

Testimony of
Consumer Directed Personal Assistance Association of New York State
to:
Senate and Assembly Joint Hearing on Health

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February 5, 2019

Good afternoon Chairwomen Krueger and Weinstein, Health Chairs Rivera and Gottfried, and all of the Legislators here today. Thank you for the opportunity to provide testimony on FY 2019-20 Executive Budget on behalf of the Consumer Directed Personal Assistance Association of New York State (CDPAANYS), our member fiscal intermediary agencies, the consumers who use the program, and those who are employed by it as personal assistants. The ramifications of this budget on the more than 70,000 seniors and people with disabilities who depend on Consumer Directed Personal Assistance (CDPA) for community-based long-term care services, the approximately 125,000 people who provide their services, and the estimated 600 fiscal intermediaries and their staff who provide support, cannot be understated. It will be devastating.

CDPA is a program founded by consumers, for consumers. Conceptualized in 1979 by people with disabilities at a time when institutionalization was the standard, CDPA encompassed both a social movement and revolutionary approach to care, one in which the consumer could hire and direct their own staff. In 1994, New York State created a pilot program for CDPA in New York City and Syracuse, and it was established statewide the following year. For the next decade, it operated in the shadows of the long term care (LTC) system. It wasn't until the shift to managed care, and specifically managed long term care (MLTC), that growth within the program began to expand rapidly. MLTC plans saw the value that CDPA offered. It is an exemplar of the triple aim: improved patient satisfaction, improved health outcomes, and lowered care costs.

CDPA remains an increasingly popular alternative to institutionalization and traditional agency home health care services. The service allows Medicaid recipients in need of long-term supports and services to recruit, hire, train, supervise and terminate their own workers, called personal assistants (PAs). Consumers receive authorizations from a managed care company or their county based on the services they need. The authorization provides the number of hours that the consumer is to receive each week, based on the services they can receive, called the plan of care.

To coordinate the services, the consumer works with a fiscal intermediary. Because many consumers do not have the responsibilities they are assuming adequately explained to them by their managed care company, the FI provides an initial role ensuring that they understand the implications of what it means for them to be responsible for recruiting, hiring, training, supervising, and terminating their own staff. The FI then works with the consumer to onboard his or her PAs, making sure that they have all of the documents and health assessments required by the Department of Health. The FI then coordinates payroll services, workers compensation insurance, unemployment and more, also serving as a check for Medicaid compliance, ensuring that consumers and their PAs are not behaving in a manner that jeopardizes the public dollar.

But, counter to what the budget presupposes, FIs provide much more than managerial coordination. The FI provides critical support to the consumer as they navigate the complexities of the program. It is well established in the research that many consumers fail within the program because they feel like they are "on an island," trying to run a small business and training people in extremely intimate and personal tasks, such as toileting or showering. Consumers will often consult with their FIs on a daily basis as the FI assists them in building developing the skills needed to succeed in the program. These calls, which can

take hours, are the unseen actions within the Medicaid program that are critical if the program is to succeed. The relationships that FIs build with their consumers are often, quite literally, the difference between a very successful use of CDPA to remain in the community and placement in an institution.

In a statement that this Department clearly does not understand the role that FIs play in this service, and the relationship that has developed between a FI and the consumers who work with them, this budget seeks to immediately eliminate nine out of every ten agencies currently providing FI services. The proposal additionally imposes an 80% cut on administrative reimbursements to surviving agencies, in a program that already has some of the leanest administrative costs within the Medicaid system. In short, the Governor's proposal does irreparable damage to CDPA, a program that was founded here in New York State and has since swept across the country, serving as a national model for self-directed care.

I want to be absolutely clear. The Governor's budget actively threatens the health, safety, and independence 70,000 senior and disabled New Yorkers who rely on CDPA services to perform such basic tasks as getting out of bed, eating, and showering. Because the program is growing rapidly, the seniors and others with disabilities have been reduced to pawns in a grand scheme of a creating a solution in search of a problem. In reality, CDPA is not the problem – it is an integral part of the solution to the fact that NY is the epicenter of the workforce crisis that is gripping the home care industry. Those from Western NY, Central NY, or the North Country have likely seen this crisis firsthand. But, according to national consulting company Mercer, the problem will squarely hit New York City by 2021, resulting in a shortage of 20,000 workers.

