistance Association of New York State, Et. al. v Zucker. State of New York Supreme Court County of Albany. 2019.

Capital District, Long Island and Central New York. The Hudson Valley is under-represented among respondents.

The demographic breakdown of respondents included 55% female, 45% male and 1% did not answer. Caucasians represented 82% of survey respondents, while 4.5% were Black and 3.6% were Multiracial. Asian-Americans, Native Americans and Central Americans equally made up 1% of respondents. Nearly 7% of respondents did not provide their race. Respondents were primarily aged 18 to 64 years old (64%) and 65 years or older (31%) with a smaller representation from minors under 18 years old (5%).

Findings

When CDPAANYS first published this survey in 2017, findings demonstrated concern regarding the length of time it took consumers to recruit and hire new personal assistants, the rate PAs quit their job due to low wages, a lack of raises in wages, and other areas. The results of the current survey vary only slightly from those reported in 2017. Differences between the two demonstrate a shift in worsening conditions across all variables surveyed.

Recruitment and Retention

Critical to the success of CDPA is the consumer's ability to recruit and retain qualified personal assistants. Not only do program rules require consumers to have a sufficient number of workers and backup PAs, without adequate workers, a consumer may be unable to ensure all tasks on their plan of care are met. Should individual cases remain understaffed or a portion of authorized care hours go unused for any length of time, consumers may find themselves unable to perform activities of daily living such as toileting or bathing, which may lead to poorer health outcomes or institutionalization.

> ***"I have had difficulty recruiting staff because I cannot offer them better wages."***
>
> *- Survey Respondent*

For many consumers, hiring sufficient PAs begins with posting an advertisement within their community. The survey asked consumers how frequently they post advertisements during the year. Presumably, rate of advertisement indicates ease of recruitment and retention. Where workers stay in their position for a longer length of time, a consumer's need to advertise decreases.

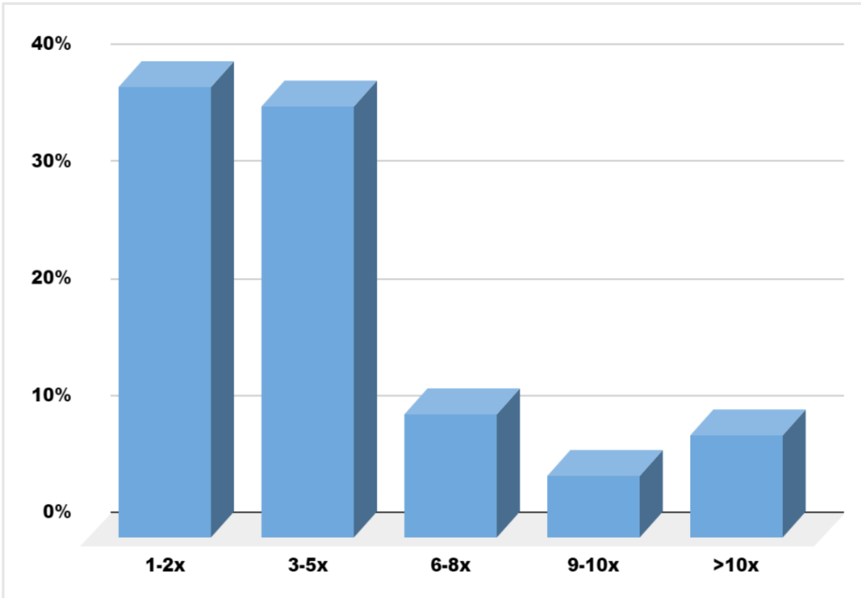
What the survey found is startling. Nearly 25 per cent of those who advertise post an advertisement more than 6 times per year; and, more than one-third of those advertisements occur almost every month (*See Figure 1*).

In fact, consumers post advertisements at the following rates:

Chart 1: Annual Frequency Consumers Advertise

Frequency (per year)	Advertisement Rate
1 or 2	38.6%
3 to 5	36.8%
6 to 8	10.5%
9 or 10	5.3%
> 10	8.8%

Figure 1: Annual Frequency Consumers Advertise



In comparison to the 2017 survey, consumers report similar rates of need to advertise frequently. The only significant rate change appears among those who advertise the least. More than 38 per cent of consumers post 1 or 2 times per year (down 10.4% from 2017) and more than 36 per cent post 3 to 5 times per year (up 11.8% from 2017).

These results speak to the increasing difficulty in recruiting and retaining PAs. As consumers need to post more frequently each year, they are potentially receiving less care or a lesser quality of care. For some consumers, a PA may leave the position before they are able to hire a new employee. These consumers may use informal supports to fill the gap, such as unpaid family or friends. Still, many consumers are seeking to replace a PA that does not meet a standard of care. Until a replacement worker is hired, consumers generally continue to work with a PA they want to otherwise fire. This practice means consumers are often navigating unsafe conditions or dealing with personality conflicts that may rise to the level of abuse or neglect on a regular basis.

Workforce recruitment issues are not unique to CDPA alone. Nationwide a home care workforce shortage has been noted by leading workforce experts. Multiple studies have been conducted to analyze how deeply worker shortages will impact recipients. New York will be the hardest hit from this workforce crisis, and we aren't yet at predicted peak of

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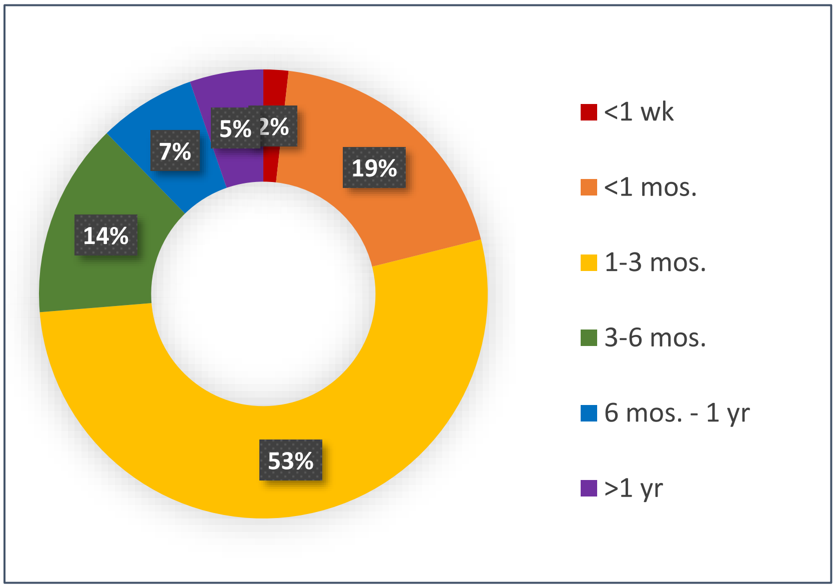
impact.[7] The ability of consumers to recruit and retain a reliable workforce will only become more difficult over the next decade, unless the State steps in to support the growing demand by ensuring worker supply is adequate.

