Combatting Discrimination in Access to Medical Care During COVID-19

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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, justiceinaging.org/resource-library. A recording will be posted to Justice in Aging's Vimeo page 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)
Discrimination in Healthcare

- Older people face ageism and bias in the healthcare system, including:
  - Stereotypes about cognitive abilities
  - Dismissing treatable medical issues as “old age”
  - Problems with access and accessibility
- Structural racism and inequities in the healthcare system combine to particularly impact disabled and older adults of color
Federal Anti-Discrimination Laws (1 of 3)

• Disability:
  • Title II of the Americans with Disabilities Act
    • Prohibits disability discrimination by public entities, including states and public hospitals
  • Title III of the ADA
    • Prohibits disability discrimination by places of public accommodations, including private healthcare facilities
  • Section 504 of the Rehabilitation Act
    • Prohibits disability discrimination by recipients of federal funding (most hospitals receive Medicaid, Medicare, etc.)
Federal Laws (2 of 3)

• Age:
  • Age Discrimination Act: Prohibits discrimination on the basis of age by recipients of federal assistance (covers most healthcare providers)
  • Many older adults also qualify as people with disabilities and are protected by disability anti-discrimination laws

• Race, color and national origin:
  • Title VI: Prohibits discrimination on the basis of race, color or national origin by recipients of federal assistance (covers most healthcare providers)
Federal Laws (3 of 3)

• Broad anti-discrimination law in healthcare:
  • Section 1557 of the Affordable Care Act: prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in HHS-funded or administered health programs or activities

• All of these laws cover both intentional discrimination and “criteria or methods of administration” that have a disparate impact on protected groups
  • No private right of action for Title VI claims
Federal Guidance

• As COVID-19 pandemic began in mid-March, there was push from the disability community for HHS’ Office of Civil Rights (OCR) to provide guidance to covered entities on their legal requirements around rationing of care
  • Letter from National Council on Disability
  • Letter from Consortium for Citizens with Disabilities
  • Letters from Congress

• By late March, disability advocates had filed four complaints about states’ crisis standards of care showing the need for immediate guidance

• HHS OCR issued a Civil Rights Bulletin on March 28, 2020, focused primarily on disability discrimination
March OCR Bulletin (1/2)

• HHS Office of Civil Rights Bulletin (March 28)
  • Purpose of guidance: “to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscious and religion”
  • Disability discrimination laws “remain in effect” during the crisis
  • It is illegal to deny medical care “on the basis of stereotypes, assessments of quality life, or judgments about a person’s worth based on . . . disability or age
  • Decisions about treatment must be based on individualized assessments based on the best available objective medical evidence
March OCR Bulletin (2/2)

• Legal obligations to make reasonable modifications to ensure equal access to treatment, including:
  • Effective communication for people who are deaf, blind, or have communication or cognitive disabilities
  • Accommodations for people with mobility impairments, use assistive devices, durable medical equipment, etc.
  • Interpreters for people with limited English proficiency
  • Plain language and multiple formats
July OCR Bulletin

• OCR issued a 2nd bulletin re discrimination on the basis of race, color and national origin during COVID-19 under Title VI
  • Highlights the disproportionate impact of COVID-19 on people of color & need for increased data collection and tracking by race and ethnicity

• Recipients of federal funding (e.g., state & local agencies, hospitals, and other healthcare providers) must, among other things:
  • Adopt anti-discrimination policies
  • Ensure accessibility of testing and care sites (including addressing transportation barriers to communities of color)
  • Ensure that people of color are not denied ICU care, rejected from hospital admissions, or subjected to excessive wait times
Discrimination in Crisis Standards
Principles of Crisis Standards of Care

- Framework used by providers when making decision to ration medical care should medical resources (e.g. beds, ventilators, medication) be in short supply.

