



Center for Public Representation

Combatting Discrimination in Access to Medical Care During COVID-19

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JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ individuals, and people with limited English proficiency.

Housekeeping

- All on mute. Use Questions function for substantive questions and for technical concerns.
- Problems with getting on to the webinar? Send an e-mail to trainings@justiceinaging.org.
- Find materials for this training and past trainings by searching the [Resource Library](https://justiceinaging.org/resource-library), justiceinaging.org/resource-library. A recording will be posted to [Justice in Aging's Vimeo page](https://Justice%20in%20Aging's%20Vimeo%20page) at the conclusion of the presentation, vimeo.com/justiceinaging.

To achieve Justice in Aging, we must:

- Acknowledge systemic racism and discrimination
- Address the enduring negative effects of racism and differential treatment
- Promote access and equity in economic security, health care, and the courts for our nation's low-income older adults
- Recruit, support, and retain a diverse staff and board, including race, ethnicity, gender, gender identity and presentation, sexual orientation, disability, age, economic class

Backdrop for Crisis Standards of Care: Discrimination in Healthcare

- People with disabilities have long faced discrimination in healthcare access, including:
 - Forced sterilization
 - Denial of organ transplants
 - Medical “futility” laws and steering towards DNRs
 - Inaccessibility of medical equipment
 - Doctors who assume people with disabilities cannot make or even be involved in their own healthcare decisions
 - Quality Adjusted Life Years (QALYs)



OCR Complaints

- National and state advocates have joined together to file more than a dozen OCR complaints since March about:
 - Discriminatory crisis standards of care
 - Initial focus on disability discrimination
 - Later OCR complaints broadened to include age and race discrimination
 - Structural health inequities
 - Impact on persons based upon incarceration, immigration status, poverty, and ability to pay
 - Hospital visitor policies
 - Discriminatory access to COVID-19 testing



OCR Crisis Standards of Care Resolutions (1 of 3)

- Early case resolutions by OCR:
 - Alabama (Apr. 2020): rescinded policy w/ categorical exclusions for people with intellectual or cognitive disabilities & people above a certain age
 - Advocates are continuing to work with the state on developing new CSCs
 - Pennsylvania (Apr. 2020): made changes to policy that had quality of life judgments & deprioritized people with certain disabilities
 - **Good changes:** removes all categorical exclusions; eliminates 10 year long-term survivability; requires individualized assessments; no reallocation of personal ventilators; triage officers receive training on implicit bias and cultural competency
 - **Problematic provisions remain:** considers short term survival up to 5 years; allows “cycle of life” (age) tie breakers



OCR Crisis Standards of Care Resolutions (2 of 3)

- Tennessee (late June 2020): Revised policy that had categorical exclusions and deprioritized people with disabilities (new areas covered by OCR in red)
 - Removes categorical exclusions based on disability
 - Removes consideration of duration of need/resource intensity
 - Removes long term survivability and only considers “imminent” mortality
 - Reasonable modifications required for assessment tools (SOFA) and to visitor policies in hospitals and all long term care facilities when necessary for equal access to treatment
 - Reallocation of vents prohibited



OCR Crisis Standards of Care Resolutions (3 of 3)

- Utah (late June 2020): Revised policy that had categorical exclusions and deprioritized people with disabilities (new areas covered by OCR in red)
 - Prohibits conditioning treatment on, steering towards, or blanket Do Not Resuscitate Orders; must educate about all treatment options
 - Prohibits categorical exclusions based on disability, consideration of duration of need/resource intensity, and reallocation of vents
 - No long term survivability & only considers short-term mortality
 - Reasonable modifications required for assessment tools (SOFA)
 - *Problematic provision: allows age as a tie-breaker*



Hospital Visitation Policies

- Federal disability law requires “reasonable modifications” of no-visitor policies when necessary to **ensure equal access to treatment**
 - May be necessary due to intellectual, cognitive, communication, or behavioral needs
 - Policies can take into account safety needs (such as requiring PPE)
 - Numerous states have issued statewide policies requiring hospitals to make exceptions for people with disabilities
 - Examples include NY, NJ, OR, CA, MA, and AL
 - A few states also apply the policies to long term care facilities (including nursing homes)



