The Geraldo Rivera Fund

Public Conversations for Change

COVID-19 Series White Paper

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What Is the Geraldo Rivera Foundation (GRF)?

The Rivera Fund seeks to organize public conversations around disability related topics to:

- Increase knowledge-sharing across stakeholders.
- Cultivate a cohort of diverse cross-stakeholder leaders that supporting person-centered, equitable policy and services for people with disabilities.
- Collaboratively advocate for person-centered, disability-related policy and/or service change.

What do we do?

The GRF cohort meets 2x a month to organize and plan the public conversations. These conversations are aimed to:

- Keep the person with a disability at the center as the storyteller – from their view – their perspective.
- Share variations of stories and experiences to help the community see the strength, resilience, and diversity within the disabled community.
- Intertwine the larger community with the I/DD community through our events where story tellers share their personal stories.

Sponsored by:

The Geraldo Rivera Fund for Social Work and Disability Studies at the City University of New York, College of Staten Island.

About this White paper

This paper was created to serve as a guide for caregivers, families, and advocates to engage in meaningful conversations with their loved ones as well as to engage in disability advocacy efforts. This paper is aimed in enhancing self-advocates, family, and community conversations as an overarching approach to support family health, well-being, and relationships. This paper offers an integrated approach to public conversations by keeping the person with the disability at the center of the narrative, through their own experiences, their own perspectives through dialogue with the community. The conversations are mapped and outlined and then analyzed to note conversational themes or patterns. The data then provides a snapshot on conversational thought, ideas, and feelings shared among GRF cohorts and the public. The GRF helps caregivers/families understand how to engage in difficult conversation such as COVID, while at the same time, help caregivers/families learn how best to the support or advocate for the person with the disability during the pandemic.

Introduction

In 2020 and through 2021, the GRF public conversations focused on resilience and growth through the COVID-19 pandemic. These conversations are a three-part series with three different perspectives of shared stories on the impact of COVID-19.

- Part 1: A Self-Advocate's Perspective
- Part 2: A Caregiver's Perspective
- Part 3: The Care Provider's Perspective

This paper provides an outline of questions/prompts used to navigate conversations regarding COVID-19 in three sessions for each series part. Responses were collected as data and then categorized by themes and/or patterns as per each of the series. The questions, prompts and data are provided in this paper along with COVID related information as well as information to engage in advocacy efforts.

Caregivers, advocates, and family members are required to exercise their own judgement in using this paper to exercise the application of information contained to be based on individual needs, the relevant circumstance and context. This paper should not be used as a substitute for information. If you are a person or caring for a person with disabilities, experiencing depression or any other mental concern, please reach out to a qualified health care provider.

GRF and COVID-19

Due to the current pandemic, the Geraldo Rivera Fund organized public conversations around disability and the impact of COVID-19. The conversations broken into three different sessions, ranging from how one was able to adapt life to COVID-19, with stories on resilience, strength, self-discovery to learning new skills. The conversations also delved into the hardships experienced by COVID such as loss, loneliness, anger and even fear. These conversations led the way to understanding the supports, networks, people, and the emotions needed to be expressed to get through such a crisis. In the end, the stories shared were inspirational and hopeful once again reaffirming the strength found in each person to overcome challenges.

The Project

The purpose of this project was to work with people in the disability community to amplify their stories and to get community members more involved in the disability related issues such as policy issues, funding, programs, community experience etc. The purpose of storytelling is to really share personal experiences that will get the community involved and activated to be engaged in advocacy!

The project started with the registration for Part 1, "A Self-Advocate's Perspective on Covid" scheduled for November 9th and November 12th, 2020. 53 people registered for 11/12 and 74 people registered for a total of 127 registrants. Registrants included people from different employment backgrounds such organizational CEOs, directors, office managers, case managers, social workers, direct support professionals, and educational professors. Other registrants included college and doctoral students and families/advocates of a person with an intellectual disability. During these two sessions, the storytellers, the people with intellectual disabilities and self-advocates, sharing their experiences on COVID-19. After the stories were shared, attendees were provided 12 prompts to enter their own thoughts, feelings and emotions related to the stories they heard through a Jamboard exercise, a Google digital whiteboard. This exercise allowed for the attendees to reflect on their own experiences with COVID.

