Continuing the March for Civil Rights:
Equal Access to Health Care

Jennifer Johnson, EdD, Administration for Community Living
Lisa Iezzoni, MD, MS, Harvard Medical School
Max Barrows, Self-Advocates Becoming Empowered (SABE)
Kara Ayers, PhD, Cincinnati Children's Hospital Medical Center

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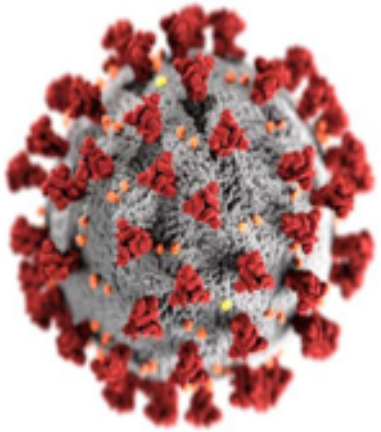
Why Health Equity is Important to Community Living

- Every part of life depends on good health – working playing, learning
- Without access to adequate health care, health is compromised which compromises overall quality of life
- Yet, people with disabilities face multiple barriers to health care:
  - Physical
  - Attitudinal
  - Societal
  - Economic
  - Availability

COVID-19 has Lifted the Veil on these Problems

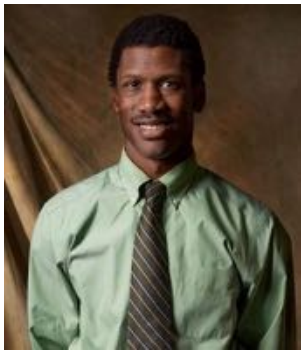
- Isolation
- Lack of clear and understandable information
- Lack of PPE
- Risk of discrimination or medical rationing



Goals of the Presentation

- To provide information about why people with disabilities experience health disparities and how that can impact on the quality community living
- To provide the perspective of individuals with lived experience on the issue of health inequities for people with disabilities and how they are working to address it
- To share how to best provide resources and information to individuals with disabilities so they can make informed decisions
- To share information about ACL funded projects to address health inequities and ACL's policy efforts

Why Do People with Disabilities Experience Health Disparities?



Max Barrows
Self Advocates Becoming Empowered
max@gmsavt.org

System Issues

- A lack of health care providers who have training or experience caring for adults with disabilities
- Many people with disabilities in their 20+s see a pediatrician because of a lack of doctors who treat adults with disabilities

- It is difficult for us to use health promotion and wellness programs because most are not accessible for people with disabilities
- *Alex stutters…and people just answer for him. He just needs time to answer. He needs longer medical appointments.* Medicaid does not reimburse providers for the additional time needed to deliver quality care
- *John is in year 3 of holding his wheelchair together with duct tape*. It is difficult to get private insurance or Medicaid to pay for specialized equipment and long-term therapies

Ableism Undermines Wellness

- Providers often **make assumptions** about our lives, our abilities, our experiences, our dreams. This influences how much and what kinds of information and treatment we get.
- People with disabilities are more committed to health and wellness decisions when we are in the driver's seat.
- "*When we show our emotions or tell people how we feel we often get more meds*." There is a lack of therapists with experience working with people with disabilities
- **Wellness - It is NOT** eliminating sickness or the absence of disability. **It IS** positive health made up of physical health, emotional health, spiritual health, mental health, social health, vocational health.

Access Barriers

- Lack of accessible transportation.
- We often have a hard time understanding information.

- *Kaiya's health issues are complicated. She needs a care coordinator. She gets Medicaid but does qualify for home and community-based services* (HCBS).
- *Marj goes to the veterinarian's office to be weighed because it is the only accessible scale in town*. Many clinics are not accessible and don't have equipment that accommodate wheelchairs or exam tables that lower.
- Low Medicaid or Medicare reimbursements leads to a lack of providers in my town.
- Many people have difficulty navigating the health care system and managing their health insurance.