When a consumer does locate a new job candidate, however, the stress and difficulty does not end. Consumers indicate that the time between posting an advertisement and first day of hire has also become longer than in 2017.

Figure 2: Average Length of Time from Advertisement to Hire



We see a significant decline in hiring length within the first month of posting a job advertisement (*See Figure 2*). In 2017, 36% of respondents successfully enrolled a candidate within the first month but most recently just 21% of consumers are able to hire in the same amount of time. With less consumers hiring in the first month, this naturally means it is taking more time overall to recruit employees.

A majority of consumers (53%) recruit and hire a PA within 1 to 3 months. Still, 14% of consumers wait 3 to 6 months to fill shifts. Similar to 2017, 7% of consumers go more than half a year without sufficient help and 5% of consumers are recruiting for more than 1 year at a time.

Placing an advertisement and the first day of work are far from the only steps in the hiring process, and it's important to understand where in the hiring process the most time is spent. Knowing at which stage consumers are struggling may provide insight on how to make the hiring process more efficient.

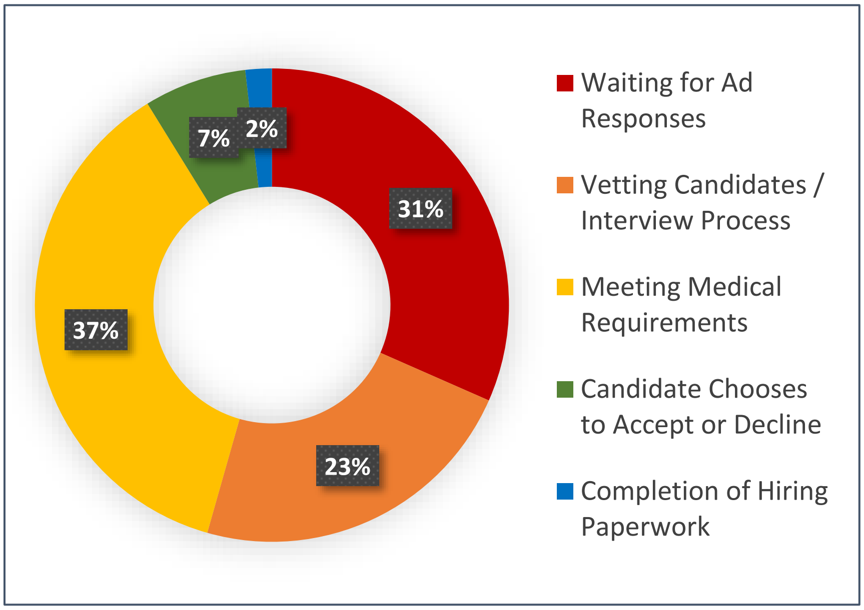
Once again, we see comparable data between the recent survey and 2017 findings. Waiting for a response to an advertisement (31%) and meeting medical requirements (37%) take the most amount of time. Holding steady between the surveys, vetting candidates and the interview process is the most prolonged part of hiring for 23% of

[7] "Demand for Healthcare Workers Will Outpace Supply by 2025: An Analysis of the US Healthcare Labor Market." Mercer HPA, 2018.

consumers, while 7% of others find it to be candidate decision-making time (*See Figure 3*).

FIs are outperforming themselves, ensuring onboarding of new PAs is prioritized. In the last few years, we see a sizable drop in consumers that find completion of hiring paperwork with their fiscal intermediary to be the lengthiest part of hiring, from 12% in 2017 to just 2% today. This may be due to FIs streamlining the process, providing quality peer supports for consumers to better prepare candidates in completing paperwork, or other FI investments that have created efficiencies this survey did not consider.

Figure 3: Hiring Process: What Takes the Longest?



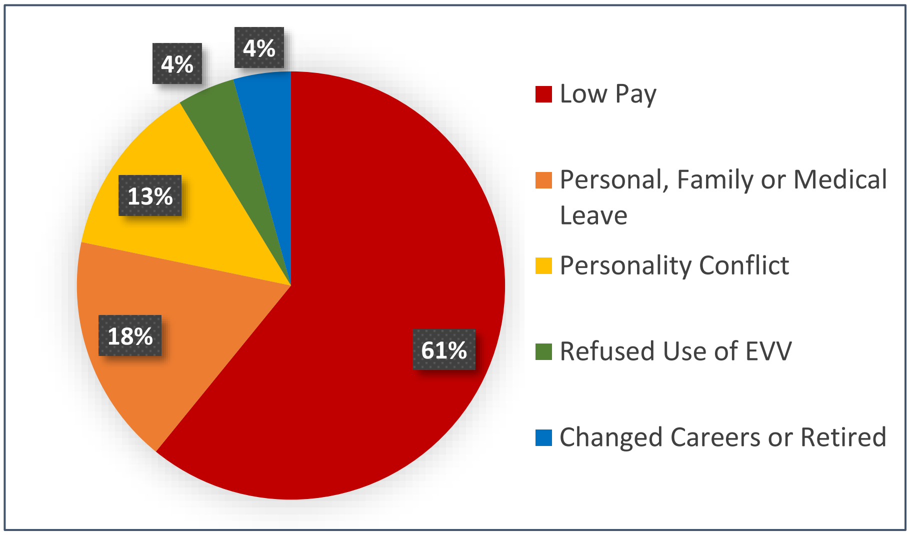
It is clear that when FIs are able to negotiate a sufficient reimbursement rate, funds are invested in the program such that consumers and workers see notable improvement. The data suggests that increased reimbursement rates lead to program efficiencies, which ultimately provides cost savings to the State as consumers are able to receive the care they need more quickly.

