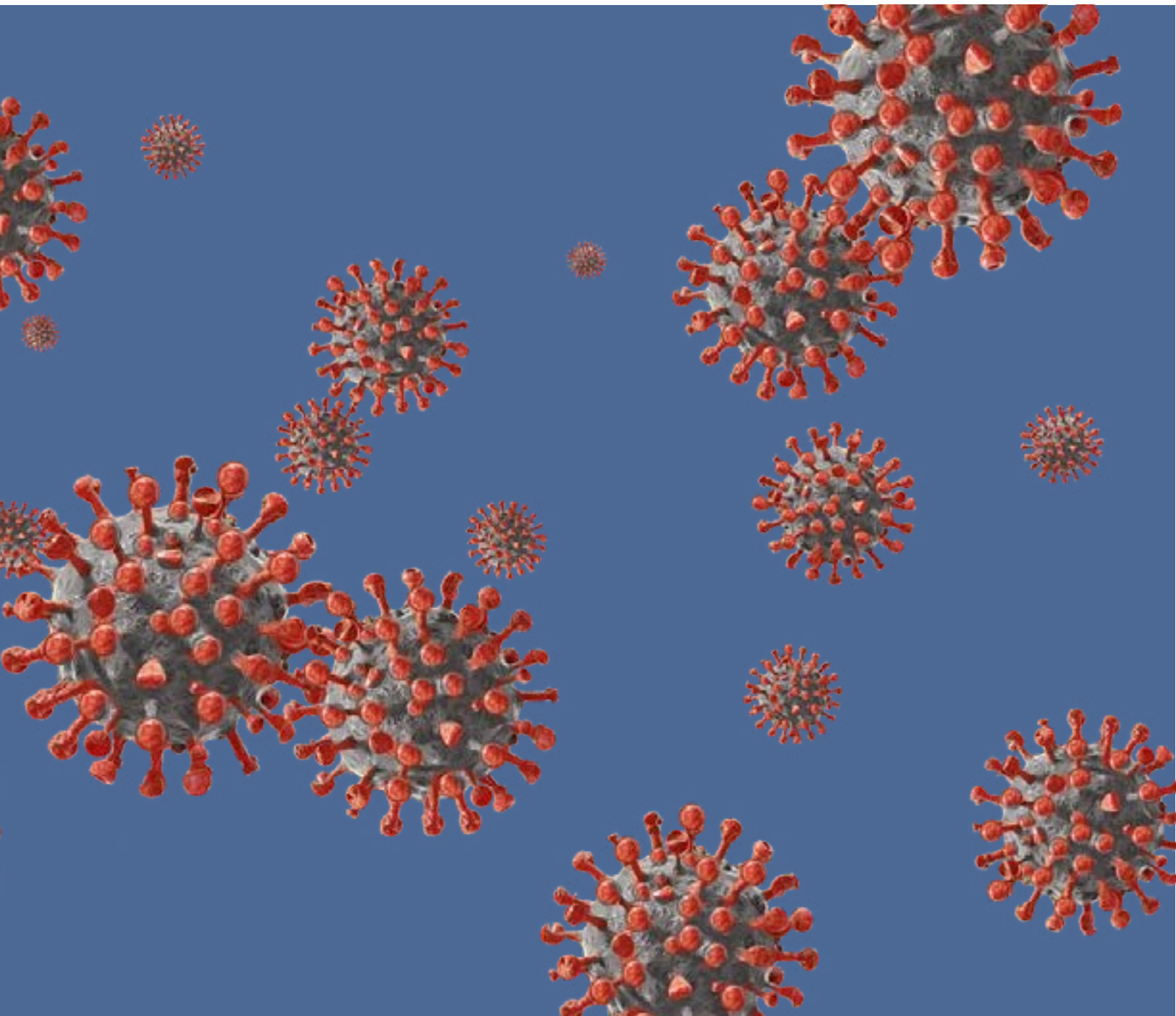




The Partnership for Inclusive Disaster Strategies

REPORT

**COVID-19 & Disability Rights
Daily Calls: February 28 - July 31**



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MISSION

The mission of The Partnership for Inclusive Disaster Strategies (The Partnership) is equal access to emergency programs and services for people with disabilities and people with access and functional needs before, during, and after disasters.

We achieve our mission through:

- Unwavering support for local disability organizations
- Community engagement, organizing, and leadership development
- Advocacy and public policy
- Training and education
- Research and technical assistance
- Disability-led disaster response and community resilience

ABOUT THE PARTNERSHIP



The Partnership for Inclusive Disaster Strategies (The Partnership) is the only U.S. disability-led 501(c)3 nonprofit with a focused mission on equal access, disability rights, and full inclusion of people with disabilities, older adults, and people with access and functional needs before, during, and after disasters and emergencies.

The Partnership actively engages with a community of local, national, and global disability rights, emergency management and public health leaders, and allies committed to equal access and whole community inclusion before, during, and after disasters. Our partners have a strong track record of protecting and advancing the rights of people with disabilities (26% of the U.S. population), and over one (1) billion people with disabilities across the globe.

Our founding organization, Portlight Strategies (which led humanitarian response and relief initiatives to meet the needs of disaster-impacted disabled communities for over 20 years), formally established The Partnership in 2016 to focus on disability-inclusive emergency management, community organizing, policy, advocacy, and training. In 2019, The Partnership received its 501(c)3 recognition under the IRS, and Portlights' legacy of direct disaster relief functions were absorbed into The Partnership as our "Portlight Relief Division."

Our network focuses on the access and functional needs of countless people who are disproportionately impacted in disasters due to inadequate planning, preparedness, and accessibility.

Additionally, we host a 24/7 Disaster Hotline for disaster-impacted disabled people who need assistance: (800) 626-4959 or email info@disasterstrategies.org.

ABOUT THE PARTNERSHIP

Experience has shown us that values of access, inclusion, and independence are imperative for achieving and sustaining community-wide disaster resilience.

A LETTER FROM THE DIRECTORS

We, at The Partnership, are incredibly thankful to our partners and supporters who have been involved and joined us in the fight for the rights and needs of people with disabilities, older adults, and people with access and functional needs.

Our voices are the strongest when we amplify our unified message. We thank you for your support and efforts to educate, advocate, and make a difference for people with disabilities in your community before, during, and after the ongoing COVID-19 outbreak and all public health emergencies and disasters.

The Partnership for Inclusive Disaster Strategies continues to hold daily COVID-19 Disability Rights Calls each and every day of the week. To join our distribution list, please email us!

Thank you,

Shaylin Sluzalis & Germán Parodi

Directors@disasterstrategies.org



REPORT OVERVIEW

The Partnership started hosting **daily** COVID-19 Disability Rights Calls on February 28th, 2020. During these on-going calls, partners across the United States come together to share good and promising practices, systemic rising issues, and community-wide advocacy engagement related to the rights and needs of people with disabilities during this public health emergency and concurrent disasters.

Between February 28 and July 31, 2020, for 154 consecutive days, disability advocates across the country joined our COVID-19 & Disability Rights calls.

Calls:

- Tracked the development of the response to COVID-19 in the U.S., and its impacts on people with disabilities, older adults, and people with access and functional needs
- Shared national and local updates
- Anticipated, addressed, and developed solutions
- Invited experts on a variety of relevant topics
- Discussed systemic issues and other challenges people with disabilities experience day-to-day
- Developed and shared resources, disability advocacy initiatives, as well as good and promising practices

This report presents:

- The findings that developed over the course of five (5) months
- A list of some of the initiatives that The Partnership and our network organized
- Weekly summaries of the discussions

INTRODUCTION

On February 28th, 2020, two (2) weeks before President Trump declared a National Emergency, The Partnership and our national network began daily calls about disability rights issues during the COVID-19 pandemic.

Initially, we met to craft a [National Disability Rights Call To Action](#) to bring attention to the need for immediate strategies and provide solutions to the upcoming hardships COVID-19 would present for people with disabilities and older adults. Federal, state, local, tribal, and territorial governments need to address the specific rights and needs of people with disabilities and older adults throughout the COVID-19 outbreak, as well as all public health emergencies and concurrent disasters.

These calls developed into ongoing daily COVID-19 Disability Rights Calls, where partners across the nation come together to:

- Share good and promising practices;
- Identify systematic rising issues; and,
- Engage in community-wide advocacy related to the rights and needs of people with disabilities and older adults during this public health emergency, as well as concurrent disasters.

As COVID-19 outbreaks spread across the United States, disability advocates, service providers, public health officials, and emergency managers mobilized themselves to:

- Analyze national and local response to COVID-19 and its impacts on people with disabilities, older adults, and people with access and functional needs;
- Strategize to protect the rights of people with disabilities and older adults in the public health emergency response;
- Advance inclusive COVID-19 policies and legislation; and,
- Organize with the goal of reducing harm to disabled people and saving lives.

DAILY CALL NETWORK

Our Daily Call Network

We are grateful for all those in our network who have joined us, and continue to join us, each and every day, and when they are able to!

[ADAPT](#)

[American Association of People with Disabilities](#) (AAPD)

[American Red Cross](#)

[Arizona State Independent Living Council](#)

[Association of Programs for Rural Independent Living](#) (APRIL)

[Atlantis Community](#)

[Autistic Self Advocacy Network](#) (ASAN)

[Brooklyn Center for Independence of the Disabled](#)

[California Disaster Strategies Coalition](#)

[Californians for Disability Rights](#)

[Centers for Disease Control and Prevention](#) (CDC)

[Center for Independence](#)

[Center for Independent Living of Central PA](#)

[Center for Public Representation](#) (CPR)

[Colorado Cross-Disability Coalition](#) (CCDC)

[Consortium for Citizens with Disabilities](#) (CCD)

[Department of Homeland Security Office for Civil Rights and Civil Liberties](#) (DHS CRCL)

[Disability Rights North Carolina](#)

DAILY CALL NETWORK

[ENDependence Center of Northern Virginia \(ECNV\)](#)

[Hawai'i State Council on Developmental Disabilities](#)

[Houston Center for Independent Living](#)

[Lakeshore Foundation](#)

[Liberty Resources CIL](#)

[Living Independence Network Corporation](#)

[Montana Disability and Health Program](#)

[National Council on Independent Living \(NCIL\)](#)

[National Disability Rights Network \(NDRN\)](#)

[New Jersey Disability Collective](#)

[No Barriers Disabled Access and Advocacy Consulting Services](#)

[Northwest ADA Center](#)

[Ohio Disability and Health Program](#)

[PA ADAPT](#)

[Paralyzed Veterans of America \(PVA\)](#)

[Roads To Freedom CILNCP](#)

[The Arc of the U.S.](#)

[U.S. International Council on Disabilities \(USICD\)](#)

[Utah Health Policy Project](#)

[World Institute on Disability \(WID\)](#)

And many more!

ANALYSIS

Patterns: COVID-19 and Disability

Since February 28th, The Partnership has held ongoing hour-long daily calls to discuss patterns on how COVID-19 is impacting the disability community across the United States. This report focuses on topics, patterns, rising issues, and advocacy efforts discussed from February 28th to July 31st, 2020.

We found:

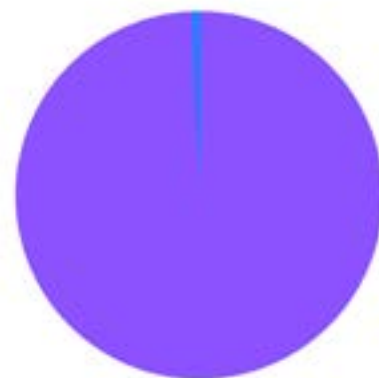
Finding 1: An outsized number of COVID-19 deaths occur in congregate settings, such as nursing facilities, other long-term care facilities, and correctional facilities, including detention centers.

