New Frontiers in Health Equity for People with Disabilities

HCBS Conference

Wednesday, August 30, 2023

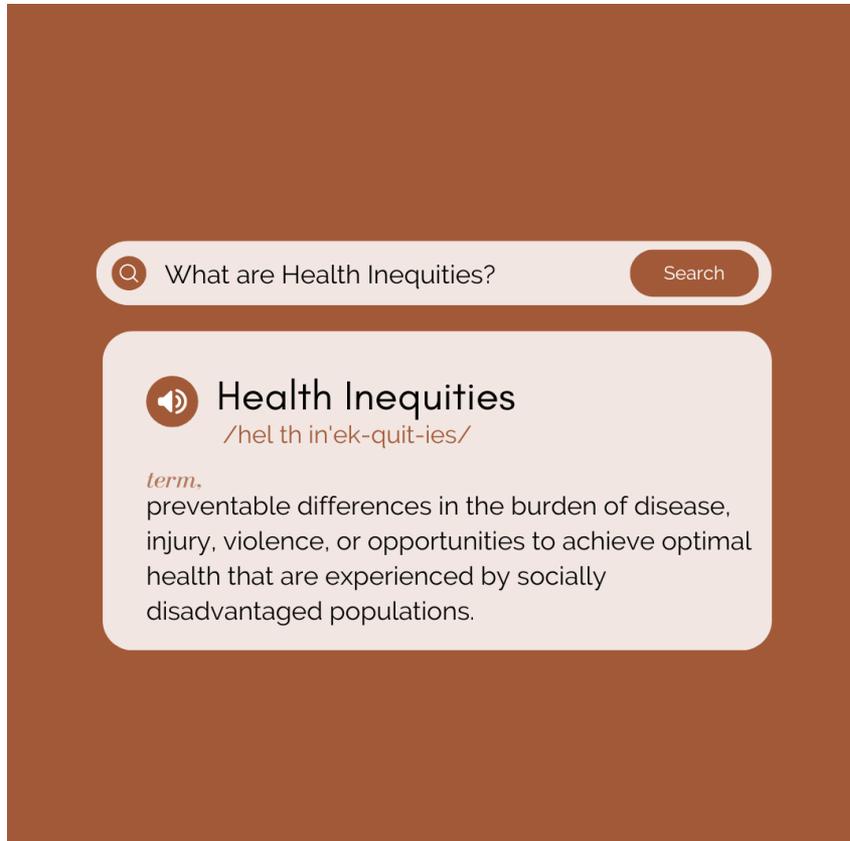*1:15pm-2:15pm*

What is it? Why does it happen?

PEOPLE WITH DISABILITIES AND HEALTH INEQUITIES

What are Health Inequities?

Health Inequities
/hel th in'ek-quit-ies/

term,

preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.

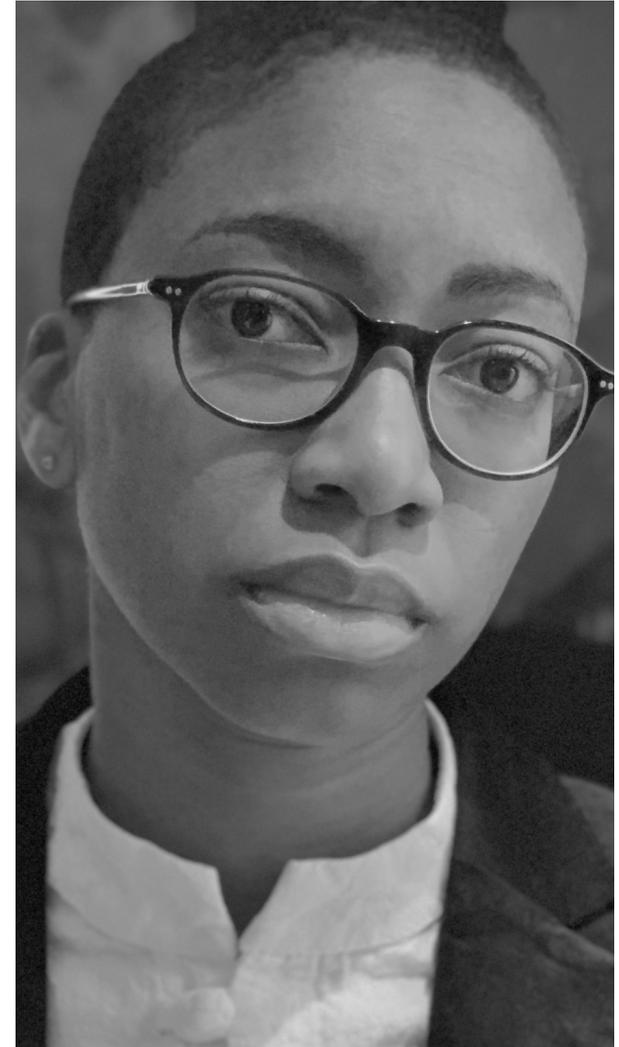"Achieving health equity is the goal, driven by the elimination of health disparities"