- Decisions should be based on individualized, clinical assessments, using the best objective medical evidence.
  - No generalized assumptions about a patient's quality of life or relative value to society.
    - See HHS Crisis Standards of Care and Civil Rights Law
    - See Evaluation Framework for Crisis Standards of Care Plans
Common Problems in CSC

• Improper evaluation of SOFA scores
• Use of long-term survivability or life-years saved
• Categorical exclusions
• Consideration of resource intensity
• Re-allocation of personal equipment
• Failure to accommodate disability (including visitation policies)
• Use of age-based tiebreakers*
SOFA Scores

• Sequential Organ Failure Assessment (SOFA) scores are a series of clinical tests used to assess a patient’s prognosis and risk of mortality.
  • SOFA scores measure respiratory, nervous, cardiovascular, liver, coagulation, and kidney levels.
  • These tests can improperly give people with disabilities worse scores, harming their chances to receive scarce resources.
Modified SOFA

• Modified SOFA (MSOFA) scores use a patient’s baseline to accurately determine the patient’s prognosis.
  • Assessment would initially be completed at admission and periodically afterwards.

• Subsequent scores are compared to the initial assessment to ensure the SOFA is not mistaking the patient’s unrelated disability as declining health or at risk of mortality.
Long-Term Survivability

• Several CSCs consider a patient’s long-term survival beyond the acute illness or injury, to “save life years” or maximize “life-years saved.”

• Always disfavors older adults and people with chronic illnesses who are perceived as having fewer life years remaining.
Additional Problems with Long-Term Survivability

• Predicting long-term life expectancy is much less accurate than assessing short-term survivability.

  • Clinical estimated survival rates are significantly more accurate for shorter durations (less than 4 weeks) and vary greatly depending on the underlying conditions.
   
  • See Journal of Pain and Symptom Management, Clinician Accuracy When Estimating Survival Duration

• Long-term survivability effected by comorbidities that disproportionately impact communities of color, exacerbating health inequities.
Disparities in Long-Term Survivability

• People of color suffer higher rates of comorbid conditions that reduce life expectancy.
  • See Brookings Institution, Black and Hispanic Americans at Higher Risk of Hypertension; Diabetes, Obesity

• These disparities are due to socioeconomic obstacles, including access to healthcare and systemic racism. Limiting access to scarce resources due to the presence of these comorbidities perpetuates the cycle of health inequality.
“Fair-Innings” Theory

• Crisis standards may base decisions on the “fair innings” or “life-cycle” principles

• Fair-innings decisions can be arbitrary, invites value judgments and bias in medical decision-making, and is not based on individualized clinical assessments.
  
  • See AGS Position Statement
Categorical Exclusions

• Categorical exclusions prevent people from receiving treatment based only on a particular diagnosis.
  • E.g. people with “severe dementia,” or “requiring assistance with activities of daily living”

• Also excludes older adults belonging in blunt age categories.
  • E.g. patients age 80+ receive palliative care.
Resource Intensity and Blanket Do Not Resuscitate (DNR)

- CSC often emphasize the need to “preserve” resources, leading to discrimination.
  - Often give lower priority to patients viewed as being resource intensive.

- Some patients are also steered towards DNRs, or DNRs are required prior to receiving services.
Age-Based Tiebreakers

• In the event two or more patients have similar clinical outcomes, CSC may include tiebreaker provisions.
  • Should not be based on age, disability, race, or other impermissible factor.

• OCR has not definitively issued a statement on age as a tiebreaker.

• Age-based tiebreakers are based on generalized assumptions, not individualized clinical assessments.
  • Alternative is lottery, not first-come, first-serve.
What to Include in CSC?

- Anti-discrimination provision
- Training
- Reasonable accommodations
- Appeal rights (including automatic reversals)
- Availability of standards (accommodations for disability and Limited English Proficiency)
- No reallocation of personal equipment
- Non-discriminatory tiebreaker provisions (e.g. lottery)
- Decisions based on individualized clinical assessments using best available medical evidence
Advocacy
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

• 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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