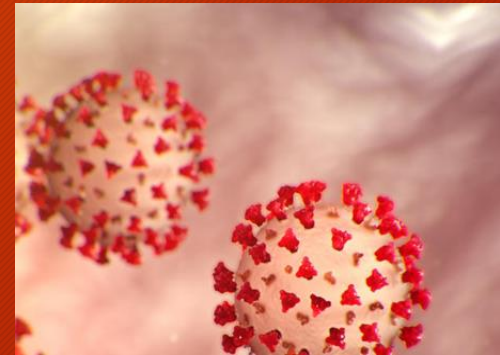


Lessons from COVID-19:

How COVID-19 May Change the World of Services to
People with intellectual and Developmental Disabilities

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Challenge: To Imagine the Future of the IDD Service System

“It is always wise to look ahead, but difficult to look further than you can see”

Winston Churchill



Canvass of a Few Thought Leaders

- John Agosta
- Sue Swenson
- Nancy Thaler
- Nancy Weiss
- Michael Smull
- Mary Sowers
- Rud Turnbull
- Ann Turnbull
- Holly Riddle
- Robin Cooper
- Steve Eidelman
- Gerry Morrissey
- Ruth Luckasson
- Marty Ford
- Ari Ne'eman
- Julia Bascom
- Amy Hewitt
- Cathy Ficker-Terrill
- Alison Barkoff
- Celia Feinstein

Categories of Feedback

- System Design
- System Financing
- Family Support
- Health Care
- Direct Support Professionals
- Deconstruction of Services
- Incidents and Quality Oversight
- Risks



System Design

- More emphasis on listening to what people with IDD and families want in terms of services and supports
- Focus on more equitable system design
- Reduction in facility based residential and day programs
- Increased emphasis on technology (telehealth, remote monitoring) that will be used to support people in smaller settings and with their families
- Emphasis on creating more inclusive communities to reduce the isolation of people with IDD and to expand friendships and relationships
- New emergency planning requirements that include accommodations during a pandemic



System Design

- Rethink behavior support given the reduction in behavior incidents since people have been at home
- Increased importance of ABLE accounts to support income stability
- Intensified planning to develop alternatives to congregate settings for people with complex needs
- Increased attention to trauma informed supports in healing settings given the trauma that people had experienced during this epidemic



System Funding

- Push for national support-based funding that is grounded in human services and that isn't tied to Medicaid
- Expansion of national funding that incentivizes movement away from congregate settings
- Expansion of funding to support technology including internet support, cell phones, maintenance and training
- Expansion of self-direction and loosening of staff requirements to include families



Family Support

- Assistance to families in the use and management of technology
- Emphasis on interdependence rather than the tension between individual versus family support
- Conversations with families to determine what worked and what didn't work during the pandemic including the loneliness, alienation and isolation experienced by families
- Clarifying the importance of allowing family members to accompany family members to the hospital
- Creation of new policies regarding visitation rules for people sheltering in place in residential settings
- Development of new policies for safe return to residential facilities for those who sheltered at home with families



Health Care

- Increased attention to discrimination in access to health care given attempts to ration care during the pandemic
- Frequent health and wellness checks
- Availability of PPE for DSPs
- Increases in telehealth
- Focus on caring for underlying chronic conditions which may have been neglected or pushed aside
- Action on emerging data on COVID risk factors for morbidity/mortality.



Direct Support Professionals

- Essential workers get the pay and protection they need
- Remarkable relationships between DSPs and people with IDD during the pandemic will be celebrated
- Expansion of leadership training and career ladders
- Recognition that person centered practices are contingent on a stable and well-paid workforce
- Expanded recruitment opportunities - building opportunities for people to discover DSP career path.



Deconstruction of Services

- Reduced need for buildings (e.g., for case management, day programs, etc.)
- New day service models without walls
- Further reduction in legacy services (sheltered workshops, congregate residential systems) and reduced domination of provider interests
- Expansion of self-direction
- Technological solutions to support more independence in employment and other day activities.



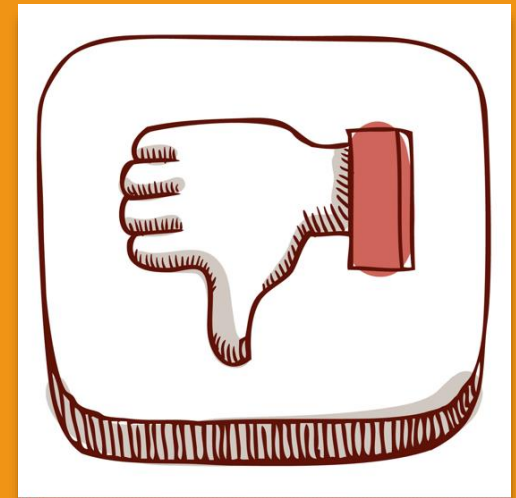
Incident Management and Quality Oversight

- Investigation into why incident reporting went down during the pandemic
- Reassessment of on-site quality monitoring in favor of remote monitoring
- Expansion of technology and the ability of participants to communicate
- Deepening understanding of what worked and didn't work during pandemic and changes in quality regulations
- Reaffirmation of the multiple domains of quality supports, and the relationship with health and safety components



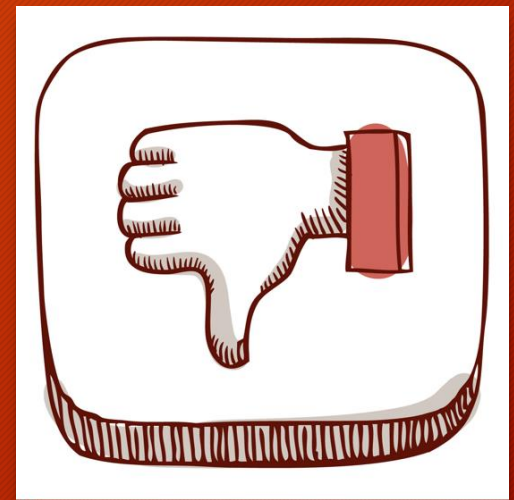
Possible Negative Fall Out

- Increased emphasis on infection control and other more restrictive licensing requirements that could abridge autonomy
- Campaigns to support models like the “Greenhouse” model which is based on individual settings on a congregate campus
- Return to a medical model
- Concern over the ability of people with IDD to make medical decisions may lead to increased guardianship



Possible Negative Fall Out

- Fiscal crisis may result in fewer DSPs and further isolation of families and individuals in need of support
- Restrictions on the ability of national advocacy organization to meet with Congress members and staff
- Employment supports in the new economy. Where will the jobs be?
- Need for compensatory education supports given time lost by students with multiple needs



But Most Importantly. . .

We must listen to what people with IDD and their families have learned during this period and what *they* want their lives to be in the future. With that in mind we can bring fresh eyes to the task of reimagining a system that meets their aspirations.