Overview: Disability Disparities

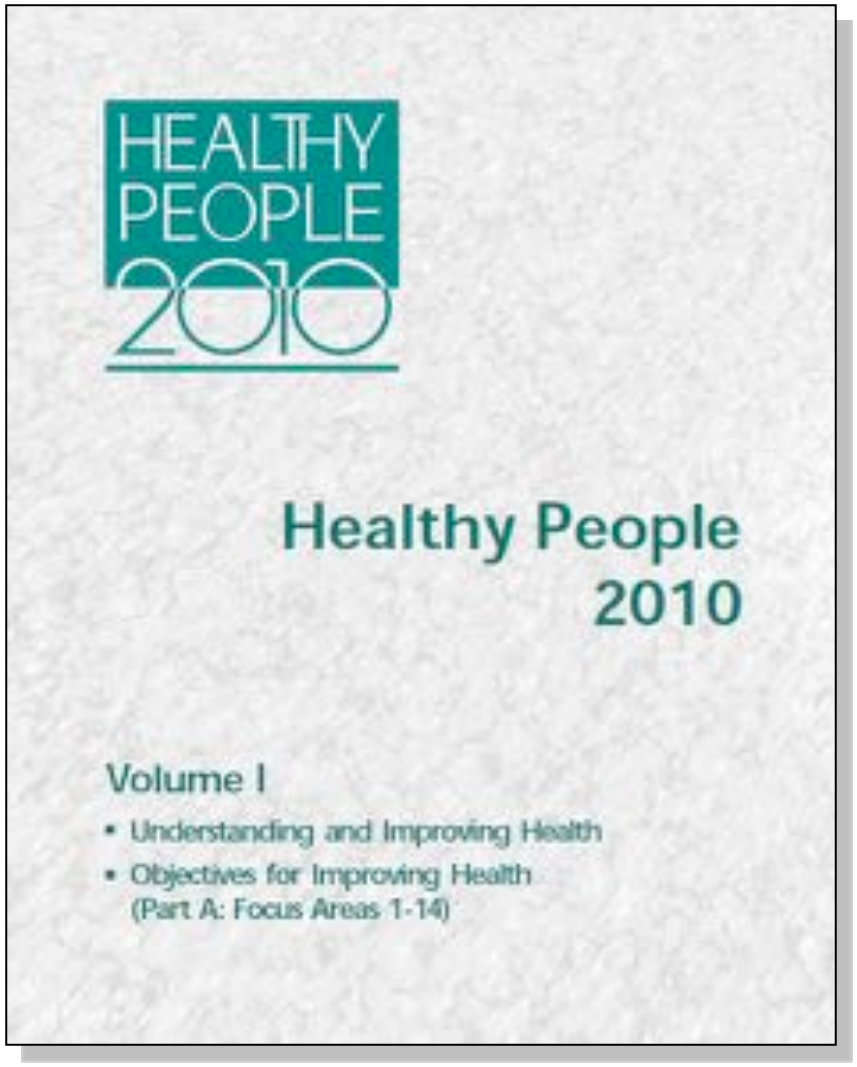
Lisa I. Iezzoni, MD, MSc
Health Policy Research Center, Mongan Institute,
Massachusetts General Hospital
Harvard Medical School
December 9, 2020


61 million persons
and numbers
growing
WASHINGTON
OREGON
CALIFORNIA
NEVADA
IDAHO
MONTANA
WYOMING
UTAH
ARIZONA
NEW MEXICO
COLORADO
NORTH DAKOTA
SOUTH DAKOTA
NEBRASKA
KANSAS
OKLAHOMA
TEXAS
MINNESOTA
IOWA
MISSOURI
ARKANSAS
LOUISIANA
WISCONSIN
ILLINOIS
MICHIGAN
INDIANA
OHIO
KENTUCKY
TENNESSEE
MISSISSIPPI
ALABAMA
GEORGIA
FLORIDA
SOUTH CAROLINA
NORTH CAROLINA
VIRGINIA
WEST VIRGINIA
PENNSYLVANIA
NEW YORK
MAINE
VT
NH
MASS
RI
NEW JERSEY
DELAWARE
MARYLAND
ALASKA
HAWAII

DISABILITY DIVERSITY

Disability type	2000	2011
Movement difficulty	19.2%	23.3%
Sensory difficulty	6.9	7.4
Mental health	1.9	2.7
Cognitive difficulty	1.9	3.3
Social role limitations (self-care, work, other social roles)	11.3	14.1
ANY DISABILITY	22.1%	26.5%

Estimates from National Health Interview Survey: U.S. civilian, noninstitutionalized population ages ≥ 18 years old; self-reported information