U.S. Population



324.1 Million NOT in congregate facilities
2.1 Million in long-term care facilities
2 Million in correctional facilities

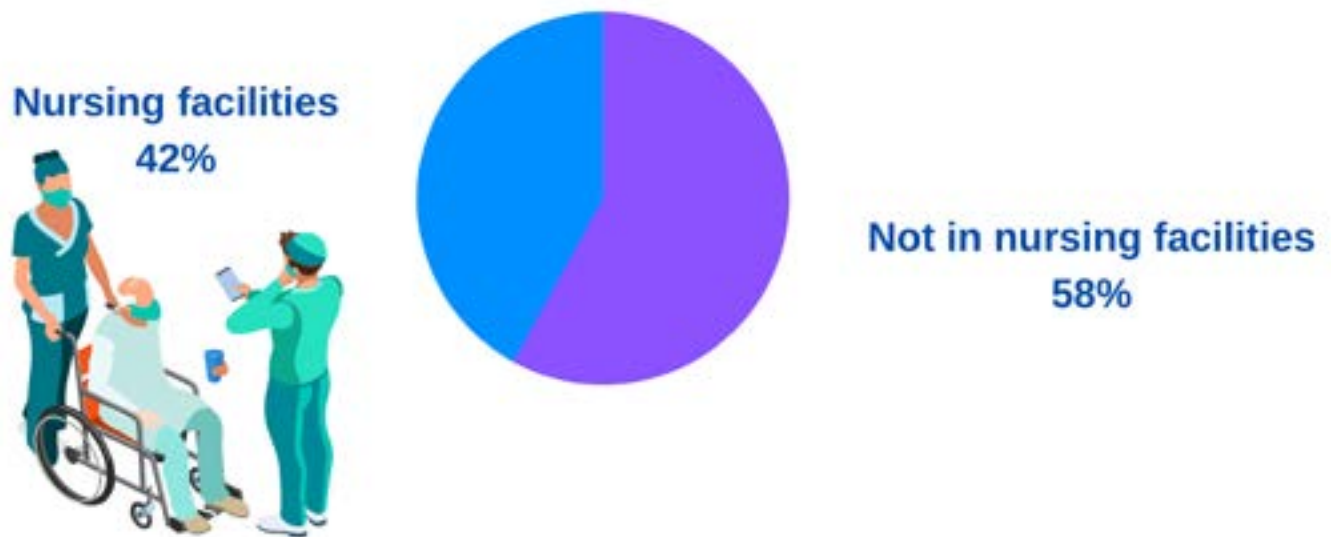
Nursing facilities
0.6%



Not in nursing facilities
99.4%

ANALYSIS

COVID-19 Deaths



As of August 20, 2020, [176,548](#) people in the United States, [including 68,000+ people who live and work in nursing facilities](#), have died from COVID-19. Despite only 0.62 percent of the U.S. population living in nursing facilities, [more than 42 percent of those who died from COVID-19 were from nursing facilities](#). [The virus has infected more than 402,000 people at some 17,000 facilities](#).

The disproportionate death toll indicates a systemic failure of nursing facilities, and other congregate facilities, to safely protect people with disabilities and older adults.

Additionally, we know that these numbers are an undercount, as nursing facilities, prisons, and other congregate facilities delayed testing, inconsistently reported infections and deaths, and [even actively concealed those who died from COVID-19](#). Meanwhile, the [nursing home lobby pushes legislation for liability shields](#) that could prevent people with disabilities, older adults, and their families from prevailing in lawsuits related to the public health emergency.

ANALYSIS

Finding 2: Black, Brown, Indigenous, and other People of Color are disproportionately represented in COVID-19 infections and deaths — in the community, nursing facilities, and in other congregate settings.

Finding 3: Even as COVID-19 outbreaks in congregate facilities soar, hospitals are more likely to discharge people with disabilities into nursing facilities than into their own homes and community settings with services and support systems.

When HHS declared COVID-19 a public health emergency on January 31, 2020, retroactive to January 27, 2020, this activated 1135 Waivers, among other actions. The 1135 Blanket Waiver fast-tracks admittance into nursing facilities and is a violation of the civil rights of people with disabilities — but civil rights are not suspended during disasters. Sometimes, COVID-19 positive patients were sent from hospitals into nursing facilities.

Finding 4: People with disabilities in hospitals across the country were denied visitors, family members, and PAS/DSP workers.

This created barriers for people with disabilities to access support systems, including equally effective communication, non-discriminatory practices, personal attendants, advocates, and ombudsmen. Two key resources evolved from this finding, the COVID-19 Pandemic Guide for Advocates in Health Care Facilities and a Checklist for People with Disabilities Preparing for Hospitalization During COVID-19 Pandemic.

Finding 5: Personal Assistant Services (PAS) and Direct Service Providers (DSP) are essential workers.

Lockdowns and stay-at-home orders due to COVID-19, as well as curfews during protests, prevented some PAS/DSP workers from providing services and supports to people with disabilities. The health, well-being, and independence of people with disabilities depend on recognizing PAS and DSP are essential workers.

ANALYSIS

Finding 6: Neither the U.S. Federal Emergency Management Agency (FEMA) nor the U.S. Department of Health and Human Services (HHS) prioritized distributing Personal Protective Equipment (PPE) to people with disabilities.

People with disabilities have had difficulty accessing PPE to make sure they, and the people in their lives, including PAS/DSP workers, have the necessary protection to minimize the spread of the disease. Additionally, [PPE distributed by FEMA to nursing facilities is often damaged](#).

Finding 7: Test sites were not accessible to people with disabilities.

Throughout the U.S., COVID-19 testing has been a significant problem. There were delays in testing, insufficient numbers of tests, a high percentage of false-negatives, and long wait times for results. However, people with disabilities encountered additional barriers to testing, such as lack of access to reasonable modifications at test sites. Drive-thru test sites are even more inaccessible to people with disabilities if they do not have a car, must rely upon somebody else to drive, or do not have access to public or other means of transportation. The Northwest ADA Center's Fact Sheet on [Accessibility at Drive-Thru Medical Sites](#) addresses this issue.

Finding 8: Students with disabilities [do not have equal access to remote education](#) despite the U.S. Department of Education's Fact Sheet on [Addressing the Risk of COVID-19 in Schools While Protecting the Civil Rights of Students](#).

Finding 9: COVID-19 [presents additional barriers to voting](#) for people with disabilities in primaries and special elections. The CDC addresses some of these concerns in [Considerations for Election Polling Locations and Voters](#).

ANALYSIS

Finding 10: People with disabilities faced unequal access to health care.

As COVID-19 unfolded across the United States, all attention turned toward our health care system. However, instead of strengthening and investing in the systems in place, discussions turned to [rationing medical resources](#). Hospitals developed guidances that were often based in implicit biases against people with disabilities and older adults. These biases resulted in denying people with disabilities equal access to medical care. Notably, [Michael Hickson](#), a Black disabled man, was denied COVID-19 treatment, and was starved and dehydrated to death in Texas.

Finding 11: People with disabilities were used in medical experiments, including experimentation with hydroxychloroquine, without their consent. ([Gill & Hubert Vs. PA Department of Health](#) (DOH), Case 2:20-cv-02038-HB)

Finding 12: The HEALS Act introduced in Congress on July 27, 2020, [could protect nursing facilities, employers, and businesses](#) from plaintiffs prevailing in legal action for up to five (5) years for discrimination, harm, and liability of death.

ANALYSIS

From our calls, research, and expertise, we know the following:

- There is an urgent need to [divert and relocate](#) people with disabilities and older adults out of congregate facilities.
- Personal protective equipment needs to be readily available to people with disabilities, older adults, their PAS and DSP workers.
- Disability-led organizations need to be [included](#) in the planning phases and throughout public health and emergency management.
- Home and Community Based Services [need sufficient funding](#) to meaningfully support people with disabilities and older adults to maintain their health, safety, dignity, and independence at home and in their communities.
- People with disabilities and their service providers need to maintain the ability to hold employers, educators, health care providers, and institutions legally accountable when their [civil](#) and [employee rights](#) are violated.

Immediate actions need to be taken by the disability community and allies in order to protect the rights of people with disabilities and older adults during the COVID-19 pandemic.

ANALYSIS

Next Steps:

1. Swiftly organize to stop any future pandemic relief or COVID-19 legislation that excludes, discriminates against, or harms people with disabilities.

The proposed [HEALS legislation](#) could exacerbate the spread of COVID-19 by shielding nursing facilities from liability. The HEALS Act could make it harder for plaintiffs or their successors to succeed in legal action against nursing facilities, businesses, and employers during the COVID-19 pandemic. In addition, the HEALS Act could enable discrimination against people with disabilities and other members of protected classes by waiving vital civil rights protections during the pandemic.

Together, we need to fight like never before to maintain our right to legal action when our rights are violated — especially when our lives are in jeopardy.

2. Advocate for an increase in funding for Medicaid and Home and Community Based Services (HCBS).

Increasing funding for Medicaid and HCBS is critical in providing the necessary supports that can keep people with disabilities and older adults out of a nursing facilities and other congregate facilities.

3. Organize at local, tribal, state, territorial, and national levels for the immediate relocation of people with disabilities and older adults in congregate settings.

4. Educate elected officials and policy-makers on the critical need to include and prioritize people with disabilities and older adults before, during, and after disasters.

ANALYSIS

Join us!

We hold Daily COVID-19 Disability Rights Calls

**6pm ET / 10pm UTC: Sunday, Monday, Tuesday,
Wednesday, Friday, Saturday**

7pm ET / 11pm UTC: Thursday

To join The Partnership's COVID-19 Disability Rights Daily Calls listserv, e-mail us at directors@disasterstrategies.org.

For more information on COVID-19 and disability rights, please visit the the archive we maintain daily:

[COVID-19 Community-Wide Resources](#)

ACKNOWLEDGEMENTS

The Partnership receives support in many different forms. We acknowledge and thank our collaborators, individual advocates, and many unnamed allies.

[American Association of People with Disabilities \(AAPD\)](#), [Association of Programs for Rural Independent Living \(APRIL\)](#), [Autistic Self Advocacy Network \(ASAN\)](#), [Consortium for Citizens with Disabilities \(CCD\)](#), [Center for Public Representation \(CPR\)](#), [National Council on Independent Living \(NCIL\)](#), [National Disability Rights Network \(NDRN\)](#), the [World Institute on Disability \(WID\)](#), and many more partner organizations. We thank you for collaborating on advocacy initiatives and look forward to continuing to collaborate strategically to advance disability rights in public health and disaster management policies and practices.

Individual advocates and allies: Thank you for your commitment and passion for disaster-impacted people with disabilities, older adults, and people with access and functional needs. Your input is a critical contribution to our daily organizing.

INITIATIVES

March 3, 2020: [The Partnership: National Disability Rights Call to Action](#)

March 9, 2020: [The Partnership: Letter to the White House COVID-19 Taskforce](#)

March 12, 2020: [The Partnership: COVID-19 Recommended Actions for Personal Assistant Services](#)

March 13, 2020: [AAPD: Template Letter to send to Insurance Commissioners](#)

March 13, 2020: **CCD and Disability Advocates** Letter to Education and Labor Committee and Transportation and Infrastructure Committee urging action to pass REAADI for Disasters Act [[E&L Letter](#)] [[T&I Letter](#)]

March 20, 2020: [CCD: Letter to U.S. Dept of Health and Human Services and Office of Civil Rights RE: COVID-19 - Disabilities and Discrimination](#)

March 21, 2020: [AAPD: Over 90 Civil Rights Organizations Urge House and Senate Leadership to Address the Needs of People with Disabilities in COVID-19 Relief Package](#)

March 22, 2020: [The Partnership: Community-Wide Take Action Alert](#)

March 23, 2020: [The Arc: Self Advocates in Leadership \(SAIL\), Disability Rights Washington \(DRW\), and The Arc of the United States \(The Arc\) filed a complaint with the U.S. Department of Health and Human Services Office for Civil Rights \(OCR\)](#)

March 24, 2020: [The Partnership: Community-Wide COVID-19 Disability Resource List](#)

INITIATIVES

March 30, 2020: [The Partnership: Legislative Recommendations](#)

April 2, 2020: [CCD: COVID-19 Package 4 Letter to Leaders McConnell and Schumer and Speaker Pelosi and Leader McCarthy](#)

April 13, 2020: [The Partnership: Open Letter to Rachel Maddow](#)

April 16, 2020: [AAPD, Bazelon Center, CPR, DREDF, and PIPC: Over 400 Organizations Sign-On Letter Urging HHS for Guidance on Medical Rationing](#)

April 20, 2020: [The Partnership: National Survey on Institutionalization in the Wake of COVID-19](#)

April 28, 2020: [The Partnership: Dear Congress Template Letter Re: READI, DRMA & COVID](#)

April 29, 2020: [CCD: Sign-On Letters - RE: Supporters in Hospitals to Governors and Hospital Administrators](#) [[Governors Link](#)] [[Hospital Admin Link](#)]

April 30, 2020: [ASAN: COVID-19 Case Tracker](#)

May 4, 2020: [AAPD, ASAN, CPR, CAP, The Arc, Little Lobbyists, NCIL: Letter to Congress Leadership RE: 5 Disability Priorities in next COVID-19 Legislative Package](#)

May 13, 2020: [The Partnership: ACTION ALERT! Legislative Sign-on Today & CMS Public Comments Needed](#)

May 15, 2020: [The Arc, ASAN, CPR, CF, DREDF, Bazelon Center: Evaluation Framework For Hospital Visitor Policies](#)

INITIATIVES

May 18, 2020: House Education and Labor Committee Member Briefing: Addressing the Impact of COVID-19 on Seniors and Individuals with Disabilities [[Briefing Link](#)] [[Kelly Buckland Testimony](#)]