Healthy People 2020

THE NATIONAL CENTER FOR
DISABILITY, EQUITY, AND INTERSECTIONALITY

Ableism:
a working definition by TL Lewis

"A system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism, and capitalism.
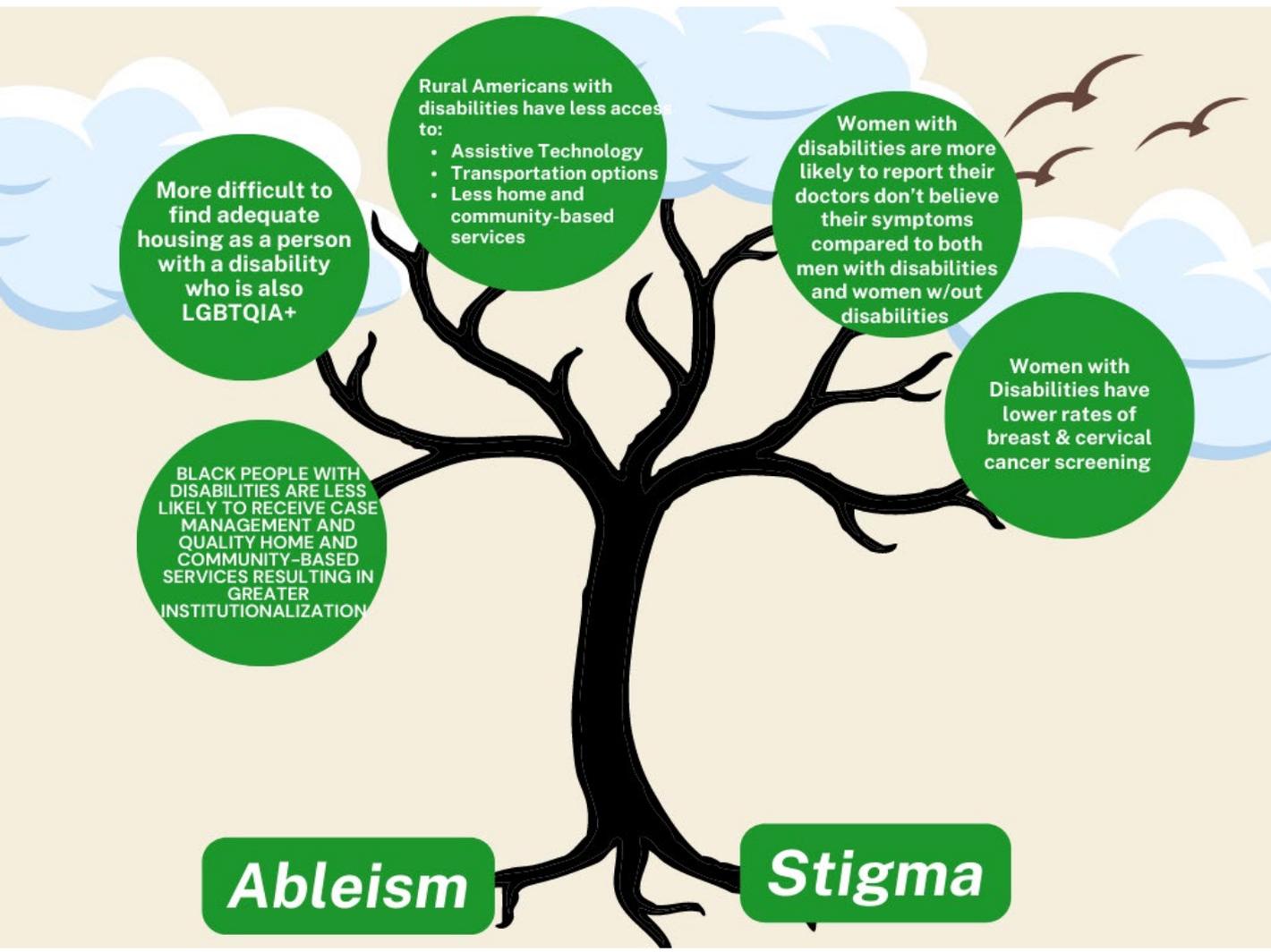
This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily (re)produce, excel, and "behave."

You do not have to be disabled to experience ableism"

Ableism as Smog – Kara Ayers, PhD

More difficult to find adequate housing as a person with a disability who is also LGBTQIA+

Rural Americans with disabilities have less access to:
- Assistive Technology
- Transportation options
- Less home and community-based services

Women with disabilities are more likely to report their doctors don't believe their symptoms compared to both men with disabilities and women w/out disabilities

Women with Disabilities have lower rates of breast & cervical cancer screening

BLACK PEOPLE WITH DISABILITIES ARE LESS LIKELY TO RECEIVE CASE MANAGEMENT AND QUALITY HOME AND COMMUNITY-BASED SERVICES RESULTING IN GREATER INSTITUTIONALIZATION

Ableism

Stigma

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Experiences with Medical Providers

- Women with disabilities are more likely to report their doctors don't believe their symptoms

