

# Center for Disability Rights, Inc.

Testimony of the Center for Disability Rights  
before the Joint Committee Budget Hearing on  
Health  
February 5, 2019

Thank you, Chairperson's Weinstein, Krueger, Gottfried and Rivera for the opportunity to offer this testimony on behalf of the Center for Disability Rights.

The Center for Disability Rights is a disability-led, not-for-profit organization headquartered in Rochester, with satellite offices in Geneva, Corning, Albany, and Canandaigua. CDR advocates for the full integration, independence, and civil rights of people with disabilities. CDR provides services to people with disabilities and seniors within the framework of an Independent Living Model, which promotes independence of people with all types of disabilities, enabling choice in living setting, full access to the community, and control of their life. CDR works for national, state, and local systemic change to advance the rights of people with disabilities by supporting direct action, coalition building, community organizing, policy analysis, litigation, training for advocates, and community education.

In previous years, the CDR has offered testimony to this joint legislative hearing on the full range of health topics in the budget. Though CDR has suggestions and concerns about many health proposals this year<sup>1</sup>, our testimony focuses solely on the Governor's proposals relating to the Consumer Directed Personal Assistance (CDPA) program because of the existential threat that these proposals pose not only to the organizations serving as fiscal intermediaries (FIs), but also to the more than seventy thousand disabled New Yorkers who rely on FIs to live in the community, and the hundreds of thousands of New Yorkers working hard to provide CDPA services. The Governor's plan will reward and incentivize organizations that provide a bare minimum of service while limiting access to the service because FIs will only be able to afford to serve individuals with very limited support needs. As a result, disabled and elderly New Yorkers who have moderate to significant support needs will be forced into institutions. If that were not bad enough, the proposal grants the Commissioner sweeping new powers to modify and even end CDPA altogether if he deems federal contributions to the program inadequate.

Before outlining the myriad harms that the Governor's plan will bring to the Disability Community and the State, I will provide some background on the Consumer Directed Personal Assistance program. CDPA is the only program serving the Disability Community that was designed by and for our community – and right here in New York. CDPA is the program that

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<sup>1</sup> For a broader understanding of CDR's analysis of the entire budget: Governor Silently Declares War On Disabled New Yorkers: Response to Governor Cuomo's 2019-2020 State of the State and Budget; <http://cdrnys.org/blog/press-releases/response-to-governor-cuomos-2019-2020-state-of-the-state-and-budget/> (Last accessed (2/1/19))

gives us the most control over our lives. It allows us to choose who enters our homes, who helps us with our most intimate tasks, and who touches our bodies - all on a schedule that works for us, not an agency. CDPA - when run correctly - empowers disabled people by giving us the control and support we need as the supervisors with the right to hire and fire our attendants and exert control over the assistance we receive. It has been so successful that it has spread across the country. This level of control is made possible by the assistance of a group of organizations known as fiscal intermediaries (FIs). FIs - who do the job correctly - provide disabled people with assistance and support in managing our services. Beyond payroll processing, this assistance includes help with attendant recruitment, support with hiring, training, and scheduling attendants as well as problem solving needed by a first time supervisor. This support is crucial. In fact, many disabled people we serve have never had a job, much less worked as a supervisor. These services are often the difference between an individual thriving in the community and being forced into an institution. Additionally, we ensure the program participants comply with labor law and Medicaid rules. Our monitoring efforts ensure the safety of consumers as we watch for signs of fraud and potential neglect or abuse.

A thorough review of the Governor's plan demonstrates that his proposal ignores the reality of CDPA and, in doing so, endangers lives.

**A per member per month flat fee will lead to mass institutionalization & the collapse of FIs**  
The proposal to change FI reimbursement to a per member per month flat rate is the most alarming part of the CDPA proposal. Not only does this proposal show little understanding of the extensive work FIs do to support disabled New Yorkers to live in the community but it will drastically limit who FIs can serve. The proposed \$100 per member per month flat fee that DoH has shared with the managed care plans - but not Disability Rights advocates - would make serving any consumers who receive more than 14 hours untenable. This disincentive to serving people with significant disabilities is yet another example of the States repeated implementation of policies that undermine our independence and freedom.

To demonstrate the dangers of this specific proposal, we can look to CDR's operations. As an Independent Living Center, CDR is committed to serving individuals with the most complex needs and ensuring everyone who wants to live in the community can live in the community. We serve 990 consumers and our administrative costs are 11.9%, well below the allowable 18%. With monthly administrative costs of \$378,739, our average consumer receives 44 hours of service per week. At that level we are still able to serve consumers who require significantly more hours, including disabled individuals who receive 168 hours of services.

Reducing payment for administrative costs to the proposed \$100 dollar per member per month fee would cut CDR's payment for administrative costs by 73%, allowing us only 3.41% for administrative costs. This is a \$279,739 reduction in payment for administrative services per month. Cutting the payment for administrative costs does not cut the actual administrative costs that FIs encounter. It is not possible to function as an FI with only 3.41% in administrative costs. FIs are currently allowed 18% and Licensed Home Care Service Agencies are allowed 28%. It is not possible to function as an FI with only 3.41% in administrative costs. In addition to all the services we provide to help disabled people successfully run their CDPA programs, we have basic organizational costs that cannot be reduced. What would you have us cut? The required Health Assessments that are not reimbursed by the State? Our insurance? Our payroll processing? Postage to mail pay stubs? Our office space where our support staff work? Our electricity?

