



Investing in Medicaid HCBS: The Biden-Harris Administration's Caregiving Initiative

June 16, 2021

BRANDEIS UNIVERSITY

The Heller School
FOR SOCIAL POLICY AND MANAGEMENT

The Lurie Institute
for Disability Policy

Community Living Policy Center

- Aims to advance policies and practices that promote community living outcomes for individuals with disabilities of all ages through research and knowledge translation.
- The CLPC received support from the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR) within the Administration for Community Living, U.S. Department of Health and Human Services (Grant # 90RTCP0004). The contents of this webinar do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the U.S. government.

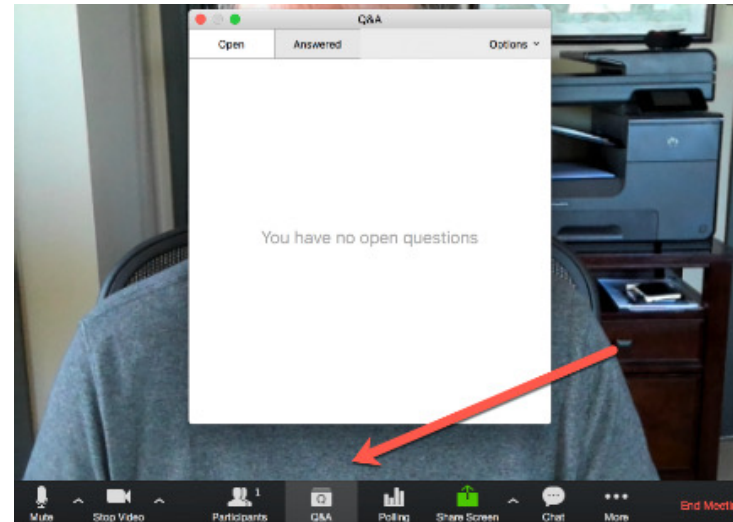
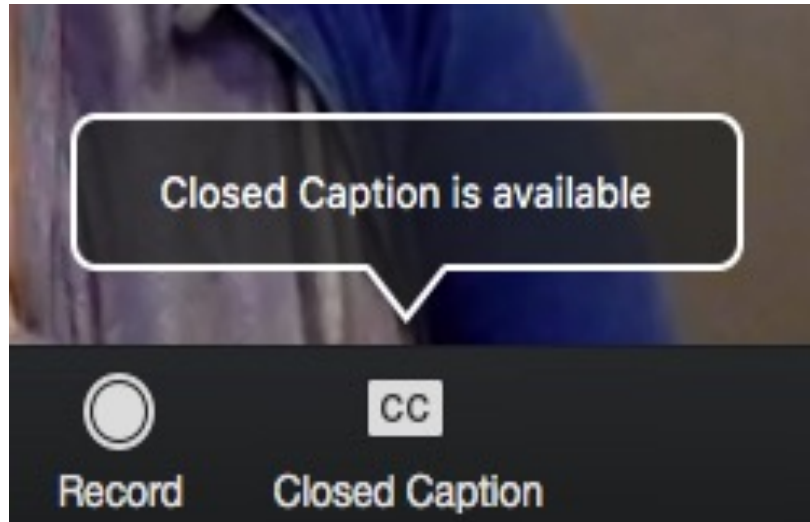


Community Living Policy Center Partners



- Lurie Institute for Disability Policy at Brandeis University
- University of California, San Francisco (UCSF)
- Association of University Centers on Disabilities (AUCD)
- Autistic Self Advocacy Network (ASAN)
- Disability Rights Education & Defense Fund (DREDF)
- Disability Policy Consortium (DPC)
- Centene Corporation
- ADvancing States
- Mike Oxford, Topeka Independent Living Resource Center
- Henry Claypool, National Policy Expert
- Disability and Aging Collaborative
- Angel Miles, Access Living

Webinar Access



- The PowerPoint and archived recording for this webinar will be available on the Community Living Policy Center website: www.communitylivingpolicy.org
- The webinar is being live captioned.

Introduction of Speakers & Panelists

Cathy Cranston

Latoya Maddox

Julia Bascom

Hi!

Julia Bascom

Autistic Self Advocacy Network (ASAN)

<https://autisticadvocacy.org>



Disability is not binary

People with IDD may have more than one disability/experience multiple categories of disability.

It is common for people with IDD also to experience mental health disabilities, chronic health conditions, sensory disabilities, and mobility disabilities.

All of these things impact the supports and services we will need.

People with IDD often require different types of support, and require support with different things, than older adults or people with physical disabilities.

For example

Different types of support within ADLs:

- Cueing/prompting
- Executive functioning supports
- Communication support

Support with different things:

- Employment
- IADLs like household organization and management, running errands, using the internet
- Support in understanding information and making decisions
- Support with self-regulation

But don't forget

The things people with DD need in order to have good lives are the same things other people with disabilities need.

