# ACL Track: Health Care Accessibility

A new frontier in business acumen

HCBS Conference, Baltimore, Maryland

8/29/2019

#### Session Overview

- Introduction to Accessible Health Care& Business Acumen (Daniel Davis/ Joseph Lugo, ACL)
- Disparities in Healthcare for People with Disabilities (Bonnielyn Swenor, Johns Hopkins University)
- Video: Disability-Friendly Health Care in Colorado (Patricia Yeager, The Independence Center, Colorado Springs)
- Centene Corporation and National Council on Independent Living (NCIL) Address Gaps in Disability Access (Karen Kimball/ Kelly Buckland)

#### **Session Goals**

- Increase understanding of health care disparities impacting people with disabilities;
- Highlight vital developments in health care accessibility policy for people with disabilities;
- Detail groundbreaking initiatives to enhance health care provider accessibility and cultural competency, involving community-based organizations (CBOs) serving people with disabilities
- Consider linkages between health care accessibility work and initiatives to build business acumen among CBOs serving people with disabilities

# Introduction to Accessible Health Care for People with Disabilities

Daniel Davis, Health Policy Analyst
Administration for Community Living
Center for Policy and Evaluation,
Office of Policy Analysis and Development

E-mail: <u>Daniel.Davis@acl.hhs.gov</u>

### Inequitable Access to Care for People with Disabilities

- Despite passage of the Rehabilitation Act of 1973 and the Americans with Disabilities Act in 1990, as well as subsequent statutes and regulations, and ongoing enforcement initiatives, many health care settings and services are still not fully accessible to individuals with disabilities.
- Only a small share of providers have medical accessible medical diagnostic equipment:
  - 2010 study of primary care offices in California found only 3.6% had an accessible weight scale, and only 8.4% had height-adjustable tables. The 2017 follow-up study showed only a modest increase to 10.9% with an accessible weight scale and 19.1% with height adjustable tables.
  - A 2014 study of 256 specialty providers asked if they would accept a referral of an obese female patient who used a wheelchair and required transfer assistance:
    - 22% of specialty provider offices could not accommodate her. Of these, 18% also could not help the her transfer onto an exam table, preventing access to an appropriate physical exam;
    - The subspecialty of gynecology had the highest rate of practices inaccessible to people with disabilities (44%).

# What is Accessible Medical Diagnostic Equipment?

- What is Accessible Medical Diagnostic Equipment? Medical Diagnostic Equipment includes tables, chairs and diagnostic imaging equipment used for medical diagnosis and treatment purposes, as well as weight scales.
  - Accessible Medical Diagnostic Equipment means Medical Diagnostic Equipment designed pursuant to the US Access Board's voluntary standards to accommodate the needs of people with disabilities and older adults with mobility limitations. Note that barrier-free access to the medical offices/ facilities in which this equipment is utilized is necessary for Medical Diagnostic Equipment to be truly accessible.
- US Access Board, Standards for Accessible Medical Diagnostic Equipment, 36 CFR Part 1195 <a href="https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards">https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards</a>

# What is Accessible Medical Diagnostic Equipment?

- What is Accessible Medical Diagnostic Equipment? Medical Diagnostic Equipment includes tables, chairs and diagnostic imaging equipment used for medical diagnosis and treatment purposes, as well as weight scales.
  - Accessible Medical Diagnostic Equipment means Medical Diagnostic Equipment designed pursuant to the US Access Board's voluntary standards to accommodate the needs of people with disabilities and older adults with mobility limitations. Note that barrier-free access to the medical offices/ facilities in which this equipment is utilized is necessary for Medical Diagnostic Equipment to be truly accessible.
- US Access Board, Standards for Accessible Medical Diagnostic Equipment, 36 CFR Part 1195 <a href="https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards">https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards</a>

### Highlights of the Accessible MDE Standards

- Set pursuant to Section 510 of Rehabilitation Act by Access Board in consultation with Food and Drug Administration
- Published in Federal Register at 36 CFR Part 1195 (1/9/17)
- Functions as voluntary industry standards unless adopted by federal agencies, or state and local jurisdictions
- To date, no Federal rulemaking to include scoping or binding standards under the ADA. We understand Massachusetts has incorporated it into its MassHealth standards.
- Compromise around low transfer height for MDE. Range of 17 to 19 inches with 5 year sunset. Research will be conducted in the interim to determine appropriate permanent standard.
- See <a href="https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards">https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/final-standards</a> and full text of the standard.