Part 2, focused on the caregiver's perspective which took place on February 16th and 18th. A total of 61 people registered for February 16th and 45 people registered for February 18th with a total of total of 106 registrants. Again, registrants included organizational CEOs, directors, office managers, case managers, social workers, direct support professionals, and educational professors. In addition, there were also advocates, family members of people with intellectual disabilities, Interns, Support Brokers and Behavioral Special Behaviorist. In this part, it was noted that there were no college or doctoral students registered. Although there were additional registrants with employment backgrounds there were 21 less people registered than from Part 1. The two sessions for Part 2, included storytellers that were caregivers and/or family members caring for their loved ones with intellectual disabilities. The caregivers shared their experiences on providing supports and care to the person with an intellectual disability during COVID-19. After the stories were shared, attendees were again provided the same 12 prompts to enter their own thoughts, feelings and emotions related to the stories they heard through the Jamboard exercise. This exercise allowed for the attendees to reflect on their own experiences with COVID while posting their responses on a digital interactive whiteboard. In this part, a survey and a poll were also provided to the attendees. The poll that was provided for both sessions asking the question, "What's your first reactions to our current remote/virtual world?" Only 27 people out of the 45 registered responded to the poll. Responses are as follows:

Response Statement	# of Responses
Miss people but I actually don't mind it!	6
Hope we get to some hybrid version of this and in person!	11
Ew take me back to the good old days of in person!	6
I could stay like this forever!	3

For the poll on 2/18/21, 25 people participated in the poll out of the 106 registered.

Response Statement	# of Responses
Miss people but I don’t mind it!	10
Hope we get to some hybrid version of this and in person!	11
Ew take me back to the good old days of in person!	2
I could stay like this forever!	1

Thus, the poll indicated that people prefer to have some type of hybrid programming with 22 in total responses for both sessions. Caregivers also did not mind the remote/virtual world with 16 responses in total, 8 caregivers preferred to go back to non-virtual platforms and 4 indicated their preference in being totally virtual.

For the survey, only 5 people completed with the statements and responses indicated below:

Survey Prompt	**Responses**
By attending this event, I learned something new about developmental disabilities that has changed my perspective.	2=agree 3=provided no response
I can see ways of incorporating some of the learning from this forum into my engagement with people with disabilities.	2=agree 3=provided no response
I am more aware of the issues impacting people with developmental disabilities.	2=agree 1=neutral 1=strongly disagree 1=provided no response
I am more committed to participating in efforts to change policies that negatively impact people with developmental disabilities.	2=agree 2=strongly disagree 1=provided no response
I have more awareness of the different ways I can support people with developmental disabilities.	2=agree 1=strongly agree 1=strongly disagree 1=provided no response
I am more motivated to support people with developmental disabilities in making positive changes.	2=agree 1=strongly agree 1=strongly disagree 1=provided no response
I will tell others about some of the issues I became aware of through this forum.	2=agree 1=strongly agree

	1=strongly disagree 1=provided no response
I am more committed to promoting change in policies and services for people with developmental disabilities.	2=agree 1=strongly agree 1=strongly disagree 1=provided no response
Overall, I found this activity to be informative; it provided me with new learning about people with developmental disabilities.	3=agree 1=strongly disagree 1=provided no response
I would like more public dialogues like this one to keep me involved in policies and service change needed for people with developmental disabilities on Staten Island.	3=agree 1=strongly disagree 1=provided no response
Overall, how would you rate your experience in this Public Conversation for Change?	3=very positive 1=positive 1=provided no response
AFTER Public Conversations for Change, how would you rate your motivation for engaging in public involvement to make changes in policies and services for people with developmental disabilities?	1=somewhat motivated 1=very motivated 2=motivated 1=provided no response

The final part of this project took place on May 4th and 6th. Part 3 focused on the care provider's perspective which included Direct Support Professionals (DSPs), agency administration, educators, and group leaders. There were 41 registrants for May 4th and 42 registrants for May 6th, with a total of 83 people registered. Although registrants were less than part 1 and 2, a variety of people attended that included organizational CEOs, directors, office managers, case managers, social workers, direct support professionals, advocates, Interns, Support Brokers and policy advisors and adjunct instructors. In these sessions, DSPs, agency administration, group leaders and educators shared their experiences on providing supports to people with intellectual disabilities during the pandemic. After the stories were shared, attendees were again provided the same 12 prompts to enter their own thoughts, feelings and emotions related to the story they heard through Jamboard allowing for the attendees to reflect on their own experiences with COVID. A survey and a poll were also provided to the attendees. In this part, there were two polls with the same question provided at each session, one at the beginning and end of each session.