Looking at hiring length is only a small part of the larger story on the health of CDPA. On the other end of the spectrum, this survey aimed to capture reasons why workers leave their employment. The survey asked consumers to give the primary reason their last 5 PAs quit.

Similar to 2017 results, the largest reason to leave CDPA employment was related to low pay (*See Figure 4*). Almost two-thirds of PAs feel they are not compensated at an adequate rate and this is reflected through an unusually high rate as to why they leave their job. Although minimum wage has risen more than $2 per hour in Upstate and $5 per hour in NYC since the first iteration of this survey, once again low pay is a major - if not the single greatest - factor impacting the ability of consumers to hire and retain workers. Wage used to be an attractive factor for individuals interested in providing this critical service to disabled New Yorkers. At one time, CDPA jobs were paid at least 150% of the minimum wage in NYC and Long Island, and above minimum wage Upstate. Shrinking reimbursement rates have driven the wage down over time. Now, fast food and most retail jobs Upstate are paid a higher hourly wage, and nearly the same rate downstate.

Of those PAs who quit due to low wages, more than 7% were directly related to PMPM implementation impact on wages and benefits. During the 6 weeks of PMPM implementation, 2.4% quit due to wage decrease and 4.8% cited a loss of overtime wages during the same time period as their primary reason to leave their job.

Figure 4: Reasons PAs Quit



It is extremely disturbing that a policy the State repeatedly has argued has no impact on consumers is responsible for almost one-tenth of provider loss. It is clear that deep administrative cuts to fiscal intermediaries, whether DOH readily wants to admit it or not, has a direct impact on consumers in a serious manner.

We see a sizable increase in PAs acknowledging to consumers that they must end their employment for personal, family or medical leave (from 8% in 2017 to 18% today). This could speak to the state expansion of the Paid Family Leave Act, which provides for 8 weeks of paid FMLA in 2018 and 10 weeks in 2019. Some employees may have chosen to take advantage of these benefits, paid for through a payroll tax, and not continue employment with the same employer upon final payment.

Other reasons provided for leaving work included personality conflicts (13%), refusal of PAs to use electronic visit verification (EVV) systems that track their whereabouts (4%), and a change in career or retirement (4%).

Current Wages and Benefits

When consumers are posed with the question if they are satisfied with the wage and benefit package they are able to offer to candidates, they remain overwhelmingly 'extremely dissatisfied' or 'dissatisfied' (*See Figure 5*). This trend tracks across all pay ranges.

> ***"It is scandalous that CDPA positions have become minimum wage jobs."***
>
> *- Survey Respondent*

Due to low response rates, we do not have sufficient data on those earning \$13.00 - \$14.99 per hour. Between the two wage brackets that fall within this

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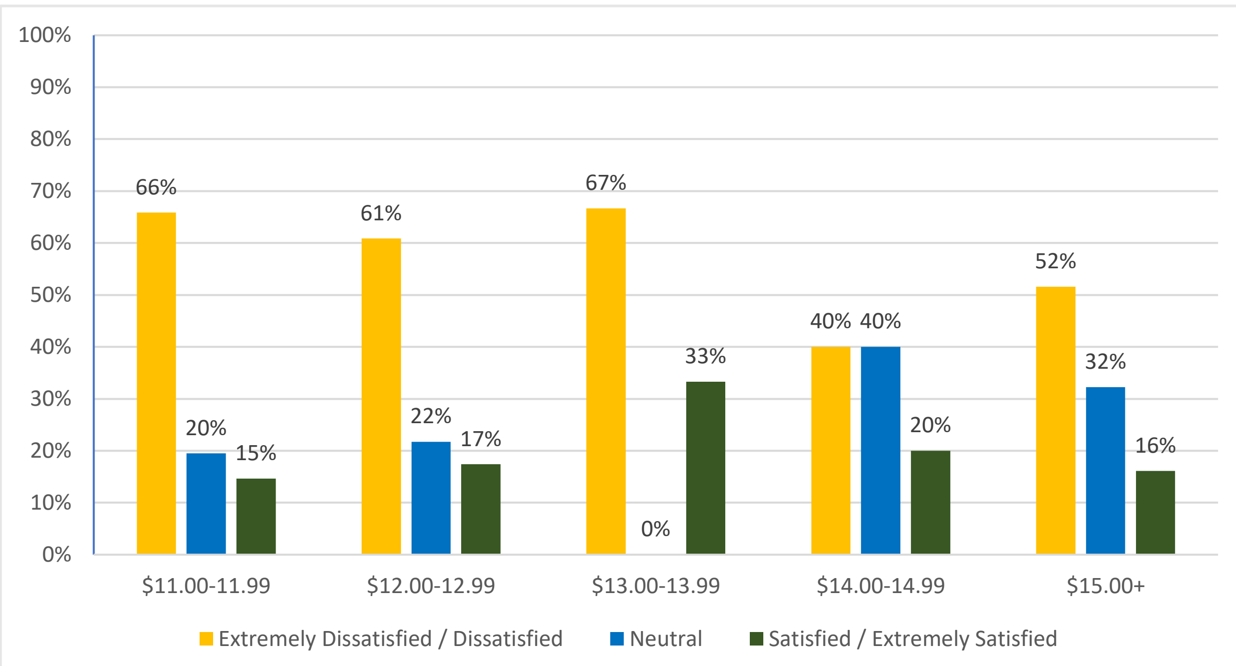
earnings range, neither of which are minimum wage, the survey captured just 8 responses. This explains the 0% 'neutral' response rate and outlier 'satisfied' or 'extremely satisfied' response rate (33%) for those earning $13.00 - $13.99 per hour, as well as the outlier responses across all satisfaction rates in the $14.00 - $14.99 per hour pay range. The two wage brackets lacking sufficient response is most likely due to the inability of FIs to negotiate a wage much higher than required by law.

In 2017, it was noted that nearly every consumer whose workers earned more than $13.00 hourly lived on Long Island where the minimum wage rate, at that time, was $13.13 per hour. Workers earning $13.00 - $14.99 per hour are now scattered across the Upstate area, with representation from the Hudson Valley and Capital District, and Western and Central New York.