### Benefits of Accessible Medical Diagnostic Equipment

In January 2017, the U.S. Access Board finalized <u>voluntary standards</u> <u>for Accessible Medical Diagnostic Equipment</u>. These standards promise considerable benefits for providers and patients alike, including:

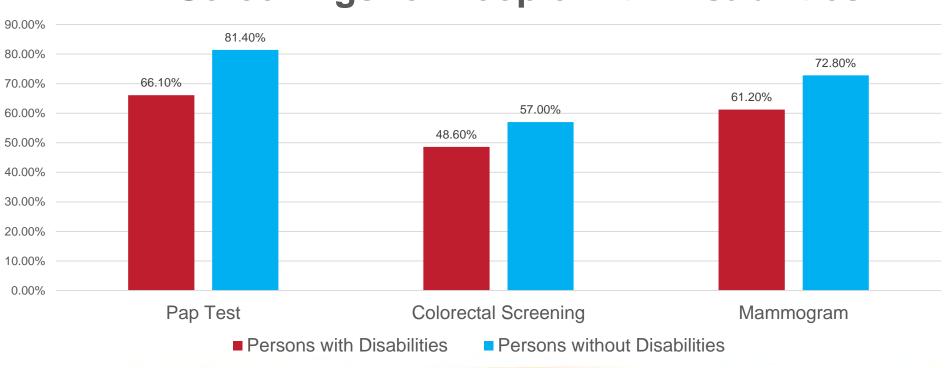
- Reducing disparities in access to preventive health care for people with disabilities and older adults who have limited mobility compared to people without disabilities;
- Providing opportunities to dramatically reduce workplace injuries, liability, and attrition by curtailing the need for nurses and nursing assistants to physically transfer patients to and from inaccessible examination equipment with a cost-effective alternative;
- Addressing the needs of the 13% and growing share of the US population with mobility disabilities.

- Individuals with disabilities are more likely to:
- Experience worse health outcomes
- Experience difficulties or delays in receiving necessary health care
- Have limited knowledge and access to sexual health information
- Have high blood pressure
- Have problems getting appointment with doctor's office as soon as needed
- Have problems with accessibility of doctor's office or clinic

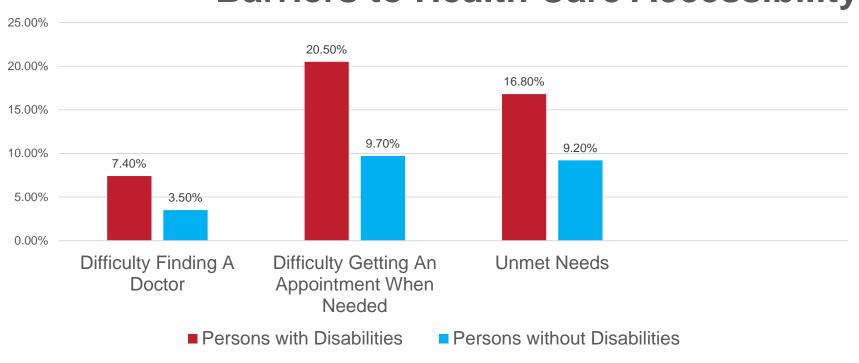
Individuals with disabilities are **less likely** to receive:

- Comprehensive preventive care, including health screening tests, weight measurement, physical exams
- Recommended care
- Routine dental cleaning
- X-rays

#### Disparities in Preventative Health Screenings for People with Disabilities



#### **Barriers to Health Care Accessibility**



- Further research shows individuals with a disability who encounter structural barriers are 2.5 times more likely to experience delayed or not to receive necessary medical care than people without a disability.
- The growing body of research identifying disability-specific barriers as contributing to a pattern of barriers to access to care has contributed to an emerging consensus, still largely not reflected in public policy, that disability is, in fact, a health disparity population.
  - ➤ **Key Study**: Gloria L. Krahn, Deborah Klein Walker, Rosaly Correa-De-Araujo, "Persons With Disabilities as an Unrecognized Health Disparity Population", *American Journal of Public Health* 105, no. S2 (April 1, 2015): pp. S198-S206.
- Better preventive care through increased use of accessible MDE results in earlier detection of life-threatening conditions, better prognoses, quality of life and health outcomes. These improvements, in turn, make health-care more cost-effective.

#### **ACL's Business Acumen Work**

Presentation by Joseph Lugo, Administration for Community Living Email Joseph.Lugo@acl.hhs.gov