May 20, 2020: [The Partnership: Take Action Alert! Tell Congress To Protect Disability Rights](#)

June 1, 2020: [The Partnership: Letter to the Attorney General RE: Investigate Nursing homes](#)

June 9, 2020: [The Arc, CPR, CF: Federal Civil Rights Resolution Makes Clear Hospital Visitor Policies Nationwide Must Accommodate Patients with Disabilities During COVID-19 Pandemic](#)

June 15, 2020: [CCD: Package Four \(4\) Sign-On Letter to Senate Leadership](#)

June 19, 2020: [The Partnership: Juneteenth Congressional Briefing](#)

June 22, 2020: [APRIL and Coalition: National Call To Action - Emergency Relocation of Congregate Setting Residents; SAVE LIVES NOW](#)

June 23, 2020: ACLU, SEIU, AAPD, ASAN, DREDF, NCIL, The Partnership, WID: Petition to HHS, CMS, CCSQ, and CDC Re: COVID-19 Response in Nursing Homes and Other Congregate Settings Where People with Disabilities Live [[Read Petition Here](#)] [[ACLU Press Release](#)] [[Cover Letter to HHS CMS, CCSQ](#)]

June 25, 2020: [The Partnership: Action Alert! Submit Comments on Senate White Paper to Protect People with Disabilities During Pandemics](#)

INITIATIVES

June 26, 2020: [**The Arc, CPR, ASAN, DREDF, Bazelon:** Resolution of Federal Civil Rights Complaint Raises the Bar in Prohibiting Medical Discrimination Against People with Disabilities During COVID-19 Pandemic](#)

July 8, 2020: [**The Partnership:** Justice for Michael Hickson Statement](#)

July 13, 2020: [**The Partnership:** Statement to Relocate Congregate Facilities #SaveDisabledLivesNow](#)

July 24, 2020: [**The Partnership:** COVID-19 Lockdown In the Caribbean](#)

July 26, 2020: [**The Partnership:** The 30th Anniversary of the ADA During a Pandemic Statement](#)

July 31, 2020: [**The Partnership:** Statement on the HEALS Act](#)

July 31, 2020: [**OCR Complaint Filed** by National Organizations on Behalf of the Family of Michael Hickson](#)

WEEKLY SUMMARIES

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WEEKLY SUMMARIES

FEBRUARY 28 - MARCH 7

Discussed:

- **Tracking COVID-19:** Mexico and Italy; Washington and California
 - » [Outbreaks in nursing facilities](#)
 - » Deaths
- **State and Federal:**
 - » Responsibilities, legal obligations, and failures
 - » Relevant Legislation: [READI & DRMA](#)
 - » States organizing efforts to prepare for the needs of the disability and older adults communities
- **Need for strategies to ensure disability rights and the continuity of services for people with disabilities and older adults in outbreak areas:**
 - » PAS and DSP staffing crisis
 - » Transportation
 - » Health care
- **Ensuring Access:**
 - » Medications
 - » PPE
 - » Durable Medical Equipment
- **Congregate Settings:**
 - » Visitation restrictions
 - » Safety of people with disabilities and older adults
 - » Staff infections

WEEKLY SUMMARIES

FEBRUARY 28 - MARCH 7

- **Accessibility issues with pandemic information and resources:**
 - » Press conferences missing ASL/captions
 - » Governmental documents not in alternate formats or equally effective communication
- **Collecting and promoting stories of COVID-19 impacts on people with disabilities and older adults**
- **Developed and Led a [National Call to Action](#):** 58 organizations signed on within the week [At time of publishing: 183 organizations signed their support]

WEEKLY SUMMARIES

MARCH 8 - MARCH 14

Discussed:

- **Federal:**

- » [The Partnership's Letter to White House COVID-19 Taskforce](#)
- » [The Partnership's COVID-19 Recommendations for Personal Assistance Services](#)
- » CCD and Disability Advocates [Letter to Transportation and Infrastructure \(T&I\)](#) and [Education and Labor \(E&L\)](#) Committees urging action to pass READI
- » COVID-19 cases and death reporting failure
- » [Public Health Emergency](#) and [National Emergency Declaration](#)
- » Federal government messaging and COVID-19 response:
 - ◇ Suppress the numbers of COVID-19 cases and deaths
 - ◇ What does the government mean by "Underlying conditions?"
- » ACL upcoming CIL guidance for operations
- » HHS not providing adequate supplies to hospitals

- **COVID-19 Cases and Death Reporting Failure**

- **State:**

- » Different state responses
- » Continuing issues with effective communication and ASL
- » No state issued statements or plans for individuals receiving In-Home supports
- » Lockdowns and stay-at-home orders began in some areas
- » Some places have drive-up testing

WEEKLY SUMMARIES

MARCH 8 - MARCH 14

- **Continuity of Services:**
 - » Insurance companies, states' stakeholder calls, and states themselves inadequately address the continuity of PAS and DSP
 - » Potential for lower standards of care and medical rationing
- **Nursing Facilities:**
 - » Olmstead decision violations
 - » No visitors
- **Accessibility Concerns:**
 - » Pandemic information and social distance education
- **Promising Practices:**
 - » Ensuring clear ASL in all press conferences
 - » Food delivery programs
 - » Nursing facility assessments via Skype
 - » Online community-led mutual aid initiatives

WEEKLY SUMMARIES

MARCH 15 - MARCH 21

Discussed:

- **COVID-19 Infection Rate and Death Reporting**
- **Federal:**
 - » [Share with Congress legislative and funding needs recommended by The Partnership](#) to address the gaps people with disabilities face in disasters
 - » FEMA Individual Assistance program - Crisis Counseling and accessibility concerns
 - » [ACL guidance](#) for CIL Operations and ILRU [Webinar Q&A](#)
 - » Disaster assistance granted does not include funds to pay for CILs or other disability organization
- **Federal Disability Advocacy Initiatives:**
 - » Advocacy to eliminate the requirement for EVV resulted in policy changes, ie. [Texas](#)
 - » What does it take for FEMA to provide funds to CILs for disaster assistance?
 - » [READI and DRMA](#)
- **State:**
 - » Some states are closing schools and implementing curfews
 - » Some cities are communicating #StayHome and only leave for essential trips
- **Continuity of Services:**
 - » Some advocacy groups in states are developing strategies to ensure continuity of services, ie. [Disability Rights California](#), [Disability Rights Pennsylvania](#)

WEEKLY SUMMARIES

MARCH 15 - MARCH 21

- **Disproportionate Death in the Disability Community:**
 - » Lack of PPE
- **Nursing Facilities:**
 - » Began “shutdowns” and started no visitor policies in NY, MD
 - » Discussed contradiction of 1135 Blanket Waivers to Olmstead decision
- **Personal Assistance Services (PAS) / Direct Service Provider (DSP):**
 - » Safety measures that PAS and DSP workers can take
 - » People with disabilities and older adults who receive HCBS should ask relevant personal protective measure questions of their workers
- **Accessibility Concerns:**
 - » Equal access to tele-education
 - » Voting Rights (upcoming primaries)
 - » Virtual meeting spaces: Captions, multiple languages, sign language
 - » Expanding ASL interpreters network, PPE for sign language interpreters, VRS
- **Other Concerns:**
 - » Restaurant closure can be an issue for those who depend on takeout
 - » Libraries in some areas are closing, can be an issue for people who need Wi-Fi and shelter
- **Promising Practices:**
 - » Neighborhood groups are doing grocery and delivery services
 - » Grocery stores dedicate specific times for people with disabilities and older adults to shop

WEEKLY SUMMARIES

MARCH 15 - MARCH 21

- **Promising Practices (cont.):**

- » [Colorado Governor issued a state-wide app](#) for service providers and recipients to discover challenges, resources, and input
- » Cross-sectorial coalition building

WEEKLY SUMMARIES

MARCH 22 - MARCH 28

Discussed:

- **Federal:**

- » HHS OCR - [Bulletin](#): Civil Rights, HIPAA, and the Coronavirus disease (COVID-19)
- » IA Crisis Counseling: Essentially a listening session, not an ongoing mental health program, concerns around equally effective communication
- » [FEMA ODIC Response to The Partnership regarding their role in COVID-19](#)
- » Problematic: FEMA list of “trusted” organizations
- » 3rd COVID-19 relief package: Critical moment for the community to advocate for disability needs [[The CARES Act and Disability Priorities](#)]
 - ◇ CARES Act allocated an extra \$85 million to CILs
- » 1135 Blanket Waivers fast-track people with disabilities into nursing facilities
- » No ASL interpreters provided by the White House for Coronavirus Taskforce daily briefings
- » DPOs still not funded federally for providing disaster assistance

- **State:**

- » Disaster declarations: FEMA will only reimburse at 75 percent, and states say they can't afford other 25 percent
- » Washington: HHS OCR [Complaint Filed Over COVID-19 Treatment Rationing Plan](#)
- » Alabama: HHS OCR [Complaint Filed Over COVID-19 Treatment Rationing Plan](#)
- » Kansas: HHS OCR [Complaint Filed Challenging Kansas' COVID-19 Treatment Rationing Policy Guidance](#)

WEEKLY SUMMARIES

MARCH 22 - MARCH 28

- **State (cont.):**

- » Tennessee: HHS OCR [Complaint Filed Over COVID-19 Health Care Rationing Guidelines](#)

- **System Advocacy Opportunities:**

- » [Disaster Relief Medicaid Act \(DRMA\) Real Emergency Access for Aging and Disability Inclusion for Disasters Act \(READI\)](#)
- » More funding for disability service providers
- » Equal access to PPE information, resources, and effective communication

- **Concerns:**

- » Medical care rationing
- » Access to test sites and test site accessibility for wheelchair users
- » Sense of invulnerability in young people
- » People are not making the connection that the people who are dying are people with “underlying health conditions,” i.e., people with disabilities
- » PPE and ventilator production
- » Difficulty gaining access and transitioning people out of nursing facilities
- » Housing and employment

- **Paying Attention to:**

- » Alternative care sites for homeless people
- » Needs of people who use assistive devices and service animals
- » Oxygen and tubing supplies for hospitals

- **Discussed:**

- » What to do/prepare if someone you know is in the hospital alone

WEEKLY SUMMARIES

MARCH 22 - MARCH 28

- **Discussed (cont.):**
 - » Backup plans for sick or unavailable PAS/DSP workers
- **Resources:**
 - » [The Partnership's COVID-19 Community-Wide Resource List](#)

WEEKLY SUMMARIES

MARCH 29 - APRIL 4

Discussed:

- **Federal:**

- » [The Partnership's Legislative Recommendations for Public Health Emergencies and Disasters](#)
- » ACL: Existing guidance and forthcoming COVID-19 Guidance
 - ◇ February 2019 - NAACHO: [Capacity-Building Toolkit for including Aging & Disability Networks in Emergency Planning](#)
 - ◇ March 30th - ACL: [Frequently asked questions during COVID-19](#)
- » Stimulus check for SSI recipients

- **State:**

- » 1135 Blanket Waivers (expedited institutionalization of people [with disabilities during disasters) approved in: Arizona, Montana, Arkansas, Nebraska, Colorado, North Dakota, Florida, Oklahoma, Georgia, Utah, Indiana, Vermont, Kansas, Wisconsin, Maine, Nevada, Massachusetts
 - ◇ Contradicting Olmstead Decision and civil rights
- » Pennsylvania: HHS OCR [Complaint Filed Over Pennsylvania's Interim Crisis Standards of Care for Pandemic Guidelines](#)
- » California: [Guidance for PAS/DSP](#) on the need for emergency back-up providers to assist In-Home Supportive Services (IHSS) recipients during the COVID-19 crisis

- **Disability Initiatives:**

- » Local community initiatives
- » Continuing disability rights and independent living work during a pandemic
- » How CILs are using CARES Act funding?