- Diagnostic Overshadowing

- Organ Transplant Denial

- Inaccessible Exam Tables and Equipment
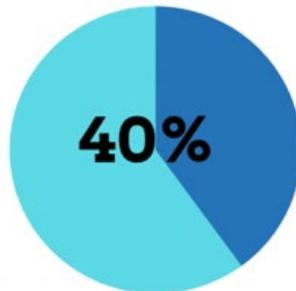
- Quality of Life
  - Michael Hickson
  - Bill Peace

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"I was lying on the cold metal table in the operating room in the midst of giving birth to my second child, in what had been a totally normal and uneventful pregnancy, when the anesthesiologist assigned to my C-section suggested that my obstetrician might want to tie my tubes. He didn't ask me. He didn't even acknowledge that I was there, though I was in a ragged state of consciousness. He said, "While you're down there, we are going to go ahead and tie her tubes, right?" At a time when I was most vulnerable, a medical professional thought it was a good suggestion , an acceptable notion, to make an assumptions with this level of this importance for me. My doctor, my husband, and I all responded unanimously: "No!" – Rebecca Cokley
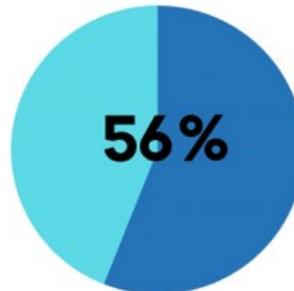
Physicians' Perceptions of People with Disabilities and Their Healthcare

CENTER FOR DIGNITY IN HEALTHCARE FOR PEOPLE WITH DISABILITIES
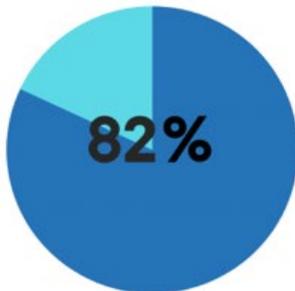
82% — 82% of Physicians reported they believed that people with significant disabilities have worse quality of life than non- disabled people

40% — Only 40% of Physicians were very confident about their ability to provide the same quality of care to patients with disabilities

56% — Just 56.5% strongly agreed that they welcomed patients with a disability into their practices

Iezzoni, et al. "Physicians' Perceptions of People with Disability and Their Health Care." https://doi.org/10.1377/hlthaff.2020.01452

THE NATIONAL CENTER FOR **DISABILITY, EQUITY, AND INTERSECTIONALITY**

COVID 19 and People with Disabilities

POLICY INTERVENTIONS IN 21ST CENTURY

COVID-19 Lifted the Veil on Health Inequities

People with disabilities are more likely than people without disabilities to:

- Have underlying health conditions that put them at higher risk of severe outcomes and hospitalization
- Experience social isolation, which was made worse during the pandemic
- Have difficulty obtaining health information they require in clear and accessible formats
- Experience difficulty accessing vaccines and treatments
- Have individuals from outside their home providing services and supports, requiring greater use of PPE
- Experience discrimination and/or medical rationing
- Be fearful of accessing health care
- Lack access to health care services
- Had lower likelihood of getting COVID-19 vaccination
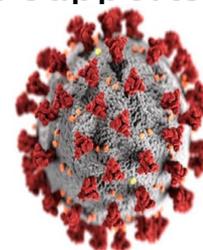
Health Equity Policy Interventions

➢**CDC Finding:** Reducing barriers to scheduling and making vaccination sites more accessible might improve vaccination rates among persons with disabilities

➢**DOJ ADA Title III Enforcement:** Settlements with Rite Aid, Kroger, CVS, HyVee and other pharmacies requiring these chains to make vaccination appointment booking websites accessible to people disabilities by complying with Web Content Accessibility Guidelines (WCAG) 2.1 (AA).

➢**CDC Funding ACL Aging and Disability Networks & Hotlines**

- To expand access to COVID-19 vaccination for older adults and persons with disabilities, CDC funded the ACL aging and disability networks to assist in vaccine access
- CDC funding also went to expand the functionality of the ElderCare locator to support access to vaccinations and to establish the Disability Information and Access Line (DIAL).

Health Equity Policy Interventions

- COVID-19–associated hospitalization rates among Medicare beneficiaries with disabilities were approximately 50% higher than rates among beneficiaries 65 and over
  - Among persons with disabilities, American Indian or Alaska Native persons experienced the highest rate of COVID-19–associated hospitalization (4,962 per 100,000).

- **Policy Interventions:** Prioritize people with disabilities and chronic conditions for vaccination and administration of antivirals such as Paxlovid, consistent with the elevated risk this population faces. Promote access to these treatments. Educate clinicians, pharmacists, family members & the broader public.

Crisis Standards of Care

- Substantial change in usual healthcare operations and the level of care it is possible to deliver due pervasive (e.g., pandemic influenza) or catastrophic (e.g., earthquake, hurricane) disaster.
- This change in the level of care delivered declared by a state government in recognition that crisis operations will be in effect for a sustained period.
- The formal declaration enables specific legal/regulatory powers and protections for healthcare providers in allocating and using scarce medical resources and implementing alternate care facility operations.