1/2020 2

# BLOCKBUSTER

BIFLIN

#### Strengthening the Aging and Disability Network "Business Acumen"

2003: Chronic Disease Self-Managemen t Program

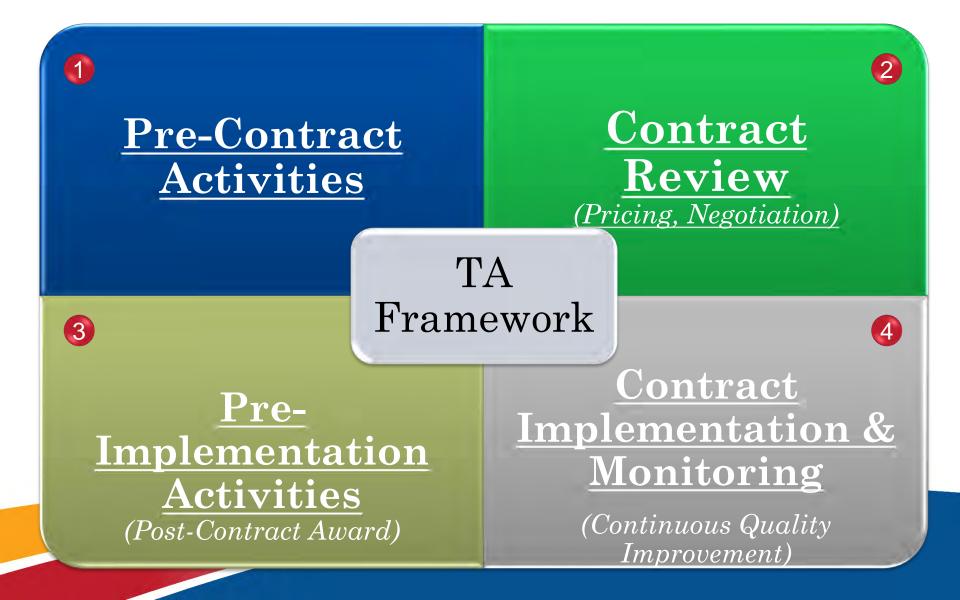
2008: National Diabetes Self-Management Training Program 2008: Veteran Directed Care Program 2012: Grants to build the business capacity of aging and disability organizations for MLTSS

2013-2016:
Business
Acumen
Learning
Collaboratives

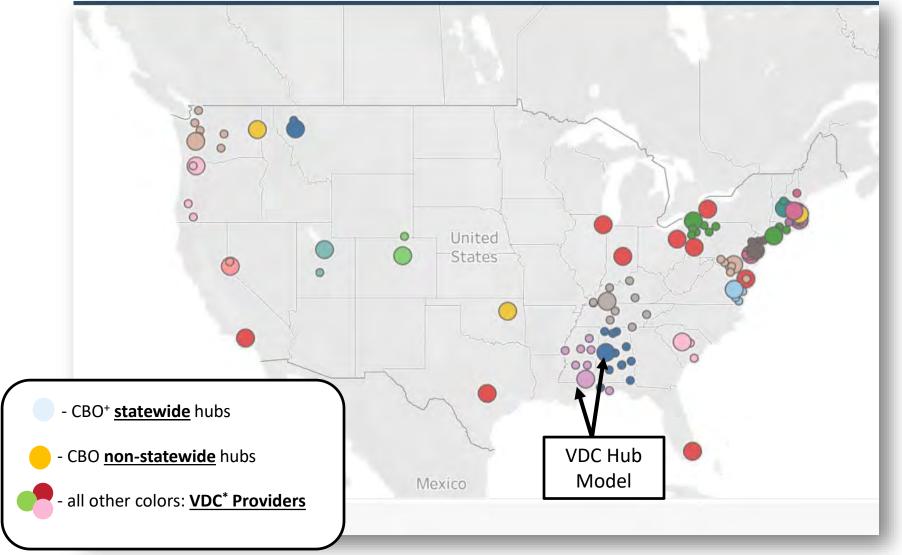
2016 – Present: 2 Business Acumen Learning Collaborative grants

2003 - Present: Engagement with public and private partners

#### **ACL Business Acumen**



#### National Network Development



<sup>\*</sup> CBO = Community Based Organization
\* VDC = Veteran Directed Care Program

#### Maturity Model – Mapping Strengths

- 5 in CT
- 5 core services for persons with disabilities:
  - Information & referral
  - Independent Living Skills Training
  - Peer Counseling
  - Individual & Systems Advocacy
  - Facilitate transitions out of institutions or youth to secondary education