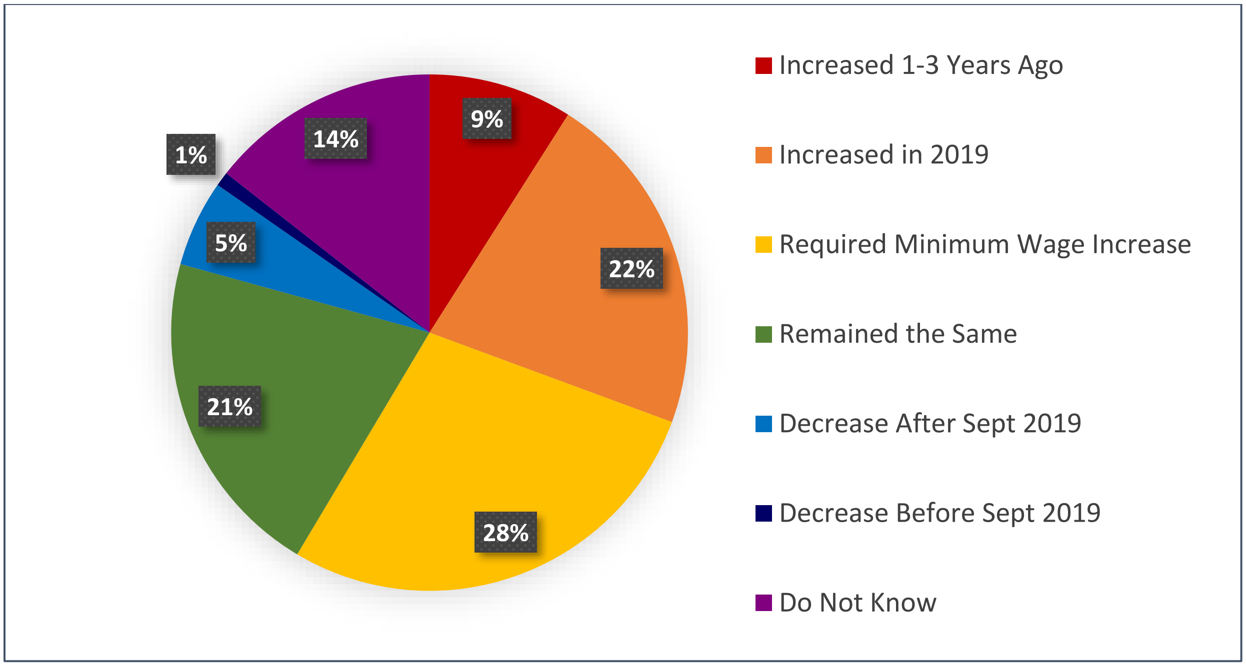
Figure 5: Consumer Satisfaction with Current Wage and Benefits Package Provided to PAs, Across Wage Brackets



Minimum wage increases bumped many PAs into the lowest ($11.00 - $11.99 per hour) and highest ($15.00 or more per hour) wage brackets, dependent upon location. As far as CDPAANYS is aware, no one outside of NYC or Long Island currently earns $15.00 or more per hour. Individuals earning $12.00 - $12.99 per hour have most likely remained in this wage bracket for quite some time. Prior to minimum wage increases, and comparative to other workers at that time, their wage was on the higher end of the spectrum. They have not seen their wages impacted by minimum wage laws and now find themselves among some of the lowest earners in their field.

In fact, when surveying consumers about their employee's last wage increase, we see that most raises were due to meeting minimum wage law requirements (28%). Some PAs saw a pay raise in 2019 that was not directly related to minimum wage requirements (22%), but nearly an equal number saw no raise at all with their wages remaining the same (21%). For 9% of PAs, their pay increased at some point 1 to 3 years ago (when the survey was last completed).

Figure 6: Last Wage Increase Received by PAs



Still, pay decreases have occurred in the same time period despite minimum wage increases statewide. Alarmingly, and as predicted by disability advocates, the survey found that in the month immediately following PMPM implementation, the rate of workers experiencing a decrease in pay jumped by 500% (*See Figure 6*).

For PAs, their ability to support themselves and their family on the wages they receive is directly tied to their ability to continue to provide care to consumers. When PAs are dissatisfied with their wages, they engage consumers in conversation by either requesting a pay increase or more hours per week they could regularly work. Once again, survey results regarding how frequently these conversations occur are in-line with 2017 rates (*See Figure 7*).

"It's really hard to get good people who will work for you for only $11.60 [per hour]. We desperately need an hourly wage increase!"

- Survey Respondent

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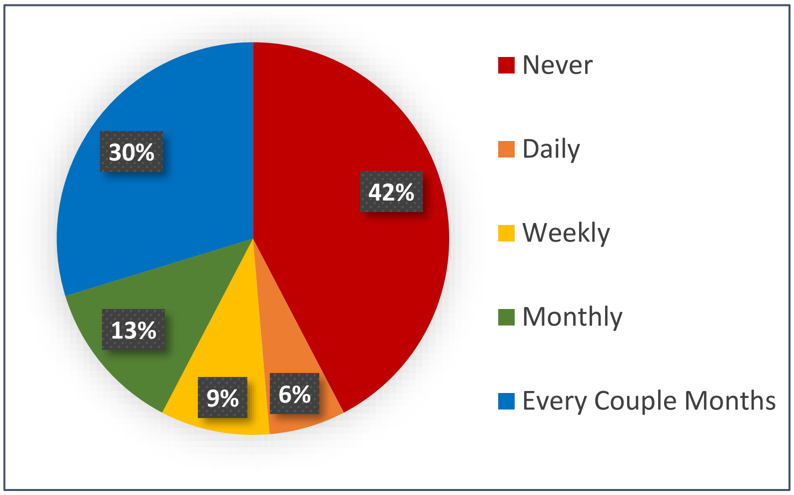
A majority of PAs find their wage to be unsatisfactory. These individuals request pay raises or more hours on a fairly regular basis. More than 1 in 4 workers are discussing pay and possibility of increased hours with their consumers at least once per month. On a daily basis, nearly 1 in 20 PAs are interacting with consumers to request more pay. Almost one-third of PAs talk about wages and hours every couple months.