Definition by Committee on Guidance for Establishing Standards of Care for Use In Disaster Situations

Health Equity Policy Interventions

National Council on Disability

An independent federal agency committed to disability policy leadership since 1978

National Council on Disability (NCD) Bioethics Series

(Autumn 2019) https://ncd.gov/publications/2019/bioethics-report-series

➢ ***Medical Futility and Disability Bias,*** found many healthcare providers critically undervalue life with a disability, where they deem treatment "futile" or "nonbeneficial" – oftentimes despite the wishes of the patient to the contrary. (PDF) (DOC)

Health Equity Policy Interventions

National Council on Disability
An independent federal agency committed to
disability policy leadership since 1978

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

NCD Chair Neil Romano COVID-19 letter to HHS Office for Civil Rights urges reminder to states of their obligations under ADA, ACA& Section 504 not to discriminate vs people with disabilities in crisis standards of care
(3/18/2020)

…Recent articles regarding the likely response to COVID-19 published by major media outlets are already predicting – unapologetically - that the lack of capacity of the US healthcare system is going to result in rationing of life-saving care for people with chronic illnesses and pre-existing disabilities… Once again, it is a forgone conclusion that people with disabilities are the most expendable group…. More evidence of the need for immediate OCR action is found in a cursory review of State protocols for standards of medical care for times of crisis – like a pandemic - that show that people with existing disabilities will be, if the plans remain the same, discriminated against in the provision of COVID-19 care.

Because this historic pandemic disproportionately threatens the lives of people with disabilities, NCD strongly urges OCR to immediately issue a notice to the nation's medical providers of their obligations for non-discriminatory medical care under the ADA, the Rehabilitation Act, and the Affordable Care Act. The notice should include a statement on the historic and deep-seated biases and stereotypes about people with disabilities that have resulted in eugenics and lack of life-saving care, ask physicians to be mindful of this when making medical treatment decisions, and make clear that, even in an environment where health care resources are limited, the civil rights of people with disabilities cannot be suspended or limited.

Health Equity Policy Interventions

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

HHS Office for Civil Rights' Bulletin 3/28/2020 .

- Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities remain in effect.
- 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 by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

Health Equity Policy Interventions

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

☆**HHS Office for Civil Rights uses early case-resolution process & TA to work with States to model& implement non-discriminatory Crisis Standards of Care**.

- OCR Reaches Early Case Resolution with Alabama After It Removes Discriminatory Ventilator Triaging Guidelines - April 8, 2020.
- OCR Resolves Civil Rights Complaint Against Pennsylvania After it Revises its Pandemic Health Care Triaging Policies to Protect Against Disability Discrimination - April 16, 2020
- OCR Resolves Complaint with Utah After it Revised its Crisis Standards of Care to Protect Against Age and Disability Discrimination - August 20, 2020
- OCR Provides Technical Assistance to Ensure Crisis Standards of Care Protect Against Age and Disability Discrimination - January 14, 2021
- OCR Provides Technical Assistance to the State of Arizona to Ensure Crisis Standards of Care Protect Against Age and Disability Discrimination - May 25, 2021

Health Equity Policy Interventions

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

☆HHS OCR issues Guidance & FAQs on non-discriminatory Crisis Standards of Care (2/4/2022)

HHS Issues New Guidance for Health Care Providers on Civil Rights Protections for People with Disabilities | HHS.gov

FAQs for Healthcare Providers during the COVID-19 Public Health Emergency: Federal Civil Rights Protections for Individuals with Disabilities | HHS.gov

…HHS clarified that federal civil rights laws apply to health care providers, including those administering COVID-19 testing, medical supplies, and medication. These rules also apply to entities providing hospitalization, long-term care, intensive treatments, and critical care, such as oxygen therapy and mechanical ventilators. Additionally, federal civil rights laws apply to state Crisis Standard of Care plans, procedures, and related standards for triaging scarce resources that hospitals are required to follow. The FAQs remind health care providers of their obligations under law and provide examples of applicability.

Web Accessibility

☆ **Disparity:** Use of Websites and Mobile Applications has created new barriers & need to ensure Americans with Disabilities have equitable access.

☆ **Notice of Proposed Rulemaking: Nondiscrimination on the Basis of Disability; Accessibility of Web Information and Services of State and Local Government Entities,**

    ☆ published by DOJ on 08/04/2023 with 60-day public comment period.

    ☆ Would apply WCAG 2.1 (AA) success criteria with certain exceptions outlined in the NPRM

    ☆ Large public entities serving jurisdictions with over 50,000 total residents would have 2 years to comply, smaller public entities with lower total populations would have 3 years to comply

☆ **READ MORE:**

    – Associate Attorney General Vanita Gupta Delivers Remarks on the Web Accessibility Notice of Proposed Rulemaking

    – Fact Sheet: Notice of Proposed Rulemaking on Accessibility of Web Information and Services of State and Local Government Entities | ADA.gov

Standards for Accessible Medical Diagnostic Equipment

<u>Nature of Disparity:</u> Lack of accessible medical diagnostic equipment.