WEEKLY SUMMARIES

MARCH 29 - APRIL 4

- **Concerns:**

- » Needs and rights excluded from federal legislation
- » Concurrent disasters: Earthquakes and tornadoes
- » Hospital visitor policies
- » Difficulty stocking up on medication, i.e., inhalers
- » Civil rights obligations and protections in a disaster cannot be waived
- » Bringing PAS/DSP into hospital
- » Transportation needs to access testing
- » Postponed Primary elections
- » Access to PPE for In-Home supports workers
- » Nursing facilities threatening people's bed space when they left facilities to stay with family or support network on therapeutic leave due to COVID-19
- » People who are positive for COVID-19 having equal access to transportation
- » People being denied access to regular use of medication because of health care rationing and for "possible" COVID-19 treatment
- » Strike teams to mitigate spread in nursing facilities

WEEKLY SUMMARIES

APRIL 5 - APRIL 11

Discussed:

- **The Partnership Hotline:** Disability Community Needs
 - » Supplies like gloves, cloth masks, and sanitation supplies
 - » Advocacy help for people discriminated in hospitals
 - » Advocacy help for job discrimination
 - » Housing resources
 - » Stimulus check questions
 - » Disability-related needs for people with disabilities, older adults, family members, organizations, and allies impacted by disasters and/or COVID-19
- **Federal:**
 - » HHS OCR Reaches Early Case Resolution With Alabama After AL Removes Discriminatory Ventilator Triage Guidelines
 - » Letter from Senators to HHS, OCR, CMS - Re: Rationing of Care
 - » Educating for the need of funds for disability-related services in federal COVID-19 response legislation "3.5/4"
 - » Questions for FEMA:
 - ◇ IA Crisis Counseling (accommodations and cultural competencies?)
 - ◇ Can funds be used to improve Americans with Disabilities Act 1990, as Amended with ADA Amendments of 2008 (ADA) accessibility?
 - » CDC: Guidance for People with Disabilities
- **State:** Six (6) states have civil rights complaints related to COVID-19
 - » Washington (3/23/20), Alabama (3/24/20), Kansas (3/27/20), Tennessee (3/27/20), Utah (4/6/20), New York (4/7/20)
 - » Resolutions in: Alabama (4/8/20), Pennsylvania (4/16/20)

WEEKLY SUMMARIES

APRIL 5 - APRIL 11

- **Concerns:**

- » Accessibility: In hospitals (Braille signage)
- » Virtual press conferences/briefing accessibility; call on doctors to push for interpreters
- » Face masks and ASL; Deaf students access to interpreters for online education
- » Grocery stores denying entry to people with service animals
- » Strike team framework
- » The government seems to be preparing to turn to volunteer organizations to fulfill responsibilities for people with disabilities in disasters
- » CPR: [Health care rationing complaints](#)
- » Alabama excluded people with intellectual and developmental disabilities in their crisis plan
- » Housing evictions
- » How can SSI and SSDI recipients receive stimulus checks?
- » Non-congregate sheltering
 - ◇ In efforts to cohort
 - ◇ For homeless individuals
- » Even when stay-at-home orders begin easing, many disabled people express the need to stay quarantined as the risk of infection continued to be high

WEEKLY SUMMARIES

APRIL 12 - APRIL 18

Discussed:

- **Federal:**

- » COVID-19 Relief legislative Package 4
 - ◇ Possible bump in HCBS funding, provisions for greater access to PPE
- » HHS OCR [Resolves Civil Rights Complaint Against Pennsylvania](#)
- » NCD facilitated Roundtables with FEMA and government agencies with disability stakeholders
- » FEMA Ambulance and Paratransit contracts, other transportation alternatives

- **Partner Initiatives:**

- » NCIL/APRIL partnering with [Centene Corporation](#) for [emergency direct care worker registry](#)
 - ◇ Pilots in two (2) states: Kansas and Pennsylvania

- **Concerns:**

- » Accessibility: Difficulties for rural Deaf individuals obtaining interpreters
- » Test site accessibility, reasonable accommodations and modifications of policies
- » The disproportionate impact of COVID-19 on Black, Brown, Indigenous and other People of Color
- » The disproportionate number of deaths in nursing facilities; [the pre-existing history](#) of nursing facilities poor infection control
- » Requirements to ensure that testing sites are accessible

WEEKLY SUMMARIES

APRIL 12 - APRIL 18

- **Concerns (cont.):**

- » Effectiveness of masks in protecting against the spread of the infection, i.e., N-95 vs. cloth masks
- » Pandemic will be here longer than being predicted
- » Challenge with providing safe sheltering for homeless people
- » Seeking a cure is leading to a shortage of health maintenance medication for many
- » Systems to support [occupational therapists](#) and help with the workforce crisis in HCBS during the pandemic to fill immediate needs and gaps in services

WEEKLY SUMMARIES

APRIL 19 - APRIL 25

Discussed:

- **Federal:**

- » CMS COVID-19 reporting not including other congregate settings (ICFs, personal care homes, group homes, psychiatric facilities, prisons, detention centers, state hospitals, alternate care facilities, other residential congregate facilities)
 - ◇ The Partnership: [National Survey Alert](#) and [Survey Results Released 5/19/20](#)
 - ◇ COVID Relief legislative package 3.5/4
- » Federal and state emergency declarations - sheltered workshops are on the list approved to receive funds
 - ◇ CILs not listed as a reimbursable entity [PAPPG Vol 4, p. 45-47](#)
- » [READI and DRMA legislation](#)
- » NCD Roundtable discussion: Disability community concerns and questions during COVID-19 pandemic, and FEMA ODIC roles, responsibilities, and obligations
 - ◇ Discussions around IA Crisis Counseling and PA Category B reimbursable assistance

- **State:**

- » States began phased re-opening
- » Oklahoma: HHS OCR [Complaint Filed Re: Crisis Standards of Care](#)

- **Nursing Facilities:**

- » 19 states reported 7,300 deaths in nursing facilities
 - ◇ Congregate settings not required to report people who die in restraints

WEEKLY SUMMARIES

APRIL 19 - APRIL 25

- **States Reopening:**

- » Individuals are left to make decisions whether to stay-at-home
- » “Vulnerable” people expected to remain at home or be society’s sacrifice
- » Right-to-risk and choice to go outside

- **Accessibility:**

- » Advocacy for access to medication, equipment, ventilators
- » Reasonable accommodations for working from home
- » Accessibility of masks

- **Concerns:**

- » Electronic medical records
- » Undocumented people at risk
- » Strike teams: Potential for disability advocates

WEEKLY SUMMARIES

APRIL 26 - MAY 2

Discussed:

- **Federal:**

- » FEMA: National Advisory Council; Category B reimbursements; possible call with FEMA's ten (10) regions
 - ◇ [The Partnership Request Meeting with all FEMA Regional Disability Integration Specialists Re: Crisis Counseling](#)
 - ◇ Concerned FEMA will not ensure equally accessible and effective Crisis Counseling that is culturally competent
 - ◇ NCD Roundtables with FEMA and government agencies with disability stakeholders
 - ◆ Discussion around IA Crisis Counseling and ensuring the monitoring and enforcement of equally effective communication

- **State:**

- » [Unprecedented: All 50 states are under major disaster declaration](#)
 - ◇ [This includes all US territories, except for American Samoa](#)
- » Pennsylvania is paying PAS workers a retainer fee using Medicaid funds
- » Nursing facilities pushing state legislation seeking liability shield to lawsuits
- » Are strike teams opportunities for involvement or more institutional focus?

- **Concerns:**

- » Nursing facility testing only symptomatic cases, so staff at the facilities that are asymptomatic are not being screened and are likely spreading COVID-19
- » Continuity of operations for PAS and DSP workers without disruption for people with disabilities and older adults in the community to prevent institutionalization

WEEKLY SUMMARIES

APRIL 26 - MAY 2

- **Concerns (cont.):**

- » Access to food
- » People with disabilities have the right to be served in settings where they are protected from infection
- » Achieving a Better Life Experience Act (ABLE) of 2014: [ABLE Accounts and stimulus checks](#)
- » PPE is still not available in many congregate facilities; cloth masks are inappropriate
- » CILs continuing to transition people out of nursing facilities, despite challenges
- » COVID-19 testing for prisoners with disabilities
- » CDC: [Responding to Coronavirus \(COVID-19\) in Nursing Homes](#)

WEEKLY SUMMARIES

MAY 3 - MAY 9

Discussed:

- **Concurrent Disasters:** [Florida fires](#)
- **Global Alliance for Disaster Resource Acceleration (GADRA):**
 - » First town hall with DPOs across the world to understand the gaps disability-led organizations face to meet the needs of their communities in response to COVID-19 and concurrent disasters [GADRA Town Hall - Session 1 - May 7, 2020](#)
- **Federal:**
 - » DHS and HHS [Civil Rights Stakeholders COVID-19 Teleconference](#)
 - ◇ Mentioned: Responsibilities are at state and local levels; no discussion of nursing facilities
 - » [FEMA ODIC response to The Partnership April 27 Request for RDIS Call](#)
 - ◇ [The Partnership email request and questions from 4/27/20](#)
 - » The Partnership met with representatives from CMS in regards to 1135 Blanket Waiver concerns (on [May 21st, CMS modified 1135 Waiver Guidance](#) to include a reference to Olmstead)
 - » In prior disasters, FEMA [provided temporary and permanent housing](#)
 - » [P&A Network Response to Medical Rationing](#) with map of complaints filed, letters sent to governors, and both
 - » CCD: Letter addressing the need for hospital visitation rights [[Governors Link](#)] [[Hospital Admin Link](#)]
- **State:**
 - » Connecticut: [HHS OCR Complaint Filed Re: Hospital Visitation Policies](#)
 - » North Carolina: [HHS OCR Complaint Filed Re: State Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic](#)

WEEKLY SUMMARIES

MAY 3 - MAY 9

- **State (cont.):**

- » Oregon: [HHS OCR Complaint Filed Re: Crisis Care Guidance](#)
- » Strike teams can be effective: Coordinating response, PPE distribution, isolating, coordinating testing, but still not testing everyone, just those displaying symptoms
- » No states have begun Crisis Counseling, although [FEMA approved 30 States on May 2nd](#)
- » Opportunity for CILs to get involved and assist with Crisis Counseling services locally

- **Concerns:**

- » 1135 Blanket Waivers: Factors that lead to people being sent to nursing facilities when under other conditions civil rights would be protected
- » How does CMS justify not providing HCBS for more costly and (and now exponentially) deadly nursing facilities?
- » Include PAS and DSPs workers - priority testing
- » Contact tracing and cultural sensitivity
- » Who enforces “no hospital visitor policy?”
- » Masks:
 - ◇ Reasonable accommodations for disabled employees who can't wear masks
 - ◇ Accessibility concerns involved in the physical act of putting on a mask
- » Interconnected: Civil rights issues, the disproportionate impact of disasters on people with disabilities, voting, and 2020 Census
- » Messaging to promote equally effective communication for the 2020 Census
- » Who is paying for PPE in nursing facilities?

WEEKLY SUMMARIES

MAY 10 - MAY 16

Discussed:

- **Federal:**

- » President announces MITRE Coronavirus [Commission on Safety and Quality in Nursing Homes](#) seeking for people to serve
- » [COVID-19 Recovery for Seniors and People with Disabilities Act](#)
- » [Coronavirus Relief for Seniors and People with Disabilities Act \(S. 3544\)](#)
- » [Nursing Home COVID-19 Protection and Prevention Act \(S.3768\)](#)
- » Introduction of Federal COVID-19 relief legislation named the HEROES Act
 - ◇ Includes seniors, people with disabilities, voting, funding for PAS and DSPs, funding HCBS, funding for housing
 - ◇ Concern: Increasing money into nursing facilities

- **FEMA:**

- » NCD Roundtable Update: Discussions around PA Category B funding and reimbursement for [PAS in non-congregate sheltering](#) and PPE
 - ◇ FEMA said they would not distribute PPE
- » Crisis Counseling delays in many areas, availability and process depends on individual states
- » How FEMA RDIS engages with DPOs and local community stakeholders on a local and national level across regions?
 - ◇ [ODIC Response](#) from 5/7/20

- **State:**

- » States are re-opening but many people with disabilities choose to stay home - no safety net or protection for disabled people

WEEKLY SUMMARIES

MAY 10 - MAY 16

- **Concerns (cont.):**

- » People with disabilities experiencing pressure and stigma for not going out
- » The pandemic's impact on voting
- » COVID-19 liability shields for nursing facilities: Legislation introduced in several states
- » Nursing facilities are absorbing the stimulus checks of people who live in them
 - ◇ People who are in nursing facilities likely do not know that this is illegal nor [how to file a complaint](#)
- » Olmstead decision is helpful only if someone actively wants to leave a nursing facility and has family or circle of supports
- » CMS proposed a rule that would weaken the Preadmission Screening and Resident Review (PASRR) regulation making it easier for people to be admitted to nursing facilities and harder for people to transition out

- **Opportunities:**

- » Employment: Now that work from home is becoming the new norm, employers need to [recognize the new options and benefit from employing people with disabilities](#)
- » [Data showing that HCBS are cheaper than nursing facilities](#)
- » Disaster housing programs: Turning temporary into permanent
- » [The Partnership's Action Alert: Organizational Sign-on opportunity - Recovery for Seniors and People with Disabilities Act](#) and CMS Public Comment Open for [Preadmission Screening and Resident Review](#)

WEEKLY SUMMARIES

MAY 17 - MAY 23

Discussed:

- **Concurrent Disaster:** [Michigan flooding](#)
- **The Partnership Update:** Releases [National Survey Results on Institutionalization in the Wake of COVID-19 | Survey Results](#)
- **Federal:**
 - » CMS revised [1135 Waiver Guidance](#) to include a reference to the Olmstead Decision
 - ◇ The Partnership followed up to seek more information, and requested CMS join The Partnership's Weekly National Stakeholder Call for an open dialog and Q&A with disability community stakeholders
 - » MFP no extension; ends in September 2020
 - » [GAO report](#) on nursing facilities identifies poor performance of infection control
 - » FEMA: Emergency Management Agency Contracts to share resources - states just need to agree to pay 25 percent of the cost
 - » [Member Briefing for House Education & Labor Committee](#): Addressing the Impact of COVID-19 on Seniors and Individuals with Disabilities [[Kelly Buckland's Testimony Transcript](#)]
 - ◇ [REAAD](#) would be particularly significant right now if passed
 - » [People in Puerto Rico and other U.S. territories have not received stimulus payments when people in the mainland have already](#)
- **Concerns:**
 - » Nursing facilities restricted access to advocates, supports, and even ombudsman
 - » [The disparity in Black and Brown nursing facility populations and COVID-19](#)

WEEKLY SUMMARIES

MAY 17 - MAY 23

- **Concerns (cont.):**

- » Hospital discharge planners role and how that could change to meet the needs of people with disabilities and older adults
- » Food distribution; how to ensure Kosher meals in hospitals, schools, and nursing facilities

- **Guest Speakers:** Misty Dion and Jodie Baney from Roads To Freedom CIL of North Central Pennsylvania

- » Discussed good and promising practices to relocate people with disabilities and older adults out of nursing facilities and other congregate facilities into temporary cohort settings like hotel, motel, or dormitory until housing and HCBS services are in place
- » Shared efforts on working with local government entities to access FEMA Public Assistance Category B reimbursement to cover wrap-around services and costs during relocation
- » Good and promising practices around advocating for expedited nursing facility transition, and how they've been successful with some transitions during COVID-19

- **Opportunities:**

- » Evacuation from nursing facilities
 - ◇ Concern: Can't just take people out of nursing facilities without established services and supports
- » Preventing and diverting people from being placed in nursing facilities
- » Support local groups in states that are working on getting people out of nursing facilities
- » Draw on people who care about Medicaid fraud issues to discuss how this plays out in the nursing facilities

WEEKLY SUMMARIES

MAY 17 - MAY 23

- **Opportunities (cont.):**
 - » **Potential strategy:** Coalesce with local P&A agencies or NDRN on potential legal approaches
 - » State strike teams are potential opportunities for CILs to provide expertise and have a seat at the table

WEEKLY SUMMARIES

MAY 24 - MAY 30

Discussed:

- **The Partnership Update:**

- » The Partnership joined [Red de Gestión Inclusiva del Riesgo de Desastres y Discapacidad de América Latina y el Caribe](#) (Red GIRDD-LAC) [English: The Disaster Risk Reduction and Disabilities Network of Latin America and the Caribbean]

- **Federal:**

- » [READI and DRMA](#) applicable during COVID-19
- » Update from House Transportation and Infrastructure Committee
- » National Legislation: [HEROES Act](#) and [Accessible Voting Act](#)
- » Presidential candidate, [Joe Biden's disability policy](#) briefing
 - ◇ Researched if Presidential candidate Donald Trump has a disability policy/vision in his campaign
- » CDC: [Guidance for Group Homes for Individuals with Disabilities](#)
- » CDC: [Guidance for Direct Service Providers, Caregivers, Parents, and People with Developmental and Behavioral Disorders](#)
- » CDC: [Guidance for People with Developmental and Behavioral Disorders](#)

- **Nursing Facilities:**

- » Strike teams: Do people who live in the nursing facilities have informed consent regarding testing?
- » CILs continue to transition people out of nursing facilities
 - ◇ Facing additional barriers to transition and diversion
- » What will happen with nursing facilities as states reopen?
- » Focused on diverting people away from placement in nursing facilities

WEEKLY SUMMARIES

MAY 24 - MAY 30

- **Nursing Facilities (cont.):**

- » Challenge: Preadmission Screening Program — main problem:
 - ◊ Discharge planners wait until discharge to plan, and the nursing facilities are considered fast and appropriate placements
- » Accessible housing and home modification requirements disproportionately place people with disabilities into nursing facilities that are lower quality than homes in the community
- » Forthcoming: APRIL and Coalition National Call for Relocation of Individuals in Nursing Facilities

- **Concerns:**

- » Nursing facilities seeking liability shield policies
- » Safe and accessible voting should have a variety of options - electronic, in-person, etc.
- » Uniting the disability rights movement
- » National anti-racism/police brutality protests

WEEKLY SUMMARIES

May 31 - JUNE 6

Discussed:

- **#JusticeForGeorge Nationwide Protests:**
 - » [Protests and riots sprung up across America after an officer from the Minneapolis Police Department killed George Floyd, a 46 year-old unarmed Black man, by kneeling on his neck for eight \(8\) minutes and forty-two \(42\) seconds](#)
 - » How to safely support activism and protests
 - » Aggressive police response to protesters is creating disabilities
 - » [#BlackDisabledLivesMatter protest](#)
- **Concurrent Disasters:** Earthquake outside of Los Angeles; watching Tropical Storm Cristobal (early evacuations), social distancing in shelters
- **Disability & Aging Collaborative & CCD:** [Sign-on Letter to the Senate](#) for Dedicated HCBS Funding in COVID-19 Package Four (4)
- **National Advocacy Initiatives:**
 - » [The Partnership: Letter to Attorney General](#) Re: Investigating Nursing Homes
- **CDC:**
 - » Working to make materials more accessible
 - ◇ CDC: [COVID-19 ASL Videos](#)
 - ◇ CDC: [Toolkit for People with Disabilities](#)
 - » CDC: [Mask Guidance](#)
 - » Opportunity to provide input on CDC guidance for voting safety and accessibility guidance
- - » Guidance for service animal handlers forthcoming

WEEKLY SUMMARIES

MAY 31- JUNE 6

- **ACL:**

- » PPE still not enough for people with disabilities, nor their PAS or DSP workers
- » Advised to work with FEMA, even though at NCD roundtable FEMA said they wouldn't distribute PPE

- **Congressional Activities:**

- » Fourth (4th) COVID-19 funding package: Community organizing to educate on the need for HCBS funding

- **Reopenings:** Inconsistent messaging of COVID-19

- » Arizona is spiking
- » How will schools reopen?

- **COVID-19 Survivors:** What are the long-term impacts?

- **Congregate Facilities:**

- » Nursing facilities:
 - ◇ Ombudsman, CILs, P&A's can be helpful
 - ◇ Facilities are reluctant to refer for transition
 - ◇ Transitions are down due to lack of access
- » **Advocacy** for emergency relocations
- » Congregate facilities are resisting and failing to comply with pre-existing disaster preparedness requirements
- » Prisons:
 - ◇ [Water shut off and sewage overflow in Texas](#)
 - ◇ COVID-19 outbreaks
 - ◇ There is a push to evacuate prisons due to increased risk of COVID-19

WEEKLY SUMMARIES

MAY 31 - JUNE 6

- **Medical Rationing:** Even if it's explicit that people with disabilities and older adults will not be denied health care, implicit biases are at play
- **Mitigating impending second-wave to prevent many deaths:**
 - » Prepare
 - » Urge strong policies
 - » Leverage resources

WEEKLY SUMMARIES

JUNE 7 - JUNE 13

Discussed:

- **ACL:** [FAQ Centers for Independent Living: COVID-19 Aid, Relief, and Economic Security Act of 2020 \(CARES Act\) Funding](#)
- **OCR:**
 - » [Resolved complaint in Connecticut](#) about access to support persons in hospitals during COVID-19 — resulted in [Connecticut Governor Executive Order](#)
 - » Took away non-discriminatory protections for sex/gender
- **FEMA:** Barriers to accountability and real action
 - » IA application: Despite [2019's GAO findings](#), FEMA still hasn't updated question #24, nor provides an easy way to request accommodations
 - ◇ **Strategy:** Ask state disability rights networks or P&As about individuals filing complaints for reasonable accommodations
 - ◇ [FEMA distributed faulty PPE](#)
- **Congress:**
 - » Make [READI](#) more concrete for delegates
 - ◇ CILs should be eligible for Category B funding
 - » We need to get the Authorizations Committee and Appropriations Committee on the same page for FEMA PA funding
 - » The Partnership is [organizing a Juneteenth Briefing](#) highlighting the relationship between racial inequality and COVID-19 in Black disabled communities
- **Medical Care Rationing:**
 - » Draft letter to Ohio Hospital Ethics Committee Re: Disability in Ethical Resource Allocation ([Final Copy 7/28/20](#))

WEEKLY SUMMARIES

JUNE 7 - JUNE 13

- **Nursing Facilities:**

- » Transitions:
 - ◇ Incentives for hospitals to divert people away from nursing facilities
 - ◇ People want to leave nursing facilities, but lack of accessible, affordable, integrated housing and no supports demoralize pursuit
 - ◇ Strategy: Restart Business Acumen Trainings for CILs
 - ◇ Barriers and disincentives to talking with the ombudsman

- **Voting:**

- » Absentee ballots in New York
- » Georgia: [Polling site in a nursing facility](#)
- » Forthcoming CDC guidance

- **Centers for Medicaid and Medicare Services (CMS):**

- » CMS “continues to be aware”
- » [62,000 dead in nursing facilities](#) [Link updates daily] but “no one has issued complaints”
- » **Strategy:** Use local news stories to identify potential people to file a complaint
- » **Strategy:** Coalesce with local P&A agencies to explore potential legal approaches
- » Why isn't CMS doing more oversight? What will they do when there is a spike?

- **Concerns:**

- » Why does health care admit people to nursing facilities?
- » A limited number of hotel rooms in rural areas in case of need for mass non-congregate sheltering

WEEKLY SUMMARIES

JUNE 7 - JUNE 13

- **Reopening:** Idaho is lifting visitation restrictions in nursing facilities
- **Media's Role:**
 - » Fragmented and contradictory messaging
 - » False sense of pandemic ending
 - » Limitations of information to change behavior
 - » Need political will and coordination with respected community leaders
- **Other Considerations:**
 - » What the disability and older adults communities need in the 100 days after the next presidency starts on January 20th, 2021?
 - » What measures need to be put in place to keep people in their homes instead of congregate facilities?
- **GADRA:** 2nd Town Hall
 - » Global DPO community forum for sharing and storytelling while reframing the debate on disability inclusion in disaster planning, response, recovery, and mitigation: [GADRA Town Hall - Session 2 - June 7, 2020](#)

WEEKLY SUMMARIES

JUNE 14 - JUNE 20

Discussed:

- **Important:** Still on the first wave
 - » Increasing cases among young people
- **Congress:**
 - » The Partnership hosted a [Juneteenth Congressional Briefing](#) on Inequality and Disproportionate impact of the COVID-19 Response on Black Disabled Communities
 - » Senator Lamar Alexander (R-TN) [White Paper “Preparing for the Next Pandemic”](#) - doesn't address long-term care facilities. ([The Partnership organized a campaign to issue public comments](#))
 - » Advocacy: [CCD sign-on letter sent to Senate leadership](#)
- **CDC:**
 - » [Guidance for Handlers of Service and Therapy Animals](#)
- **States:**
 - » Reopening: Spikes correspond with reopening: FL, AZ, TX, OK
 - » Nebraska: HHS OCR [Complaint Filed Re: Discrimination in Nebraska's state testing program \(TestNebraska\)](#)
 - » Ohio: Draft recommendations submitted to Governor: Transition out of facilities
 - ◇ Clear guidance around medical rationing and people with disabilities and older adults at the decision-making table
 - » Colorado: Conducting stakeholder meetings about expediting people out of nursing facilities, including asymptomatic, similar to [non-congregate sheltering for the homeless population](#)
 - » California: [Requiring the use of face masks in public](#)

