



# HEALTH EQUITY ROUND TABLE

## Impacts and Implications of COVID-19 on the IDD Community

### Abstract

This document provides an overview of PCCS' first Health Equity Roundtable. Panelists discussed the impacts of COVID-19 on the IDD community, addressed vaccine hesitancy and mistrust, and focused on how the IDD community can move forward from the COVID-19 pandemic.

Nisha Tumber, MSW

[ntumber@pccsny.org](mailto:ntumber@pccsny.org)  
Published 6/22/2021



*“We are a not for profit organization creating social change within communities by supporting people with disabilities on their search for identity and acceptance.”*

**Acceptance**

**Equity**

**Support**

## Contents

Topics discussed: .....2

Organizational Attendees: Panelists included: .....2

Ongoing Challenges and barriers for people with IDD: .....2

Call for Action/Action Steps .....3

    Professionalization of the DSP role.....3

    Work with local legislators.....4



“We are a not for profit organization creating social change within communities by supporting people with disabilities on their search for identity and acceptance.”

Acceptance

Equity

Support

# Staten Island Performing Provider System Collaborating Partner

RE: Health Equity Roundtable Quarter 1 Summary Report

## Topics discussed:

Person Centered Care Services hosted our first Health Equity Roundtable on June 16, 2021 at 1pm via Zoom. The topic discussed was *Health Equity Roundtable: Impacts and Implications of COVID-19 for People with Intellectual and Developmental Disabilities*. During this roundtable we meet with medical professionals across the borough as we discuss the importance of the COVID-19 vaccine, vaccine hesitancy, COVID-19 testing, precautions and the impact that COVID-19 has had on Staten Island agencies and on individuals with intellectual and developmental disabilities.

## Organizational Attendees: Panelists included:

- Michael J. Cusick, State Assembly of New York, 63rd District,
- Dr. Meghan Hamwey
- Dr. Vincent Siasoco, MD, MBA
- Jennie Sutcliffe,
- Dr. Frederick Wetzel, Ph.D
- Dr. Ginny Mantello, MD
- Michael Weinberg
- Jill Cornell

The event was hosted by Nisha Tumber, Director of Special Initiatives, and co-hosted by cRis marchioNNe, Executive Director, Alexa Donnelly, Deputy Executive Director, and Alyssa D’Agosto, Communications Manager.

## Ongoing Challenges and barriers for people with IDD:

During the panel, participants were given the opportunity to take part in break out rooms with the panelists to discuss specific topics. The breakout rooms had the following topics:

- Dr. Ginny and Jennie Sutcliffe & Meghan Hamwey
  - How can we continue to address vaccine hesitancy?
  - What can we do to ensure that people with disabilities, IDD providers and DSP’s can get vaccinated?
- Frederick Wetzel and Michael Weinberg



*“We are a not for profit organization creating social change within communities by supporting people with disabilities on their search for identity and acceptance.”*

### Acceptance

### Equity

### Support

- What can providers do in navigating the impact of COVID-19 and future pandemics?
- What plan can be put in place to help IDD providers with
  - Jill Cornell & Vincent Siasoco
    - What can we do, as providers, to prepare for the next pandemic?
    - Personal preparedness/community preparedness
  - Michael Cusick
    - Where do legislators stand in getting funding/support to professionalize DSP role (for turnover rates)?
    - What will legislators do to advocate for individuals with IDD and IDD providers and their employees?

In the breakout rooms during the event, participants/panelists were asked to formulate a “call to action” plan on the specific topics to brainstorm on the next steps on how we can best advocate for people with disabilities. Ideas were posted on a [jamboard](#) and shared after the breakout rooms returned to the main room. When discussing the COVID-19 vaccine, the participants raised questions regarding the accessibility of the vaccine, the potential long-lasting side effects, and the efficacy of the vaccine. The questions raised were pertinent to the disability community because parents. Self-advocates and loved ones of family members with disabilities raised these questions because of their hesitancy in getting the vaccine. One participant shared that she had difficulty in getting her son vaccinated because of the lack of options for in-home vaccinations. Participants were able to share their personal stories and concerns with the panelists, and in return, received resources to combat these existing barriers. The ongoing challenges and barriers for people with intellectual and developmental disabilities are not limited to just the accessibility and hesitancy of the COVID-19 vaccine, but also in the overall impacts of COVID-19 pandemic on individuals with IDD and IDD providers/agencies. The discussions amongst panelists and participants shed a light on the impacts of COVID-19 on providers and the need to advocate for more funding and support.

