Reopening Site-Based Programs for People with DD

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June 25, 2020
Disclosures

I have no financial interests to disclose.

*We all want to support people with disabilities to direct their own lives. Anyone who provides or funds services has a competing interest with the person served. The needs and perspectives of people who provide and fund services are critically important, but they need to be considered separately. Competing interests must be acknowledged and managed.
All Regional Center Clients are at High Risk

<table>
<thead>
<tr>
<th>CDC Definition of High Risk For Covid-19</th>
<th>Definition of DD per Lanterman Act</th>
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<tbody>
<tr>
<td>Limited mobility</td>
<td>Mobility</td>
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<tr>
<td>Need personal assistance</td>
<td>Self care</td>
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<tr>
<td>Trouble with communication</td>
<td>Language</td>
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<tr>
<td>Trouble understanding or accessing information</td>
<td>Learning</td>
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<tr>
<td>Trouble practicing preventive measures (hand washing/distancing/rely on touch)</td>
<td>Self Direction</td>
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<td></td>
<td>Capacity for Independent Living</td>
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<td>Capacity for Economic Self Sufficiency</td>
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What does the data show?

Reporting is incomplete, but there is enough data to know that people with DD are getting sick and dying at more than twice the rate of the general population.

- Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis

- COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities
Is it safe to return to previous life?


- There is currently no specific, Food and Drug Administration (FDA)-approved treatments for COVID-19
- There is currently no vaccine to prevent COVID-19.
- Treatment is currently supportive.
- The best way to prevent illness is to avoid being exposed to this virus.
New reported cases in California, by day

San Francisco Chronicle
How do pandemics end?

- They continue until everyone susceptible is infected. If getting infected makes people either die or become immune, it will eventually peter out.
- We contain it with testing, contact tracing and quarantine.
- They become endemic like the flu and we learn to co-exist with the virus long term.
What Are the High Risk Protocols?
https://www.the-ntg.org/

• Direct Support Professionals (DSP) are considered to be in the same general risk category as health care personnel when providing care for people exposed or diagnosed with Covid-19.

• DSPs are essential for the health and well-being of the people they serve.

• If there is potential that a DSP may be splashed or sprayed by bodily fluids, use facemask, eye protection, disposable gloves, and a gown.

• Wear gloves when touching client. Launder clothes in hot water.

• Practice everyday prevention actions with clients without suspected or confirmed Covid-19.
Group Homes


In congregate living settings, several factors may facilitate the introduction and spread of COVID-19.

- residents employed/programs outside the home
- residents who require close contact with staff or Direct Service Providers
- residents who have trouble understanding information or practicing preventive measures
- residents in shared living spaces.
- In addition, GH residents who have underlying medical conditions may be at risk of serious illness with COVID-19.
What Are Everyday Prevention Actions?

- Physical distancing and isolating
- Wearing cloth face coverings
- Covering mouth and nose with cough or sneeze, throwing in trash, washing hands
- Cleaning and Disinfecting
- Hand washing or sanitizer
What Are the Things People with Developmental Disabilities have difficulty with?


- Physical distancing and isolating (reminders supervision)
- Wearing cloth face coverings (exceptions)
- Covering mouth and nose with cough or sneeze, throwing in trash, washing hands (visual or verbal reminders)
- Cleaning and Disinfecting (not if there are sensory or respiratory issues)
- Hand washing or sanitizer (assistance supervision)
Face Masks

- Wearing cloth face coverings may be difficult for people with sensory, cognitive, or behavioral issues.
- Cloth face coverings are not recommended for children under 2 or anyone who has trouble breathing or is unconscious, incapacitated or otherwise unable to remove the covering without assistance.
- Cloth face coverings are not PPE and should not be worn in place of proper PPE for the care of clients with known or suspected COVID-19.
CDC High Risk Guidelines in a Nut Shell

- Don’t get sick. You are at high risk and so are the people who serve you.
- There isn’t much we can do if you get sick.
- People with DD aren’t necessarily at higher risk than others… unless they have the characteristics of people with DD.
- People who serve people with DD should follow all the general guidelines… except people with DD have difficulty complying.
- …but don’t get sick.
Assessing risk of a proposed program

- How many close contacts will it add to my life? (people who I will be within 6 feet of for more than 15 minutes)
- Are those close contacts following everyday prevention procedures strictly and limiting their contacts outside the program?
- Will I know who they are if they or I get exposed to Covid-19 so we can quarantine or isolate?
- Am I able to do everyday prevention measures strictly?
- Is the ventilation good where I will be?
- How long are my close contacts? (more time = increased risk)
- Who will I expose if infected and what consequences will there be?
- Do I have a safe and reliable plan for when I am exposed?
What does this mean for Day Programs?

Bottom Line:

- Programs that primarily serve people with DD cannot safely run indoor programs with group activities.
- Doing so is against medical advice per CDC.
- This situation may not improve in the next few years.
- If we proceed with opening day programs, it will be a disaster for our community.
- Day program participants and staff will get exposed and will in turn expose family, roommates and residential service providers. Regional centers will be overwhelmed with needs they don’t have the capacity to meet. Hospitals and skilled nursing homes are not safe back up plans.
What are safer alternatives?

- Hire household members to provide service
- Have a single, consistent aide or small team of 1-3 people provide service in your home with precautions
- Have a consistent aide take you out into the community in private transportation
- Meet 1:1 outside, in uncrowded places with precautions
- Take drives
- Do window and drive by visits
- Take virtual trips
- Participate in the exciting, growing online social, spiritual, educational, and vocational worlds.
Person Centered Planning

Everybody needs:

- A room of their own
- Activities to stay meaningfully engaged most of the day
- Daily exercise
- Connection to and ways to build circle of support
- Regular contact with case coordinator and advocates
- Barrier free wellness checks and oversight
- Sunlight and fresh air daily
- Attention to mental health
- Community outings to low risk places
- Inclusion activities

This is possible for EVERYONE!
What can I do with minimal or no risk?
Be creative! Online inclusion activities have never been more available

- Set up a regular Facetime or call
- Make treats or art and deliver them to friends who may feel lonely
- Have a dinner party where each household cooks one course and delivers it to the others. Meet up to eat together online!
- Attend exercise, art, music, religious, or educational programs online.
- Plant a garden or nurture a plant
- Get a pet
- Take pictures on your neighborhood walk and share them with friends and family
I want to take the risk to attend day program

- Ask how many additional close contacts you will have and how to minimize them. A close contact is anyone who gets within 6 feet for 15 minutes or more.

- Ask what procedures are in place to trace the contacts of every person in the program so they can quarantine.

- Develop a plan to have a service provider or family member on call at all times who is able and willing to do Covid-19 care. They must be able to pick you up within an hour of getting a call.

- Secure medical quality protective equipment, private transportation, and a safe place for you to go where you won’t expose others for your emergency plan

- Make a backup plan in case your service provider or family member is unable to help