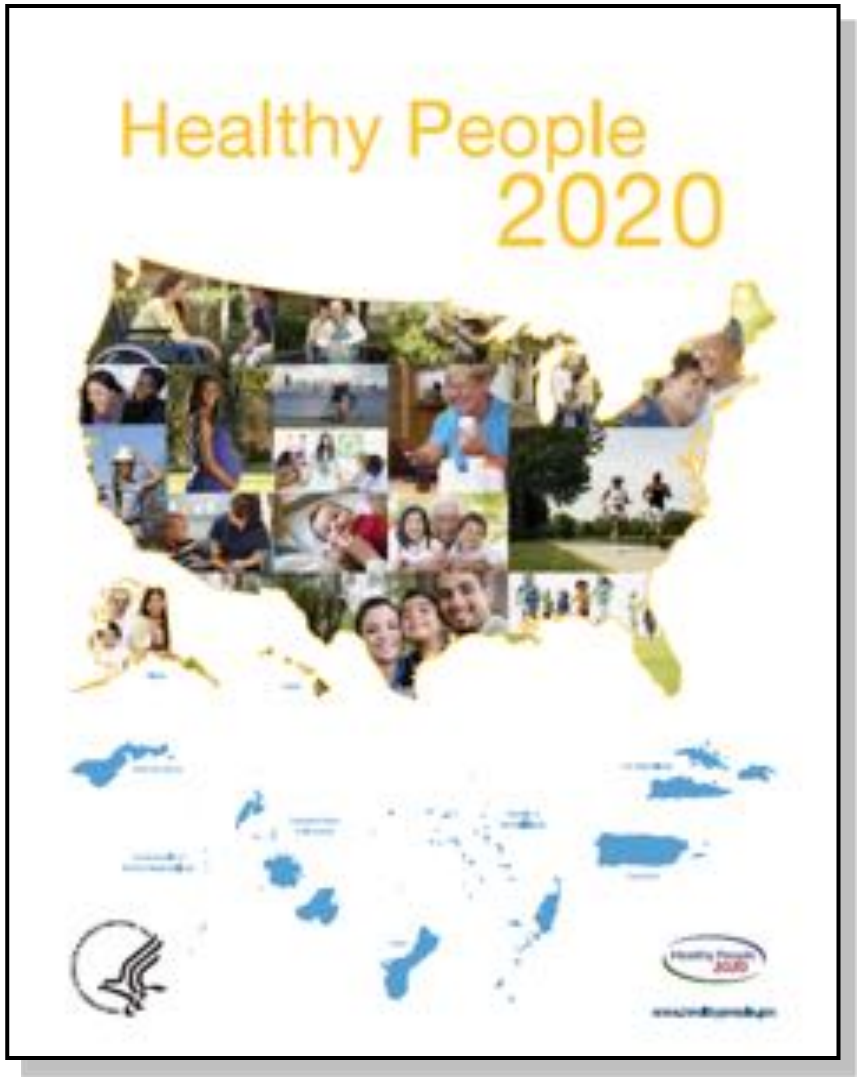

HEALTHY PEOPLE 2010
Healthy People 2010
Volume I
• Understanding and Improving Health
• Objectives for Improving Health
(Part A: Focus Areas 1-14)

Healthy People 2010

- Published in 2000: decennial *Healthy People* initiative of U.S. DHHS
- First time that persons with disabilities listed as group that might experience disparities in care (Chapter 6)
- Attributed disparities partially to erroneous assumptions about daily lives, values, and expectations of persons with disabilities

Common misconceptions about people with disabilities contribute to troubling disparities in the services they receive, especially an "underemphasis on health promotion and disease prevention activities.“

Healthy People 2010


Healthy People
2020

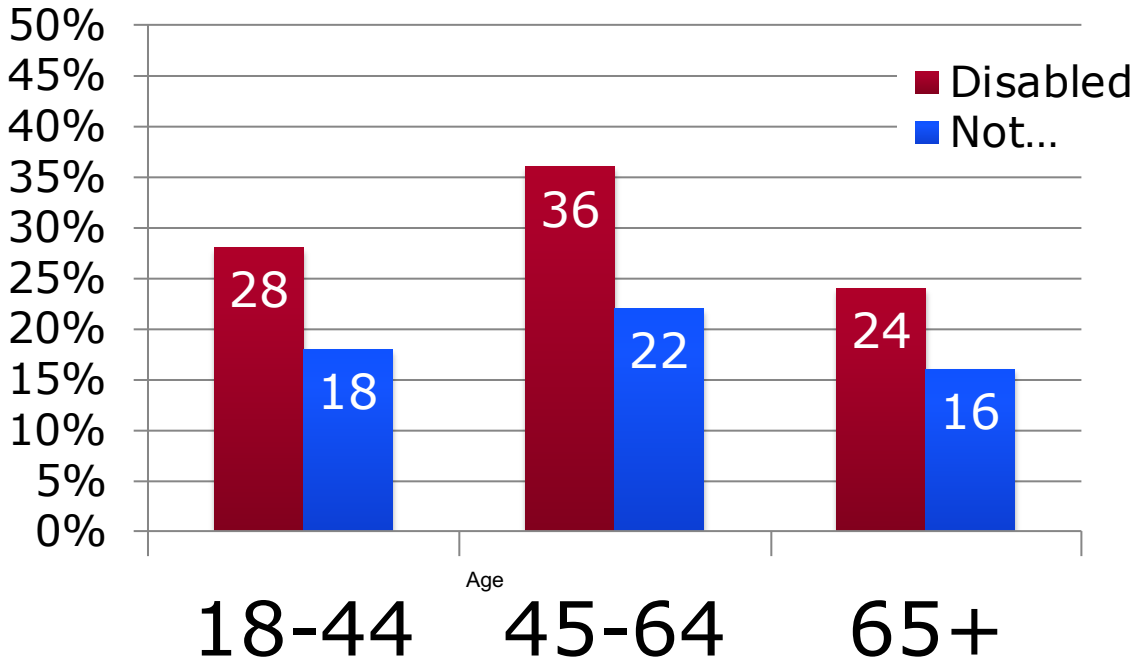
SOCIAL DETERMINANTS OF HEALTH

- Low incomes
- Low education
- High unemployment rates
- Poor housing, inaccessible housing, and/or housing insecurity
- Significant transportation problems
- Food insecurity
- Domestic violence, intimate partners, or caregiver abuse (men and women)