WEEKLY SUMMARIES

JUNE 14 - JUNE 20

- **States (cont.):**
 - » Connecticut: [Executive Order by Governor](#) to test in nursing facilities
 - ◇ Can stop testing when no new positive tests for 14 days
 - » Idaho: [Rolled back an opening phase](#)
- **MITRE:**
 - » [25 Experts Named](#) to Independent Coronavirus Commission for Safety and Quality in Nursing Homes
- **Red Cross:** [Non-Congregate Shelter Accessibility Checklist](#)
- **National Mass Care Strategy:**
 - » [Accessibility and Inclusive Resources](#)
 - » [Multi-Agency Pandemic Sheltering Job Aid](#)
- **Nursing facilities:**
 - » [Hospital to Home model](#): Colorado Springs CIL diverts people so they are not placed in nursing facilities; money saver for hospitals
 - » 1135 Blanket Waivers: Ongoing use during national emergency declaration to expedite institutionalization; continues to be an ongoing and real threat, each and every day
 - » Efforts to relocate people out of congregate settings need to ensure community wrap-around services
- **Data:** Incomplete sources: [ACS and CDC's Social Vulnerability Index](#)
- **Media:**
 - » How to obtain better engagement on issues? How to engage culturally?
- **Representative terms matter:**
 - » At-risk/vulnerable people vs. people with disabilities

WEEKLY SUMMARIES

JUNE 21 - JUNE 27

Discussed:

- **Juneteenth Briefing:** [Recording post-production](#)
- **Federal:**
 - » FEMA PA Category B funding: Congregate residential facilities, “daycare” and “sheltered workshops” are some of the private nonprofits serving disabled people that are eligible for funding
 - ◇ **Strategy:** CILs need to be added to the list of eligible entities in PA Category B
- **Congress:** COVID-19 relief package 4
- **CDC:**
 - » [Guidance for Nursing Facilities](#)
 - » [Guidance on the Effectiveness of Cloth Masks](#)
 - » [Considerations for Election Polling Locations and Voters](#)
 - ◇ With input from the National Coalition for Accessible Voting
 - ◇ Discouraging the usage of nursing facilities as polling sites
 - ◆ Recommendations for accessibility and safety of people with disabilities people with disabilities are explicitly mentioned under sections:
 - Masks, signs and messages, shared objects, modified layouts and procedures, alternative voting options for voters with symptoms, mail-in ballots, and be prepared

WEEKLY SUMMARIES

JUNE 21 - JUNE 27

- **States:**

- » Discussing freezing or rolling back reopening due to outbreaks

- **Advocacy:**

- » APRIL and Coalition: [National Call to Action](#) - Relocate Congregate Facilities & Save Lives Now
 - ◇ Letter sent to National Governors Association
- » [ACLU Petition to HHS, CMS, CCSQ, CDC](#) Re: COVID-19 Response in Nursing Homes, Other Congregate Settings Where People with Disabilities Live

- **Nursing Facilities:**

- » Some people are reporting not being allowed to leave their rooms — these may be possible complaints to the state health department and OCR
- » [Michael Hickson](#), a Black disabled man in Texas, had COVID-19, was denied care, starved and dehydrated to death
- » Need stories that tell what disabled people are going through
- » Repurposing institutions and re-employment of nursing facility staff

- **Rationing:**

- » [HHS OCR Resolution](#) of Federal Civil Rights Complaint in Tennessee health care policy to avoid long-term survivability as discrimination against people with disabilities and forbids reallocating personal ventilators
- » [Resolution Raises the Bar in Prohibiting Medical Discrimination Against People with Disabilities During COVID-19 Pandemic](#)

WEEKLY SUMMARIES

JUNE 21 - JUNE 27

- **Guest Speaker:** [Steve Kaye, PhD](#)
 - » Shared experience in disability-related data and what's worked in the past, lessons learned, and potential advocacy opportunities
 - » Discussed systemic barriers and issues related to accurate and full data that represents the true magnitude of the disproportionate impact people with disabilities (especially those in nursing facilities and other congregate settings) represent in the COVID-19 death toll.
- **Concerns:**
 - » Problematic data collection:
 - ◇ Understand undercounts; a way to improve is “How many people need help with x activity?”
 - ◇ Population-based statistics is better than service provision data, which leaves people who don't receive services out
 - ◇ ACS includes people in congregate settings at the national level
 - ◆ Cannot get a breakdown for meaningful information on types of congregate settings

WEEKLY SUMMARIES

JUNE 28 - JULY 4

Discussed:

- **The Partnership Announcements:** [Looking Back to Move Forward by June Kailes](#)
- **Federal:**
 - » Senators Casey (D-PA), Wyden (D-OR), and Peters (D-MI) released report: [COVID-19 in Nursing Homes](#)
 - » Sen. Mitch McConnell (R-KY): Wants liability shields for facilities even though there have been cross-sectorial advocacy efforts around asking for increased funds for Home and Community Based Services
 - » Next Federal relief package:
 - ◇ Emphasis on paid workforce and evictions moratoriums
 - ◇ How would HCBS/LTSS funds serve the disability community?
 - ◇ Is there the potential to add in an “enforcement” piece regarding nursing facilities?
 - » ODIC upcoming ADA anniversary event
 - » NCD Roundtable Update: Discussions around how states can utilize FEMA Public Assistance Category B funding to relocate people out of nursing facilities and other congregate settings into cohort non-congregate sheltering like a hotel, motel, or dormitory
- **CDC:** [Guidance for Direct Service Providers](#)
- **National Messaging:** Mix messaging continues, causing confusion
 - » Colorado parks reopened and rewarded people for wearing masks
 - » Advantages of rewards vs. threats
 - » The leadership of both major political parties is starting to have a more unified message on the importance of masks

WEEKLY SUMMARIES

JUNE 28 - JULY 4

- **States:**

- » Some states enforcing masks
- » California: 50 counties return to lockdowns **States (cont.):**
- » Florida: Lockdowns in Miami-Dade
- » Chicago, Illinois: Requiring visitors from certain states to self-quarantine
- » Arkansas: Increased testing and contact tracing

- **Health Care:**

- » [The Partnership issued a Statement Demanding Justice for the Murder of Michael Hickson](#)
- » Barriers to access medication, especially for regular users of hydroxychloroquine and remdesivir

- **Deinstitutionalization:** Strategizing to get people out of nursing facilities and other congregate settings

- » Challenge institutional bias in public and families
- » Increasing funding for HCBS can prevent people from being sent to nursing facilities and help in transitioning out of congregate settings
- » Prove to Managed Care Organizations (MCOs) that it is cheaper to divert people from nursing facilities and provide supports in the community
- » It's never worked to focus on making nursing facilities better; need to focus on getting people out
- » Need to include group homes and psychiatric institutions
- » Nursing facilities financially benefit when holding COVID-19 positive persons, yet again people with disabilities are only beneficial as income

WEEKLY SUMMARIES

JUNE 28 - JULY 4

- **Data:**
 - » Data and reporting changes regarding congregate care deaths
 - » CDC is specifically deploying teams to evaluate data in hotspots
 - ◇ CDC: [Disability and Health State Programs](#)
- **Accessibility:** Testing sites continue to be a concern
- **Access to PPE:**
 - » For a disabled and older person employing PAS and DSP workers
- **AT/DME:**
 - » Barriers to access Assistive Technology (AT) and Durable Medical Equipment (DME) during a disaster/the pandemic
- **Potential Alternative to Police Response:**
 - » [CAHOOTS](#) project out of Oregon

WEEKLY SUMMARIES

JULY 5 - JULY 11

Discussed:

- **GADRA:** [Launch of Global Alliance for Disaster Resource Acceleration](#)
 - » Desired outcome: Connect funders with disability-led organizations doing disaster work ([more GADRA information](#))
- **Federal:**
 - » House passed HEROES Act; waiting for Senate
 - » Senator McConnell (R-KY) priorities: Nursing facility liability relief, no funding for disability services or supports; maybe education/special education funding
 - » Next relief package: Senate new bill; HCBS request is based on HEROES Act; affordable accessible housing
 - » CRCL shares [DHS statement](#) that during the 2020 Wildfires season, "...there will be no immigration enforcement initiatives associated with evacuations or sheltering related to the wildfires, except in the event of a serious public safety threat."
- **States:**
 - » Washington: The Partnership is conducting [Community Resilience trainings and conference](#)
- **Data:** What is the comparison between 2019 and 2020:
 - » Deaths from chronic conditions
 - » Number of nursing facility deaths
- **Health Care:**
 - » [Veterans received experimental "COVID cocktails" without consent](#)

WEEKLY SUMMARIES

JULY 5 - JULY 11

- **Deinstitutionalization:**

- » If person is separated from AT/DME, then the person will be sent to facilities
- » Explore possibility of legislative changes to address 1135 Blanket Waiver

- **Individual:**

- » [Melissa Marshall's book release announcement *I Can't Swim But I Haven't Drowned Yet - Notes from a Disability Rights Activist*](#)

WEEKLY SUMMARIES

JULY 12 - JULY 18

Discussed:

- **CDC:**
 - » [School Decision-Making Tool for Parents, Caregivers, and Guardians](#)
 - » [Back to School Planning: Checklists to Guide Parents, Guardians, and Caregivers](#)
- **States:**
 - » Report recommends rolling back reopening phases of 18 states, including: CA, NV, AZ, ID, UT, TX, KS, AR, LA, AL, TN, NC, SC, FL, IA
 - » Georgia Governor is suing cities if they mandate masks
 - » Arizona: HHS OCR [Complaint Filed Re: AZ's Crisis Standards of Care](#)
- **Crisis Counseling:**
 - » FEMA requires certain numbers in state before making Crisis Counseling funds available
 - ◇ Montana did not meet the threshold
 - » FEMA: [30 states approved for Crisis Counseling in May 2020](#)
 - » Which states have Crisis Counseling operational/available, are people using it, and how are accommodations being provided?
- **Concern:**
 - » President Trump is calling for “liability shields” for health care providers and employers
 - ◇ Liability shields would prevent investigations and legal action over discrimination complaints including, but not limited to, layoffs, access needs, and testing

WEEKLY SUMMARIES

JULY 12 - JULY 18

- **Voting Concerns:**

- » Need a variety of methods
- » Concerns about mail-in ballots for people who can't read print
- » Concerns about if people will be forced to go to polls at-risk of pandemic
- » Will older volunteers at poll sites show up?
- » COVID-19 concerns will impact transportation to polls
- » Advocacy item: Implement early voting
- » Education and Information: REV UP Summit - [Power: The Disability Vote](#)
 - ◇ Vice President [Joe Biden's Remarks](#)
 - ◇ [Senior Advisor for the Trump 2020 Re-election Campaign, Lara Trump's Remarks](#)

- **MITRE:**

- » Independent Coronavirus Commission on Safety and Quality in Nursing Homes [Launches Additional Public Input Option](#)
- » The Partnership Submitted:
 - ◇ [Recommendations for PAS/DSP](#)
 - ◇ [The Partnership's Letter to Attorney General](#)
 - ◇ [The Partnership statement to relocate](#)
 - ◇ [APRIL and Coalition letter to relocate](#)

- **Film Festival:** [Revisioning Recovery](#)

- » [Part 1 of Panel Recording](#)
- » [Part 2 of Panel Recording](#)

WEEKLY SUMMARIES

JULY 12 - JULY 18

- **Testing:**

- » There is a need for less invasive COVID-19 tests, more accurate and faster test results
- » Some places have said “too invasive” as reason to not test in congregate settings
- » Is the saliva test a potential reasonable modification?

- **Education:**

- » Not reopening universities means that international students will no longer be allowed to stay in the U.S.
 - ◇ ([In reversal, federal government will allow international students to stay in the U.S. while taking only online classes](#))
- » Reopening schools will disparately impact students and parents with disabilities
- » CDC is working to address school issues
- » Would IDEA funds be used at the expense of individual assistance?

- **Guest Speakers:**

- » Contact tracer: Callers asked questions about how contact tracer connected people to resources and how to engage with people with disabilities and ensure equal effective communication with Deaf, Hard of Hearing and DeafBlind individuals.
- » Disability Policy Director: Shared his perspective on the next relief package and current political barriers. Highlighted key points from HEROES Act to be advocating for, and the importance of, a unified messaging from the disability community. Shared Sign-on for Senators: [Congressional Letter to Senator McConnell](#).

WEEKLY SUMMARIES

JULY 12 - JULY 18

- **Guest Speakers (cont.):**

- » Cathy Ludlum: A disabled woman who was at high risk of being institutionalized, due to lack of consistent/reliable and safe/precautious PAS workers, or workers willing to be live-in attendants. Cathy shared what worked and didn't in her personal experience managing PAS during a pandemic.