Figure 7: Frequency PAs Request More Hours or Pay Increase



These conversations, while important in any job, are more difficult on CDPA consumers because they have no direct control over wages. A consumer's ability to schedule PAs for more hours is limited between overtime restrictions, total hours permitted on their authorization, and a need to ensure they maintain sufficient staffing levels such that fill-in opportunities between PAs are available.

[I]n the month immediately following PMPM implementation, the rate of workers experiencing a decrease in pay jumped by 500%.

Should a consumer with 80 hours authorized per week, for example, choose to hire just two PAs at full-time hours each, there remains no back up PA available to take on hours when one worker becomes sick, leaves town, or otherwise cannot work their regularly scheduled shifts. However, should the same consumer split their hours between three or more PAs, a full-time position is only available to one worker. Discussions of providing a worker with more hours necessitates the consumer to reduce the regular hours another PA can work.

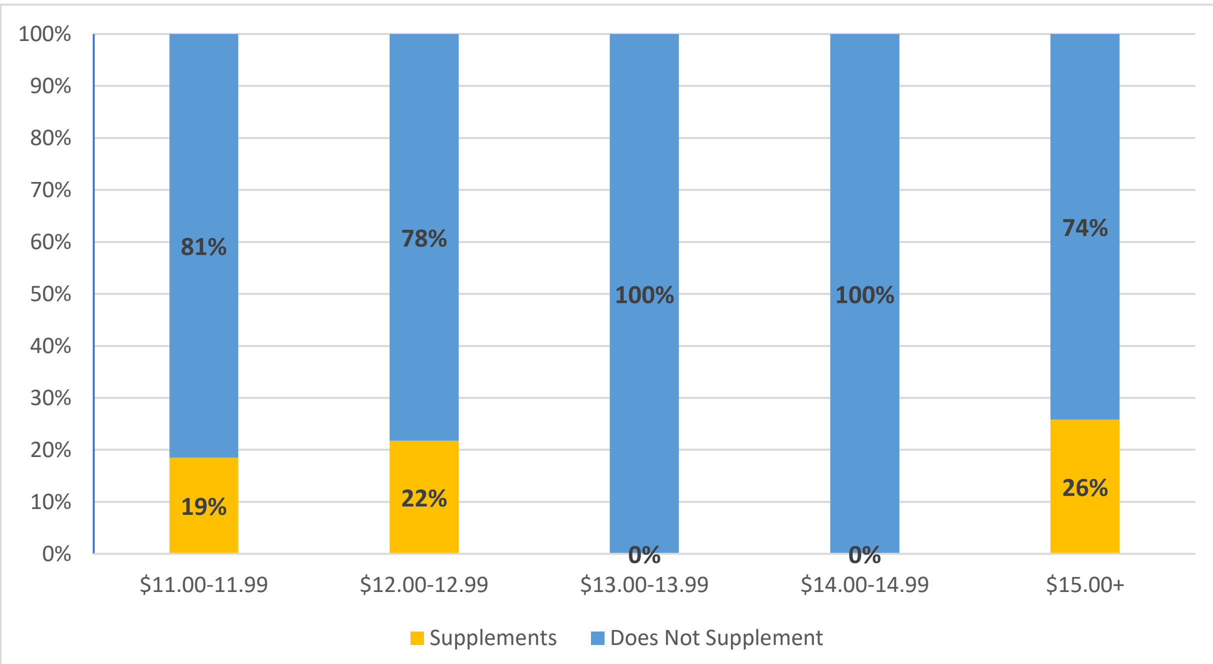
Many consumers are pressured to offer a higher wage not just because current workers ask but because potential workers are able to readily locate similar jobs for better pay. Home care is one of the top 10 fastest growing job industries in the United States.[8] Consumers are competing against private pay employers and even hospitals on recruiting websites like Care.com or Indeed, where wages are listed for candidate consideration before they submit a resume. While consumers have no control over wages and benefits, some consumers choose to supplement the wage. These costs may come from the

[8] "Employment Projections – 2018-2028". *News Release*, Bureau of Labor and Statistics. Sept 2019.

meager funds available from consumers' fixed incomes or low wages they receive themselves. It may also be that family chips in to offer money to PAs.

Medicaid cost-sharing and premiums serve as a barrier to care.[9] Federal rules prohibit states from imposing premiums or co-pays on Medicaid recipients. When CDPA consumers are unable to recruit or retain a workforce without supplementing the Medicaid wage with out-of-pocket funds, and the State chooses to overlook this need, or in the case of this year's budget, exacerbate it with a 25% cut to Home Care Workforce Recruitment and Retention funding, it may be worth further investigation if the State is in violation of these federal rules. Further, supplemented wages are unreported and untaxed income. The State's unwillingness to ensure reimbursement rates are adequate, such that CDPA wages remain competitive, has created a grey market.

Figure 8: Consumers Supplementing Wages Across Pay Ranges



On average, the survey found that consumers across all pay ranges supplement PA wages by $222.96 per week. Consumers are more likely to supplement the wage (26%), at any amount, for those PAs earning the highest hourly wage of greater than $15 (*See Figure 8*). This is most likely a reflection on the cost of living in NYC and Long Island. Even at the lowest wage range, 19% of consumers supplement their wage on a weekly basis. Consumers with PAs earning $12.00 - $12.99 per hour supplement their workers' wage more than one-fifth of the time.

[9] "Premiums and Cost-Sharing in Medicaid: A Review of Research Findings." *Kaiser Commission on Medicaid and the Uninsured*, Kaiser Family Foundation, Feb 2013.

Once again, we find that there is not sufficient data in the two pay ranges $13.00 - $13.99 and $14.00 - $14.99.