The question posed was, "On a scale of 1-5 how comfortable do you feel that you have the tools to advocate for and with the disability community?" 1 being at the lowest ranking and 5 at the highest. 24 people participated in the poll in the first session and 24 in the second session. The results for polls are as follows:

<table>
<tr><th colspan="2">Poll 5/4/21 Beginning of Session</th></tr>
<tr><th>Scale</th><th># of Responses</th></tr>
<tr><td>1=least uncomfortable</td><td>1</td></tr>
<tr><td>2=uncomfortable</td><td>1</td></tr>
<tr><td>3=neither comfortable nor uncomfortable</td><td>7</td></tr>
<tr><td>4=Comfortable</td><td>7</td></tr>
<tr><td>5=Very Comfortable</td><td>8</td></tr>
<tr><th colspan="2">Poll 5/4/21 End of Session</th></tr>
<tr><th>Scale</th><th># of Responses</th></tr>
<tr><td>1=least uncomfortable</td><td>1</td></tr>
<tr><td>2=uncomfortable</td><td>1</td></tr>
<tr><td>3=neither comfortable nor uncomfortable</td><td>2</td></tr>
<tr><td>4=Comfortable</td><td>7</td></tr>
<tr><td>5=Very Comfortable</td><td>13</td></tr>
</table>

<table>
<tr><th colspan="2">Poll 5/6/21 Beginning of Session</th></tr>
<tr><th>Scale</th><th># of Responses</th></tr>
<tr><td>1=least uncomfortable</td><td>1</td></tr>
<tr><td>2=uncomfortable</td><td>2</td></tr>
<tr><td>3=neither comfortable nor uncomfortable</td><td>4</td></tr>
<tr><td>4=Comfortable</td><td>13</td></tr>
<tr><td>5=Very Comfortable</td><td>2</td></tr>
<tr><th colspan="2">Poll 5/6/21 End of Session</th></tr>
<tr><th>Scale</th><th># of Responses</th></tr>
<tr><td>1=least uncomfortable</td><td>0</td></tr>
<tr><td>2=uncomfortable</td><td>0</td></tr>
<tr><td>3=neither comfortable nor uncomfortable</td><td>4</td></tr>
<tr><td>4=Comfortable</td><td>9</td></tr>
<tr><td>5=Very Comfortable</td><td>5</td></tr>
</table>

After the sessions for part 3 concluded, a survey was provided to evaluate participant's learning, 21 care providers completed the survey. Survey prompts with responses are indicated below:

Survey Prompts	**Responses**
By attending this event, I learned something new about developmental disabilities that has changed my perspective.	3=agree 6=Strongly agree 2=neutral 10=provided no response
I can see ways of incorporating some of the learning from this forum into my engagement with people with disabilities.	5=agree 6=strongly agree 10=provided no response

I am more aware of the issues impacting people with developmental disabilities.	9=agree 10=strongly agree 1=strongly disagree 1=provided no response
I am more committed to participating in efforts to change policies that negatively impact people with developmental disabilities.	18=agree/strongly agree 1=strongly disagree 1=neutral 1=provided no response
I have more awareness of the different ways I can support people with developmental disabilities.	8=agree 11=strongly agree 1=strongly disagree 1=provided no response
I am more motivated to support people with developmental disabilities in making positive changes.	4=agree 13=strongly agree 1=strongly disagree 2=neutral 1=provided no response
I will tell others about some of the issues I became aware of through this forum.	8=agree 11=strongly agree 1=strongly disagree 1=provided no response
I am more committed to promoting change in policies and services for people with developmental disabilities.	7=agree 11=strongly agree 1=strongly disagree 1=neutral 1=provided no response
Overall, I found this activity to be informative; it provided me with new learning about people with developmental disabilities.	4=agree 14=strongly agree 1=strongly disagree 1=neutral 1=provided no response
I would like more public dialogues like this one to keep me involved in policies and service change needed for people with developmental disabilities on Staten Island.	4-agree 13=strongly disagree 1=strongly disagree 2-nuetral 1=provided no response
Overall, how would you rate your experience in this Public Conversation for Change?	4=positive 16=very positive 1=provided no response

The Storytellers

Below are some of the descriptive themes of the self-advocates, caregivers and care providers that participated in sharing experiences on COVID with the GRF.