WEEKLY SUMMARIES

JULY 19 - JULY 25

Discussed:

- **The Partnership Announcements:**

- » Relationships that will strengthen financial sustainability
- » Preliminary plans to start similar community calls in the Caribbean
- » [NPR Story on Disability & Disasters featuring The Partnership Co-Executive Directors!](#)

- **Federal:**

- » U.S. White House Coronavirus Task force [recommends mask usage](#)
- » COVID-19 Relief Legislative package 4: Community needs to advocate for Home and Community Based Services
- » [The Partnership prepared and sent questions for FEMA ODIC stakeholders call](#)
- » NCD Roundtable Update: NCD will no longer facilitate roundtable conversations with FEMA
- » ODIC will initiate a monthly stakeholder call starting on [7/23/20](#) this call did not allow for an open dialog
- » [Marcie Roth provides testimony](#) at a congressional hearing on the "[Experiences of Vulnerable Populations During Disasters](#)"
- » Implementation of the [DHS Disability Access Directive](#)

- **Concurrent Disasters:**

- » Hurricane Gonzalo in Trinidad and Tobago
- » Hurricane Hannah landfall in Texas

WEEKLY SUMMARIES

JULY 19 - JULY 25

- **States:**

- » Arizona: [Federal complaint filed on crisis standards of care](#)
- » Texas: [Federal complaint filed on health care rationing](#)

- **Contact Tracing:**

- » Is there a national approach?
- » “Disability 101” needed in training and communicating with people who are Deaf and Hard of Hearing

- **Advocacy Item:**

- » In many states, nursing facilities continue to accept patients who are COVID-19 positive
 - ◇ If a person in these facilities are exposed to COVID-19 as a result of these transfers, they, or their family, may file a complaint with their state's Department of Health
 - ◇ The Partnership's [Disaster Hotline](#) can also help [\(+1 \(800\) 626-4959 / info@disasterstrategies.org\)](#)

WEEKLY SUMMARIES

JULY 26 - JULY 31

Discussed:

- **The Partnership Announcements:**

- » Issued: [The Partnership Statement on the HEALS Act](#) and [Statement: 30th Anniversary of the ADA During a Pandemic](#)
- » Forthcoming: The Partnership's Daily COVID-19 Disability Rights Calls Report: February 28 - July 31

- **Concurrent Disasters:**

- » Tropical Storm Isaias impacting [U.S. Virgin Islands, Puerto Rico, and the island of Hispaniola causing power outages and taking at least two \(2\) lives](#); heading towards The Bahamas and the U.S. east coast
 - ◇ Florida having issues with COVID-19 and sheltering, and [closing test sites](#) in preparation to Isaias
 - ◇ Hurricane Douglas emergency in Hawai'i
 - ◇ FEMA procedural barriers to coordinating relief during concurrent disaster

- **Federal:**

- » Public Charge:
 - ◇ [The U.S. District Court for the Southern District of New York issued a temporary injunction against the rule due to COVID-19](#)
 - ◇ Partially stayed by the Second Circuit Court of Appeals, meaning that the rule is currently in effect nationwide, except in the states of New York, Connecticut, and Vermont
 - ◆ [Updated information on the Public Charge Rule](#)

WEEKLY SUMMARIES

JULY 26 - JULY 31

- **[HEALS Act](#)**: Senate COVID-19 relief legislation package 4 acquires name, “HEALS Act”
 - » Does not include funds for HCBS
 - » Imposes liability shields for employers, hospitals, schools, and congregate facilities from legal action for COVID-19 related matters during the Public Health Emergency Declaration or until 2024
 - » Potentially rolls back civil rights
 - » [CPR: Action Alert](#)
 - » Advocacy focus: Many legal protections and civil rights obligations people with disabilities have long fought for are in jeopardy, if the HEALS Act passes, as it is drafted at this point
 - » [CPR: Bill Summary and Disability Priorities](#)
 - » [CPR: Comparison of HEROES vs HEALS](#)
- **National:**
 - » [OCR Complaint filed by national organizations on Behalf of the Family of Michael Hickson](#)
 - » Major retailers are emphasizing and enforcing mask usage including [American Airlines and Southwest Airlines](#), which will not allow anyone without a mask on planes, including as an accommodation for a disability
- **Reopening:** A few weeks left for schools and universities to reopen
 - » Local: A school in Missoula, MT is providing technology for students for hybrid classes
 - » CDC: [Guidance on Reopening Schools](#)

WEEKLY SUMMARIES

JULY 26 - JULY 31

- **In four (4) months, fourteen (14) complaints were filed with the Health and Human Services Office of Civil Rights:**
 - » [Washington](#) (3/23/20), [Alabama](#) (3/24/20), [Kansas](#) (3/27/20),
 - » [Tennessee](#) (3/27/20), [Pennsylvania](#) (4/3/20), [Utah](#) (4/6/20),
 - » [New York](#) (4/7/20), [Oklahoma](#) (4/21/20), [Connecticut](#) (5/4/20),
 - » [North Carolina](#) (5/5/20), [Oregon](#) (5/8/20), [Nebraska](#) (6/17/20),
 - » [Arizona](#) (7/17/20), [Texas](#) (7/22/20)
 - » At the time of printing, there are only four (4) resolutions:
 - ◇ [Alabama](#) (4/8/20), [Pennsylvania](#) (4/16/20),
 - ◇ [Tennessee](#) (6/26/20), [Connecticut](#) (6/9/20)
 - ◇ HHS OCR took the longest to resolve Tennessee's complaint, taking a total of 104 days to resolve
 - ◇ Comparatively, Pennsylvania's resolution took the shortest amount of time to resolve, taking only 13 days
 - » 10 cases still remain unresolved
- **Telehealth:** Concerns regarding availability and comfort with technology
 - » Need to assert for inclusion in telehealth initiatives
 - » Expecting CILs will connect individuals with technology, but not given full resources or supports
- **Guest Speaker:** Senior disability policy advisor: Liability shields in the HEALS Act
 - » HEALS Act's intent: Waives employment and civil rights laws enabling disability and age discrimination
 - » HCBS not included and civil rights are at risk
 - » Unified community advocacy needed now more than ever

WEEKLY SUMMARIES

JULY 26 - JULY 31

- **Personal Accounts of COVID-19:**

- » One (1) of the participants on the calls shared their experience with having COVID-19
- » Other participants shared they knew, on average, 10 people who had COVID-19 or died from it

- [HHS Healthy People 2030: Need to ensure includes people with disabilities](#)

- **Advocacy:**

- » Is there a dedicated platform that supports organizing efforts for various disability rights and other civil rights advocacy opportunities?
- » [NCIL 2020 Annual Conference on Independent Living](#): Highlighted successes, lessons learned, and how conducting virtual conferences are becoming part of long-term practices which allow for inclusive and increased participation
- » The Partnership Co-Executive Directors received the NCIL Region III Advocacy Award

NEXT STEPS

At the time of publishing, August 20, the United States has had 5.5 Million confirmed COVID-19 cases and 172,958+ deaths.

Approximately, 70,900 COVID-19 deaths will be associated with nursing facilities. There are many more unknown deaths from other congregate facilities, which are not required to report COVID-19 data.

It is critical for the disability community to continue organizing, anticipating, and strategically responding to rising COVID-19 issues impacting people with disabilities and older adults.

Our COVID-19 and Disability Rights Calls continue each and every day.

Disability advocates and our supporters seek to find solutions for impacted people with disabilities, older adults, and people with access and functional needs that fall through the gaps of disaster planning, policies, and programs.

The Partnership and our network continue to organize to include the rights and needs of people with disabilities and older adults in COVID-19 and disaster legislation and policies. (Please see our [legislation priorities](#).)

“Our resiliency relies on our community and amplifying a strong and unified message!”

~ Shaylin Sluzalis

NEXT STEPS

We invite you to join our daily COVID-19 Disability Rights Calls.

We thank you for your support and efforts to educate, advocate, and make a difference for people with disabilities and older adults in your community before, during, and after the ongoing COVID-19 outbreak and all public health emergencies and disasters.

Disabled lives truly depend on collaborative advocacy.

To join:

S, M, T, W, F, S: 6pm ET / 10pm UTC
TH: 7pm ET / 11pm UTC

Zoom Meeting

<https://zoom.us/j/2114337114>

Password: 336330

or Meeting ID: 211 433 7114

Or +1 301 715 8592 US

Meeting ID: 211 433 7114

To join our distribution list, please email:

Directors@disasterstrategies.org

We appreciate our partners and supporters who have been involved and joined us in the fight for the rights and needs of people with disabilities including older adults, and people with access and functional needs throughout all phases of COVID-19 planning and response, and all public health emergencies and disasters.

KEY CONCEPTS & DEFINITIONS

1135 Blanket Waivers: Once the President has declared an emergency, the Secretary of Health and Human Services may “temporarily waive or modify certain Medicare, Medicaid, and Children’s Health Insurance Program (CHIP) requirements.”

Among these waivers is 1135, which includes temporarily revoking the 3-day hospital stay requirement and [Preadmission Screening Process](#) that is designed to comply with the U.S. Supreme Court, “rebalancing services away from institutions and towards supporting people in their homes.” Once 1135 Waivers are allowed, hospitals may bypass the screening process because they claim to need hospital beds. Thus, 1135 Waivers can fast-track people with disabilities into nursing facilities without going through the process. (Read a 1135 Waiver at a Glance, from the Centers for Medicare and Medicaid Services.)

“The Federal Government continues to issue conflicting guidelines about the institutionalization of people with disabilities. For example, the Department of Justice (DOJ) in their [2007 ADA Tool Kit](#) states that “people should receive services in the most integrated setting appropriate to the needs of the person, and only persons who require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital” should be placed in those more restrictive settings. In contrast, [CMS] repeatedly issues waivers to their institutional placement rules during disasters, allowing states to place disaster-impacted people with disabilities in nursing homes and other institutional settings.”

“...The integration mandate in the [U.S. Supreme Court Olmstead](#) decision and federal guidance from DOJ, DHS, and FEMA on serving people with disabilities in the most integrated setting appropriate to the person, including in a disaster.”

KEY CONCEPTS & DEFINITIONS

1135 Blanket Waivers (cont.): (National Council on Disability 2019 Report, [Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters.](#))

- During the current pandemic, where congregate settings are hot zones for COVID-19, 1135 Waivers put people with disabilities into institutions that are gravely dangerous settings.
- Bypassing the Preadmission Screening and Resident Review process contradicts the Olmstead decision.
- This could also potentially introduce COVID-19 into nursing facilities.
- The Center for Public Representation has [more information on the other Waivers](#) that are often invoked.

Access and Function Needs (AFN): People with “access and functional needs” are individuals who face barriers to full inclusion and participation in society before, during, and/or after disasters. These individuals may need assistance due to a disability or condition (temporary or permanent), but may not have any kind of diagnosis or specific evaluation.

Many individuals within a community will have access and functional needs during an emergency, such as a need for assistance to get to a safe place.

AFN can refer to individuals who have:

- Physical, developmental or intellectual disabilities;
- Chronic conditions or injuries; or
- Limited English proficiency.

KEY CONCEPTS & DEFINITIONS

AFN (cont.): AFN can also refer to individuals including:

- Older adults;
- Children;
- People who are low income, homeless and/or transportation disadvantaged (i.e., dependent on public transit); or
- Pregnant women.

Accessibility: Accessibility refers to physical environments and methods of communication (sign language interpreters, material in multiple formats) that comply with federal laws such as the ADA and the Rehabilitation Act mandating access for people with disabilities.

Category B - Emergency Protective Measures: (See FEMA Public Assistance)

Centers for Independent Living (CILs): “Centers for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. CILs are unique in that they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization. Centers for Independent Living Provide:

- Peer Support
- Information and Referral
- Individual and Systems Advocacy
- Independent Living Skills Training
- Transition [School age to employment or university and diversion and relocation from nursing facilities]”

The [definition](#) is from the [National Council on Independent Living](#), where you can find more information. [Find your local CIL at ILRU](#).

KEY CONCEPTS & DEFINITIONS

Civil Rights: “Civil rights are an expansive and significant set of rights that are designed to protect individuals from unfair treatment; they are the rights of individuals to receive equal treatment (and to be free from unfair treatment or [discrimination](#)) in a number of settings — including education, [employment](#), housing, public accommodations, and more — and based on certain legally-protected characteristics.” (This [definition](#) is from FindLaw.com)

In this report: We refer to civil rights that protect people with disabilities under laws including the Rehabilitation Act of 1973 (29 U.S.C. § 701 et seq), the Americans with Disabilities Act (42 U.S.C. § 12101 et seq), and state statutes.

Cohort: One (1) person per room during quarantine and isolation-setting.

Concurrent Disasters: Two (2) or more disasters, including pandemics, that happen at the same time.

Congregate Settings: “A congregate setting is an environment where a number of people reside, meet, or gather in close proximity for either a limited or extended period of time. Examples of congregate settings include [nursing facilities, assistive living facilities, psychiatric institutions,] homeless shelters, group homes, prisons, detention centers, schools, and workplaces.” (This [definition](#) is from the Virginia Department of Health.)

Circle of Supports: A group of people that “forms a community around a specific individual (focus person) with ... disabilities to assist him or her to achieve personal goals.” (This [definition](#) is from the Encyclopedia of Clinical Neuropsychology).

