



# The Grassroots Project

Engage. Connect. Advocate.

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Administered by Human Services Research Institute  
with funding from the Administration for Community Living



Today's webinar:

An Overview of H.R. 1

Significance for People with  
Disabilities

State level perspective and a panel  
discussion

# Webinar logistics

- Participants will be muted during this webinar. Please use the chat feature in Zoom to ask questions and communicate with the hosts.
- Toward the end of the webinar, panelists will have an opportunity to respond to questions that have been entered into the question-and-answer portal.
- The webinar will be live captioned in English and live interpreted in Spanish.
  - Live English captions can be accessed by clicking the “CC” button at the bottom of your Zoom screen.
  - Live Spanish interpretation can be accessed by clicking the “interpretation” button at the bottom of your Zoom screen (world icon). Once in the Spanish channel, please silence the original audio.
  - Se puede acceder a la interpretación en español, en vivo haciendo clic en el botón "interpretation" en la parte inferior de la pantalla de Zoom (icono del mundo). Una vez en el canal español, por favor silencie el audio original.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



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- Follow-up questions and feedback about the webinar can be addressed to [grassroots@hsri.org](mailto:grassroots@hsri.org). This email address is not monitored during the webinar.
- Grassroots Project webinars are not officially approved for Continuing Education Units (CEUs). However, we do provide a confirmation of attendance in case an organization wishes to use participation in our webinars to grant credit for internal requirements. Zoom will automatically send attendees a confirmation of attendance one day after the webinar.
- All registrants will receive a link to the webinar recording and other materials such as slides and resources shortly after the webinar.
- Additionally, Grassroots Project webinars and associated materials such as plain language summaries and transcripts are archived on the Grassroots Project website:  
<https://www.hsri.org/projects/the-grassroots-project/>

# Who's here?

“In what ways do you identify with the disability community? Please select all that apply.”

1. Person with a disability/disabled person
2. Person with a disability who uses long-term services and supports and/or a home and community-based services waiver(s).
3. Advocate
4. Family member/loved one of a person with a disability/disabled person
5. Person working in a disability organization
6. Caregiver or staff supporting a person with a disability

# Today's webinar: An overview of H.R. 1

In this national webinar, the Grassroots Project will host a walkthrough and overview of H.R. 1, focusing on how the legislation pertains to people with disabilities.

Designed as an informational session, we hope this webinar will support participants in understanding the legislation and staying informed as the policy environment evolves.

We will hear from national experts and advocates about parts of H.R. 1 with particular significance for people with disabilities.





# Today's Speakers

- Jennifer Johnson, AoD
- Alison Barkoff, GWU
- Sarah Swanson, UNMC
- Ben HsuBorger,  
#MEAAction
- Jessica Podesva, NCIL
- Erin Prangely, NACDD



**Jennifer Johnson,**  
Deputy Commissioner  
of the Administration  
on Disabilities



**Dr. Jennifer Johnson is the Deputy Commissioner of the Administration on Disabilities (AoD), part of the U.S. Department of Health and Human Services' Administration for Community Living.**

**AoD's mission is to equip individuals with disabilities of all ages with opportunities, tools, and supports to lead lives of their choice in their community. Its programs are working to create change and improve the lives of the estimated 61 million individuals with disabilities living in the US by advancing opportunities for inclusion and participation in the community, employment and financial well-being, and independence and self-determination.**

**Dr. Johnson has served as the Deputy Commissioner since September 2019, with a focus on improving the quality, accountability, and evidence base of AoD's programs and initiatives. She supports planning and oversight of AoD's \$355 million budget that funds a number of disability programs and projects across the US and its territories.**

**Her 30-year career in government, academia, national organizations, and school systems demonstrates a clear commitment to improving opportunities for people with disabilities to lead full lives in the community, with emphases on improving outcomes for people with disabilities**



**Policymaker  
messaging around  
the goals of H.R. 1  
related to Medicaid  
has included:**

- Tightening of eligibility and oversight standards
- Reduction in Federal spending
- Shifting more control to states

# Grassroots Project

The ACL Grassroots Project: Engage. Connect. Advocate. launched in 2023-2024 with the goal of supporting national, state, and local disability advocates to build networks and grow advocacy leadership, with the intention of driving disability policy and supports to serve disabled people and communities robustly and wholly.

# Project approaches

- Develop **structures, processes, and relationships** necessary to build the next generation of **cross-disability, cross generational, and culturally diverse leaders** within the disability community.
- 
- **Connect, grow, and strengthen networks of grassroots disability focused people and coalitions** supporting each other to engage in improving disability support systems at the local, state, and national level.