Part 1: A Self-Advocate's Perspective

In this part, self-advocates, people with intellectual disabilities shared their experiences on how they were supported during the pandemic, emotions, and feelings of managing the city's lockdown, separation from friends and families and how they adapted to the changes, demonstrating their creativity and resilience during COVID-19. They were seven people that shared their stories on 11/9/21 and 3 on 11/12/21, with a total 10 self-advocates. Th stories shared included emotions of fear, anger, and frustrations of not knowing how COVID would transform their everyday lives but, there were also stories of creativity, strength, and hopefulness, as these self-advocates managed the pandemic.

Part 2: A Caregiver's Perspective

In this part, we heard stories from the parents and other caregivers on how they managed the pandemic. In the first session on 2/16/21, there were four parents and one aunt that shared their stories on proving care and supports to their loved ones during the pandemic. Three of the caregivers shared their experiences on the person they supported contracting COVID. These stories shed light on the emotions of anger, anxiety, and fear in caring for someone with COVID and how they managed their health and everyday supports. Four caregivers shared stories on the difficulty in trying to navigate remote services and learning as their day programs were closed and one parent spoke about pulling their loved one out of their community residence because of contracting COVID.

For the session on 2/18/21, they were also five caregivers that shared their stories. In this session, we had one caregiver that talked about the complexities of navigating medical service delivery, two caregivers shared their experiences with having programs closed and trying to support their loved ones at home and two caregivers also spoke about learning how to navigate virtual environments. Again, these stories delved into the anger, frustrations, anxiety, and fear of the unknown that comes with COVID-19. At the same time, there were feeling of hopefulness, community and strength that kept these caregivers working toward the future. In all, the stories shared highlighted the strength and resilience of these caregivers as they advocated for their loved ones and learned new skills in managing virtual environments.

Part 3: The Care Provider's Perspective

In part 3, DSPs, agency administration, group leaders and educators shared their experiences on providing supports to people with intellectual disabilities during the pandemic. There were six participants in the first session on 5/4/21 and five for the second session on 5/6/21, totaling to 11 participants in all. In these stories, care providers shared their experiences in managing the complexities of trying to provide support services to people with disabilities. Discussions ranged from agency administrators developing COVID policies, educators developing and managing virtual learning environments to DSP work schedules, personal protective equipment (PPE) concerns and supporting people with intellectual disabilities manage the COVID crisis. These stories were also marked with strength and resilience as the care providers talked about the challenges in obtaining the necessary guidance in adapting to COVID, maintaining safety to ensure continued services, to person advocacy. Again, anger, frustrations and fear were the point of emotions expressed but, with a determination to ensure individualized, person-centered supports for the people they served.

The Data

Part 1: A Self-Advocates Perspective

The same conversational questions/prompts were provided to the self-advocates for Part 1- A Self-Advocates perspective on two separate sessions that were conducted. The data below shows the theme responses for both sessions. The responses and the # of times the response were referenced are indicated below:

Q1: What was the resilience that you heard in this story?

Session 1	# of Responses
Staying Motivated	5
Strength/Positivity	7
Maintaining Health	3
Achievements	4
Session 2	**# of Responses**
Staying Motivated	5
Strength/Positivity	5
Skills	9

Q2: What emotions did this story bring up for you?

Session 1	# of Responses
Depression	2
Loss	3
Inspired	4
Hopeful	4
Session 2	**# of Responses**
Loneliness/Loss	4
Anger/Frustration	6

Fear	5
Understanding	8

Q3: What has the Storyteller learned about themselves during this time?