➢ **<u>READ MORE</u>:**
   ➢ **Administration for Community Living Fact Sheet** Wheelchair-Accessible Medical Diagnostic Equipment: Cutting Edge Technology, Cost-Effective for Health Care Providers, and Consumer-Friendly
   ➢ **National Council on Disability Report: Enforceable Accessible Medical Equipment Standards: A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities**

Standards for Accessible Medical Diagnostic Equipment

> **Intervention:** *Implement & enforce standards for accessible medical diagnostic equipment*

☆ [United States Access Board finalized standards for accessible medical diagnostic equipment January 9, 2017](#).

- Due to a lack of data on height of commonly used wheelchairs, the minimum transfer height for accessible MDE was initially set as a range between 17 and 19 inches, with a sunset period, with an agreement to conduct additional research & update the standard once sufficient data became available.
- **Note**: these standards are voluntary -- not binding – until, and unless the Department of Justice and/or other federal agencies implement them under the Rehabilitation Act, which requires people with disabilities have equitable access to federally funded programs and services.

Administration for Community Living

Increasing Life Expectancy of Individuals with Disabilities by Promoting Health Equity

Vision for Health Equity

- AoD envisions living well with a disability where individuals with disabilities experience:
  - Better health outcomes and reduced health disparities that increases life expectancy
  - Equitable access to health care that supports achieving maximum physical, emotional, social, and economic well-being consistent with cultural values
  - Person-centered and self-directed care where decisions are supported
  - Culturally competent providers that value and respect personal preferences and communication methods

Goal for Health Equity

AoD's overall goal is to increase equal access to health care to support healthy living across the lifespan. We aim for:

- The broader environment and systems to have:
  - Health care systems that plan for accessible services for individuals with disabilities
  - Medical professionals with greater cultural competency in serving individuals with disabilities by treating people with respect and dignity, presuming competency in decision-making about their health care
  - Health care is influenced by and responsive to social factors impacting the health of individuals with disabilities
  - Health surveillance data that is inclusive of people of people with ID/DD and used to inform programs, policies, and practice

Goal cont.

- Individuals with disabilities, including those with intersectional identities to:
  - Be seen as experts on their own health and disability
  - Receive person-centered health care
  - Have increased access to health care procedures
  - Have opportunities to provide input on social factors related to their health
  - Be recognized through health surveillance data as an underserved/unserved population

Promoting Health Equity	FY23
Empowering Youth with ID/DD to Manage Their Healthcare Transitions	$485
Strengthening the Healthcare Workforce	$350
National Center for Diversity, Equity, and Intersectionality	$500
Co-Occurring ID/DD and Mental Health Disabilities	$650
State Inter-system Service Training and Planning to Support the ID/DD Population with Co-Occurring Mental-Behavioral Health Issues	$545
Community Based Transition Implementation Grants (2 – IA, WI)	$400
ID/DD Counts!	$175
Augmentative and Alternative Communication Planning (Planned for 2023)	$350
Total	**$3,445**

PROJECT HIGHLIGHTS

Empowering Youth to Lead their Healthcare Transitions

- Improving healthcare outcomes and quality of life for young people with ID/DD by equipping them with person-centered resources on transitioning from pediatric to adult healthcare systems.
  - Every year, 750,000 young people with disabilities enter adulthood but health policy and health care delivery for young adults have not kept pace
  - The healthcare system does not address the needs of young people with disabilities transitioning from pediatric to adult care very well.
  - As a result, the amount of care provided to adults with developmental disabilities by pediatric providers and children's hospitals is far too great.
  - Youth with disabilities need the tools to make these healthcare transitions person-centered and accessible so they can thrive, learn, work, earn, and participate in community life.

Empowering Youth with ID/DD to Manage Their Healthcare Transitions

- Primary Grantee: Family Voices
- Other Core Partners:

    Got Transition

    SPAN Parent Advocacy Network

    University of Missouri UCEDD

    University of Wisconsin UCEDD

Healthcare Transitions: Activities

- Landscape Analysis of existing efforts to identify gaps in services and supports
- Resource Development and Dissemination based on Universal Design for Learning principles
- Youth Steering Committee (YSC)
- The Youth Development Initiative, peer-mentored by members of YSC
- National Community of Practice, co-led by YSC and including other ACL grantees
- State Community of Practice to pilot materials and provide feedback
- Website and Social Media
- Mobile App designed for youth with ID/DD to use during healthcare transitions
- Project ECHO on youth healthcare transitions for sustainability

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

- Primary Grantee: Rush University, College of Nursing
- Other Core Partners:
    - St. John Fisher College, Golisano Institute for Developmental Disability Nursing
    - University of Illinois at Chicago, HealthMattersTM Program
    - University of Minnesota, Institute on Community Integration
    - Villanova University, M. Louise Fitzpatrick College of Nursing

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

- 5-year grant to Rush University to build the capacity of the future health care workforce by addressing the lack of content about individuals with ID/DD in current inter professional 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.

