

Summary Report on the Impact of COVID-19 on Individuals with Intellectual/Developmental Disabilities

Senator David Carlucci

A virtual forum to accept public comments concerning the impact of COVID-19 on individuals with intellectual/developmental disabilities, their families, and essential service providers.

With Senators in Attendance:

Sen. Shelley Mayer
Sen. Roxanne Persaud
Sen. John Liu
Sen. Todd Kaminsky
Sen. Simcha Felder
Sen. Kevin Parker
Sen. Monica Martinez

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Letter to Governor Andrew M. Cuomo:

The Honorable Andrew M. Cuomo
Governor of New York State
NYS State Capitol Building
Albany, NY 12224

Dear Governor Cuomo,

On August 26, 2020, my office hosted a virtual webinar forum to discuss the impact of COVID-19 on individuals with intellectual/developmental disabilities, their families, and essential service providers. This report summarizes the main takeaways from this forum, highlighting the key issues and the actionable steps that can be taken to remedy them. As such, I look forward to working with you to improve the realities faced by the disability community and to ensure that they can endure this crisis.

During this forum, members of the New York State Senate heard from representatives of parent-advocates, service providers, and coordinated care organizations, who discussed the problems that they face as the pandemic persists. As you know, the pandemic has created an array of challenges, from the visitation ban, inflexible telehealth practices, and lack of communication between agencies, parents, and providers. Further, the recently proposed cuts of twenty percent to the Office for People with Developmental Disabilities (OPWDD) risk exacerbating these concerns.

As we grapple with these issues, my office has developed a list of preliminary recommendations (page 7), to begin mediating these issues. These recommendations include restructuring telehealth to better adapt to I/DD, establishing coherent testing and visitation policies for OPWDD, extending housing subsidies so our most vulnerable can continue to live independently, authorizing family caregivers to provide community habilitation under the Home and Community Based Care Waiver during this extraordinary circumstance.

I look forward to working with you on these recommendations to improve the realities faced by individuals with intellectual/developmental disabilities, their families, and essential service providers. Our State's most vulnerable depend on it.

A full speakers list can be found on page 3. The webcast of the forum can be found, [here](#), on my personal Senate page.

Sincerely,

A handwritten signature in black ink, appearing to read "D. Carlucci", with a stylized flourish at the end.

Senator David Carlucci
38th Senate District

List of Speakers:

Panel 1: Service Providers 1

- Susan Constantino, President & CEO
CP Unlimited
- Rhonda Frederick, President & CEO
People, Inc.
- Al Kaplan, Senior Policy Advisor
AHRC NYC
- Ron Colavito, CEO
Access: Supports for Living

Panel 2: Advocates

- Harvey Weisenberg, Former Assemblyman
- Jim Karpe, Parent Co-Chair
Queens Council on Developmental Disabilities
- Leslie Feinberg, Founder
Supporting Our Youth & Adults Network (SOYAN)
- Barbara Masur, Legislative Chairperson
GROW
- Kathy Bunce, Co-Chair
Developmental Disabilities Alliance of Western NY (DDAWNY)
- Margaret Vogt, Parent Advocate

Panel 3: Service Providers 2

- Jane Zemon, Chief Program Officer
The Arc Rockland
- Mary Grace Giuliano, COO
The Institutes of Applied Human Dynamics (IAHD)
- Sally J. Colletti, CEO
Advocates for Autism, Inc.
- Marjorie Watson Ley, Controller
Another Step, Inc.

Panel 4: Coordinated Care Organizations

- James Moran, CEO
Care Design NY
- Yoel Bernath, CEO
Tri-County Care

Summary of Statements:

This is the summary report depicting the statements given at Senator David Carlucci's Virtual Forum to discuss the impact of COVID-19 on individuals with intellectual/developmental disabilities, their families, and essential service providers on August 26, 2020.

At the height of the pandemic, individuals with intellectual disabilities, their families, and essential service providers were broadly left in the dark. Rhonda Frederick noted the surprises that her provider organization faced at every turn, including a notification received on July 10 that their day programs would be reopening on July 15, just five days later. Susan Constantino spoke about the lack of guidance issued to help providers access Personal Protective Equipment (PPE), and the difficulty getting provider staff designated as "essential." Many providers and advocates highlighted the erratic nature of their correspondence with OPWDD, who did not provide coherent testing procedures, safety protocols, and updates as they weathered the pandemic.

This lack of communication extended to families as well, as indicated by Jim Moran, who noted that for months, families were completely unaware of the status of their loved ones. Parents and advocates could get neither staff nor family members in to visit their loved ones, many of whom were unable to speak or advocate for themselves. Barbara Masur echoed this point and indicated that the problem stemmed from restrictive visitation policies, which barred parents regardless of their willingness to take the necessary safety precautions.

These rigid policies also prevented many individuals with intellectual and developmental disabilities from receiving care through OPWDD, leaving family members to pick up the added responsibility. Leslie Feinberg notes that, in many cases, these family members had to forgo work to become full-time caregivers but were unable to access any financial compensation through OPWDD.