Session 1	# of Responses
Self-Growth	8
Resilience	4
Session 2	**# of Responses**
Strength/Bravery	4
Skills	5
Resilience	8

Q4: What have you heard during this story that related to growth?

Session 1	# of Responses
Self-Awareness	12
New Skills	4
Session 2	**# of Responses**
Self-Awareness	6
Self-Discovery	12
New Skills	2

Q5: Who/What helped the storyteller get through the pandemic? What and/or who contributed to the person's success during covid-19?

Session 1	# of Responses
Family/Friends	8
Entertainment	3
Community	2
Session 2	**# of Responses**
Family/Friends	5
Entertainment	4
Community	11
Self-Motivation	7

Q6: What was the greatest challenge the storyteller shared about their experience during the pandemic? How did it change them? (Positive or Negative)

Session 1	# of Responses
Loneliness	3

Change in routines	6
Session 2	**# of Responses**
Anxiety	
Change in routines	

Q7: What did you relate to the storyteller?

Session 1	# of Responses
Safety	2
Fear	3
Understanding	7
Session 2	**# of Responses**
Challenges/Hardships	12
Fear	4
Lack of understanding	5

Q8: What is the importance of having a support system?

Session 3	# of Responses
Family/Friends	6
Self-Growth	3
Health/Emotional	11
Community	7

Part 2: A Caregiver’s Perspective

The same conversational questions/prompts were provided to the self-advocates from Part 1. In Part 2, A Caregiver’s perspective, two separate sessions were also held. The data below shows the theme responses for both sessions. The responses and the # of times the response were referenced are indicated below:

Q1: What was the resilience that you heard in this story?

Session 1	# of Responses
Strength	8
Supports	6
Communications	4
Session 2	**# of Responses**
Self-growth	16
Supports	4

Q2: What emotions did this story bring up for you?

Session 1	# of Responses
Strength	8
Supports	6
Communications	4
Session 2	**# of Responses**
Self-growth	16
Supports	4

Part 3: The Care Provider's Perspective

The same conversational questions/prompts were also provided to the care providers. In Part 3, A Care Provider's perspective, two separate sessions were also held. The data below shows the theme responses for both sessions. The responses and the # of times the response were referenced are indicated below:

Q1: What was the resilience that you heard in this story?

Session 1	# of Responses
Motivation	2
Adaptability	12
Creativity	2
Session 2	**# of Responses**
Compassion	4
Commitments	10
Adaptability	6

Q2: What emotions did this story bring up for you?

Session 1	# of Responses
Strength	5
Sorrow	5
Inspiration	9
Session 2	**# of Responses**
Hopefulness	10
Positivity	3
Anxiety	9

Q3: What has the Storyteller learned about themselves during this time?

Session 1	# of Responses
Courage	7
Adaptability	6
New Skills	4
Session 2	**# of Responses**

Appreciation	7
New Skills	4
Team Empathy	6

Q4: What have you heard during this story that related to growth?

Session 1	**# of Responses**
Self-Growth	14
Resilience	11
Session 2	**# of Responses**
New Skills	6
Hopefulness	7
Advocacy	9

Q5: Who/What helped the storyteller get through the pandemic? What and/or who contributed to the person's success during Covid-19?

Session 1	**# of Responses**
Technology	7
Community	8
Hobbies	5
Strength	4
Session 2	**# of Responses**
Information	4
Hobbies	5
Hopefulness	2
Community	11

Q6: What was the greatest challenge the storyteller shared about their experience during the pandemic? How did it change them? (Positive or negative)

Session 1	**# of Responses**
Emotional Health	12
Additional Responsibilities	4
Staying Positive	9
New Skills	5
Session 2	**# of Responses**
Emotional Health	9
Additional responsibilities	5
Obtaining Information	9

Q7: What did you relate to the storyteller?

Session 1	# of Responses
Motivation	9
Hopefulness	5
Anxiety	7
Session 2	**# of Responses**
Empathy	6
Anxiety	4
Staying Positive	10

What is the Data Saying?