Because CDPA has proven so efficient, it has survived despite a protracted workforce crisis that is the direct result of stagnant reimbursement rates. Where the crisis has already hit hardest, CDPA is the only thing holding the system together. In Western NY, it is routine for a Medicaid recipient in need of long term care to be offered 30 hours of home care or 50 hours of CDPA – not because they like CDPA that much more, but because they know they cannot fill 50 hours in a traditional home care setting.

If the cuts proposed by the Governor go through, it will force consumers and their families to make heart-wrenching decisions about whether they can continue to live at home and in their communities, or enter nursing homes against their wishes. The continued decision to ignore this growing crisis, in addition to the new, dubious plan to repeal and replace CDPA in the Executive Budget, would render these outcomes inevitable.

If passed, the first thing the "new CDPA" will accomplish is putting hundreds of FIs, and thousands of their staff, out of operation as of January 1, 2020. From that date forward, only three groups will be authorized to act as a FI - Independent Living Centers; organizations that have held continuous contracts with their local departments of social services from no later than January 1, 2012; and an organization or organizations who have a contract with the state as part of a mini-bid process with no guidelines around it.

The contention that there are now too many FIs in New York to maintain these efficiencies has been the sole justification for this measure. CDPAANYS recognized that without any authorization process in place, an unmitigated increase in organizations operating as FIs would occur with little oversight and thus advocated on behalf of legislation to create one. We first informed the Department of this when the transfer from fee-for-service to managed care occurred and were dismissed. We then worked with the Legislature and unanimously passed legislation certifying FIs in 2015, which was vetoed. It was not until the Legislature inserted authorization in the budget in 2017 that we finally gained an idea of who was in the program. After six months, applications for authorization were due on December 15, 2017. A year and a half later, we are now seeing the first authorizations issued, with some rejections coming out as well.

However, rather than allow the application process to determine which agencies were fit to serve consumers, the Executive Budget ignores the will of the legislature and undermines this statutory course of holistic review. Now at the same time the Department is seeking to eliminate 90% of fiscal intermediaries in the state, it is issuing authorizations for operation to some of the same FIs it would put out of business in this budget. This alone shows that the left hand is not paying attention to what the right hand is doing. FIs who have been informed they are operating in concurrence with the rules of the program will have their business taken away just months after it was approved. Speculating about whether or not this inaction was the express intent of the Department is futile, but it makes little sense that if the body was concerned with fraud and bad actors, it would neglect the tools at hand to address these issues.

This measure also overlooks one of the main reasons that CDPA is so popular: cultural and linguistic competency, two problems gripping the entire health care industry, are eliminated by CDPA. When people are in control of who they hire, they will not hire someone who does not speak their language or understand basic cultures norms. There are scores of spoken languages, and even more dialects throughout New York. Dietary guidelines and other cultural norms are critically important to New Yorkers for religious and other reasons. New York is home to Queens, the most diverse neighborhood in America. We pride ourselves on our inclusivity, yet this proposal would indiscriminately strip that principle from seniors and people with disabilities.

The second policy contrived in the Executive Budget is the administrative rate restructuring from a percentage of direct care costs to a flat, per-member per-month (PMPM) rate. This proposal belies the lack of understanding the Department has of CDPA itself, and the role of FIs. The Department points to the growing costs associated with the administrative component of FIs while not possessing the information for any of the 90% of FIs it would put out of business – those who do not contract with fee-for-service. Since cost reports for those who contract with managed care only weren't mandated until last year's budget, the Department will not have this information until this year.

Despite the lack of information possessed by the Department, they are right in one analysis, administrative costs have increased for FIs, but not for the reasons given by the Department. The fee-for-service rate is divided into two components – the direct care and the administrative piece. The direct care ceiling has been frozen for nearly a decade. During that time, administrative costs have increased

tremendously due largely to inflation; but, also because of direct actions taken by the Department. Commercial rents, particularly in New York City, have nearly doubled. Wages have risen. And, the Department's privatization of Medicaid to managed care plans means that FIs went from billing a singular entity in fee for service to coordinating with the more than 50 managed long term care (MLTC) plans, many of which routinely deny legitimate claims. This means FIs went from needing one staff person to bill the state, who immediately turned around payments, to an entire unit to bill over 50 plans, most of whom reject clean claims multiple times, further increasing staff needed to perform a task as basic as getting paid for services needed.