The specific supports may look slightly different but the end goals are the same.

We have the same right to choice and control over our services—and to services that are person-centered, respectful, and supportive of our dignity, autonomy, and self-determination.

Compare and contrast

- Adult day services
- Supervision
- Behavior supports
- “Residential services”
- Supported employment
- Companionship
- ?
- Supported living, personal care/direct support services, chore/homemaking assistance, etc.

The DD community wants:

- HCBS that are *truly* community-based
- More individualized services
- Greater access to self-direction and control over services
- Support to achieve personal goals and high expectations

All of these require most states to redesign major parts of their systems.

The HCBS settings rule is the *floor*, not the ceiling.

The Administration's proposal

- Serious funds to make serious changes
- Could be designed in many different ways
- Will hopefully address:
 - DSP wages and turnover
 - Supporting providers who want to transform their models
 - Access to services in non-disability-specific settings, especially shared/supportive living and supported employment
 - Quality of services—genuinely person-centered
 - Paradigm changes
 - Waiting lists

Amber Christ

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ individuals, and people with limited English proficiency.

To achieve Justice in Aging, we must:

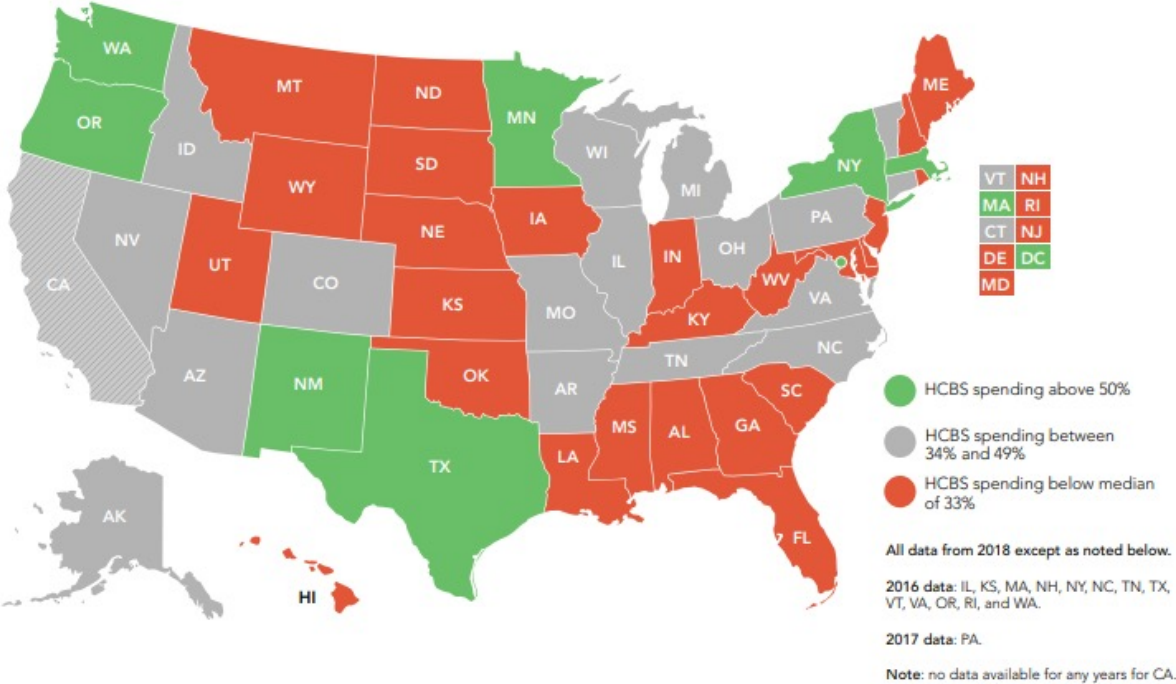
- Acknowledge systemic racism and discrimination
- Address the enduring negative effects of racism and differential treatment
- Promote access and equity for our nation's low-income older adults in economic security, healthcare, and the courts
- Recruit, support, and retain a diverse staff and board, including along lines of race, ethnicity, gender, gender identity and presentation, sexual orientation, disability, age, and economic class

Medicaid is the Backbone of Our Long-Term Care Infrastructure

- Medicaid is the primary payer of HCBS
- Yet, because HCBS is an optional and not required Medicaid benefit, there are significant gaps in access to services:
 - State-based inequities
 - Population-based inequities
 - Race-based inequities

Older Adults & HCBS

HCBS Spending on Older Adults and People with Physical Disabilities by State as a Percentage of LTSS Spending



Half of states spend more on institutional care than HCBS for older adults & people with physical disabilities.

Source: CMS Medicaid Long Term Services and Supports Annual Expenditures Report Federal Fiscal Years 2017 and 2018.