The Self-Advocate's Perspective

1. Anxiety and inspiration were the common emotions brought up during both sessions when self-advocates shared their stories on their experiences during COVID.
2. Self-growth and acceptance were found in both sessions on what self-advocates learned about themselves while managing issues related to COVID.
3. The development of new skills and self-advocacy were the common themes in both sessions related to growth.
4. Self-Advocates on both sessions related that family, friends, their community, and service providers helped them get through COVID.
5. There were two differences noted for challenges that were experienced, first session included situational hardships whereas in the second session, emotional hardships were noted.
6. Fear, anxiety and shared COVID related situations were the common themes on how people related to the storyteller.

The Caregiver's Perspective

1. Supports was the common theme in both sessions for resilience heard in the story. In session 1, strengths and communication were some other themes heard while in session 2, it was self-growth.
2. Anxiety and Inspiration were the common themes found for emotions brought up during the stories.
3. Self-growth and acceptance were the common theme in both sessions for what the storyteller learned about themselves.
4. New skills and advocacy were the common themes in both sessions related to growth.
5. Family, friends, community, and service providers were the common theme in both sessions for who helped during COVID.

6. Two differences noted, first session included situational hardships vs. emotional hardships in session two for noted challenges.
7. Fear, anxiety and shared COVID experiences were common things on how people related to the storyteller.

The Care Provider's Perspective

1. Adaptability was the common theme care providers related to the resilience shared in
2. the stories.
3. Hobbies and community helped care providers during the pandemic.
4. Care providers in both sessions expressed their greatest challenges as concerns over there emotional health and additional responsibilities.
5. Care providers in both sessions also expressed high anxiety as what the storyteller related with the listeners.
6. Mental Health and Community were the themes in both sessions for the importance of having a support system.
7. Hopefulness was a recurrent theme found among care providers mentioned in three of the questions for both sessions on:
   - What emotions brought up during the storytelling.
   - What was heard in the story related to growth.
   - Who/What helped the storyteller during COVID?

Call to Action!

1. **Professionalizing the role of DSPs and receiving more recognition since they are now identified as "essential workers."**

   DSPs are on the frontline staff of the COVID-19 outbreak. They are essential workers who are risking their own health daily to provide critical supports to people with disabilities. We hear about other health care professionals – nurses, doctors, nursing assistants – but direct support professionals remain largely invisible. In national survey of DSPs conducted by the University of Minnesota, found that DSPs worked additional hours during the pandemic and experienced significant schedule changes.

Additional Hours Worked	Schedule Changes
1-15 hours= 29%	Worked more hours=34%
16-30 hours=10%	Worked fewer hours=18%
31+ hours=15%	Worked different shifts=30%
	Worked different settings =29%

This study also showed that DSPs were impacted by the pandemic increasing the amount of turnover.

COVID DSP Turnover
Knew someone who left because of COVID=42%
Feared becoming infected=34%
Feared infecting others=13%
Left after testing positive for COVID=9%

Thus, the Minnesota study mirrors the emotions and feelings of the DSPs that participated in the GRF. DSPs have been in crisis long before the pandemic. DSPs are paid less than workers with far fewer skills. These professionals not only provide personal care, but also coordinate health and social services, assist in building job and social skills, provide transportation, and so much more and as such should be recognized as part of the health workforce and identified as true professionals. DSPs provide services that are largely human interactive meaning, DSPs will always be at an increased risk for contracting COVID-19 and as such community members, advocates, service providers and families need to amplify their voices in calling for government to permanently raise pay, benefits, and professional training for the staff supporting individuals with disabilities as they are, after all, essential workers. In all, we must all work toward government recognizing DSPs as true, essential heath workers. To join in the movement for action, please refer to following links to join in the action efforts:

- The Arc
- The Autistic Self Advocacy Network
- The American Network of Community Options and Resources (Ancor)
- The National Association of Councils on Developmental Disabilities (NACDD)
- Staten Island Developmental Disabilities Council (SIDCC)
- Brooklyn Developmental Disabilities Council (BDDC)
- Manhattan Developmental Disabilities Council (MDDC)
- Queens Council on Developmental Disabilities (QCDD)

2. **Call for increased trainings on emergency preparedness, health, and safety.**