KEY CONCEPTS & DEFINITIONS

Contact Tracing: “Contact tracing involves identifying people who have an infectious disease (cases) and people who they came in contact with (contacts) and working with them to interrupt disease spread. This includes asking people with COVID-19 to isolate and their contacts to quarantine at home voluntarily.” (This definition is from the CDC, [Contact Tracing](#).)

Crisis Counseling: “Short-term interventions that involve assisting disaster survivors in understanding their current situation and reactions, mitigating stress, developing coping strategies, providing emotional support, and encouraging linkages with other individuals and agencies that help survivors in their recovery” (This [definition](#) is from the U.S. Department of Health and Human Services Substance Abuse and Mental Health Administration and FEMA.)

[At the time of publication, Crisis Counseling is the only Individual Assistance that is activated.]

Crisis Standards of Care: (See: Medical Care Rationing and Crisis Standards of Care)

Disabled Persons Organization: “Disabled persons’ organizations or DPOs are representative organizations or groups of persons with disabilities, where persons with disabilities constitute a majority of the overall staff, board, and volunteers in all levels of the organization” (This [definition](#) is from the [Disability Rights Fund](#).)

Direct Service Provicer (DSP): (See: Personal Assistance Service (PAS) and Direct Service Provider (DSP))

KEY CONCEPTS & DEFINITIONS

Diversion: Refers to the process by which people with disabilities, who are at risk of being placed in nursing facilities or other institutions, are provided the advocacy and support that enable them to stay in the community, thus preventing institutionalization. These supports include Home and Community Based Services, Durable Medical Equipment, and access to medication.

Equally Effective Communication: Refers to the obligation under the ADA and the Rehabilitation Act to provide communication that is equally effective for people with communication disabilities. This could include providing sign language interpreters, CART, materials in multiple formats that make communication equally effective.

FEMA Individual Assistance (IA): Some disaster declarations authorize the Individual Assistance when FEMA can provide assistance to individuals and households, including:

- Temporary housing
- Crisis Counseling - survivors, social/emotional connections to community
- Disaster case management - info to access emergency services
- Legal services
- Unemployment assistance

Important information regarding IA:

- The kind of declarations determines which, if any, Individual Assistance services are active.
- During the pandemic, the only authorized Individual Assistance is Crisis Counseling.

FEMA Public Assistance: Public Assistance (PA) is FEMA's largest grant program providing funds to assist communities responding to and recovering from major disasters or emergencies declared by the President.

KEY CONCEPTS & DEFINITIONS

FEMA Public Assistance (cont.): The program provides funding for emergency assistance to save lives and protect property and assists with funding for permanently restoring community infrastructure affected by a federally declared incident. Through the PA Program, FEMA provides supplemental Federal grant assistance for debris removal, emergency protective measures, and the restoration of disaster-damaged, publicly owned facilities and specific facilities of certain private non-profit organizations. ([FEMA Public Assistance Program](#))

FEMA Public Assistance Category B Emergency Protective Measures: The Federal government may provide state, local, tribal and territorial (SLTT) governments reimbursement for a range of services listed under Category B of FEMA's Public Assistance program. (For a list of potentially reimbursable services, including for survivors with disabilities, see pages 120 - 123 of [FEMA's Public Assistance and Policy Guide](#).)

- Centers for Independent Living and other Disabled Persons Organizations do not currently receive any reimbursement for the disaster services they provide.

Home and Community Based Services (HCBS): "HCBS are long-term services and supports (LTSS) funded under Medicaid – the state and federal partnership that covers health care for very low-income people – to support people with disabilities in their home and community rather than in an institutional setting like a nursing home. The vast majority of people prefer HCBS over institutional care which not only allows them to live independently but provides these services in a more cost-effective way." (Definition is from AAPD's [HCBS Medicaid Fact Sheet](#).)

KEY CONCEPTS & DEFINITIONS

HCBS (cont.): HCBS includes a wide scope of services, such as home-delivered meal programs; home health care, durable medical equipment; personal care; caregiver and client training; hospice care, homemaker and chore services. You can find more examples and information from the [Centers for Medicaid and Medicare](#).

Institutional bias: The conscious or unconscious belief that people with disabilities belong, or are better off, in institutions including nursing facilities. Ageism is often, but not always, a factor.

- The Social Security Act of 1935 created the booming business of congregate care facilities with its exclusionary language around eligibility for benefits. The amendments to the bill further relegate people with disabilities to institutions.
- Institutional bias underpins traditional disaster planning, response, and recovery, as demonstrated by 1135 Waivers (see: Blanket Waivers 1135).

Isolation: Separates sick people with a contagious disease from people who are not sick. (This [definition](#) is from the CDC.)

Liability shields: Legislation initiatives at the state and federal levels that would “shield businesses, non-profits, schools, or medical providers from liability for serious harm related to COVID-19, which would threaten the safety of people with disabilities and older adults in congregate settings, make it easier for employers to escape liability for discrimination and safety violations in the workplace, and allow businesses to refuse to accommodate disabled people.” (Definition from the CPR’s [analysis of the Senate HEALS Act](#).)

KEY CONCEPTS & DEFINITIONS

Long-Term Support Services (LTSS): “Long-term services and supports (LTSS) encompasses a variety of health, health-related, and social services that assist individuals with functional limitations due to physical, cognitive, or mental conditions or disabilities. LTSS includes assistance with activities of daily living (ADLs, such as eating, bathing, and dressing) and instrumental activities of daily living (IADLs, such as housekeeping and managing money) over an extended period of time. The goal of LTSS is to facilitate optimal functioning among people with disabilities. While most LTSS is delivered by informal, unpaid caregivers (such as family or friends), this paper focuses on the formal, paid LTSS industry. LTSS are delivered in a variety of settings, some institutional (e.g., intermediate care facilities for people with intellectual and developmental disabilities [IDD] and nursing homes), and some home and community-based (e.g., adult day services, assisted living facilities, and personal care services). The financing and delivery systems have historically favored institutional settings, although government policies and advocacy efforts have facilitated a shift toward greater home and community-based services (HCBS) use.” (Definition from [An Overview Of Long-term Services And Supports And Medicaid: Final Report](#), a 2018 Report by Health and Human Services Office Of The Assistant Secretary For Planning and Evaluation.)

Medical Care Rationing and Crisis Standards of Care: Rationing is the “deliberate and systematic withholding of beneficial goods or services from some elements of the population on the grounds that the society cannot afford to extend them” (Definition from [The National Politics of Oregon's Rationing Plan by Lawrence Brown](#).)

- **Crisis Standards of Care:** In a disaster, a state government may declare that the provision of health care may substantially change. This is called, “Crisis standards of care” and may include problematic guidance regarding the allocation of resources to people with disabilities (medical rationing).

KEY CONCEPTS & DEFINITIONS

Nursing facilities: We use the language of “nursing facilities” rather than “nursing homes” because they are institutional facilities, not homes.

Olmstead Decision (Olmstead v. L.C.): “On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

The Supreme Court explained that its holding ‘reflects two evident judgments.’ First, ‘institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life.’ Second, ‘confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.’” (The [definition](#) is from ADA.gov U.S. Department of Justice Civil Rights Division)

Personal Assistance Service (PAS) and Direct Service Provider (DSP): Individuals who use Personal Assistance Services (PAS) receives “assistance with performing activities with daily living that an individual would typically perform if [they] did not have a disability and that is not otherwise required as a reasonable accommodation, including but not limited to,

KEY CONCEPTS & DEFINITIONS

Personal Assistance Service (PAS) and Direct Service Provider (DSP) (cont.): assistance with removing and putting on clothing, eating, and using the restroom.” (This [definition](#) is from the CDC.)

“Direct Service Providers (DSPs) include personal care attendants, direct support professionals, paraprofessionals, therapists, and others. They provide a wide variety of home and community-based, health-related services that support people with disabilities.” (The [definition](#) is from the CDC.)

Personal Protective Equipment (PPE): “Personal protective equipment (PPE) refers to protective clothing, helmets, gloves, face shields, goggles, facemasks and/or respirators or other equipment designed to protect the wearer from injury or the spread of infection or illness.” (This [definition](#) is from the U.S. Food and Drug Administration.)

Promising Practice: “...an intervention, program, service, or strategy that shows potential (or “promise”) for developing into a best practice. Promising practices are often in the earlier stages of implementation, and as such, do not show the high level of impact, adaptability, and quality of evidence as best practices.” This [definition](#) is from the Public Health Agency of Canada)

Quarantine: Separates and restricts the movement of people who were exposed to a contagious disease to see if they become sick. (This [definition](#) is from the CDC.)

Relocation: In the context of the COVID-19 pandemic, “relocation” refers to the action of temporarily relocating people in nursing facilities and other congregate settings into cohort settings (like a hotel, motel, dormitories) until a permanent and safe transition to the community can occur.

KEY CONCEPTS & DEFINITIONS

Strike Teams: Some state Departments of Public Health developed “Strike Teams” to provide intervention in congregate settings with COVID-19 outbreaks. For example, this is from [Maryland's Strike Team FAQ](#):

“To provide immediate intervention in nursing homes and other congregate living facilities where COVID-19 is confirmed to be present,... ‘strike team’ operations [can be implemented] to assist with assessment, testing and clinical care for individuals in nursing homes, including:

- Assessment teams to quickly evaluate each situation on-site, to determine equipment and supply needs;
- Testing teams to identify those in close contact with a confirmed case and collect and send out specimens to produce the fastest results available;
- Clinical teams to provide on-site medical triage and to stabilize residents.”

Transition: Transition is a long-term process, often taking months or even years, to assist people out of institutions to live in the community. The goal is to develop sustainable supports that can ensure a person can “get out and stay out” of an institution.

ACRONYMS

ABLE: Achieving a Better Life Experience Act of 2014

ACL: Administration of Community Living

ACLU: American Civil Liberties Union

ACS: American Community Survey

ADA: Americans with Disabilities Act 1990, as Amended with ADA Amendments of 2008

ADLs: Activities of Daily Living

APRIL: Association of Programs for Rural Independent Living

ASL: American Sign Language

ASAN: Autistic Self Advocacy Network

BIAA: Brain Injury Association of America

CAP: Center for American Progress

CARES Act: Coronavirus Aid, Relief, and Economic Security Act of 2020

CART: Communication Access Real-time Translation

CCD: Consortium for Citizens with Disabilities

CCSQ: Center for Clinical Standards and Quality | CMS

CDC: Centers for Disease Control and Prevention

CIL: Center for Independent Living

ACRONYMS

CMS: Centers for Medicare and Medicaid Services

CPR: Center for Public Representation

CRCL: (DHS) Office of Civil Rights and Civil Liberties

DHS: Department of Homeland Security

DME: Durable Medical Equipment

DOJ: Department of Defense

DPO: Disabled Persons' Organization

DREDF: Disability Rights Education & Defense Fund

DRMA: Disaster Relief Medicaid Act

DSP: Direct Service Provider

EVV: Electronic Visit Verification

FEMA: Federal Emergency Management Agency

GAO: Government Accountability Office

HCBS: Home and Community Based Services

HEALS Act: Health, Economic Assistance, Liability Protections, and Schools Act

HEROES Act: Health and an Economic Recovery Omnibus Emergency Solutions Act

ACRONYMS

HHS: Department of Health and Human Services CF: Communication First

HIPAA: Health Insurance Portability and Accountability Act of 1996 (Pub. L. 104-191)

IA: (FEMA) Individual Assistance

IADLs: Instrumental Activities of Daily Living

ICF: Intermediate Care Facility

IDD: Intellectual and Developmental Disabilities

IHSS: In-Home Services and Supports

ILRU: Independent Living Research Utilization

LTSS: Long-Term Services and Supports

MCO: Managed Care Organization

MFP: Money Follows the Person program

NACCHO: National Association of County and City Health Officials

NCD: National Council on Disability

NCIL: National Council on Independent Living

NDRN: National Disability Rights Network

NDY: Not Dead Yet

ACRONYMS

OCR: (HHS) Office of Civil Rights

ODIC: (FEMA) Office of Disability Integration and Coordination

IRS: Internal Revenue Service

PA: (FEMA) Public Assistance

P&As: Protection and Advocacy Systems

PAS: Personal Assistance Services worker

PASRR: Preadmission Screening and Resident Review

PPE: Personal Protective Equipment

REAAID Act: Real Emergency Access for Aging and Disability Inclusion in Disasters Act

RDIS: (FEMA) Regional Disability Integration Specialist

SEIU: Service Employees International Union

SSDI: Social Security Disability Insurance

SSI: Supplemental Security Income

UTC: Coordinated Universal Time

VRS: Video Relay Service

WID: World Institute on Disability