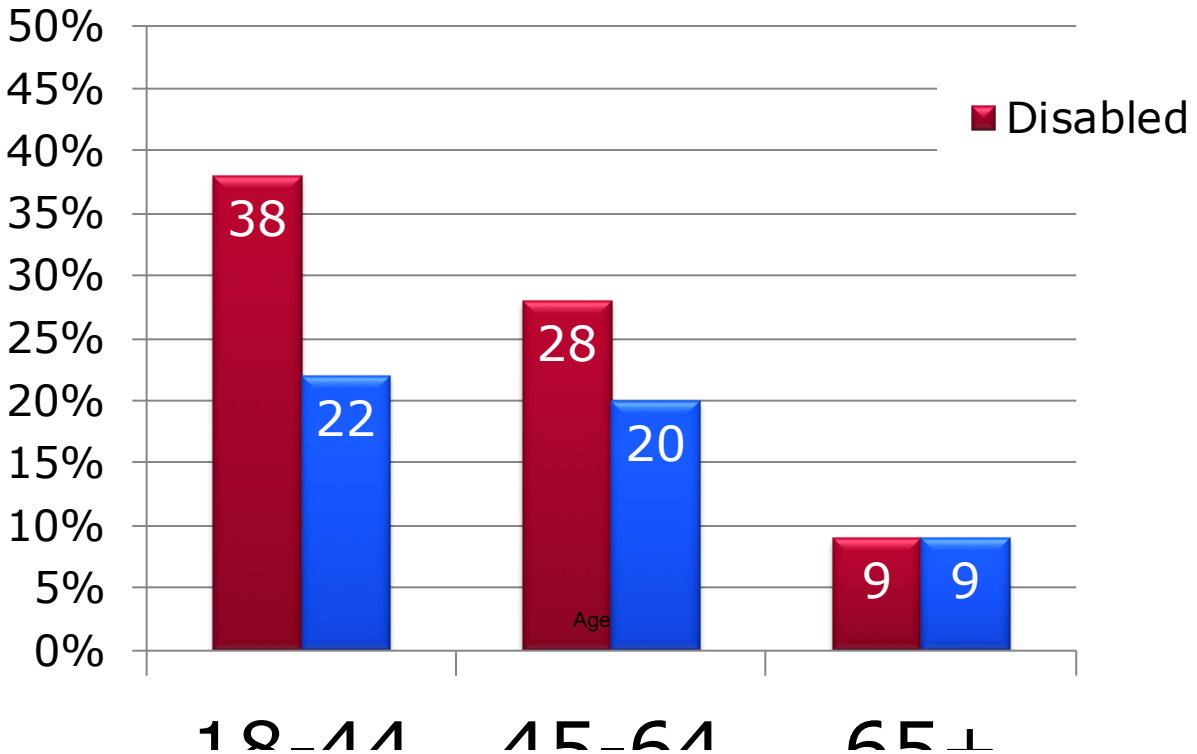
RACE/ETHNICITY INTERSECTIONALITY

- 24% for whites
- 30% for Black Americans
- 31% Hispanics
- 16% for Asians
- 25% for Native Hawaiians or Other Pacific Islanders
- 40% for Native Americans or Alaskan Natives