#### CENTERS FOR INDEPENDENT LIVING MAKE COMMUNITY LIVING POSSIBLE







# Using Margin to Drive Mission

# Disparities in Healthcare for People with Disabilities

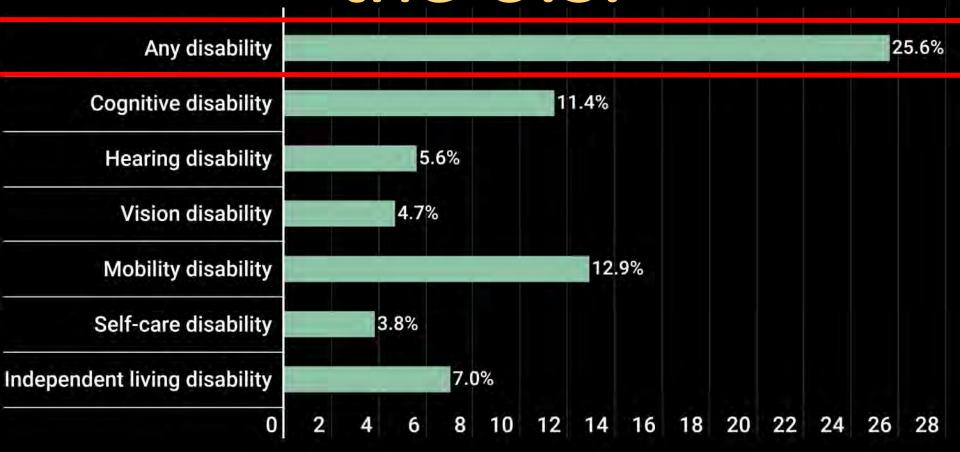
#### Bonnielin Swenor, PhD, MPH

**Associate Professor** 

The Wilmer Eye Institute | Johns Hopkins School of Medicine
Department of Epidemiology | Johns Hopkins Bloomberg School of Public Health
Johns Hopkins Center on Aging and Health

@BonnieSwenorPhD

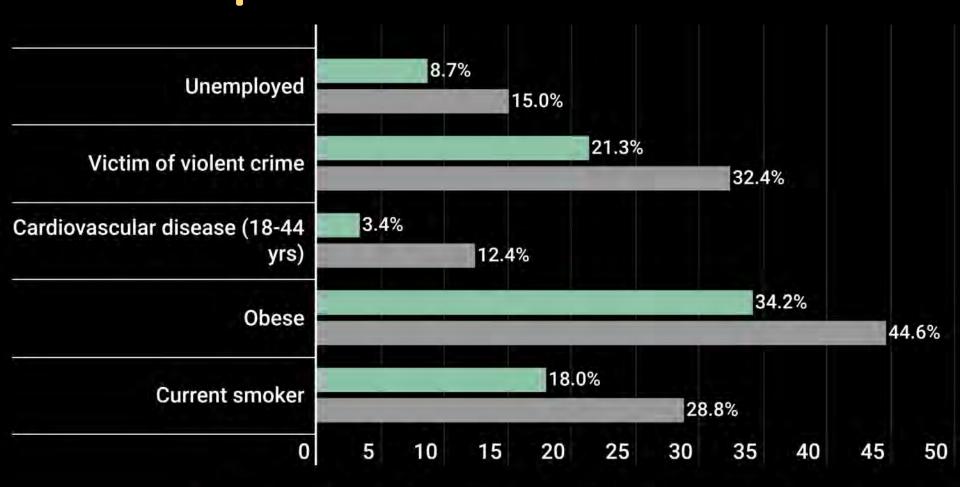
# Disability is common in the U.S.



American Adults 18 yrs or older (BRFSS Data)

CDC. Disability and Health Data System (DHDS) Data [online]. [accessed Aug 25, 2019]. URL: https://dhds.cdc.gov.

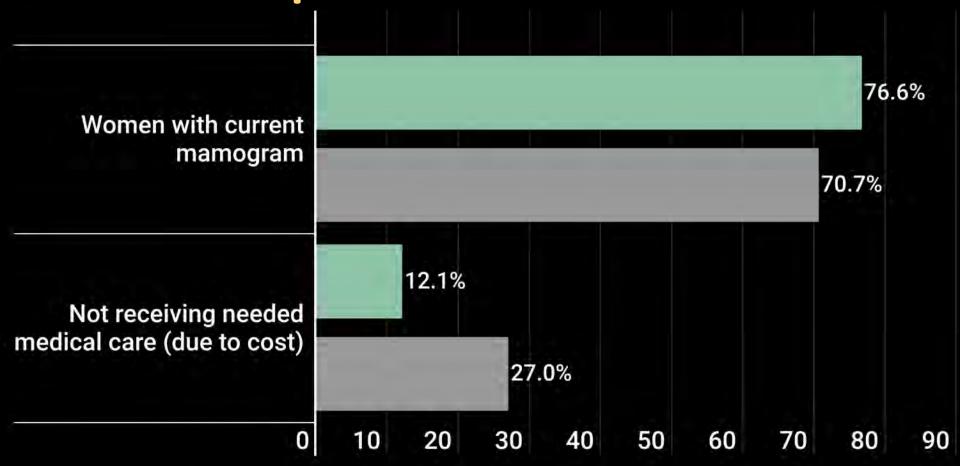
# Health Disparities Exist for People with Disabilities



People without disabilities
People with disabilities

Krahn et al. Persons with disabilities as an unrecognized health disparity population. AJPH. 2015.