# Key Partners

- A funded National Advocacy and Action Coalition (NAAC)
- An advisory State Agency Partnership Group (SAPG)
- Supported State and Local Advocacy and Action Coalitions (StAACs and LAACs)

# H.R. 1 and Its Significance for People with Disabilities

**Alison Barkoff, J.D.**

Hirsh Health Law and Policy Associate Professor  
and Program Director

GW Milken Institute School of Public Health

# Key Changes From H.R. 1

**Reductions in  
Medicaid Funding  
and Impacts on  
Home and  
Community Based  
Services Over Time**

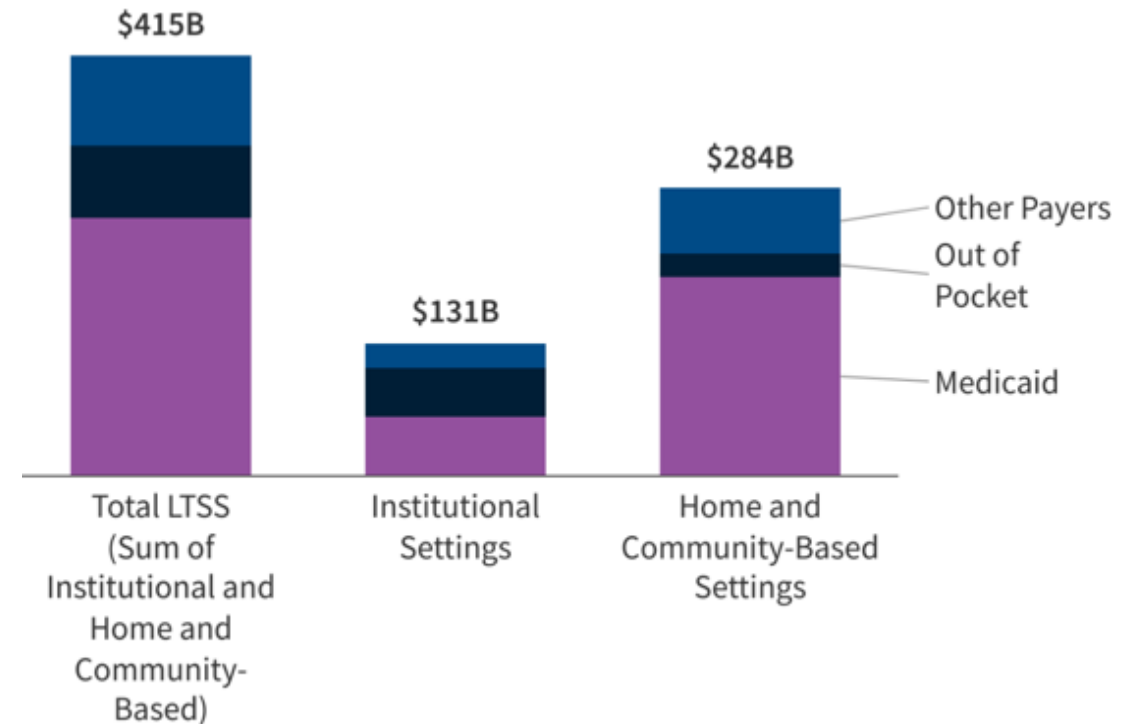
**New Flexibility in  
1915(c) Waivers for  
People Who Do Not  
Meet An  
Institutional Level  
of Care**

**Changes in  
Medicaid Coverage  
Due to Work  
Reporting  
Requirements**

# Home and Community-Based Services

# Medicaid is Critical for People with Disabilities

- Medicaid is the **primary funder of long-term services and supports**, both in institutions and in the community
- Vast majority of people with disabilities who need LTSS **prefer to live in their own homes and communities**
- Home and Community-Based Services (**HCBS**) **can cover a range of services** like personal care, adult day, respite, habilitation, transportation, and home modifications



# State budgets: Medicaid HCBS is optional

- States *must* provide institutional care to all Medicaid beneficiaries who need it because it is a “mandatory service”
- State do not *have* to provide HCBS at all and, if they do, they can limit the number of people who get HCBS because it is an “optional service.”
  - Because HCBS are optional, most states have waiting lists. Currently more than 600,000 are on HCBS waiting lists across the country.
- Because HCBS is an *optional* service, states have a lot of flexibility to decide about how to structure their HCBS program, including how many people they will serve, what services they will provide and at what levels, and reimbursement rates.

# H.R. 1 and HCBS

- Changes to federal Medicaid financing through H.R. 1 have **increased pressure** on state's Medicaid budgets
- H.R. 1 **does not directly reduce funding** for LTSS generally or HCBS specifically, but does **significantly reduce federal Medicaid funding** to states
- States often need to adjust funding for **optional services** to balance their budgets.

# History Repeating?

- Historically, when states have faced shortfalls in their Medicaid budgets, **optional services like HCBS have been cut**
- We are already starting to see proposals to cut HCBS in numerous states

Exhibit 1. Number of states reducing HCBS spending between 2010 and 2012 and average reduction.

