



COVID-19: Know Your Rights and Prepare

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About the Presenter

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*Nurses' attitudes and emotions toward caring
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Disclaimer

- The information presented in this webinar is for educational purposes only and should not be interpreted as legal or medical counsel.
- All information presented in this webinar is publicly available, and I advise you to refer to the reference sources at the conclusion of this presentation

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Outline

- Getting Equitable Health Care is the Law
- Reasonable Accommodations: What You Need to Know
- Who to Ask and When
- Reasonable Accommodations to Ask For
- Make a Plan for Sickness at Home
- Don't Neglect Mental Well-Being
- Resources To Help You

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Equitable Health Care is the Law

Section 504 of the Rehabilitation Act of 1973

Titles II and III of the Americans with Disabilities Act of 1990

Section 1557 of the Affordable Care Act

Together, these laws **prohibit discrimination against individuals with disabilities** across a wide variety of contexts, including health care services.

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Equitable Health Care

Case law and regulations

Not only outright discrimination but also, also

- “thoughtlessness”
- “indifference”
- “benign neglect”

See Alexander v. Choate, 469 U.S. 287, 29596 (1985)

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Equitable Health Care

Case law and regulations

Discrimination is providing “an aid, benefit, or service that is **not as effective** in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement” as that provided to people without disabilities

28 C.F.R. 35.130(b)(1)(iii) (2010)

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Equitable Health Care

Case law and regulations

Discrimination is “**eligibility criteria** that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity”

28 C.F.R. 35.130(b)(8).

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No provision in the ADA, Section 504, or Section 1557 of the ACA, nor in any other federal law authorizes the waiver of these requirements during a public health emergency.

-- Disability Rights Education and Defense Fund

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Office of Civil Rights Bulletin

“As such, persons with disabilities should not be denied medical care on the basis of **stereotypes**, assessments of **quality of life**, or judgments about a person’s **relative “worth”** based on the presence or absence of disabilities or age. Decisions...for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

March 28, 2020

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Health Care Rights

- Full and equal access to health care services and facilities
- Reasonable accommodations
 - **Adjustments** to policies, practices, and procedures when necessary to make health care services fully available to individuals with disabilities, unless the modifications would fundamentally alter the nature of the services

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Who to Ask and When

- **Ask** for reasonable accommodations from the very beginning with the registration process and at every opportunity.
- **Any** member of the staff you encounter in a hospital is required to help with a reasonable accommodation, whether they are a doctor, nurse, nursing assistant, secretary, housekeeper, dietary aid, etc.
- Consider this an **ongoing process** and not a one-time request

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Reasonable Accommodations to Ask For

- Allowing a **support person to remain with the individual** and provided with PPE
- Reasonable **modifications of the triage protocol**- ex: how long a person can remain on a ventilator; adaptation of screening tools
- **Ask** to see triage decisions; **appeal** when appropriate

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Reasonable Accommodations to Ask For, 2

- Clear **communication in a way the individual understands**
- **Accommodations for the individual's communication** (ex. Letterboard/iPad charged & within reach at all times)
- Take **extra time to listen to the individual** and what they need
- Provide **information that is accessible** (ex. in an easy-read format)

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Reasonable Accommodations to Ask For, 3

- **Work closely with individual and guardian/advocates** for self-determination and supported decision-making
- Provide a **quiet space** to wait and be examined
- Use of **special equipment** as needed
- Use of **own medication and equipment** as needed, clearly labeled as “personal property of _____; Do NOT reallocate”

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Protecting Your Rights, 1

- Speak up as soon as you can.
- Show them the legal references and give them a copy of the Office of Civil Rights Bulletin from March 28, 2020
- The hospital should have a webpage or information in a patient handbook about disability discrimination. Show them this information.

CommunicationFIRST COVID-19 Toolkit

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Protecting Your Rights, 2

- Contact the hospital's Patient Relations office or Civil Rights Coordinator. File a grievance if needed.
- If necessary, file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically at www.ocrportal.hhs.gov/ocr/portal/lobby.jsf.

CommunicationFIRST COVID-19 Toolkit

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Make a Plan for Sickness at Home

- Contact individual's health care provider for needed prescriptions and recommendations ahead of time
- Talk with back-up caregivers/support persons in the event you become ill
- Identify aid agencies for support, ex: food, mental health counseling, resources

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Preparing for the Hospital

- Prepare a document(s) of essential information. Make multiple copies and laminate or place in sleeve protectors.
 - See Disability COVID-19 Forms by State from Stonybrook University
 - Power of Attorney or guardianship papers
 - CommunicationFIRST printable
 - Letter to provider staff, see #NobodyIsDisposable
 - Copy of legal rights, see
 - Include a humanizing photo of the person enjoying something

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Preparing for the Hospital

- Send any communication tools, instructions, chargers, and batteries all labeled with the individual's name. This includes eyeglasses, hearing aids as well as AAC.
- Consider bringing your own medications and equipment
- Enlist friends, family, and advocates to send cards, pictures, and photos. This human being is valued.
- If you are the contact person, call **every** shift.
- #NobodyIsDisposable suggests writing on the chest with Sharpie

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Don't Neglect Your Mental Well-Being

- This is NOT vacation. Lower your expectations.
- Maintain a routine as much as possible
- Take breaks from reading, watching, or listening to the news
- Stay in touch with others by phone or email
- Share your concerns about how you are feeling. Ask for help.
- Get in some physical activity every day
- Practice gratitude and positive thinking.