

All of Us Research Program

What All of Us Partners Need to Know to Successfully Include People with Disabilities in Outreach



National Institutes
of Health

Presented to CPGI Network

December 18, 2018

American Association on Health and Disability

- Reduce Health Disparities
- Advocate for Community Inclusion
- Promote Full Accessibility
- Integrate Disability into Public Health Agenda
- Advance Knowledge Translation & Disability Research



AAHD Mission: To promote health and wellness for people with disabilities

Disability-Focused Rationale for Involvement

Disability Law Timeline

- The Rehabilitation Act §504 – 1973
- Individuals with Disabilities Education Act (IDEA) – 1975
- Voting Accessibility for the Elderly and Handicapped Act – 1984
- Air Carrier Access Act – 1986
- Fair Housing Act (FHA) is amended – 1988
- Americans with Disabilities Act (ADA) – 1990
- Money Follows the Person – 2005
- Affordable Care Act (ACA) – 2010

Health Disparities for People with Disabilities

- According to HHS, 12.5% of the population has a disability which “seriously limits” them
- People with a disability are:
 - Over twice as likely to not see a doctor due to cost
 - Over 30% more likely to be obese
 - 60% more likely to smoke
 - Over 2.5 times more likely to develop diabetes

Health Disparities for People with Disabilities

- ◎ Women with a disability are:
 - Less likely to have a current mammogram
 - Less likely to have a current pap test
- ◎ People with a disability are:
 - Over 3.5 times more likely to have cardiovascular disease (18-44 y.o.)
 - Just under 3 times more likely to have cardiovascular disease (45-64 y.o.)

Health Disparities for People with Disabilities – Social Determinants

- ◎ People with disabilities:
 - Have double the unemployment rate among those within the workforce
 - About 35% more likely to have less than a high school education
 - Less likely to report sufficient social & emotional support