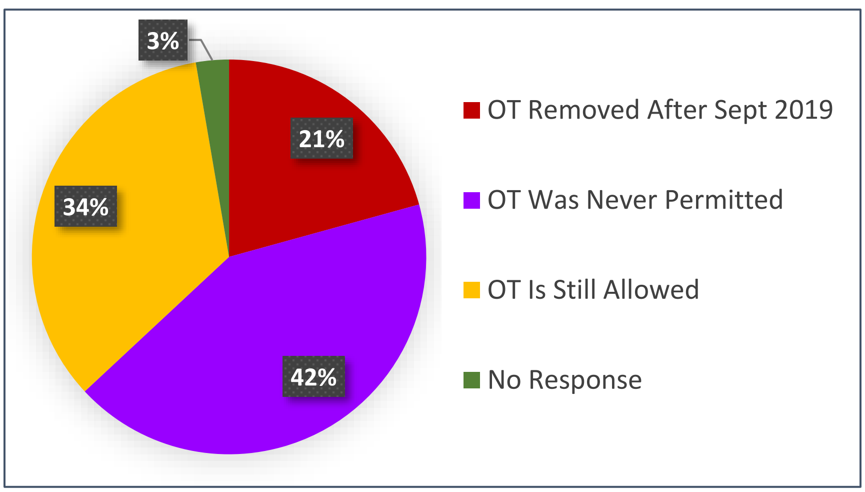
In addition to financial supplement of wages, 9 out of every 10 consumers indicate that they provide other benefits to PAs at high rates. These include flexible schedules (74%), paying for food or meals during work hours (50%), providing entertainment services (15%), exchanging live-in accommodations such as lowered or free rent (14%), annual cash bonuses (10%), or reimbursing transit or gas costs (9%). One out of every twenty consumers even pay for PA vacation time.

Per Member Per Month (PMPM) Impact on Wages and Benefits

In addition to loss of base wages immediately following PMPM implementation, PAs also experienced changing FI policies regarding overtime hours. New to the survey this year were questions indicating whether overtime policies had changed during CY 2019 (*See Figure 9*) and, if changes occurred, whether pay rates and benefits were restored following the court's order to reverse PMPM implementation (*See Figure 10*).

For many consumers, their ability to schedule PAs is limited by internal FI policies governing maximum weekly hours and/or total days per week the consumer must bear in mind. These policies are attempts to limit overtime spending and have been instituted for many years following an update to the Fair Labor Standards Act effective January 2015.

Figure 9: PMPM Implementation Impact on PA Overtime (OT) Benefits



To better understand how overtime may or may not have been impacted by PMPM implementation, the survey asks consumers whether their FI permits them to schedule overtime on a regular basis. To avoid any bias associated with PMPM or administrative cuts in general, the survey never uses the terms "per member per month" or "PMPM," instead opting to measure changes based on September 1, 2019 as a discussion time frame.

Just 3% of consumers did not respond to the question. Most consumers have not been permitted to schedule overtime at any time in the last few years (42%). Nearly a third of consumers may schedule PAs for overtime regularly and have not seen that ability

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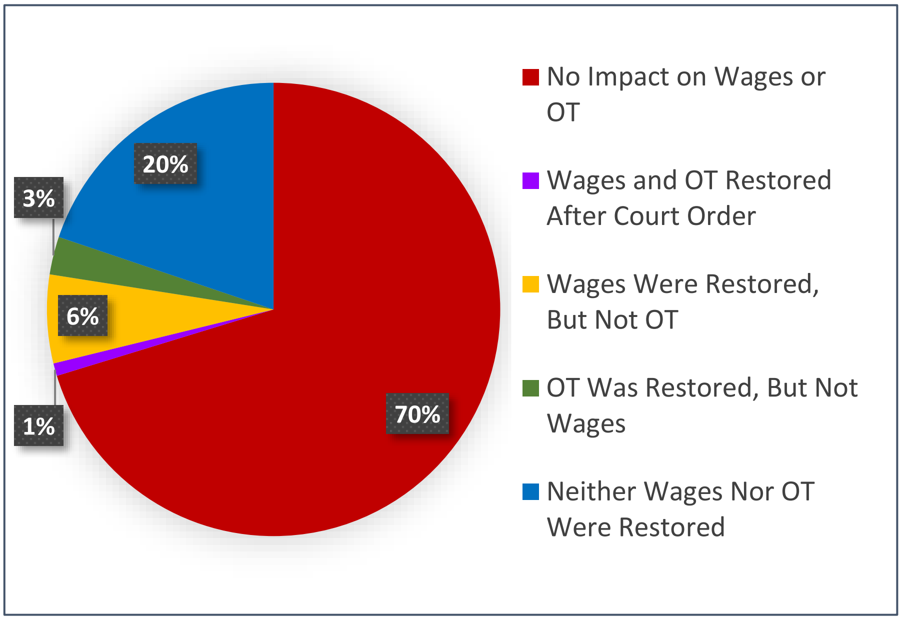
impacted (34%). However, more than one-fifth of consumers that had overtime scheduling ability prior to September 1, 2019 saw those permissions denied upon PMPM implementation (21%).

Figure 10: Restoration Status of Wages and Overtime (OT) Benefits Impacted by PMPM Implementation



For some FIs, the court's decision to overturn PMPM implementation had no effect on their ability to reinstate wages or overtime. This is because some MLTCs chose to renegotiate contracts with FIs to reflect the reimbursement rate change, and nearly all of them did so with no knowledge of or consideration toward the wages provided prior to September. These FIs unwittingly locked themselves into a legal contract. Still, some FIs may have found that preserving lowered base wages and removal of overtime was one way they could continue to save funds or retain consumers over time in anticipation of the State's continued attack on the program.

Looking at changes to both the wage and overtime beginning September 1, 2019 and on, nearly one-third of workers were directly impacted from PMPM implementation. As implementation was underway for just 6 weeks, this should be disturbing. For those seeking to distort this data, the 'no impact' figure should not be lauded as an indication that declining administrative reimbursement rates would pose minimal impact on consumers and workers. These changes were hardly around for 6 weeks and 30% of workers had their pay cut. At a time when recruitment and retention is considerably challenging, and low pay is responsible for almost two-thirds of workers leaving the industry, the overall impact of PMPM must be recognized for the destructive process it was intended to be. Should administrative cuts as deep as PMPM become future regulation, New Yorkers with disabilities will first find themselves unable to retain their current workforce, unable to attract new workers to these jobs, and ultimately will lose services through an imperfect transition process as fiscal intermediaries are powerless to maintain solvency.

"Overtime cuts have made it harder to find workers."

- Survey Respondent

Analyzing restoration status of wages and overtime more closely, of the 30% that were impacted, nearly two-thirds of workers did not see their wages or overtime reinstated to pre-September 2019 levels. The brief time PMPM existed in practice still today has a continued effect on PAs and, ultimately, consumers.

