

# Institute on Public Policy for People with Disabilities

## Senate Healthcare and Human Service Work Group Testimony

Respectfully Submitted By:  
Kathy Carmody, CEO  
The Institute on Public Policy for People with Disabilities

May 13, 2020

Good Afternoon and thank you Senator Hunter and workgroup members for the opportunity to share information with you regarding the impact of COVID19 on people with intellectual and developmental disabilities (hereafter referred to as I/DD) and the community agencies across Illinois that support them. My goal today is to share an overview of the current I/DD community landscape in Illinois including what we know about the impact of COVID19 on:

- the lives of people with I/DD supported by community agencies across Illinois
- community organizations providing 24/7 residential supports to nearly 16,000 adults with I/DD
- the Illinois community I/DD system

As well as identify key pressure points on the community I/DD system resulting from the pandemic and items for your consideration as you move ahead with FY21 budget discussions.

First, I want to acknowledge the work our state agencies have done to support and sustain I/DD community services. IDHS prudently and proactively moved to suspend Community Day Services on March 17. This action assured reduced exposure among people with I/DD well ahead of steps taken in other states. IDHS has also instituted a retention payment program whereby community organizations that provide Community Day Services will retain state payments through the remainder of FY20 so they can resume operations when permitted. Community residential providers inclusive of Community Integrated Living Arrangement or CILA group homes, as well as Intermediate Care Facilities for the Developmentally Disabled or ICFDDs received an approximate 20% rate increase to account for daytime staff hours that aren't typically included in their rate, and CILA providers received a 10% rate increase to account for increased COVID19-related expenses. ICFDD's are awaiting that additional increase but we understand it is a matter of processing it rather than a question of whether it is committed. There has been frequent and responsive communication from our state partners and while I think we all acknowledge challenges facing community organizations and the people they support we appreciate the administration's attention.

Moving on to the impact of COVID19 on people with I/DD in community settings. Approximately 11,600 people living in CILA settings and approximately 4,800 people living in community ICFDD settings

continue to receive daily, 24/7 care from community organizations across Illinois. The state is responsible for an additional approximately 1,600 people living in state operated developmental centers. While other sectors of the social service system are negatively impacted by the pandemic due to a decline or suspension on service delivery, I/DD residential programs continue to support some of our most vulnerable Illinoisans during the pandemic.

We do have affected residents and staff and unfortunately, deaths attributed to COVID19. IDHS recently moved to having regional Independent Service Coordination or ISC agencies keep track of cases in their region. The most recent numbers indicate that 182 people in CILA settings and 275 people in ICFDD settings have tested positive, with unfortunately 21 deaths. It is widely assumed that these numbers are low estimates based on the challenges in securing testing that many organizations across Illinois face.

Community organizations supporting people in residential settings, like other sectors of the health care industry, have been forced to adapt to the current landscape and make significant changes to their business and service models. In an effort to reduce exposure among CILA residents (nearly 30% of whom are age 60+ and many of whom have co-morbid conditions), agencies have changed their staffing model where possible from a shift-staff to a live-in model. This model greatly reduces exposure and risk however it is a costly proposition which cannot continue indefinitely. In addition to paying overtime and premium wages to staff working under the live-in model, organizations are also paying staff who are not working regular wages to retain them. While this approach has indisputably saved lives, it is not a long-term sustainable staffing model. You may have read the article in today's Chicago Sun Times about Trinity Services, an Institute member and their heroic team member Mr. Roosevelt Journigans who has been living in a Trinity facility for over a month with 2 more weeks still to go. In addition to the live-in model, organizations have widely implemented enhanced wages to staff working during this period in recognition of the risks they are exposed to on a daily basis. While our direct support workforce is as heroic and essential as other members of the healthcare sector, they unfortunately, are not as identifiable as many of their peers in that space.

Challenges abound for I/DD community organizations and I'm proud and humbled to share with you the resiliency, compassion and initiative that community organizations have shown in confronting these. I'd like to now discuss some systemic challenges that impact organizations' ongoing efforts to keep people healthy and safe. I've had the chance to discuss with a few of you the challenge that PPE and testing access poses for the I/DD community. A special shout-out to Sen. Steans and the Steans Family Foundation for acquiring much-needed PPE items that were made available to IDHS community partners. This inventory is greatly appreciated and filled a critical void. However, the acquisition of PPE items remains elusive and a daily challenge, as well as a critical fissure in organizations efforts to keep residents and staff healthy and safe. Many organizations have nothing more than cloth face coverings – not surgical, KN95 or N95 masks,

for use by staff and residents. PPE items that organizations have been able to purchase are without exception, at premium prices. While many organizations have ongoing supply chains, we have never needed to purchase PPE items at the rate necessary today and much of that supply is being diverted to acute health care settings. I can attest to this personally as the Institute was able to purchase some essential PPE items including N95 and KN95 masks for at-cost sale and distribution to community organizations, but at a well-above retail cost.

Agencies face the same challenge we all do in purchasing hand sanitizer, disinfecting wipes and yes, toilet paper needed in group home and ICFDD settings. Imagine trying to shop for those items for a 6, 7 or 8 person CILA home, as well as food supplies, when most inventory is limited to 1 or 2 items for purchase. I don't necessarily expect legislative action on this challenge, I just want to share the day-to-day realities facing community providers.

Testing remains haphazard. ICFDD and CILA settings are not fully understood by health departments at the local, county and perhaps state level. While testing access is increasing at drive-up locations, the on-site testing being conducted in nursing facilities has not been extended to residential settings serving people with intellectual and developmental disabilities. While people have not left these settings since the stay at home order, many are still exposed to a number of different staff who do not have regular testing access. On Friday the CEO of an Institute member organization in Chicago shared with me that a resident of a CILA site who is deaf, blind and developmentally disabled showed symptoms of COVID19 and was hospitalized where he indeed tested positive despite not having left his home for nearly 8 weeks. The same access to testing, frequency and rapid results needed in other better understood sectors of the healthcare field must be available to people with intellectual and developmental disabilities and the staff and agencies that support them.

The final topic I want to address is that as you look to the FY21 budget, that you consider the essential role that community organizations play in supporting people with intellectual and developmental disabilities. Without the network of community agencies supporting more than 16,000 people across the Illinois, the state itself would need to assume direct responsibility for their daily care. We know the challenge the state has faced in its state operated developmental centers where 340 residents and 522 staff and residents have tested positive; it would be contrary to every doctrine of public health prevention strategy to consider those settings as alternatives to community residences. We acknowledge the unprecedented budgetary challenge facing the state, but nonetheless implore you to assure the sustainability of the I/DD community system as you move forward. Thank you for your time today and I'm happy to try and respond to any questions you may have.