National Center for Disability, Equity, and Intersectionality

- Primary Grantee: University of Cincinnati UCEDD
- Other Core Partners:

    Morehouse School of Medicine,

    National Cultural Competency Center

    Kennedy Krieger Institute

    Autistic Self Advocacy Network

National Center for People with Co-Occurring ID/DD & Mental Health Disabilities

- An estimated 30 to 70 percent of ID/DD have a mental health (MH) disability
- More than one in four adults living with severe MH issues also have a substance use disorder (SUD)
- Despite this high prevalence level, in most states, there is a chronic lack of a whole-person approach supporting individuals with co-occurring ID/DD and MH issues, with and without SUDs.
- This often prevents individuals with complex support needs from getting a coordinated approach to clinical services and community-based supports.

National Center for People with Co-Occurring ID/DD & Mental Health Disabilities

- Primary Grantee: National Association of State Directors of DD Services

- Other Core Partners:

  - National Association of State Menta Health Directors (NASMHPD)

  - National Association for the Dually Diagnosed (NADD)

National Center for People with Co-Occurring ID/DD & Mental Health Disabilities

- Additional Partners:
  - Autistic Self Advocacy Network
  - Center for Systemic Therapeutic Assessment, Resources and Treatment (START) Services at the University of New Hampshire Institute on Disability
  - Communication FIRST
  - Green Mountain Self-Advocates
  - Nisonger Center at The Ohio State University
  - Sonoran Center for Excellence in Developmental Disabilities at the University of Arizona.

National Center for People with Co-Occurring ID/DD & Mental Health Disabilities

- Five-year cooperative agreement to establish a national, person-centered, culturally competent training center for building capacity in state and local service systems to support individuals with co-occurring intellectual and developmental disabilities (ID/DD) and mental health disabilities living well.
- Goals:
  - Create systems changes, such as policy changes and financial changes to address barriers to effective mental health services and community-based support
  - Train supporters such as family members and direct support professionals
  - Improve access to services and supports

State Inter-system Service Training and Planning to Support the ID/DD Population with Co-Occurring Mental-Behavioral Health Issues

- Support for convening multi-disciplinary teams of I/DD state agency and mental and behavioral health state agency personnel to:
  - Develop and implement a shared training infrastructure tailored to the state's needs
  - Improve coordination between the two agencies in collaboration with other key partners around the services they jointly provide to people with co-occurring mental health and ID/DD.

State Inter-system Service Training and Planning to Support the ID/DD Population with Co-Occurring Mental-Behavioral Health Issues

- Grantees:
  - University of Illinois Chicago
  - University of Kentucky Research Foundation
  - The Ohio State University
  - Utah State University
  - University of Alaska Anchorage
- Teams are addressing:
  - Siloed systems and funding mechanisms that make accessing treatment extremely difficult.
  - The tendency towards diagnostic overshadowing where many individuals are referred for behavioral supports when what they may need instead, or in addition, is mental health supports/treatment.
  - Helping providers know what a mental health disability looks like in people with ID/DD.
  - Addressing the perception that either DD or MH systems have more resources and should take responsibility for service provision
  - The overall lack of cultural competency among providers in serving people with ID/DD and mental health disabilities, and in particularly serving people with ID/DD and other intersectional identities.

Community Based Transition Planning Grant

- Grantees: Iowa and Wisconsin UCEDDs
- Creating a coordinated system for providing comprehensive transition supports from pediatric to adult health care for youth and young adults with intellectual and developmental disabilities (ID/DD).
- Activities:
  - Convene a consortium of people with ID/DD and existing partners including, healthcare providers and systems, state government, and community service agencies.
  - Conduct a comprehensive review and analysis (CRA) of needs, gaps, and barriers; in current state systems, policies, and strategies; existing partnerships; and evidence-based and promising practices that address healthcare for people with ID/DD.
  - Prepare a comprehensive plan and pilot model(s) that are actionable, practical and realistic based on the census of the consortium at the end of this planning year.
  - Disseminate the CRA and pilot model(s) to partners, stakeholders and parties who might be interested in replication or other use.

National Center for Disability, Equity, and Intersectionality

- Five year grant to create and maintain a national center that will focus on resources to increase equitable access for people with marginalized identities
- Supports EO 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government

The National Center for Disability, Equity, and Intersectionality
Leah Smith, MPA
Associate Director

Follow us @ThinkEquitable

We aim to identify and address inequities in healthcare, community living, and justice.