Just 3% of workers saw their wages and overtime restored following the court's decision to order PMPM null and void. Another 20% reported that wages were restored but overtime policies remained such that consumers could not schedule a worker for more than 40 hours per week. And 10% of workers had overtime permissions reinstated but did not see their base wage restored.

What is most disturbing is that once again the DOH was acutely aware that, despite their claims that consumer services would not be impacted, the PMPM reimbursement was doing just that. Despite knowing the reimbursement they are proposing is unsustainable with overtime costs, they prevented FIs from restricting overtime at all as of the implementation of a new Request for Offers, where the DOH will limit the FIs it allows to operate. This decision ignores the financial realities shown by the efficiencies FIs have created, and the level of importance and satisfaction consumers assign to their FIs.

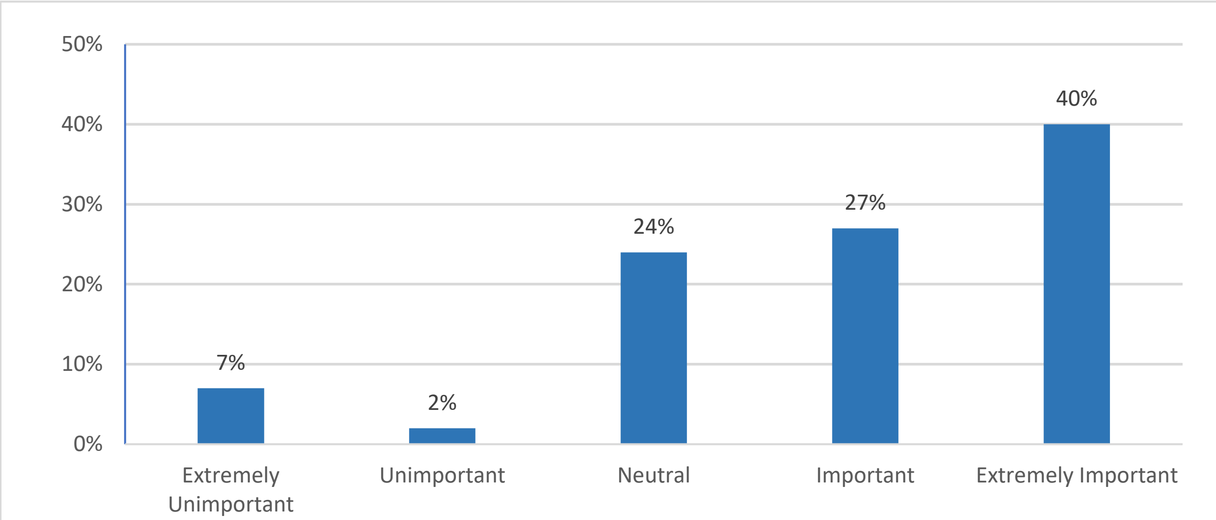
FI Importance and Satisfaction

Consumers overwhelmingly believe that their success in CDPA is reliant on their FI of choice.

Fiscal intermediaries vary greatly in their efficiencies and programming. In addition to payroll services and onboarding, many FIs are able to provide secondary programs and services that support consumers in their goal to maintain independence. These programs and services not only help brand each FI and attract consumers in a marketplace of a multitude of options, they are vital to the success of consumers in CDPA. Without these services, many consumers would lose access to their communities, be unable to recruit and retain PAs at current levels, or navigate MLTC services including durable medical equipment (DME) access such as Hoyer transfer lifts and power wheelchairs.

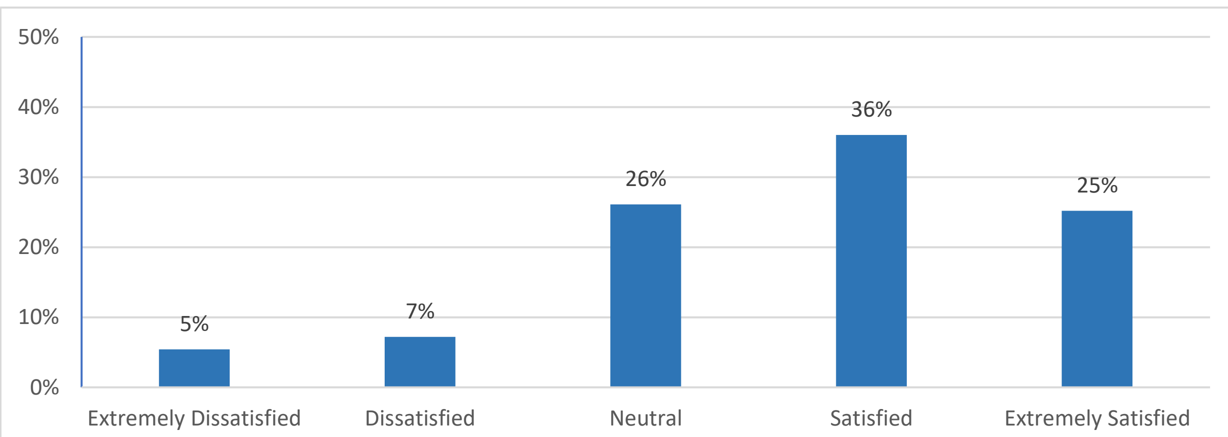
Of all consumers who participated in the survey, almost 8 in 10 receive services beyond PA onboarding and payroll from their FI. The most requested services included: clarification on CDPA responsibilities (58.8%); recruiting resources (40%); assistance working with MLTCs (18.8%); employer trainings to provide skills for PA supervision (17.7%); identifying local community resources (16.5%); peer mentoring services (14.1%); participation in a consumer advisory committee (14.1%); access to non-English speaking FI staff (14.1%); dispute resolution between consumers and PAs (11.8%); providing best practices in lifting, transferring and other matters related to the provision of CDPA services (9.4%); and offering educational opportunities to access independent living skills that are not directly CDPA-related (8.2%).

Figure 11: Importance of FI in Consumer Success with CDPA



Consumers overwhelmingly believe that their success in CDPA is reliant on their FI of choice. More than two-thirds of consumers indicate that their FI is 'important' or 'extremely important' to their success (67%). Just 9% of consumers do not connect their success in CDPA with their FI (*See Figure 11*).