   It is important to continue training DSPs so they can obtain the information and tools to know how to protect themselves. By having current, accurate and accessible training on COVID-19, DSPs will not only understand how to manage risk of COVID infection but also learn how to protect oneself, the people they serve thus reducing anxiety and fears. It is important to note, that this training and its material should also include accessible means of communication to people with disabilities such as Braille or PECS (Picture Exchange Communication Systems), that may make it easier for people with IDD to understand. COVID trainings, guidelines and safety procedures should always be provided as to minimize risk of infection between DSPs but also through the people they support. Current available trainings can be found in the following sources:

- New York Alliance for Inclusion and Innovations
- Office for People with Developmental Disabilities (OPWDD)
- National Alliance for Direct Support Professionals (NADSP)
- The American Network Community Options and Resources

3. **Vaccine education and access for DSPs and people with disabilities.**

   The data of this project also demonstrated the need to address DSPs own health and safety. Governments must collect information on DSPs to identify gaps in the availability of the COVID-19 vaccine. Once this information has been gathered, IDD service provider organizations can then work to enhance DSPs emotional and mental health by offering health initiatives that includes programs for routine COVID-19 testing, COVID-related medical care and vaccinations thorough opportunities that includes establishing guidelines and connections with medical networks, to ensure a process for care, treatment, and vaccinations. By establishing connections and relationships with local medical facilities, collaborative processes can be established to treat DSPs and people with IDD while ensuring equitable medical services. Such a collaborative networks and processes can be considered as “reasonable accommodations” under the Americans with Disabilities Act thus increasing protections for people with IDD and their DSPs. Provider organizations can obtain vaccine information to identify gaps in availability for DSPs and the people being served through the following sources:

- Office for People with Developmental Disabilities (OPWDD)
- New York State COVID19 vaccine
- Care Design New York
- NYC Vaccine Command Center
- New York State COVID-19 Vaccine Tracker

4. **Advocacy to develop evidence-based strategies for teaching people with IDD to use telehealth.**

   For people with IDD, telehealth poses potential challenges if they have trouble using internet-based training or computer technology due to the complexity of the systems or a lack of digital literacy. Service providers, families, and people with IDD would benefit greatly from evidence-based strategies in learning and teaching how to effectively use telehealth interventions. Through the development of telehealth trainings, service providers can demonstrate techniques to people with IDD while at the same time offer education to families and caregivers on how to effectively support people in using telehealth. to support. The link below provided regulatory and guidance information on Telehealth:

- Office for People with Developmental Disabilities (OPWDD)

5. **Healing discussions/supports around the grief and loss during COVID for people with IDD, caregivers, providers etc.**

   The data of this project also related to the emotions and feelings of the people with IDD, their families/caregivers and their DSPs as they related stories of grief as to the loved ones that have lost due to the pandemic. Common reactions to grief include shock, disbelief, denial, anxiety, anger, sadness and loss of sleep or appetite and government should provide additional funding in assisting provider organizations provide therapeutic supports to the people with IDD, their families/caregivers and DSPs who are experiencing loss. In addition, as the wave of COVID now begins to diminish, these therapeutic services can also support transition into 'the new normal for people with IDD, families/caregivers and their DSPs. In researching COVID related support groups for people with intellectual disabilities and their caregivers, none were found affirming the need for these services.

6. **Inform service providers that do not provide "medical" services to have more comprehensive medical information for people supported.**

   Conversation in the GRF also related the lack of medical information from service providers that do not provide medical services. Although these organizations do not provide medical services, medical information should be streamlined and provided to the people supported, families/caregivers and DSPs as these organizations are often looked to as informational resources. Having readily, accessible information in platforms such as organizational COVID hotlines, information posted on websites or by simply having COVID medical related monthly meetings can impact DSPs understanding of COVID to effectively cope with the stress of the pandemic for people supported and for those on the job. Thus, IDD service providers should consider assigning specific administrative employees or the hiring of new employees for the development of COVID task force. With streamlined medical information, not only will people know where to obtain medical services, the service provider organization will also eliminate confusion and misinformation.

7. **Increase advocacy through DSP involvement in groups like disability councils, NADSP, etc.**

DSPs are the frontline, essential workers supporting people with IDD and as such, should also be provided a platform to advocate for themselves and the people they support. DSPs need to be invited in advocacy effort groups to amplify their voices, their experiences, and their needs in working to improve support services.