# HealthCARE Disparities Exist for People with Disabilities



People without disabilities
 People with disabilities

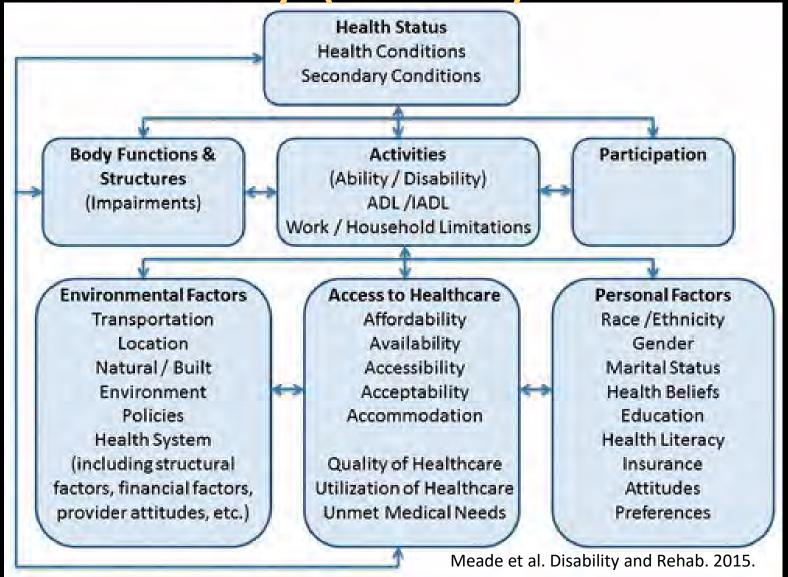
Krahn et al. Persons with disabilities as an unrecognized health disparity population. AJPH. 2015.

# 

#### Racially Social, Economic and Cultural Influences Disparate Clinical Financial Incentives **Decisions** Patient Input Institutional Design Legal Environment (Subject to ambiguity Cultural Influences and misunderstanding) Interpretation Intervention Medical History Patient Preferences Data Subjectivity of Uncertainty with respect to efficacy perception Multiple diagnostic Multiple treatment alternatives alternatives Physical Examination Diagnostic Test Results Stereotyping Prejudice Conscious and Conscious and unconscious unconscious

Meade et al. Disability and Rehab. 2015.

# Model of Healthcare Disparities and Disability (MHDD)



# Model of Healthcare Disparities and Disability (MHDD)

Health Status
Health Conditions
Secondary Conditions

### Access matters!

#### **Environmental Factors**

Transportation
Location
Natural / Built
Environment
Policies
Health System
(including structural factors, financial factors, etc.)

#### Access to Healthcare

Affordability
Availability
Accessibility
Acceptability
Accommodation

Quality of Healthcare Utilization of Healthcare Unmet Medical Needs

#### **Personal Factors**

Race /Ethnicity

Gender

Marital Status

**Health Beliefs** 

Education

Health Literacy

Insurance

Attitudes

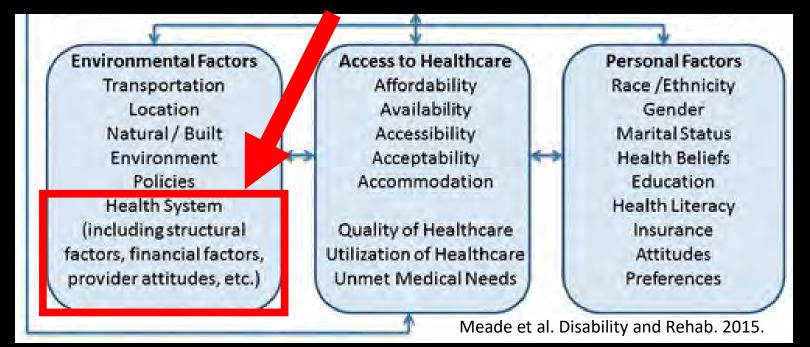
Preferences

Meade et al. Disability and Rehab. 2015.