While OPWDD does have a stipulation within their 1915(c) Home and Community Based Care Waiver, which permits payment of family caregivers in extraordinary circumstances, according to OPWDD, the COVID-19 pandemic is not being considered an extraordinary circumstance. The flexibility of person-centered service delivery through the Self-Direction model has been stymied by OPWDD's freezing of budgets, with no clarification of when this will be lifted and for the person whose needs have changed during the pandemic.

Beyond family caregiving, many individuals with intellectual and developmental disabilities were forced to alter their routines as the pandemic raged. In the switch from in-person to telehealth services, many were left without adequate access to care. As Jim Karpe notes, telehealth did help many, but for many individuals with intellectual and developmental disabilities, telehealth services were unable to adapt to the care that they needed. From the provider perspective, Yoel Bernath mentions that the rules surrounding telehealth are so rigid because of over-regulation and calls for more flexibility in the provision of telehealth services.

In addition to the effect of the pandemic, the plurality of speakers voiced concerns about the proposed twenty percent cut to OPWDD. Speakers unanimously condemned these cuts, noting

the real impact that they will have on every element of the disability community, from the individuals with intellectual/developmental disabilities themselves, to Direct Support Professionals (DSPs), and the solvency of providers. Al Kaplan noted that the provider sector has already lost more than \$175 million in both costs and revenue due to the pandemic, and a further cut from the State will reduce the number of available beds for our state's most vulnerable, while forcing many homes to close entirely. Harvey Weisenberg noted that these cuts would most immediately affect DSPs, who are already overworked and underpaid in a profession that has immense turnover. Reduced facilities, combined with the further destabilization of the DSP profession, will surely reduce the quality of care that can be provided to individuals with intellectual/developmental disabilities.

These cuts will not only reduce quality of care, they will reduce the flexibility of care as well. As noted by Sally Colletti, many individuals with intellectual/developmental disabilities have thrived under self-direction and the relative independence that it provides. However, proposed cuts to OPWDD threaten the housing subsidy to these individuals, not only risking their independence, but also threatening their housing in the midst of a global pandemic.

This report offers recommendations to improve the current state of affairs for individuals with intellectual/developmental disabilities, their families, and essential service providers in New York State. We hope that you find this report useful in your professional capacity. It is our expectation that the report offers hope to those in the disability community as they continue to endure the COVID-19 pandemic.

Recommendations:

The forum produced several general recommendations related to OPWDD's operations during the COVID-19 pandemic, as well as specific proposals that can be turned into legislation. Senator Carlucci believes that the recommendations described herein will improve upon the current methods New York is using to address the needs of the most vulnerable New Yorkers. OPWDD and providers can better address the needs of the developmentally disabled using these recommendations. Senator Carlucci will work to advance current legislation and draft new legislation to put these important legislative ideas into action.

- 1) **S.8557/Carlucci** – This legislation authorizes voluntary providers of supports and services to individuals with intellectual/developmental disabilities to be reimbursed within thirty days of billing for COVID-19 related costs and expenses. This would facilitate the desperate need for cash flow to already beleaguered providers during this unprecedented time.
- 2) **S.3484/Carlucci** – This legislation provides clarification relating to the establishment of a developmental disability clinician advisory group by the commissioner of health. The creation of this advisory group is crucial to ensuring that the providers of supports and services to our most vulnerable individuals are compensated appropriately for the care they provide.
- 3) **Restructuring Telehealth services and regulation at OPWDD** – This draft proposal would require OPWDD to restructure their regulations for first-time seekers of OPWDD services to allow for telehealth initial assessments during the COVID-19 pandemic.
- 4) **Recognizing the enormous contribution and sacrifice of Direct Support Professionals (DSP's) providing services during the pandemic** – This draft proposal would ensure front line direct care and clinical staff, who serve and protect a vulnerable population, are compensated properly as they serve a population often ill-equipped to self-distance or who cannot tolerate wearing a mask.
- 5) **Establishing a coherent, universal testing policy and a flexible visitation policy for all OPWDD facilities** – OPWDD must issue a coherent set of testing policies to be applied ubiquitously across all OPWDD facilities for staff, visitors, and service recipients. Further, when such standard is applied, flexibility in visitation should be granted to families who have tested negative and taken the necessary steps to protect themselves and their loved ones.
- 6) **Continuation of OPWDD housing subsidies so that I/DD New Yorkers can continue to live as independently as possible** – OPWDD needs to continue to provide these subsidies or negotiate with landlords on behalf of clients to maintain their current independent living situation.
- 7) **Authorize Home and Community Based Care Waivers for any reasonable application** – During the pandemic, many family members have been forced to operate

as full-time caregivers for their loved ones, as standard care is inaccessible. These family members ought to be eligible for approval as Community Habilitation providers, under the Home and Community Based Care Waiver, which would allow them to be paid for their services. OPWDD must authorize these waivers for any reasonable application during these unprecedented times.