- The Association of University Centers on Disabilities
- The Arc
- The Autistic Self Advocacy Network
- The American Network of Community Options and Resources (Ancor)
- The National Association of Councils on Developmental Disabilities (NACDD)
- Staten Island Developmental Disabilities Council (SIDCC)
- Brooklyn Developmental Disabilities Council (BDDC)
- Manhattan Developmental Disabilities Council (MDDC)
- Queens Council on Developmental Disabilities (QCDD)

8. **Increase training around natural vs formal supports and how they differ - how formal supports can work to connect people to natural supports.**

GRF participants also spoke on feelings of isolation during the pandemic. Thus, it is important for DSPs (as formal supports) learn to work with families/friends/communities (natural supports) to combat feelings of isolation and loneliness during time of crisis. Service providers must provide trainings on how to continue these relationships due to their vital support and assistance they offer in maintaining the quality and security of life for people with disabilities.

- Administrative Memorandum- Distinguishing Agency Volunteers from Natural and Community Supports

9. **Call for sustainability, funding, and political support?**

The COVID-19 pandemic has intensified crises that have long been plagued by Medicaid-funded and the trauma experienced this past year will resonate with all of us but, specifically for people with IDD as they try to make sense of a world no longer the same. The participants of the GRF have demonstrated how people with IDD feel isolated, insecure, and anxious as they struggle to understand this new world. Meanwhile, the DSPs, families and caregivers that provide supports are beyond exhausted. As such, it is imperative that federal, local governments and local political leaders work on reform to evaluate and prioritize long-term sustainability by investing in community-based providers and the DSPs they employ. Continue advocacy efforts here:

- The Association of University Centers on Disabilities
- The Arc
- The Autistic Self Advocacy Network
- The American Network of Community Options and Resources (Ancor)

- The National Association of Councils on Developmental Disabilities (NACDD)
- Staten Island Developmental Disabilities Council (SIDCC)
- Brooklyn Developmental Disabilities Council (BDDC)
- Manhattan Developmental Disabilities Council (MDDC)
- Queens Council on Developmental Disabilities (QCDD)

10. **Call for people to join the GRF**.

    It is imperative that these conversations continue so we are calling for people to join the GRF to continue amplifying voices and engaging in conversations to work toward social change. Above all, the GRF is designed to be a space for advocates who believe in the power of connecting, collaborating, and supporting to create change. If you believe that

    innovations are needed to empower providers to improve quality outcomes, then we need you to be involved. If you're ready join us, please email us at mailto:riverafundforchange@gmail.com or visit the GRF website at https://riverafundforchange.wordpress.com/ and help us continue the conversations for social change.

Resources

Stay Connected with the Geraldo Rivera Fund

- Facebook: https://www.facebook.com/pccsny/
- Instagram: https://www.instagram.com/pccsny/
- LinkedIn: https://www.linkedin.com/company/person-centered-care-services
- Twitter: https://twitter.com/PCCSny
- Website: https://pccsny.org/
- YouTube: https://www.youtube.com/channel/UCY1zsp62HwW2VgkDtFAZTVQ

Advocacy Tools:

- Advocacy Video: https://www.youtube.com/watch?v=dja7P4kQCtI&t=0s
- Staten Island Developmental Disability Council: https://siddc.org/
- Ancor Advocacy Campaign: https://www.ancor.org/amplifier?fbclid=IwAR1lPP1SR_e0Jx9xmG4kzvP4nsjbfoCguPo3PldqSD6D2rhpxX0Ox2yrcE
- National Alliance for Direct Support Professionals: https://nadsp.org/

COVID-19 Supports/Information

- Coronavirus Guidance: https://opwdd.ny.gov/coronavirus-guidance
- COVID Vaccine: https://opwdd.ny.gov/coronavirus-guidance/covid-19-vaccine
- COVID Relief Support group: https://www.alignable.com/groups/alignable-covid-relief-support-group/events/resiliency-recovery-overcoming-the-impact-of-covid-19-jun-2021
- COVID-19 Resources for the Disability Community: https://www.accessliving.org/our-services/covid-19-resources-for-the-disability-community/
- Coping through COVID: https://www1.nyc.gov/site/acs/about/covidhelp.page

References

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