OCR Complaint and Resolution re: Hospital Visitor Policies

- OCR complaint filed regarding CT's statewide hospital policy, which limited in person support to people w/ IDD receiving state services
- Highlights of CT OCR Resolution (June 2020):
 - Requires all hospitals to allow designated persons (family members, staff, or others) to support any disabled patient that may need such support
 - Requires hospitals to provide available personal protective equipment (PPE) to support persons to keep them safe
 - Includes procedures for COVID-19 screening of support persons and for supporters to safely take breaks and leave and re-enter the hospital
 - Encourages hospitals to mitigate the risk associated with support persons supporting COVID-19-positive patients



Additional Areas of OCR Engagement

- Inaccessible COVID-19 testing programs
 - OCR complaint vs NE for its failure to make its statewide drive-in testing program accessible to people with disabilities and older adults who do not drive, have access to transportation, or are in congregate care facilities
- Visitor policies in long term care facilities
 - Disability and aging advocates have met with OCR, CMS and CDC re revising HHS guidance documents regarding “essential visitors” in long term care and congregate facilities
- COVID-19 vaccine distribution
 - Disability and aging advocates submitted a letter to OCR re ensuring forthcoming HHS vaccination guidance is fair and non-discriminatory



OCR Case Resolution Process (1 of 3)

- OCR has been using its “early case resolution” process for the COVID-19 complaints
 - OCR (relatively) quickly engages with the state
 - OCR provides technical assistance and compliance advice
 - No formal investigation or issuance of finding of a legal violation
 - Case is resolved with the revision of the state or provider policy; no formal settlement agreement



OCR Case Resolution Process (2 of 3)

- Positives
 - OCR resolution not only impacts state policy but has ripple effects nationally
 - Stakeholders can use OCR resolutions in advocacy in their states
 - Builds “precedent” for legal principles to be used in other OCR complaints or OCR future guidance (i.e., organ transplantation, medical futility, QALYs)
 - States may respond to OCR even if not respond to stakeholder advocacy
 - Relatively quick process



OCR Case Resolution Process (3 of 3)

- Limitations
 - Resolution depends on willingness of the state
 - Complainants are not directly a part of negotiations → OCR may agree to provisions that the complainants do not like
 - OCR's focus is on legal violations; stakeholder advocacy can be much broader
 - A few important issues are only addressed in negotiated/stakeholder engaged CSC (e.g. California)



State-Based Advocacy: California

- Coalition building with state advocates including Protection and Advocacy groups (P&As), disability rights, aging advocates, and health advocacy groups is crucial.
- Justice in Aging, Disability Rights California, Disability Rights Education and Defense Fund (DREDF) and others collaborated with California's Department of Health and Human Services.
 - Drafted demand letter to CA-DHHS with suggested revisions to CSC.
 - Subsequently engaged with state officials and healthcare providers to create favorable CSC.
 - [See Justice in Aging Press Release](#)

Tips for Drafting Demand Letter

- First, develop a strategy with coalition partners (including Justice in Aging and CPR).
 - Consider drafting OCR complaint too – look for complainants!
- Acknowledge unique challenges of COVID-19 and efforts made to respond to the crisis.
- Frequently cite to OCR resolutions.
- Suggest telephonic meeting to discuss problems in CSC and or red-lined edits with recommendations.

Implementing CSC

- Training
 - Healthcare providers, disability rights advocates, aging advocates
 - “Know Your Rights” fact sheet
- Monitoring
 - Establish system to monitor compliance with CSC and report issues
 - California: Improved CSC is not binding on providers; work with local advocacy and provider groups to track provider issues

Benefits and Challenges to State-Based Advocacy

- Benefits
 - Can add expanded protections and provisions
 - Amicable process
 - Opportunities for future collaboration
- Challenges
 - Poor engagement from providers/officials
 - Reluctance to release CSC or adopt statewide standard
 - Not binding/mandatory
 - Challenges to litigation

Resources

- HHS OCR Bulletins:
<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf> and
<https://www.hhs.gov/sites/default/files/title-vi-bulletin.pdf>
- CPR Medical Rationing Page:
<https://www.centerforpublicrep.org/covid-19-medical-rationing>
 - Includes links to tools for stakeholders to assist with evaluating CSCs and hospital visitor policies, all complaints and resolutions, and other background documents



Additional Resources

- [Justice in Aging care rationing](#)
- [Find local Protection and Advocacy \(P&A\)](#)

Questions?

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