

Testimony of Nick Cappoletti, CEO, LIFEPlan CCO NY
Before the Joint Legislative Public Hearing on the 2021 Executive Budget Proposal: Topic
Mental Hygiene
Addressing State Budget Cuts and their impact on Individuals with Intellectual or
Developmental Disability
February 5, 2021

Good Afternoon: My name is Nick Cappoletti, I am the CEO of LIFEPlan CCO NY, one of the seven Care Coordination Organizations in New York State serving over 110,000 New Yorkers with Intellectual and Developmental Disabilities. On a personal level, I am the father of a 30-year-old son, Mark Cappoletti, a young. with an Intellectual and Developmental disability. Mark was born with a rare genetic syndrome, Autism and multiple co-occurring medical and behavioral health issues. I am personally vested in this discussion.

I would like to thank Senator Mannion, Senator Brouk, Senator Harckham, Assemblymember Abinanti, Assemblymember Gunther, Assemblymember Steck and the members of the Assembly and Senate for holding this hearing and for the opportunity to testify today.

The purpose of LIFEPlan and the State's other six IDD Care Coordination organizations is to support people with intellectual and/or development disabilities in New York State. To help them lead safe, healthy and integrated lives in their community. We also help their families with the enormous challenges associated with caring for people with IDD.

Ten years ago, Governor Cuomo committed that New York State would provide "care management for all" as part of his Medicaid Redesign initiative. People with intellectual and developmental disabilities waited over seven years to receive the benefits of comprehensive

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care management. In 2018, IDD Care Coordination organizations were created including LIFEPlan with the policy objective to improve the quality of healthcare and community services for people with IDD. Blending the traditional role of the Medicaid Service Coordinator with the focus of a health home care manager, CCOs are responsible for improving health outcomes, reducing preventable hospitalizations and emergency room visits and providing supports for people to lead integrated lives in their communities. CCOs also provide a vital safety net to the 108,000 people with IDD.

Most individuals with intellectual or developmental disabilities (I/DD) require a multitude of services. These can include physical health, habilitative, mental health, workforce readiness, housing, food security, transportation and other community-based services. These critical services can be required on an on-going or emergency basis and must be coordinated for the individual.

Approximately 38,000 people with IDD live in what is most commonly referred to as a group home, where their needs are met on a 24X7 basis. Over 80,000 people with IDD, the vast majority, live in the community either in their own homes or with family. Many of these people have fragile support networks and are only one heartbeat away from needing crisis services to meet their needs.

Care Managers are a critical support for people, in many cases, the only lifeline. They provide a critical service to an acute population 24 hours a day, 7 days a week. They help people access food, obtain safe and secure housing, receive needed medications, access medical and

behavioral health services. Care Managers help people avert crisis situations that could lead to placement in other settings, such as hospitals, mental institutions, nursing homes, and also jail.

People with IDD are a vulnerable population that has been marginalized for over a century.

People with disabilities who come from underserved populations are at even more risk- many are not even aware that these services exist.

The State's seven CCOs have worked collaboratively from the start, and then increasingly so during the past year to support the population throughout the COVID pandemic. Sharing best practices, population health data and taking collective action to benefit the population we serve.

You have heard what the CCOs' role is, now let's talk about how the State is responding to the work of the CCOs. Last July, the State implemented an almost 16 rate cut- prior to any known economic impact of the pandemic. As part of the recently proposed State Fiscal Year 21-22 budget, OPWDD is planning an additional 23% cut effective 7/1/21. This represents a 39% rate cut over a 12-month period.

This is not transparent – you will not find this in any budget document or bill. There has been no impact planning on the part of the State for what this will mean to the CCOs or the population they serve. The short story, however, is that the state is creating a scenario where CCOs will *no longer be financially viable entities, ending the promise of Care Management for the most vulnerable population during a national pandemic.*

Comment [CK1]: An Additional 23% cut

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The CCOs cannot sustain this cut. The CCOs will not be able to continue to operate at this level of reduction. There is no service to fill the void.

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This pandemic has highlighted the fragility of this population. It has also highlighted the weaknesses of our current system of OPWDD services.

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There is emerging research that indicates that the people with developmental disabilities are more vulnerable to COVID. Articles in Disability and Health Journal (V 13, Iss 4, 2020) and the American Journal of Psychiatry (August 28, 2020) report that individuals with I/DD face anywhere from a two to ten times greater risk of dying from COVID-19 because of their underlying and chronic health conditions and living arrangements. More than ever, during COVID-19, individuals with I/DD found themselves in very precarious situations and they have been disproportionately isolated and without the necessary supports and services that they need. The care coordination system has again been the lifeline- seamlessly coordinating a broad spectrum of supports that have connected thousands of people to shelter, food, medicine, and needed services.

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The current system does not readily respond to people who have immediate needs. The CCOs, through a care manager, support families and help them meet their needs.

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- People like Ellen, who has significant physical disabilities. She went home to her family in the beginning of COVID and ten months later is still home. Families in this type of a situation are overwhelmed with the care their family members need. There is a lack of available OPWDD community supports to assist such as respite, and COVID has only

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exasperated this problem. Care Managers continue to advocate, but without available services, they are doomed in a failed OPWDD system.

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- People like Ed, someone with an intellectual disability who was just released from a four-year prison term. People with disabilities often land in jail because of lack of sufficient community supports and services. How could Ed, and others like him, end up in jail? He has a significant developmental disability and he did not get services when needed to avert an insituational placement? Ed's Care Manager recently helped him maintain his benefits, and his home.

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- Andrew has Autism. He also has behavioral health issues that can lead to aggressive behaviors. Andrew was brought to the emergency room last October after a behavioral episode with his mother. Another common problem for people with disabilities is extended time in the hospitals. This is an unnecessary and unfortunate bi-product of the lack of available medical and behavioral health providers knowledgeable about people with disabilities. This often leads to people inappropriately accessing care. Care Managers are the advocates for these types of situations. They help people like Andrew find competent providers or avoid and mitigate medical or behavioral health crises. Andrew remained in the ER for 12 days even though he did not present with any medical or behavioral concerns to validate this length of stay.

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These are a few of many stories that highlight the following issues:

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• Our system of services needs an overall plan both for the remainder of this pandemic as well as future crises or disasters. We can assume this will not be the last.

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• People with IDD living in the community living either on their own or with their families are especially vulnerable to cuts in services. This group of individuals receives the smallest percentage of IDD funding.

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• Many parents and care givers, like Ellen's mom, who either cannot work or are working from home need community-based services such as respite and community habilitation. We have young people who have graduated from or aged out of school need transition supports.

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• Many direct services cannot be delivered via telehealth and we must support the providers so that they can support the people they serve.

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• There are several thousand people who are waiting for OPWDD eligibility who are without services. Many more people from underserved communities, people of color, who are eligible for these services but because of language or cultural barriers, are not linked to services. These are people who end up in crisis and fall through the services cracks in our society. This is a social justice issue, a human rights issue.

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• A pandemic is not the time to cut vital care management and direct services for a vulnerable population.

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- *Now is the time to take bold action at transforming this system- looking at new models of service provision that are more effective and efficient combined with a reduction in unnecessary mandates.*

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- *The short and long-term viability of this system is at risk if it stays on its current trajectory.*

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Thank you for your time today.

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