Disability Across the Lifespan

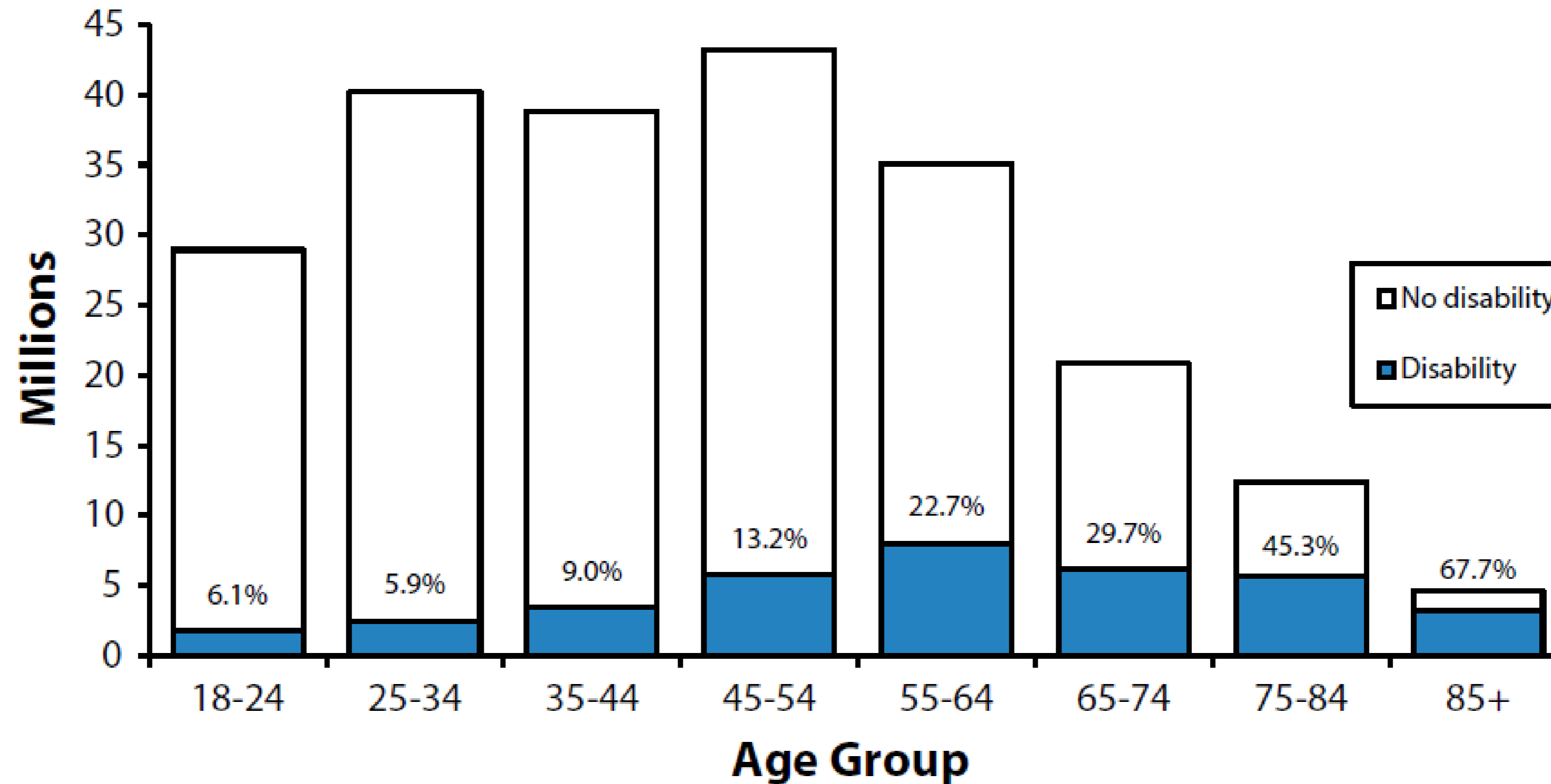
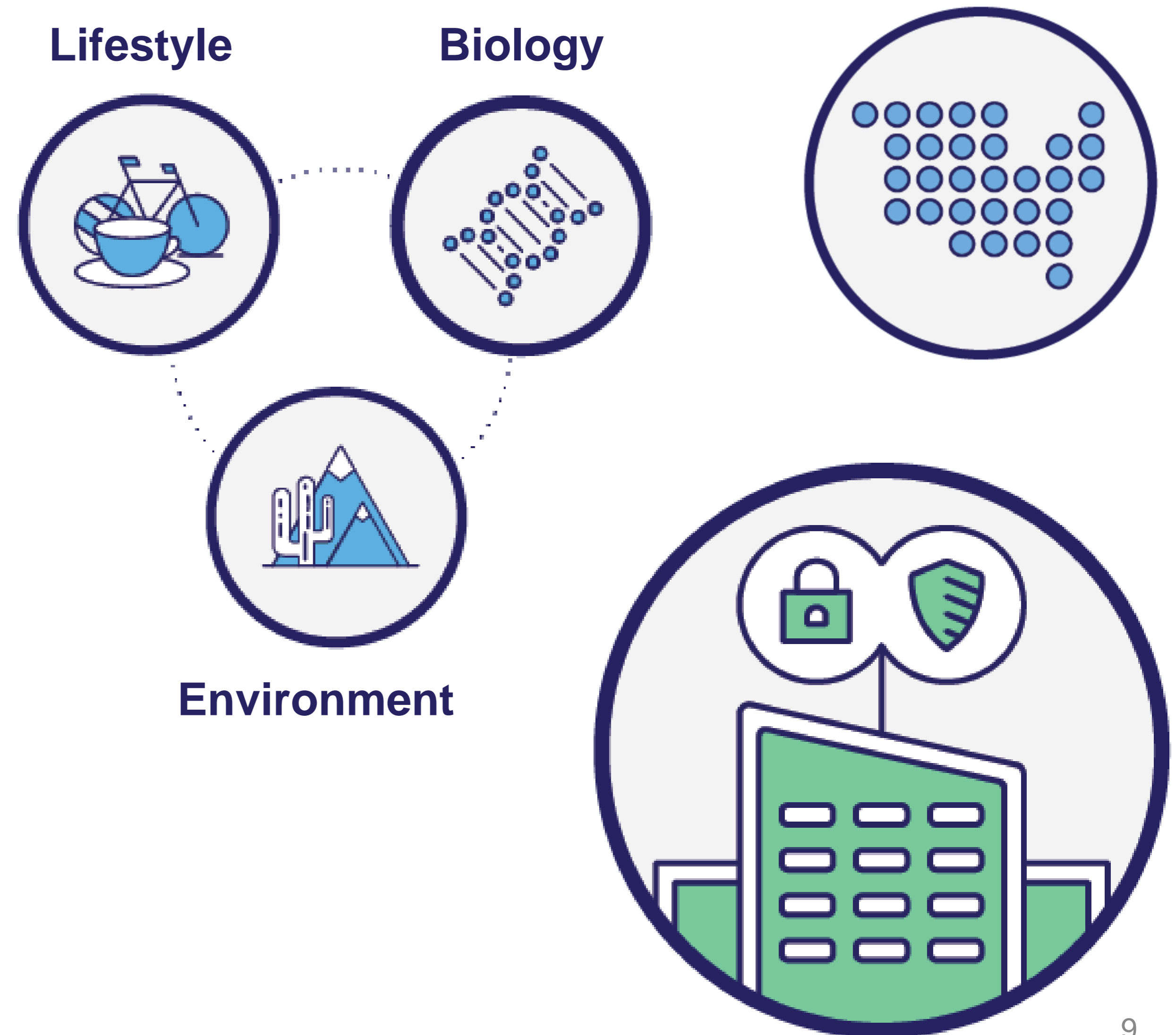


FIGURE 1—Weighted population estimate of adults with disabilities and adults without disabilities by age group: National Health Interview Survey, United States, 2010.