In a meeting with the health plans, the Department indicated that its analysis was that, currently, fiscal intermediaries administrative costs would translate to \$280 per member, per month (PMPM). We have absolutely no idea of where this number is coming from. In a brief survey of our members, the average PMPM that would be necessary to continue to service to current consumers would be about \$450-550, a number that is about 14-18% of their direct care costs. But these facts are not influencing the Department. Their proposal would lower the administrative cost to \$100 PMPM – an unprecedented 80% cut.

What we did determine is that there were a few FIs whose administrative costs were significantly lower. These FIs were those who, for whatever reason, had a significantly lower hour consumer mix. What we have learned is that FIs whose consumers use 14 hours or less could operate. It is clearly easier to administer cases where consumers have lower services. There are fewer workers. The case is less intensive. The problems are fewer. The Medicaid compliance needs are less.

It is clear that the move to limit the PMPM to such an abysmally low rate is meant to put FIs out of business, even those the Governor deems lucky enough to survive his initial culling. However, more deviously, imposing an artificially low PMPM is a backdoor cut to FIs that would drastically reduce the amount of hours they are able to service, creating chaos and service terminations for consumers approved for more than 14 hours per week. In effect, all but the consumers requiring the least amount of assistance would be shut out of the very program designed and fought for by the very people that use it. The state would effectively eliminate high hour cases by ensuring that consumers who need them cannot find an agency that can afford to serve them. Combining this with the home care crisis previously mentioned will only make it worse.

Perhaps the most onerous line in the entirety of the Executive's replacement legislation reads, "Notwithstanding any provision of this section or any other law to the contrary, the provisions pertaining to consumer directed personal assistance services and fiscal intermediaries pursuant to this section shall only be available if the commissioner of health determines that there is adequate Federal Financial Participation to fund such programs and/or entities." This establishes, in clear language, provides unprecedented authority to the current or any future Health Commissioner to single-handedly eliminate a Medicaid benefit, with no oversight from the Legislature.

The Department of Budget has indicated that by gutting CDPA, the state will save \$75 million. While not exactly forthright about how these savings will be achieved, the department has ironically maintained

that this overhaul, based on opaqueness and smokescreens, will elicit a new standard of transparency and efficiency. In reality, these proposals will create a continuity of care disaster for at least 50,000 New Yorkers enrolled in CDPA that will lead to institutionalizations and premature deaths. It grants unprecedented, unilateral power to a departmental commissioner with no regard to legislative oversight.

CDPAANYS urges both houses to reject these care-cutting overtures and instead allow the legislatively sanctioned authorization process to work as intended. Furthermore, we ask that you address the impending workforce crisis that will only exacerbate costs and reduce vital community based care access. Balancing the budget on the backs of seniors and people with disabilities isn't a New York value, and this is your opportunity to right the ship and secure the promise of long-term care for middle and working class New Yorkers as it navigates uncertain treacherous waters.

Other measures in the budget that CDPAANYS is concerned about, and urges the Legislature to reject, include:

- **Provisions that would “modernize” rules governing service reductions, fair hearings, and other protections for Medicaid recipients.** Like the PMPM fee from DOH, this proposal is an assault on those who require the most services from the state. It would allow plans to almost unilaterally cut hours while those who need 24/7, live-in, or other high hour authorizations suffer and are ultimately forced into institutions.
- **The continuation of the Medicaid Global Cap.** The Medicaid Global Cap served a necessary purpose; however, it has lived its useful life and is not imposing undue hardship on a Medicaid program who enrollment has increased tremendously. The Medicaid Global Cap was a useful tool; but, it cannot accommodate the growth in the Medicaid program that has occurred over the years, or the explosion within Managed Long Term Care, an industry that barely existed when the cap was imposed. It is time to either reimagine this cap or eliminate it entirely.
- **The continuation of the elimination of the trend factor, and the impact that has on the direct care ceiling.** When the trend factor, which adjusts hospital, nursing home, and home care rates for inflation, was frozen, it locked the direct care component of such rates in place. At this point, direct care rates have been frozen for so long that every provider in the state is losing money on an hourly basis because the costs associated with putting a worker in the field for one hour have increased well beyond the cap. Even if the trend is not restored and rebased, the state must rethink the direct care ceiling and allow it to grow, ending a decade worth of stagnant wages for workers mandated by the state.

Thank you, I appreciate the opportunity to testify before you today and look forward to working with you to defend the rights of seniors and people with disabilities as they seek to live independent lives in their communities and I welcome any questions, now or in the future.