# Model of Healthcare Disparities and Disability (MHDD)

Health Status
Health Conditions
Secondary Conditions

### So does the system



# 

# Addressing Healthcare Disparities for People with Disabilities

#### Access

- Affordability
- Accessibility
- Acceptability
- Accommodation

#### System-level

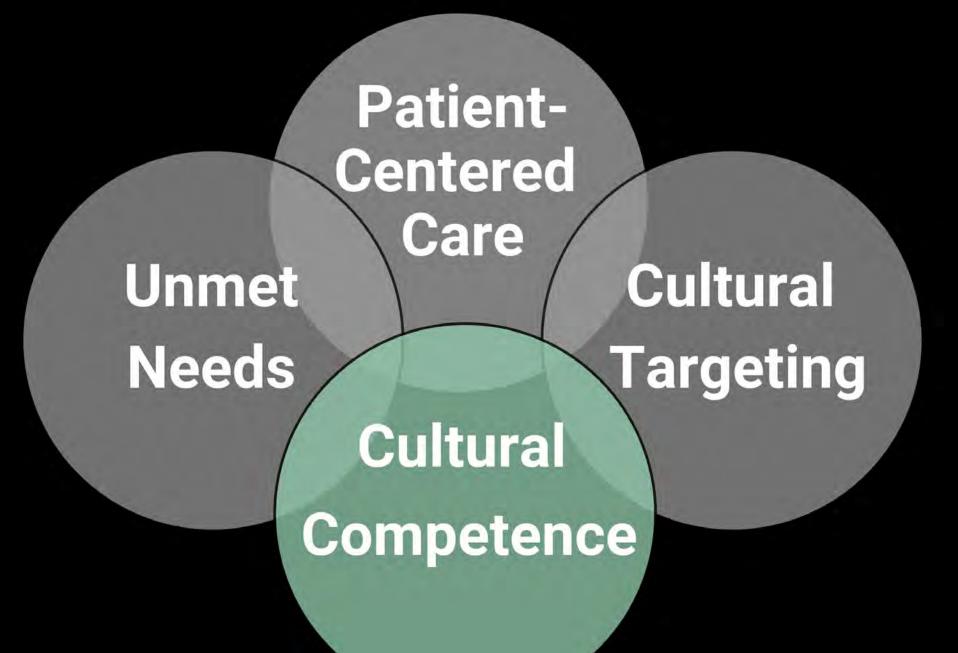
Cultural Competence and Attitudes

# Addressing Healthcare Disparities for People with Disabilities

- Access
  - Affordability
  - Accessibility
  - Acceptability
  - Accommodation
- System-level



Cultural Competence and Attitudes



# Cultural Competence: A Medical Education Requirement

 U.S. Liaison Committee on Medical Education began requiring "cultural competence" in 2000



# Cultural Competence: A Medical Education Requirement

 U.S. Liaison Committee on Medical Education began requiring "cultural competence" in 2000

"Ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients."

## Why disability cultural competence matters

## Disability cultural competence impacts healthcare interactions

## Disability cultural competence impacts healthcare interactions

- Communication
  - Ask about communication preferences
  - Use person-first language, or mirror language patient uses
  - Avoid outdated terms (i.e. "handicapped")

## Disability cultural competence impacts healthcare interactions

#### Communication

- Ask about communication preferences
- Use person-first language, or mirror language patient uses
- Avoid outdated terms (i.e. "handicapped")

#### Knowledge & Attitudes

- Be aware of and avoid common societal stigmatized views of disability
- Be aware of and address challenges to healthcare access and utilization

Original Article

Exploring issues relating to disability cultural competence among practicing physicians

Nicole Agaronnik a, Eric G. Campbell, Ph.D b, Julie Ressalam, MPH, CHES b, Lisa I, Iezzoni, MD, MSc a, c, \*

# Qualitative interviews with 20 physicians to assess disability cultural competence

Agaronnik et al. Disabil Health J. 2019.

Mongan Institute Health Policy Center, Massachusetts General Hospital, United States

b Center for Bioethics and Humanities, University of Colorado School of Medicine, United States

<sup>&</sup>lt;sup>c</sup> Department of Medicine, Harvard Medical School, United States

#### How Physicians Defined Disability

- "... disability is where they are completely dependent on somebody, like a caregiver"
- "... someone who requires extra help or special accommodation"
- "... someone who has either a physical or mental handicap that impairs their ability to do what they want to do ..."
- "someone has pain or has a limited range of motion in their extremities. That's why they cannot work or function as normal."

## Language used to describe disability

- 1. "Normal" and "Abnormal"
- 2. "Handicap"
- 3. "Suffering from"
- 4. "Wheelchair-bound" and other outdated terms
- 5. Language that is not "person-first"

# More work is needed

PatientCentered
Care
Unmet
Needs
Cultural
Competence

### The National Curriculum Initiative in Developmental Medicine (NCIDM)

- Partnership between:
  - American Academy of Developmental Medicine and Dentistry (AADMD)
  - Special Olympics International (SOI)
  - CDC

 Enhance curriculum to addressing gaps in medical education to serve patients with intellectual/developmental disabilities (IDD)

# Personal Perspective



#### Disability Inclusion — Moving Beyond Mission Statements

Bonnielin Swenor, Ph.D., M.P.H., and Lisa M. Meeks, Ph.D.

Dr. L. graduated summa cum laude from an Ivy League medical school, but her dream of becoming a physician-scientist the costs of the software (\$2,000) and of covering her clinical duties overnight. Dr. L. was forced to leave academic medicine in favor

has been given to the challenges faced by faculty members with disabilities.