## Call for Action/Action Steps

In order to best advocate for and support IDD providers, families and self-advocates, we must:

1. Professionalize the role of the Direct Support Professional
2. Work with local legislators to campaign for the disabled and request funding for local IDD providers

### Professionalization of the DSP role

Direct Support Professionals (DSP’s) provide essential care to the people they support, and during the height of the pandemic, DSP’s were expected to continue the same level of care—despite the high number of COVID-19 rates. It is during this time that DSP’s became titled as “essential workers.” Historically, DSP’s have high consistent turnover rates, and during the height of the pandemic, DSP’s were essential workers that continues to provide critical support



*“We are a not for profit organization creating social change within communities by supporting people with disabilities on their search for identity and acceptance.”*

### Acceptance

to individuals with disabilities to help them lead more independent lives and a better quality of life. COVID’s negative impact on the disability community both highlighted the important role Direct Support Professionals play in the lives of people with disabilities as well as exacerbated the existing workforce shortage. Individuals impacted by disability devote countless hours trying to recruit, hire, train and retain DSPs--the workforce shortage harms an individual’s right to community participation and drains families. The professionalization of the DSP role will ensure that DSP’s are rewarded and recognized for the hard work that they do.

### Equity

### Support

#### Resources

- [National Alliance of Direct Support Professionals \(NADSP\)](#): Moving from Crisis to Stabilization
- [Recognizing the Role of Direct Support Professionals Act](#): Click here to learn more about the bipartisan legislation to address the critical need for Direct Support Professionals in the workforce

#### Work with local legislators

The COVID-19 pandemic had an impact on *everyone*, however, with this pandemic, when the majority of the population is affected, the minority of the population is forgotten about. During the height of the pandemic, NYS IDD providers were faced with 20% budget cut. Self-advocates and their loved ones, and IDD providers must actively engage with local politicians to ensure that the voices of individuals with disabilities are heard. Furthermore, we must hold politicians accountable in ensuring that all the voices of the population they represent are heard. Politicians hold the power to make change in our communities, so we need to engage them in the conversations that are taking place in the IDD communities.

#### Resources

- [Resources for Voters with Disabilities](#)
- [American Association People with Disabilities](#): REV UP campaign
- [Voter Registration](#): Click here to see if you are registered to vote
- Not Registered to vote? [Register here](#)
- [The ARC: Policy and Advocacy](#)

#### Emergency Preparedness for People with Disabilities

During the breakout room discussions with Jill Cornell and Vincent Siasoco, participants discussed the importance of emergency preparedness for people with disabilities. The lack of resources available for people with disabilities during this time contributed to hardships and difficulties faced by people with disabilities during this time. To prepare for the next pandemic, it is imperative that resources be put in place for people with disabilities. For example, providers must continue to offer telehealth, advocate for funding, have emotional support options available and have an understanding of health disparities and unpreparedness barriers. Most importantly, it is important that all these solutions be accessible to the person receiving those supports. In order to support families and caregivers with emergency preparedness, providers and agencies should



*“We are a not for profit organization creating social change within communities by supporting people with disabilities on their search for identity and acceptance.”*

### **Acceptance**

have policies put in place that specify the guidelines in ensuring preparedness for people with disabilities.

### **Equity**

### **Support**

#### *Resources*

- [Disability and Health Emergency Preparedness | CDC](#)
- [National Technical Assistance and Training Center on Disability Inclusion in Emergency Preparedness](#)
- [New York City Office of Emergency Management](#)

#### Vaccine Mistrust and Hesitancy

In order to combat the low vaccination rates amongst Direct Support Professionals (DSP's) and individuals with disabilities, it is imperative that agencies work towards outreach to these populations to address the mistrust and hesitancy experienced. Mistrust and hesitancy can be addressed by hosting community information sessions to discuss the COVID-19 vaccine, and what to expect. More importantly, it is important to address the accessibility in receiving the vaccine. Caregivers expressed concerns in the accessibility of the vaccine because their loved ones may not be comfortable in rooms with overstimulation. In order to be accessible, pharmacies must have the option of delivering the vaccine in-home, or creating accessible spaces at the vaccination site.

#### *Resources*

- [Disability Information and Access Line](#): If you are having difficulty getting vaccinated, call 888-677-1199
- [#VaccinateByADA: Strategies for COVID-19 Vaccine Access and Confidence for People with Disabilities](#): Register here to attend this webinar
- [Vaccine Resource Center](#)
- [COVID-19 Vaccination Challenges for People with Disabilities](#)
- [COVID-19 Vaccine toolkit for People with Disabilities](#)