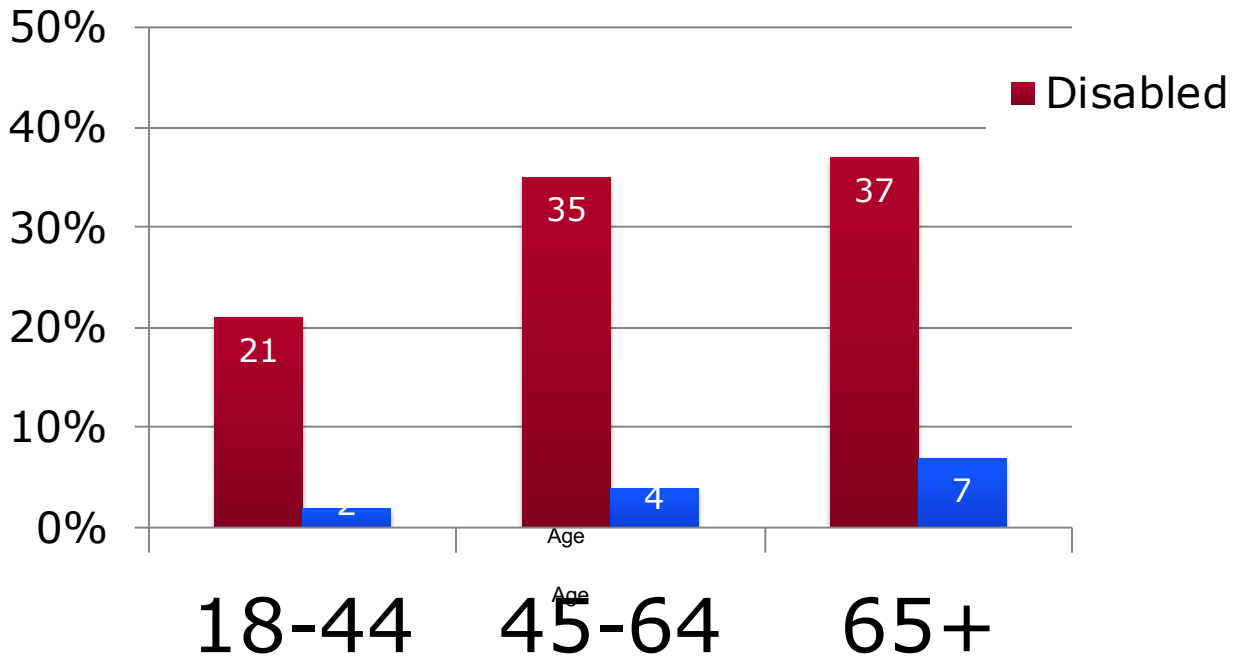
OBESITY BY AGE



TOBACCO SMOKING



FAIR OR POOR HEALTH



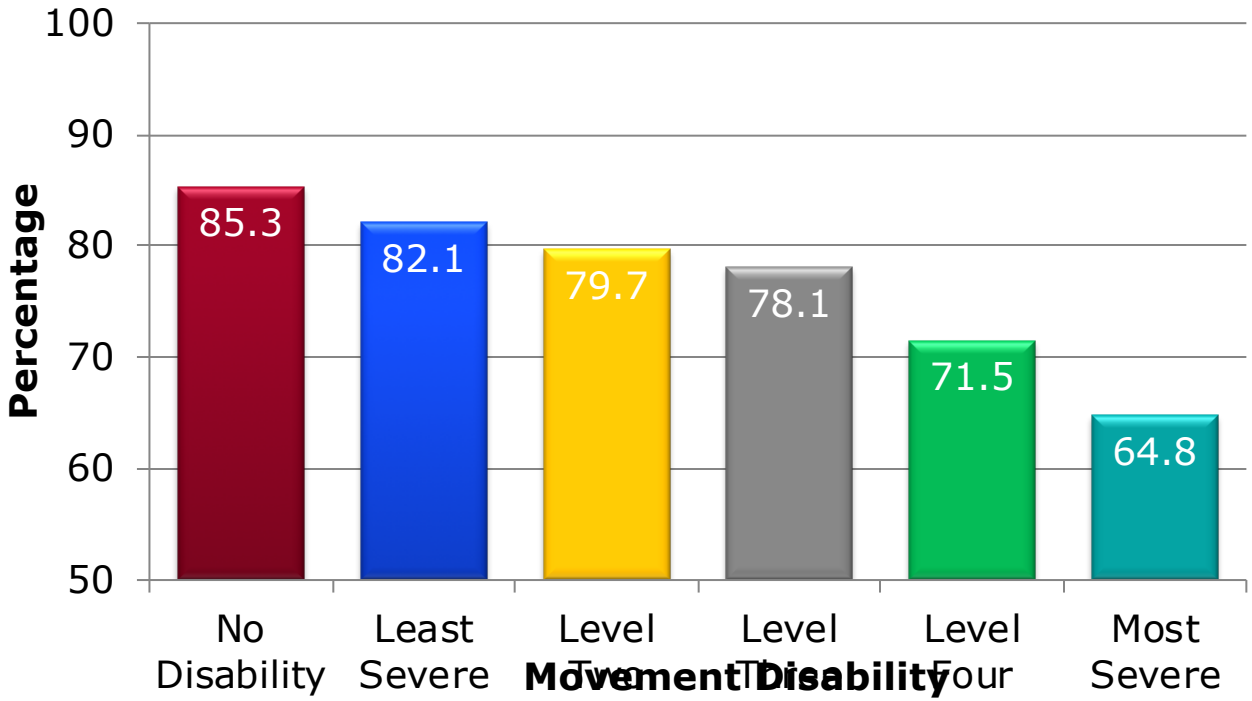
HEALTH CARE DISPARITIES

- Screening and preventive services
- Reproductive health and pregnancy care
- Cancer diagnosis and treatment
- Communication with health care professionals
- Satisfaction with care
- No data on disability routinely available on standard data sets – findings come primarily from state and federal surveys