One problem is the lack of

# We need more doctors and researchers with disabilities

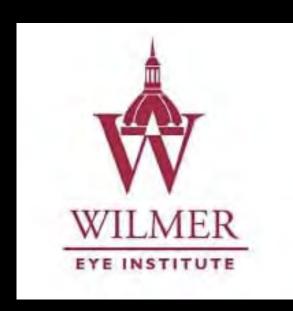
an adjusted work schedule to permit 8 hours of sleep per night, which reduced her migraines and tion of American Medical Colleges (AAMC) report addressed strategies for removing barriers for tion of people with disabilities in science. According to its 2019 renort, 10% of employed scientists d engineers reported having a sability; more than half (55.7%)



The NEW ENGLAND

JOURNAL of MEDICINE

### Thank You







### Disability-Friendly Healthcare in Colorado

Video Presentation by Patricia Yeager, Independence Center, Colorado Springs Colorado





# Centene Corporation and the National Council on Independent Living Address Gaps in Disability Access – An Award Winning Idea

An Overview of the Centene and NCIL Provider Accessibility Initiative (PAI)



### What is the Goal of the Provider Accessibility Initiative?

- Provide equal access to quality health care and services that are physically and programmatically accessible
- for our members with disabilities and their companions with disabilities
- by increasing the percentage of Centene's providers that meet minimum federal and state disability access standards.



### Why are We Focusing on Provider Disability Access?

- It's the right thing to do
- Medicaid and Medicare members with disabilities receive less preventative care than those with no disability
  - https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Brief-Physical-AccessibilityBrief.pdf
- ➢ It's a federal requirement
- People with disabilities say we should
  - Centene National Disability Advisory Council
  - Local Health Plan Member Advisory Councils (CA, FL, KS, MI, OH, PA, and TX)



#### How are We Accomplishing Our Goal?

- 1. Improve the accuracy, completeness, and transparency of provider self-reported disability access data in Provider Directories so that members with disabilities have the most accurate, accessible, and up-to-date information possible related to a provider's disability access by:
  - a. Integrating standard, corporate disability access requirements in provider on-boarding, cultural competency training, credentialing, contracting, etc.; and
  - a. Conducting Accessibility Site Reviews (ASRs) on specialty and ancillary providers with specified volumes of business over 12-month period.



#### How are We Accomplishing Our Goal?

- 2. Allowing providers to apply for a grant from the Centene National Barrier Removal Fund (BRF) that includes:
  - a. Funding to remove disability access barriers; and
  - b. Technical assistance from the National Council on Independent Living (NCIL), local Centers for Independent Living (CILs), and local health plans.



#### **National Barrier Removal Fund**

- Partnership with NCIL
- Funding available in 6 pilot states:
  - Illinois, Texas, and Ohio (2018)
  - Kansas, Florida, and New Mexico (2019)
- In 3 main areas of disability access:
  - Building Modifications
  - Diagnostic Equipment
  - Programmatic Access



**Provider Accessibility Initiative** 

## 2018 & 2019 Outcomes To Date



#### Project Outputs (2018 & 2019)

- ➤ 144 health care providers across IL, TX, OH, KS, FL, and NM received over \$1,000,000 in grants from the Centene Barrier Removal Fund.
- ➤ Grantees range in size, location (urban and rural), and specialty (e.g. primary care, OB/GYN, mental health, addiction recovery, dentistry, podiatry, urology) and include both physical and programmatic access improvements.
- ➤ 123,000 of Centene's members with disabilities (and their companions with disabilities) have improved access to health care, along with the countless other people with disabilities seen by those providers who are not Centene members.



#### Project Outputs (2018 & 2019)

- Over 2,600 onsite Accessibility Site Reviews (ASRs) conducted across 7 states (California, Illinois, Texas, Ohio, Kansas, Florida, and New Mexico) by health plan staff and 31 different ClLs.
- ➤ In 2018 and 2019, NCIL received **255 Barrier Removal Fund (BRF) applications** across 6 states (Illinois, Texas, Ohio, Kansas, Florida, and New Mexico), and **provided over 150 hours of technical assistance** to applicants and grantees.
- ➤ Six locally based Barrier Removal Fund committees that included local members with disabilities, directors from local Centers on Independent Living, and providers, reviewed and scored 176 of the 255 applications.