What is precision medicine?

Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in lifestyle, socioeconomics, environment, and biology.

It is a radical shift in how each of us can receive the best care possible based on our unique makeup.



All of Us Values

- Participation in the *All of Us* Research Program will be **open** to interested individuals
- The program will reflect the rich **diversity** of America
- Participants will be **partners** in the program
- Trust will be earned through robust **engagement** and full **transparency**
- Participants will have **access** to information and data about themselves
- Data from the program will be broadly **accessible** to **empower research**
- The program will adhere to the PMI **Privacy** and **Trust** Principles and the PMI **Data Security** Policy Principles and Framework
- The program will be a catalyst for **innovative research** programs and policies

**NOTHING ABOUT US,
WITHOUT US!**

Disability Messaging

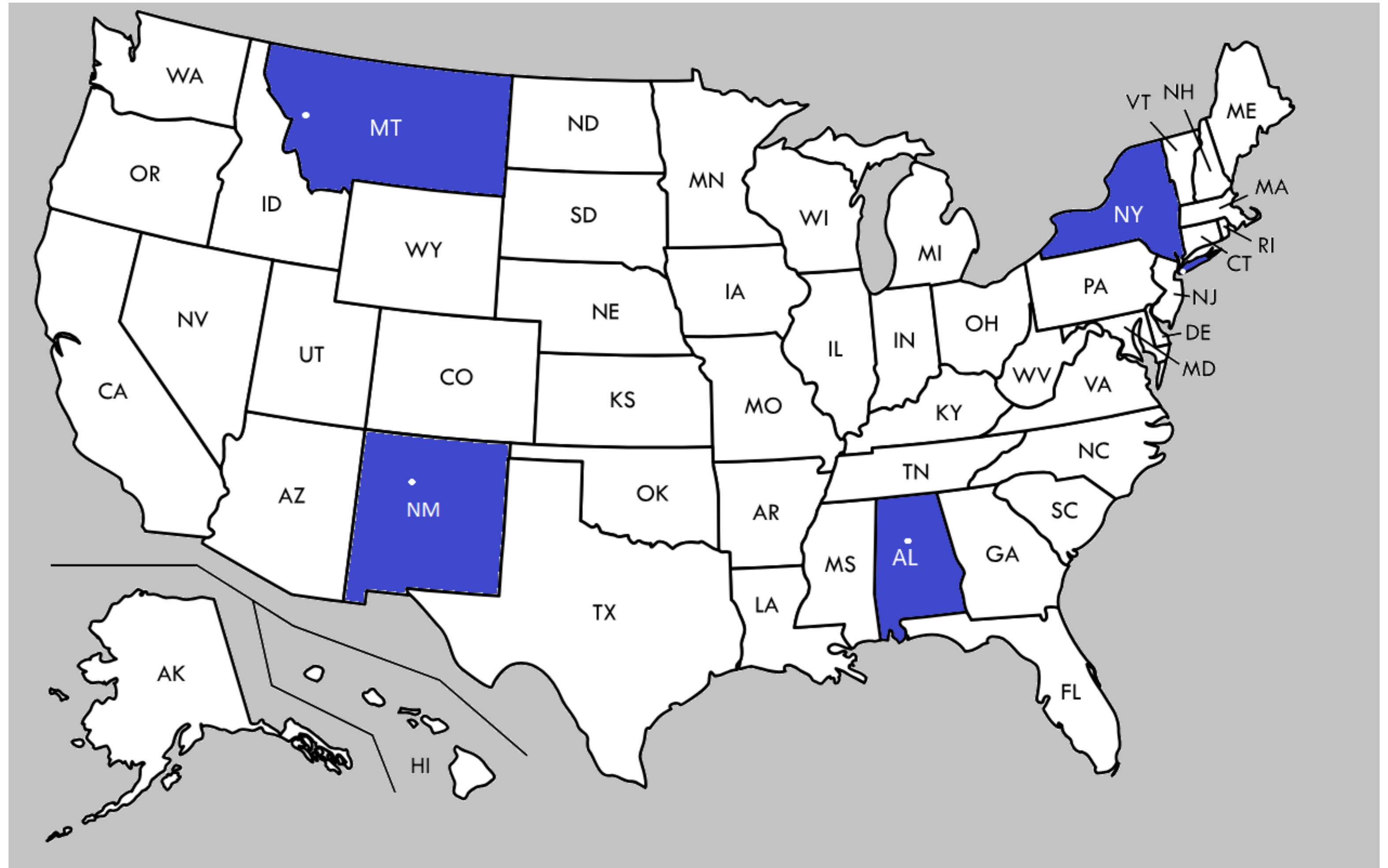
AAHD Role

- Identify and fund 4 trusted intermediaries
- Develop a disability-focused rationale for involvement in *All of Us*
- Review *All of Us* program materials and messages to ensure appropriateness for persons with disabilities
- Conduct national education and outreach on *All of Us* to the disability community