The proposal operates under the assumption that FI administrative costs are fixed and can be reduced through efficiencies, but as our example shows, FI costs are neither fixed nor can they be greatly reduced. Even two consumers with the same number of hours can generate very different administrative costs. A consumer receiving 30 hours a week, served by one attendant will, require less administrative services than another consumer receiving the same hours who has four attendants and high turnover. Payroll processing is far from a fixed cost. Administrative costs are also exacerbated by the current workforce crisis. Higher turnover of attendants adds to both recruitment and Human Resources costs. In addition some administrative costs, such as required health assessments, utilities, and real estate taxes are not in an FIs power to reduce.

In reality ILCs and other FIs often go far beyond payroll processing. Losing services such as training consumers to manage their own employees and giving consumers a safe venue and assistance for recruiting can often be the difference between thriving in the community and being forced into a nursing facility. These services are not counted as direct care, so they are categorized as administrative costs despite the necessity of these services.

This proposal will cost the State far too much, not only financially, but in human lives. In disincentivizing FIs to serve disabled people with more complex needs, the proposal will drive many people with disabilities into far more costly institutions. Alternatively, people will go without the services they need and die sooner due to lack of adequate care. Either way, it is too high a price to pay and we urge the legislature to reject this proposal.

#### **Arbitrarily limiting FIs will eliminate good services and leave gaps in service**

The second part of the Governor's proposal is aimed at reducing the number of FIs operating in the State. The State has identified bad actors among FIs, such as homecare agencies operating with barely altered practices under the auspices of CDPA, FIs that are serving as marketing agents for managed care companies, and FIs that are flush with investments trying to cash in on this model. This is why we and other FIs across New York have worked with State to introduce an FI authorization process to eliminate bad actors from the program. This process that has only just begun. If the Governor or DoH is finding the process inadequate, they have the power to make it more stringent instead of implementing a new requirement that will not eliminate all bad actors, but will eliminate some good actors.

In the Governor's proposal, the basis by which the reduction in FIs will be made makes little sense. Instead of basing this reduction on targeted criteria such as quality of the services being provided, the proposal established arbitrary criteria. This wipes out the vast majority of FIs – including some that provide excellent services, and it is likely to leave major service gaps and will unnecessarily disrupt the lives of disabled people and attendants across the state.

As was mentioned earlier, ILCs have traditionally advocated on behalf of individuals with the most complex needs and in some cases, like CDR, this has meant they may not have the best relationship with county social services who more concerned with the bottom line and local politics than a person's right to live in the community. As a result, a number of county social service departments refuse to contract with their local ILCs for FI services. A significant reduction of FIs in a county will leave hundreds - if not thousands - of disabled people looking to switch FI services. While ILCs can function as FIs still, disabled people who want to use an ILCs services may be prohibited from doing so if the county has refused to contract with the ILC. Even now, the President and Vice President of CDR's board may not use the organization they lead as their fiscal intermediary. The State needs to address this petty political injustice.

### **A single statewide FI will offer reduced service to both consumers and attendants**

The Governor has also proposed creating a statewide fiscal intermediary, awarded by the Commissioner of Health, with a no bid contract based unstated criteria. The Governor's proposal offers no justification, unless the State's aim is to eventually get rid of the remaining FIs and move to one statewide FI, bringing in an out of state company to serve as the singular FI. Doing this would eliminate local support as a statewide entity with this level of funding could never provide the one-on-one supports that FIs - like CDR - currently provide. In addition, other states that have taken this approach have experienced significant problems. In Pennsylvania, where Public Partnerships Limited was brought in as a single statewide FI, the costs of the company putting together the systems needed to operate in the state led to the state advancing the FI ever increasing sums that cost the State much more than the previous system of multiple FIs ever did. The state also reported greater problems exerting oversight over a statewide FI which led to overpayments to some attendants and missed payments to others<sup>2</sup>.

The size of a statewide no bid FI contract in New York is likely to attract interest from companies from across the country. No company coming in will have the requisite knowledge to serve the varying contexts that make our state so unique. An outside company would also fill many of the jobs serving New Yorkers out of state, meaning this will take thousands of jobs away from the dedicated disabled & nondisabled New Yorkers who are currently providing FI services. Jobs that are currently filled by skilled and knowledgeable New Yorkers. This is not a risk the state should be exposing itself to and the legislature should reject it entirely.

### **Conclusion**

This is proof an ongoing war against New Yorkers with significant disabilities. Last year's budget incentivized the Managed Long-Term Care plans to institutionalize disabled people with the most complex support needs. The only reason the State's nursing home carve out has not yet resulted in significant institutionalization is because the Federal government has not approved the State's amendment. Now the Governor is trying to disincentivize fiscal intermediaries from serving these individuals too. The Supreme Court has affirmed our right to live in the community, and New York has even created an Olmstead Plan committing to deinstitutionalization and community integration, but now the State is threatening the lives and freedom of 70,000 disabled New Yorkers and the livelihood of hundreds of thousands of people that work to support disabled people in the community.

CDPA - and the support provided by FIs - allows disabled people to live independently in the community with control over our own lives and saves the State from paying for far more costly institutions. We urge the legislature to intervene and stop these proposals that will not only kill this program but the many people it serves.



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<sup>2</sup> Eugene A. DePasquale-Auditor General Commonwealth of Pennsylvania Department of the Auditor General Performance Audit Department of Public Welfare's Oversight of Financial Management Services Providers - <https://www.paauditor.gov/Media/Default/Reports/speDPWPPL111413.pdf> (Last accessed - 2/1/19)