Figure 12: Consumer Satisfaction Rates of Fiscal Intermediaries



When asked about consumer satisfaction of FIs, a similar story appears. Two-thirds of consumers are 'satisfied' or 'extremely satisfied' with their FI. And just 12% of consumers are 'extremely dissatisfied' or 'dissatisfied' (*See Figure 12*). Given that consumers have choice over their FI and are able to switch to another agency at any time, these few consumers with negative views of their FI are most likely commenting on low wages and lack of sufficient benefits.

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Recommendations

Consumer-directed services offers individuals the opportunity to be independent and in control of their lives. No other long-term care program provides equivalent benefit to recipients. More than 70,000 disabled people rely on CDPA services each day to live in their homes and communities with dignity. Their PAs are vital to the success of this program. Strengthening and preserving CDPA is an objective that is both prudent and cost effective. To that end, CDPAANYS recommends the State take the following actions:

- **Restore the $45 million in funding cuts to the Home Care Workforce Recruitment and Retention fund.** As COVID-19 has rampaged through New York, politicians have been quick to laud our "healthcare heroes." But, while health care professionals of all stripes, including PAs, rightfully condemn lack of access to testing and personal protective equipment, home care aides and PAs may have suffered the ultimate insult. This study clearly shows that home care workforce recruitment, while growing rapidly, is not keeping pace with demand. Retention of the workforce is even worse, and is in fact likely colored by the fact that family will often work for lower wages, as long as they can still afford basics such as rent and food. If New York values health care workers, these funds must be restored before the end of this Legislative session.

- **Raise and maintain the wage of personal assistants statewide.** At one point, home care jobs used to pay a respectable wage that permitted workers to afford to care for themselves and their families. While minimum wages have risen across the state, a ten-year freeze in reimbursement rates has meant CDPA workers have seen their wages decline compared to other low wage industries. Many PAs continue to earn at, or just above, minimum wage. In parts of the state, fast food workers make as much as two dollars more per hour than PAs. Improving wages will assist consumers in recruiting and retaining workers, as well as help minimize the anticipated growing workforce shortage by attracting workers back to the industry. A wage raise means PAs are more likely to remain in their job for a longer period of time, which leads to improved health outcomes for Medicaid recipients and decreased hospital stays. These jobs are essential to ensuring tens of thousands of New Yorkers with disabilities stay alive and healthy. When employees are paid well, the program works for everyone.

- **Decline the proposed regulations amendment to 18 NYCRR 505.28 that would make per member per month a permanent reimbursement rate structure for fiscal intermediaries.** The brief implementation of per member per month (PMPM) in September 2019 led to worker wage decreases, loss of benefits such as overtime pay, and negatively impacted consumers as they experienced worker resignations. The State is now proposing a permanent reimbursement rate structure change for fiscal intermediaries that mimics the same PMPM change responsible for these unnecessary and harmful effects. A continuation of such a policy will only lead to the decimation of CDPA and will harm thousands of lives

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along the way. Workers will lose their livelihoods as their dismally low wages are further cut. Consumers will be unable to replace PAs that leave the industry, forcing them into alternative home care programs or institutional care at significantly higher cost to the state. We can no longer claim that reimbursement rate cuts to such a degree will have no impact on consumers. It is unconscionable to move forward with the proposed regulation. The State must withdraw and decline their per consumer per month amendment without haste.

Conclusion

The global pandemic that is COVID-19 has hit New York. As the virus continues to spread rapidly, individuals will require hospitalization and medical resources that are already in short supply. Services like Consumer-Directed Personal Assistance (CDPA) help the State 'flatten the curve' and minimize the burden on local hospital systems by keeping consumers healthy and safe within their homes.

Modifying Medicaid to the tune of billions in the midst of this crisis is foolish and irresponsible. Budget cuts will not only devastate CDPA but will crush hospitals at a time when they are needed the most. Persons with disabilities and their home care providers are a high-risk group of individuals that are often overlooked for priority medical care or personal protective equipment. It's imperative that the State do everything in its power to minimize exposure to COVID-19 within the home care population and ensure access to CDPA for all currently eligible consumers.

"We are hopeful that as part of the budget, as part of looking at the Medicaid system, they will realize that if there is a system-wide failure of CDPA, that's going to generate more costs than the savings they'll look to achieve."

-Bryan O'Malley, CDPAANYS Executive Director

Consumer-directed services is one of the most cost efficient and effective long-term care programs in New York State. Any proposal that limits eligibility, reduces administrative reimbursement rates or stalls wage increases threatens the program and will eventually cost the State more money over time. As the population ages and younger disabled populations live longer, the growth in CDPA will continue to rise. The State must move quickly to more accurately plan and budget for long-term care needs for the population that exists today. Changes to the program that attempt to slow the rate of growth will, in actuality, simply be a denial of services to individuals that require home care. These populations will see higher costs to the Medicaid program in terms of avoidable hospitalizations, increased rates of medications, and potential permanent institutionalization.

Moreover, for those individuals that remain eligible for and receive CDPA services, a strong workforce is vital for their success and health. Without adequate wages and benefits to attract workers to home care positions, people with disabilities and seniors face an increasing risk of institutionalization. New York State can and should be at the forefront of the home care industry workforce shortage crisis that is gripping the nation.

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About CDPAANYS

The Consumer Directed Personal Assistance Association of New York State supports consumer directed personal assistance providers and recipients in all counties of New York State, offering supportive services, including, but not limited to: advocacy, systems change, and the promotion of consumer control and self-determination.

CDPAANYS is an independent association, the only such organization in New York State to exclusively represent fiscal intermediaries. CDPAANYS has worked closely with the New York State Department of Health to build CDPA since the very beginning, and has served as the sole organization fighting for many of the rights and freedoms enjoyed by consumers, personal assistants and fiscal intermediaries.

About Pax Ratio, Inc.

Pax Ratio, Inc. is a small policy consulting firm based in Orange County, NY. Our services focus on the intersection of disability and healthcare policy as they relate to improving systems efficiencies. We offer public policy expertise in areas including Medicaid, Medicare, electronic visit verification, Americans with Disabilities Act compliance, and consumer directed services.

We currently offer services to non-profit organizations, small businesses and government entities.