Alzheimer's and Dementia

- Institutionalization
 - **75%** of individuals at age 80 with a diagnosis of dementia or Alzheimer's reside in a nursing facility.
- Unpaid Caregiving
 - Family members and friends provided approximately \$257 billion in unpaid care to individuals living with Alzheimer's and other dementias in 2020.

Racial Inequities

- Black & Hispanic older adults are disproportionately more likely to have Alzheimer's and dementia.
- Black dementia caregivers are more likely to provide more than 40 hours of care per week; 69% less likely to use respite services.
- Hispanic, Black, and Asian American dementia caregivers report greater care demands, less external help, and greater depression.

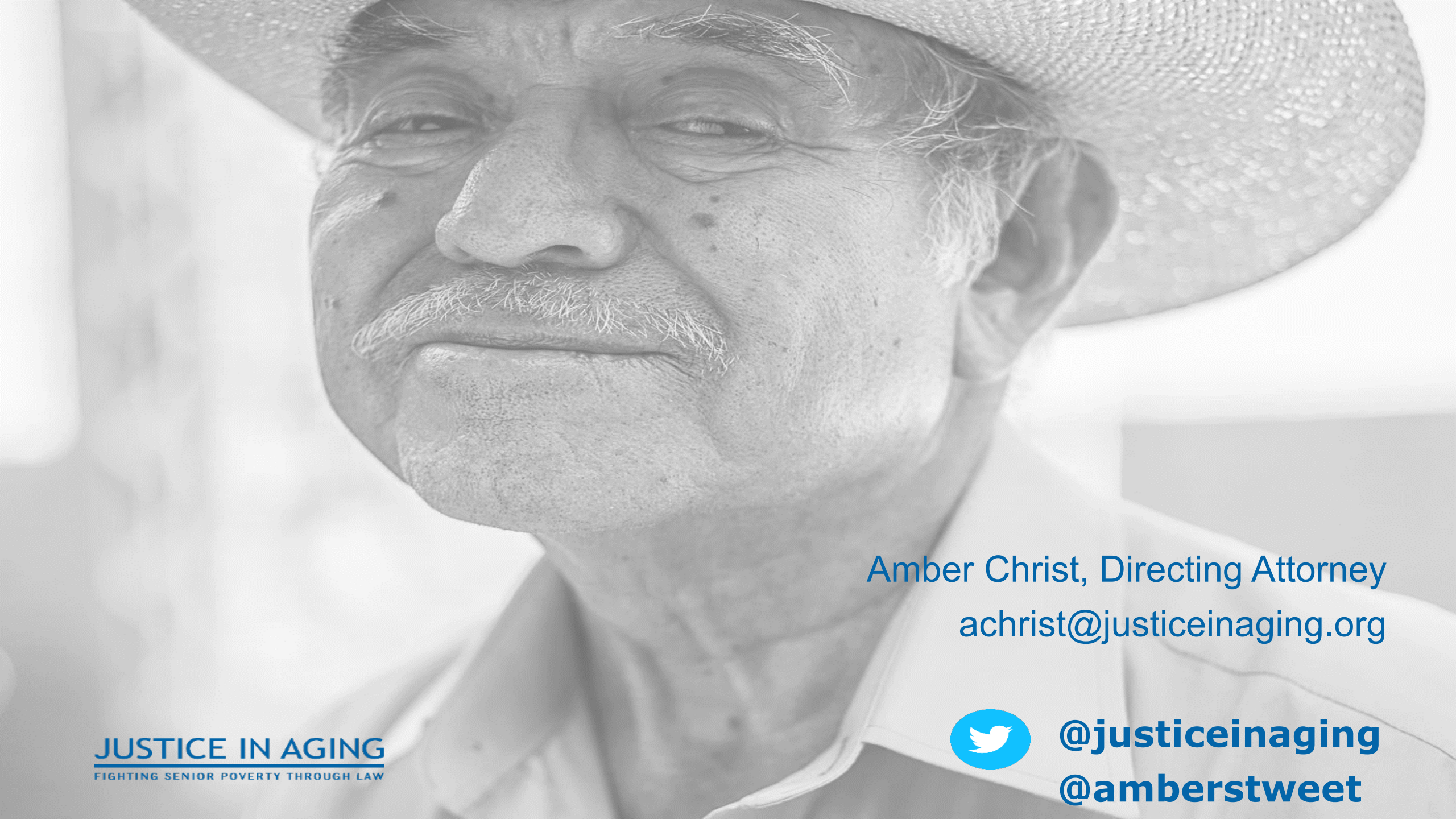
What is Needed

- Personal care/direct support services
- Companionship
- Help with cleaning, laundry, shopping, paying bills
- Supportive day programs
- Case management & coordination
- Respite

American Jobs Plan

Transformational—represents a 33% increase in HCBS spending annually

- Addresses the disparities in access based on state, race, age, and disability
- Expands services and eligibility
- Addresses policies that perpetuate the institutional bias
- Provides supports for the workforce



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Moderated Discussion

Thank You for Attending

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