	Spent less per person*		Served fewer people		Either/both
	# States	Average reduction	# States	Average reduction	# States
IDD Waiver programs	33	10.8%	8	2.2%	36
Other Waiver programs / PCS	35	11.8%	20	8.3%	41
Home health	23	22.2%	29	15.1%	40
<b>Cuts to any program</b>	<b>47</b>		<b>40</b>		<b>51</b>

# Ways States Might Reduce HCBS In Response to Changes in Federal Medicaid Funding

**Elimination of HCBS programs or services within programs**

**Reduced waiver slots or service caps**

**Reductions in HCBS provider rates**

**Higher eligibility for HCBS programs (esp. Level of Care)**

**Reduced capitation rates**

**Policies that move people into more congregate supports**

# Impacts When HCBS Funding Is Reduced

**Decreased utilization of HCBS and longer HCBS waiting lists**

**Worsened direct care workforce crisis**

**Increased number of family caregivers**

**Higher use of institutional care**

**Increased physician visits, ER visits, and mortality**

**Increased use of congregate settings over individualized supports**

# H.R. 1's New HCBS Flexibility

- **Creates a new HCBS flexibility for 1915(c) waivers that do not require an institutional level of care**
  - Could be helpful to serve people with behavioral health needs or whose impairments do not yet meet an institutional level of care
  - H.R. 1 requires states to ensure that the new services do not negatively impact the waiting list for traditional 1915(c) services
  - Authority begins in July 2028
  - \$100 million total available to states to implement the new authority
- **The potential for states having resources in the short term to take advantage of this new HCBS flexibility is unknown**

# Community Engagement Requirements

# Disabled People Are Part of the Medicaid Expansion Population

- **An estimated 20% or more of the expansion population has disabilities**
  - Includes people with mental health disabilities, substance use disorders, or people who have impairments that do meet the strict SSI/SSDI standards
- **ACA Medicaid expansion has increased access to LTSS**
  - 1 in 5 enrollees under 65 who use institutional LTSS and 1 in every 10 enrollees under 65 who use Medicaid HCBS are eligible for Medicaid through the ACA expansion

# H.R. 1 Community Engagement Requirements

- **Who:** Adults 19 to 64 in states that took up the Affordable Care Act's Medicaid expansion option
- **Requirement:** 80 hours/month of work or community engagement unless the person can prove they meet an exemption
- **Proof:** Must verify meet requirements at application & every 6 months
- **Scope:** Nationwide – no state opt-out
- **Timeline:** States must implement by **Jan. 2027**
  - Good faith extensions in H.R. 1, but CMS has said will use sparingly

*The Congressional Budget Office estimated **5+ million** people may lose coverage, mostly due to administrative burdens*

**Source:** CBO, [https://www.cbo.gov/system/files/2025-06/Wyden-Pallone-Neal\\_Letter\\_6-4-25.pdf](https://www.cbo.gov/system/files/2025-06/Wyden-Pallone-Neal_Letter_6-4-25.pdf)

# Exemptions Specific to Disabled People and Caregivers

- **Medically frail**

- Blind or SSI/SSDI disability
- Has substance use disorder
- Has a “disabling mental disorder”
- Serious or complex medical condition
- Disability that significantly impairs 1 or more Activity of Daily Living

- **Others**

- Disabled veterans; optional temp. exemptions (inpatient care, travel for extended medical care)

- **Caregiver of a child under 14 or disabled person**

- Broad definition of caregiver in the RAISE Family Caregiver Act

# Ways Grassroots Can Work With Your State

## Exemption Definitions

- Collaborate to develop definitions for disability in “medically frail” and caregiver exemptions as broad as possible, consistent with H.R. 1 and forthcoming CMS guidance

## Verification, Data & Application

- Explore all data sources, including MCOs, claims data
- Add questions to application to flag likely to be exempted
- Self-attestation whenever allowed

## Limit Burdens

- Maximize length of exemptions
- Minimize the look back to 1 month & the # of months of compliance per redetermination
- Minimize redeterminations to every 6 months

# Grassroots Outreach and Partnerships Will Be Key

**Centers for Independent Living**

**Aging and Disability Resource Centers**

**Protection and Advocacy Agencies**

**State Councils on Developmental Disabilities**

**Mental Health Organizations**

**University Centers for Excellence in Developmental Disabilities Education, Research, and Service**

# Thank you!

Alison Barkoff, J.D.