THE NATIONAL CENTER FOR
DISABILITY, EQUITY, AND
INTERSECTIONALITY

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Partner Organizations
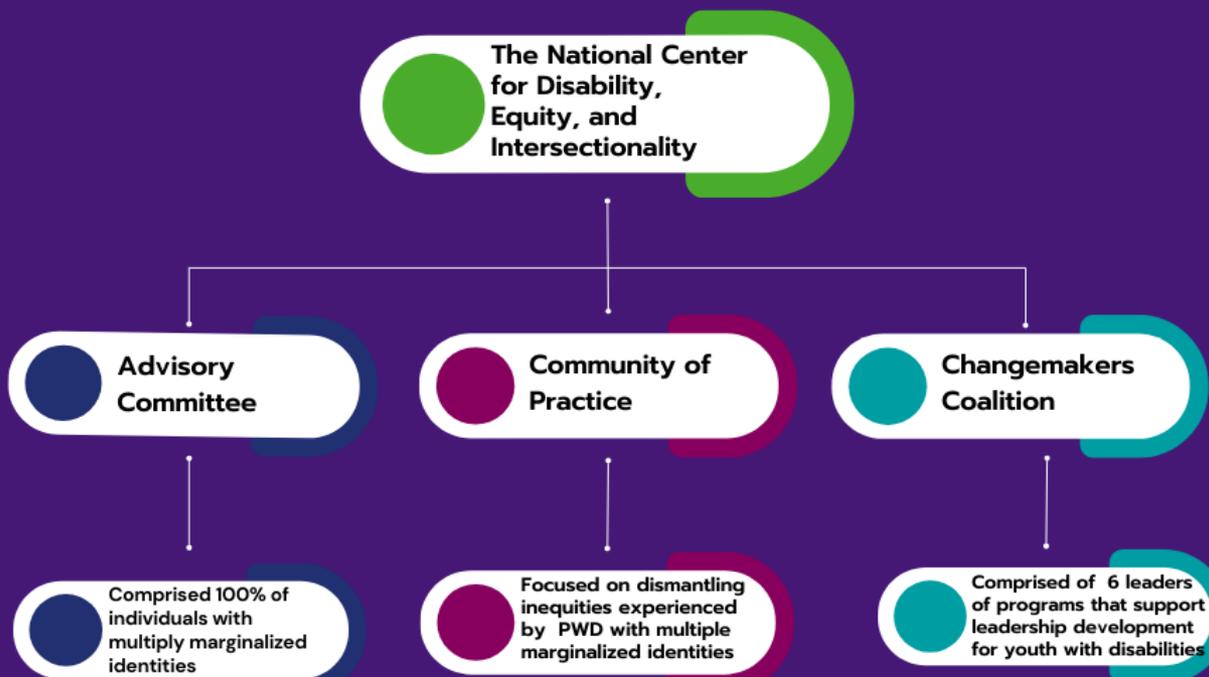
Some of Our Work So Far…

- Legislative Review of the Accessibility of School Mass Shooting Drills

- Review of Reparations Programs Compensating People with Disabilities After Forced Sterilization

- Webinar on the Intersection of Ableism and Racism in Healthcare
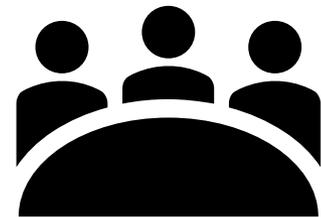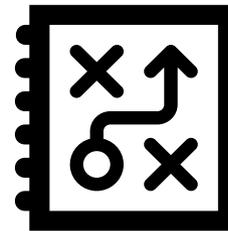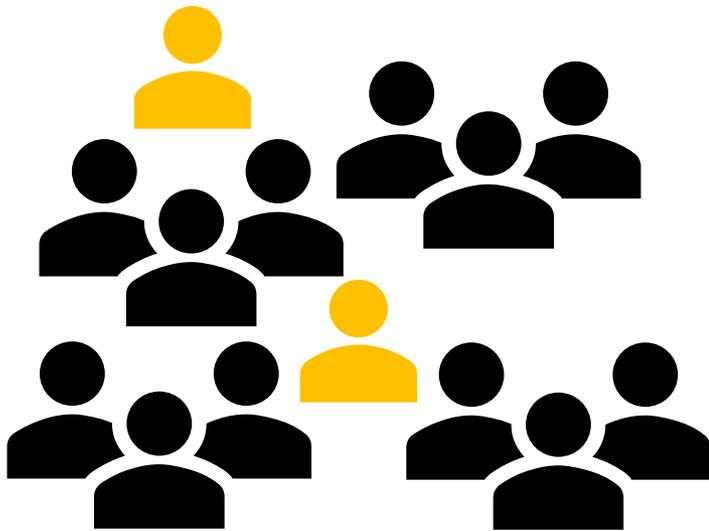
Follow Our Work