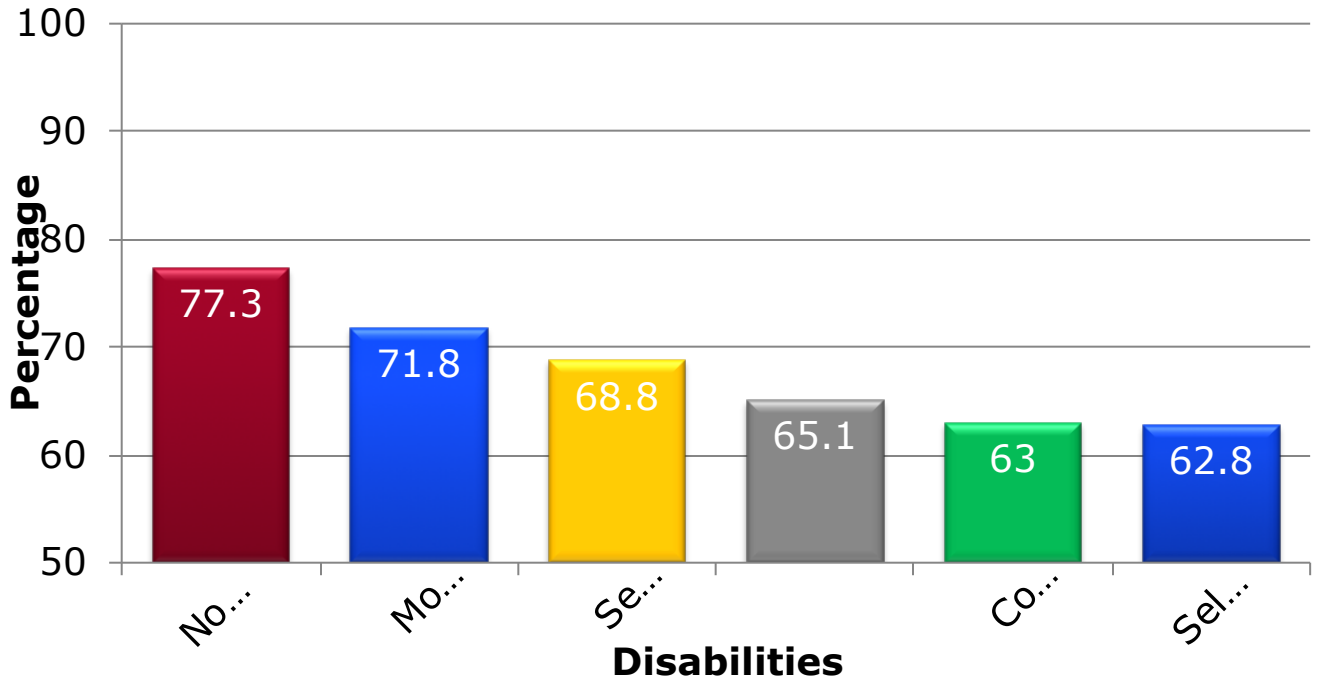
POTENTIAL CAUSES OF DISPARITIES

- Patients' complex underlying health conditions and competing priorities
- Disadvantages in social determinants of health
- Patients' preferences for care
- Inadequate training of health care professionals
- Ineffective communication accommodations
- Inaccessible medical diagnostic equipment, including weight scales and exam tables
- Inadequate knowledge about ADA mandates for equitable care

PAP TEST RATES 2010: MOVEMENT DISABILITY



MAMMOGRAM RATES 2010



National Survey of MDs

SURVEY PARTICIPANTS

- Randomly selected from national records
  - Internal medicine
  - Family practice
  - Rheumatology
  - Neurology
  - Ophthalmology
  - Orthopedics
  - Obstetrics/gynecology
- Sample size = 714 participants; weighted overall response rate = 61.0%

PROVIDING QUALITY CARE, n = 714

Overall how confident are you in your ability to provide the same quality of care to patients with disability as you provide to patients without disability …?

- Very confident = 42%
- Somewhat confident = 48%
- Not very confident = 9%
- Not at all confident = 1%

QUALITY OF CARE, MOBILITY DISABILITY

Thinking about the broader health care system, how would you rate the quality of care of patients with **significant mobility limitations** receive compared with patients without such limitations …?

- A lot better = 3%
- A little better = 6%
- The same = 35%
- A little worse = 46%
- A lot worse = 9%

QUALITY OF CARE, SERIOUS MENTAL ILLNESS

Thinking about the broader health care system, how would you rate the quality of care of patients with **serious mental illness** receive compared with patients without such limitations …?