Four Partner Sites

- Lakeshore Foundation – Birmingham, AL
- University of Montana Rural Institute – Missoula, MT
- University of New Mexico Center for Development and Disability – Albuquerque, NM
- Center for Independence of the Disabled, NY – New York, NY



All of Us Materials



Be one in a million

Join the All of Us Research Program

JoinAllOfUs.org
(844) 842-2855



The All of Us logo is a service mark of the U.S. Department of Health and Human Services.

Messaging – What Resonates with the Disability Community

- ◎ Everyone is invited
- ◎ More treatments for my disability
- ◎ Better care for secondary conditions for those with my disability
- ◎ Helping future generations of people with my disability
- ◎ Getting researchers to consider disability as a variable

Accessibility and Etiquette

Accessibility Challenges When Planning and Hosting An Event

- Parking Lot Accessibility
- Building Accessibility
- Elevator Accessibility
- Ramp Accessibility
- Meeting Room Accessibility
- Restroom Accessibility
- Alternative Formats (braille, large text, audio)
- Packaging and Messaging of Materials
- Font Size

Disability Etiquette – People with All Types of Disabilities

- ⦿ Introduce yourself, offer a handshake.
- ⦿ People with limited hand use or those who wear artificial limbs can usually shake hands.
- ⦿ Always ask before providing assistance.
- ⦿ Speak directly to the person and not their attendant, interpreter, family member, etc.
- ⦿ Do not pet service animals without asking the owner first.
- ⦿ Ask questions if you are unsure how to proceed.

Disability Etiquette – People with Mobility Disabilities

- ⦿ Do not push/touch a person's wheelchair/scooter without their permission.
- ⦿ Place yourself at eye level in front of the person's wheelchair to facilitate conversations.

Disability Etiquette – People who are Blind or Low Vision

- Always introduce yourself and anyone else who is present.
- Tell the person if you leave the room. Explain interruptions.
- Offer to read information to the person when appropriate.
- If you are asked to offer guidance, offer your arm so the person can grasp your elbow and proceed at a normal pace. Do not take a person's arm and move them by the elbow.

Disability Etiquette – People who are Deaf or Hard of Hearing

- Get the person's attention before you begin to communicate.
- Let the person establish their preferred method of communication for your conversation. (Ex: lip reading, sign language, note writing.)
- Use gestures and visual cues. (Ex: holding up items that you are discussing.)
- Explain interruptions.

Disability Etiquette – People with Speech and Language Disorders

- Be patient, respectful, and sensitive.
- Do not interrupt or finish the person's sentence.
- If the person uses any assistive technology devices, make sure the devices are within the person's reach.

Disability Etiquette – People with Cognitive or Intellectual Disabilities

- Keep communication simple. Use short sentences and complete one topic before moving to the next.
- If possible, use pictures and visual aids.
- Ask if the person has any questions or if they would like for you to clarify anything.

Disability Etiquette – People with Mental Health or Behavioral Health Disabilities

- If a person seems anxious or agitated, speak calmly and offer to repeat information.
- If a person seems nervous or confused, offer to break things down step-by-step to help them understand.
- Respect a person's choice of language or terminology. For example, if they ask you to refer to something as a “mental health condition” instead of a “mental illness,” listen to their request.

Resources

AAHD Resources Available

- ◉ Disability Etiquette Fact Sheet: nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-17/
- ◉ Accessibility Self-Assessment Guide: <https://www.aahd.us/wp-content/uploads/2012/10/Facility-Assessment-5-20-13-.pdf>
- ◉ Tip Sheet: Engaging People with Disabilities in Evidence-Based Programs <https://www.ncoa.org/resources/tip-sheet-engaging-people-with-disabilities-in-evidence-based-programs/>
- ◉ Tip Sheet: Developing Partnerships with the Disability Community <https://www.ncoa.org/resources/developing-partnerships-disability-community/>
- ◉ AAHD's Resource Center: <https://www.aahd.us/resource-center/>
- ◉ Sign up for AAHD's newsletters: <https://www.aahd.us/contact/>

Questions?

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