www.ThinkEquitable.com
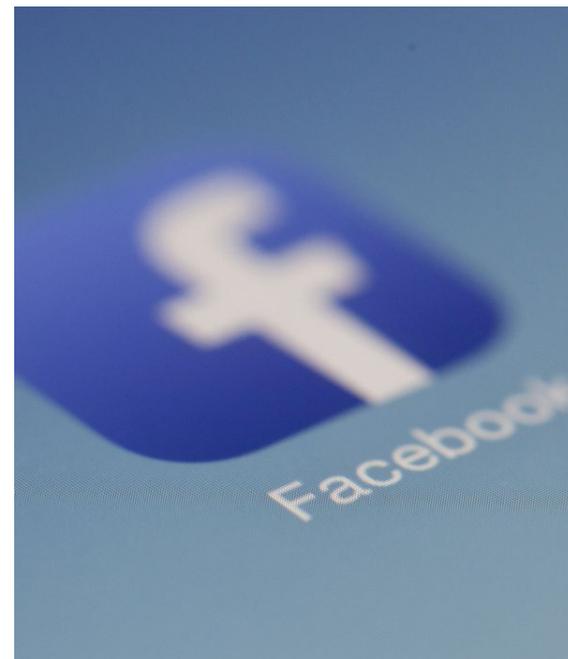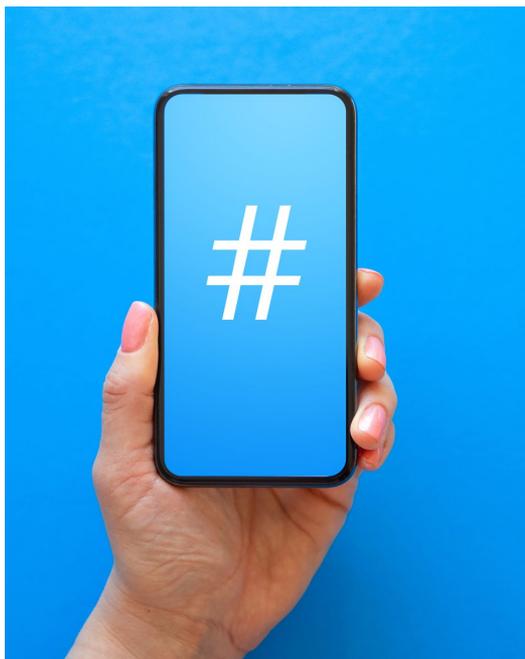
Follow us on social media @ThinkEquitable and #ThinkEquitable

I/DD Counts!   https://acl.gov/iddcounts

Since 2019, ACL has led the I/DD Counts!, a cross-agency initiative:

I/DD Counts!

A priority is to advance awareness of the need for I/DD data and promote advances in I/DD data through connecting people with I/DD, researchers, policy makers, public managers, service and health care providers, insurers. Basically: anyone who is involved in the collection and use of data.

- [In public health and other survey data](#)

Or

- [In the administration of public programs (administrative data)](#)

I/DD Counts DATA SUMMIT

November 17-18, 2022

This summit is…an opportunity to connect with each other and re-commit to our shared goal: that people with I/DD will have data they need to tell their health story, to advocate for needed health services and ultimately have better health outcomes.

Alison Barkoff,
Acting Administrator and Assistant Secretary for Aging, Principal Deputy Administrator, ACL

- Building from previous gatherings, with expanded participation

- Opportunities to present on efforts underway and engage in problem-solving dialogue

- Recommendations included:

  - Further work to explore data linkages, interoperability, and syntheses across datasets.

  - Enhance state/local capacity for analyses inclusive of people with I/DD

I/DD Counts Summit Priority Areas

Partnerships

Survey Data

Administrative Data

Tools and Skills for Analyses

Sharing Information

Roadmap for I/DD Data

ACL Administration for Community Living

Enhanced Partnerships

- **Enhance partnerships** with people with I/DD, federal, state and local partners
- **Recruit input** from diverse stakeholders
- **Coordinate across federal agencies** and partners
- **Establish thematic workgroups**
- **Note other I/DD data sources**, tools and special studies
- **Establish partnerships** with organizations able to create data on health of persons with I/DD

Survey Data

- **Develop, test, and implement I/DD identifiers** for surveys
- **Promote consistent survey** definition of I/DD
- **Disaggregate data** by other disability type and other demographics
- **Consider** "overall disability" vs I/DD
- **Promote routine use** of disability as demographic
- **Standardize strategies** for proxy vs self-report
- **Ensure ongoing quality** and accuracy of data

Administrative Data

- **Document what we know**
- **Engage entities** that have or use administrative data on people with I/DD
- **Engage insurers** and payors
- **Enhance and expand collaborations** among grantee researchers
- **Promote and use consistent or aligned definitions**
- **Develop and disseminate standardized methods** for data links
- **Conduct survey of state practices** and model analyses
- **Examine health status** items being tracked

Capacity for Analysis

- **Examine data frameworks** from other countries
- **Modernize data infrastructure**
- **Examine linkages, interoperability and synthesis** across datasets
- **Develop standards** for data analysis
- **Conduct analytics** on key indicators of health
- **Establish benchmarks** to compare with other data
- **Conduct comparative studies** with large datasets
- **Evaluate systems and policies**
- **Identify need for new data**
- **Consider creating Center of Excellence in I/DD Health Data**
- **Consider enhancing state and local capacity through trainings**

Data Use and Dissemination

- **Estimate I/DD prevalence**
- **Engage with people with I/DD**
- **Develop communication plan** for reaching key audiences
- **Establish standards and best practices** for communicating accessible data briefs for different audiences
- **Develop multiformat communication**
- **Translate data** for evidence-based health access and utilization
- **Develop guidelines** for communication with different audiences
- **Develop and maintain a website** as resource

ID/DD Counts! | ACL Administration for Community Living

Questions?