- A lot better = 2%
- A little better = 5%
- The same = 16%
- A little worse = 41%
- A lot worse = 36%

MEASURING WEIGHT

- 399 of 714 participants said they routinely record weight
- 22.6% (SE = 2.2) reported they "always" or "usually" use an accessible weight scale for patients with significant mobility limitations
- Ask patients with significant mobility disability for their weights
  - 8.1% always ask patients
  - 24.3% usually ask patients
  - 40.0% sometimes ask patients
- Self-reported weights are documented to underestimate weight among people with disability

HEIGHT-ADJUSTABLE EXAM TABLE

- 40.3% (SE = 2.2) always or usually used a height adjustable exam table or lift device when caring for patients with significant mobility disability
- Specialists had much higher adjusted odds of using accessible exam table than primary care physicians: OR = 1.96 (1.29, 1.99, P = 0.001).
- Major reasons for not transferring patients:
  - Lack of lift devices (44.9%) or accessible tables (25.4%)
  - Fear about injuring patient: 25.1%
  - Patient refusals: 13.3%
  - Fears about staff injuries: 10.2%

PERCEIVED QUALITY OF LIFE

In general, compared with persons without disability, do you believe the overall quality of life of persons with significant disability is …?

- A lot better = 2%
- A little better = 2%
- The same = 13%
- A little worse = 44%
- A lot worse = 39%

KNOWLEDGE OF OBLIGATIONS TO PATIENTS UNDER ADA

How much do you know about your legal responsibilities or obligations as a physician under the ADA when caring for patients with disability?

- A lot = 14%
- Some = 50%
- A little = 28%
- Nothing = 8%
- [Major issue with some Crisis Standards Care in early COVID-19 pandemic …]

EVIDENCE GAPS

- Persons with disability routinely excluded from randomized clinical trials conducted to test treatment effectiveness and generate scientific evidence base
  - e.g., little evidence to guide cancer treatment decisions
- Small numbers of cases
- General gaps in scientific evidence
  - Often medicine is not evidence-based
  - Gaps in evidence concerning rehabilitation therapy as practiced in communities, home-based care

FUNDING SOURCES

- National Cancer Institute, "Examining Disparities in Cancer Screening for Persons with Disabilities," R01CA160286-01A1
- *Eunice Kennedy Shriver* National Institute for Child Health and Human Development, "Surveying Physicians to Understand Health Care Disparities Affecting Persons with Disabilities and Identify Approaches to Improve Their Care," Grant No. R01 HD091211-01A1
- *Eunice Kennedy Shriver* National Institute for Child Health and Human Development, "Exploring Timeliness of Cancer Diagnoses in Persons with Significant Physical Disability," Grant No. R21 HD095240-01

Administration for Community Living

Increasing Life Expectancy of Individuals with Disabilities by Improving Health Equity

Improving Health Equity

- **Center for Policy and Evaluation**
  - Accessible Medical Equipment
  - Ensuring non-discrimination, network adequacy & cultural competency
- **Administration on Disabilities**
  - ID/DD Data Initiative
  - Partnering to Transform Health Outcomes with Persons with ID/DD (PATH-PWIDD)
  - Center for Dignity in Health Care for People with Disabilities

CPE: Policy Development

- Promote accessible, culturally competent health care delivery & accessible medical diagnostic equipment (MDE) using fact sheets, public education, partnerships & measure development

- Worked with CMS to Clarify that Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability in transplant policy through Medicare payment rules

- Advocate for Network Adequacy for ID/DD individuals across all payer

CPE: Policy Development

- Partner across HHS to ensure Crisis Standards of Care, vaccine distribution, testing and hospital visitation policies in response to COVID19 do not discriminate on the basis of disability; and

- Support Maintenance of Effort for HCBS within Medicaid, while ensuring CARES funding & PPE reach I/DD individuals residing in the community and the providers that serve them.

AoD: ID/DD Data Initiative

- Collaborating with federal and non-federal partners to:
  - Establish and maintain valid and reliable prevalence rates on individuals with intellectual disabilities and developmental disabilities (ID/DD)
  - Improve data about health status and factors that influence health outcomes of individuals with ID/DD

AoD: Partnering to Transform Health Outcomes with Persons with ID/DD (PATH-PWIDD)

- Building the capacity of the future health care workforce by addressing the lack of content about individuals with ID/DD in current interprofessional health education curriculum.
- Rush intends to impact more than 30 medical education programs and the training of 15,000 students during the five-year project.
- *PATH-PWIDD* program includes active roles for advocates with ID/DD and their families during the entire project period.

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

An ACL-funded effort to address ableism in healthcare and reduce healthcare inequities

Kara Ayers, PhD

Director of the Center for Dignity in Healthcare for People with Disabilities

Associate Director, UC Center for Excellence in Developmental Disabilities (UCCEDD)

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

The Role of Ableism in Healthcare Inequities

- Ableism is a set of beliefs or practices that devalue and discriminate against people with disabilities.