#### Project Outputs (2018 & 2019)

- 60 Accessible Exam Tables (1 accessible OB/GYN table, 2 accessible podiatry exam chair, 1 accessible dentist chair)
- > 19 Accessible Scales
- > 56 Automatic Door Openers
- > 10 Renovations to Parking Lot
- 15 Restroom Improvements (Faucet paddle handles, ADA toilet, handrails, etc.)
- > 10 Entrance Improvements

- 9 Interior Building Improvements (Vinyl flooring, widening of doorways less than 32' wide, waiting room chairs without side arms, portable air filter, portable blood pressure machine, Hoyer lift)
- > 11 Ramps
- 45 Programmatic Access Improvements (details in later slide)
- > 12 wheelchairs

#### 2018 Outcomes





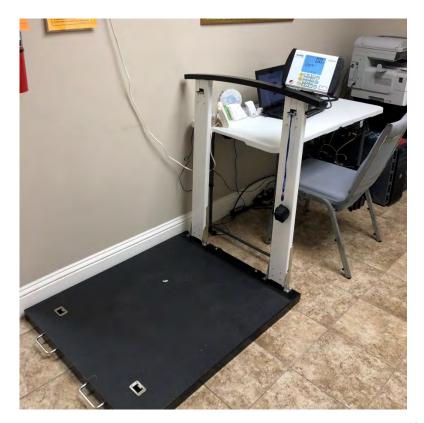
Rock Island County Council on Addictions

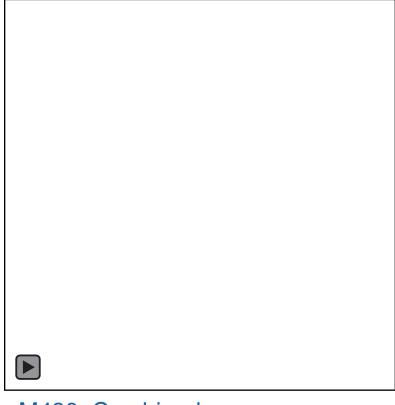






#### 2018 Outcomes





Roll-on scale

The UpScale M430. Combined accessible exam table and scale.

Penne Jaster,
 Nurse Practitioner
 at Life Choices
 Medical Clinic

#### CENTENE® Corporation

#### 2018 & 2019 Outcomes: Programmatic Access

Noise Cancelling Headphones

Digital
Annunciator for
Elevator

Assistive Listening Devices

Braille Signage & Materials

Sound Proofing Walls

TV/DVD Sensory Accommodations

Weighted Stuffed Animals

**Natural Lighting** 

Weighted Blankets

Circadian Lighting Video Remote Interpreting (rural location, 1 ASL interpreter)



#### **National Awards**



2019 CMS Health Equity Award Centene ranked #7





#### **Next Steps**



Implementation in 3 additional states every year for the next 5 years



Track member-level health outcomes

## What's Next in Health Care Accessibility?

- QUALITY MEASURE DEVELOPMENT
- DEMONSTRATING EFFICACY AND VALUE OF ACCESSIBLE MEDICAL DIAGNOSTIC EQUIPMENT
- EXPANDING CLINICIAN TRAINING TO ENHANCE CULTURAL COMPETENCY AND EXPERTISE SERVING PEOPLE WITH DISABILITIES

#### Learn More: ACL

X-Rays Meet the ADA: Making the Case for Accessible Health Care blog and fact sheet available at:

https://acl.gov/news-and-events/acl-blog/x-rays-meet-ada-making-case-accessible-health-care

#### **Learn More: CMS Office of Minority Health**

- Getting the Care You Need: A Guide for Individuals with Disabilities <a href="https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/Getting-the-Care-You-Need.pdf">https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/Getting-the-Care-You-Need.pdf</a>
- Navigating Health Care with a Disability: Our Stories, a Focus on People with Disabilities: <a href="https://youtu.be/VgbPFV0i3vA">https://youtu.be/VgbPFV0i3vA</a>
- Navigating Health Care with a Disability: Our Stories, a Focus on the Provider: <a href="https://youtu.be/\_aydKRTPplg">https://youtu.be/\_aydKRTPplg</a>
- Modernizing Health Care to Improve Physical Accessibility:
   Resources Inventory: <a href="https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/OMH-Modernizing-Health-Care-Physical-Accessibility.pdf">https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/OMH-Modernizing-Health-Care-Physical-Accessibility.pdf</a>

#### **Learn More: Other Federal Agencies**

#### **National Network of ADA Centers**

1-800-949-4232 (free TA on ADA) Website: www.adata.org

Centers for Disease Control - Disability& Access to Health Care

https://www.cdc.gov/features/disabilities-health-care-access/

**US Department of Justice:** for ADA technical assistance see <a href="https://www.ada.gov">www.ada.gov</a> or call ADA Information Line at 800-514-0301 (voice) or 800-514-0383 (TTY)

Independent Living Research Utilization (ILRU)

https://www.ilru.org/topics/health-and-wellness

**National Council on Disability (NCD)** 

https://ncd.gov/policy/healthcare

## Thank you. We will now take questions for panelists.