- Ableism is one contributing factor to why people with disabilities have worse health outcomes than people without disabilities.

- Ableism in healthcare is a type of medical discrimination.

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

The Role of Ableism in Healthcare Inequities

Establishment of Center

- a **three-year project** to establish a Center for Dignity in Healthcare for People with Disabilities (CDHPD).

The Center's **goal** is to identify and reduce life-limiting healthcare inequities for **people with intellectual and developmental disabilities** (ID/DD) by improving access to anti-discriminations medical protocols.

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Areas of Focus

Four original areas of focus:

1) Prenatal diagnostic testing
2) Organ transplantation
3) Aging/End-of-Life
4) Mental health/Suicidality

- Now also includes a workgroup related to COVID-19

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Gap Analysis: Process

- 219 unique entries
- Variety of sources analyzed
  - Peer reviewed
  - Laws/policies
  - Gray sources
- Analyzed to reveal gaps in knowledge and suggest potential solutions

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Gap Analysis

- Gaps and solutions considered for:
  - Policy/legislation
  - Healthcare system/services
  - Healthcare professionals
  - Patients
  - Researchers

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Gap Analysis-Major Themes

- Gaps identified include:
  - Biases and assumptions that drive policies
  - Lack of consistency across healthcare systems
  - Little training on collaborative medical decision-making models

- Examples of potential solutions identified:
  - Increasing transparency in healthcare policy-making
  - Including people with developmental disabilities in decision-making
  - Increasing research on bias and stigma

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Ongoing efforts

- Subcommittees dedicated to each focus area
- Center advisory board oversees work
- Resources available
  - Final gap analysis report
  - COVID-19 Fact Sheet for People with Disabilities
  - Safeguarding Against Disability Discrimination

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Next steps

- Subcommittees continue progress on action plans
- Share findings from gap analysis
- Survey ethics committees
- Continue to ~~infiltrate~~ update medical guidelines and best practices to be anti-ableist

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

Future collaborations and complementing efforts

- Partnering to Transform Health Outcomes with Persons with Intellectual Disabilities and Developmental Disabilities (PATH-PIDD)-new ACL complementary grant
- #DocswithDisabilities

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES

- If you'd like to learn more about the Center for Dignity, email us at Centerfordignity@cchmc.org.
- Follow us on Twitter or Like us on Facebook at:

@ThinkEquitable

Self-Advocates Working to Improve Health Equity

Max Barrows
Self Advocates Becoming Empowered
max@gmsavt.org

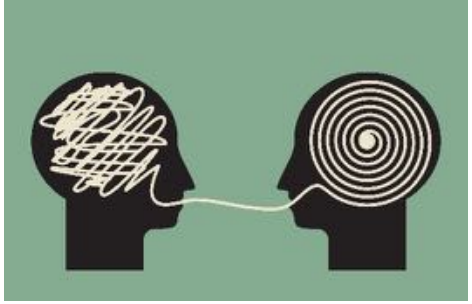
Americans with Disabilities Act (ADA)

- Title 3 of the ADA prohibits discrimination in public places
- We have the right to get accessible services in public places.
- Public places are required to make changes if something isn't accessible to people with disabilities.
- The ADA says people with disabilities have a right to effective communication. This means that whatever is written or spoken must be as understandable to people with disabilities as it is for people who do not have disabilities.
- When we have access to effective communication, we can show what we want and need.
- This is key to supporting a person with a disability in making decisions about their health.

sanys
SELF-ADVOCACY ASSOCIATION OF NEW YORK STATE

NEW YORK STATE OF OPPORTUNITY. Office for People with Developmental Disabilities

- SANYS and OPWDD met weekly to revise a COVID Hospital Visitor Policy allowing children and pregnant women to be accompanied. The Department of Health (DOH) amended the guidance to include people with IDD.
- They also pushed DOH to issue guidance regarding triage and potential rationing of life saving treatment during the pandemic. They advocated for guidance to hospitals:
    - clarifying the civil rights of people with IDD
    - to use health assessments not be weighted by the fact that a person has a disability
    - to use assessments based only on clear, objective medical criteria.



Plain Language Information During COVID-19

- Information about COVID-19 is complicated. We made documents and videos in plain language for people with disabilities. We created plain language glossaries.
- Change is fast and constant. We run 2 national Zoom meetings a week with people with disabilities from 34 states to:
  - Explain unemployment benefits & stimulus checks
  - Teach new social skills and coping skills
  - Recognize and respond to online scams
  - Teach online platforms for telehealth and getting services
  - Share adapted OSHA training for workers to be accessible
  - Model advocating safety concerns when working with support staff and if someone in your household is exposed.
  - And much more…

Many people have said we have become family!

Questions?