# H.R. 1 and Key Changes in States

**By: Sarah Swanson, MPH**

**AUCD Consultant & Assistant Professor**

**UNMC Munroe-Meyer Institute (Nebraska's UCEDD)**

# H.R. 1 and Key Changes in States

Largest reduction of federal funding to  
Medicaid in history

- Commonwealth Fund, October 2025

20% reduction of federal funding to  
the SNAP program

- Harvard Kennedy School, Nov. 2025

Changes how some states  
finance Medicaid

- Commonwealth Fund, Dec. 2025

# Timeline for H.R.1 Implementation Requirements



**Medicaid community engagement  
requirements in expansion group  
2026**



**Medicaid funding changes**

**2028**



**SNAP funding changes**

**2028**

# Examples of Medicaid Optional Benefits

- **Dental Services**
- **Dentures**
- **Eyeglasses**
- **Physical Therapy Services**
- **Occupational Therapy**
- **Personal Care Services**
- **Home and Community Based Services**
- **Private Duty Nursing**
- **Prosthetic Devices**
- **Prescribed Drugs**

# Current News

Aligning Idaho's state tax with federal tax cuts is estimated to cost **\$155 million in 2026** and **\$175 million in 2027**

**Idaho Capital Sun** ▲


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### Idaho governor approves \$22M in Medicaid disability budget cuts

Bill calls for cuts to residential habilitation providers' reimbursement rates, which come on top of other recent pay cuts

BY: KYLE PFANNENSTIEL - MARCH 27, 2025 9:31 AM



**Idaho Capital Sun** ▲

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### Idaho cuts doctor pay rates for Medicaid. More cuts could come, Health and Welfare says.

Cuts could leave fewer doctors in the state who accept Medicaid, a health insurance program for people with low incomes, disabilities, pregnant moms and some seniors

BY: KYLE PFANNENSTIEL - AUGUST 26, 2025 2:25 PM



### Impact of state budget cuts gets real as lawmakers start trimming Medicaid programs

By Bente Birkeland and John Daley · Mar. 12, 2026, 7:50 pm

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MEDICAID

## NC Medicaid leaders seek funding strategy as federal work requirements – and their costs – loom

Officials present hospitals, more taxes on health insurers and state savings as options to cover rising adminis

by Jaymie Baxley  
January 30, 2026

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## NC NEWSLINE

STATE, LOCAL GOVT. EDUCATION ENVIRONMENT COURTS, JUSTICE COMMENTARY PODCASTS NATIONAL

FEDERAL GOVERNMENT HEALTH STATE, LOCAL GOVT.

## North Carolina to cut Medicaid rates by 3% across all providers in October

Inpatient services and autism treatment will see cuts of up to 10%, while coverage for GLP-1 drugs for weight loss will cease.

BY: BRANDON KINGDOLLAR - AUGUST 13, 2025 4:12 PM

Twitter X Facebook LinkedIn Email RSS



HEALTH

## Oregon lawmakers confront ballooning Medicaid costs

Updated: Jan. 14, 2026, 9:39 a.m. | Published: Jan. 14, 2026, 6:30 a.m.





A nurse in Bryan Health's neonatal intensive care unit uses a stethoscope to listen to the heart of a baby born more than 10 weeks premature in 2023. A proposal from the Department of Health and Human Services would eliminate retroactive coverage for Medicaid-eligible patients, including newborns and pregnant women. Photo courtesy of Bryan Health.

**Nebraska seeks to end retroactive Medicaid coverage  
Hospital leaders say it will have a 'disastrous' impact**

State officials say the move would save the state millions of dollars and incentivize hospitals to enroll low-income Nebraskans sooner.



**Nebraska Examiner**

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**Families urge lawmakers, DHHS to stop Medicaid waiver caps for Nebraskans with disabilities, elderly**

'If we get a drop in our quality of care, I know for a fact I would be dead,' says Derek Caster, whose care is covered under Aged and Disabled Waiver

BY: ZACH WENDLING - JANUARY 20, 2026 5:30 AM



# Nebraska Changes Course




Good Life. Great Mission.

Administration & Support | Divisions & Offices | Licensing & Regulations | Assistance Programs | Children, Families & Seniors | Public Data | Health & Wellness | Vital Records

**News Release**

## Governor Pillen Directs DHHS To Make Critical Changes To AD Waiver

For Immediate Release: 1/27/2026

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**MEDIA CONTACT**  
Erin Maier, (531) 893-1359  
[erin.maier@nebraska.gov](mailto:erin.maier@nebraska.gov)

*Nebraska Families' Input Drives Key Changes Ahead of Waiver Renewal*

**Lincoln, NE** – At the direction of Governor Jim Pillen, and following a thorough review and extensive public input process, the Nebraska Department of Health and Human Services (DHHS) is revising proposed changes to the Aged and Disabled (AD) Waiver.

“I am truly appreciative of the Nebraskans who reached out to my office and participated in the public feedback process,” said Governor Pillen. “Based on my conversations with dedicated family members and AD Waiver recipients, I directed DHHS to take a second look at the proposal and make necessary changes to ensure Nebraska families continue receiving the support they need.”

*Medicaid*  
Medicaid Matters New York  
*Matters*

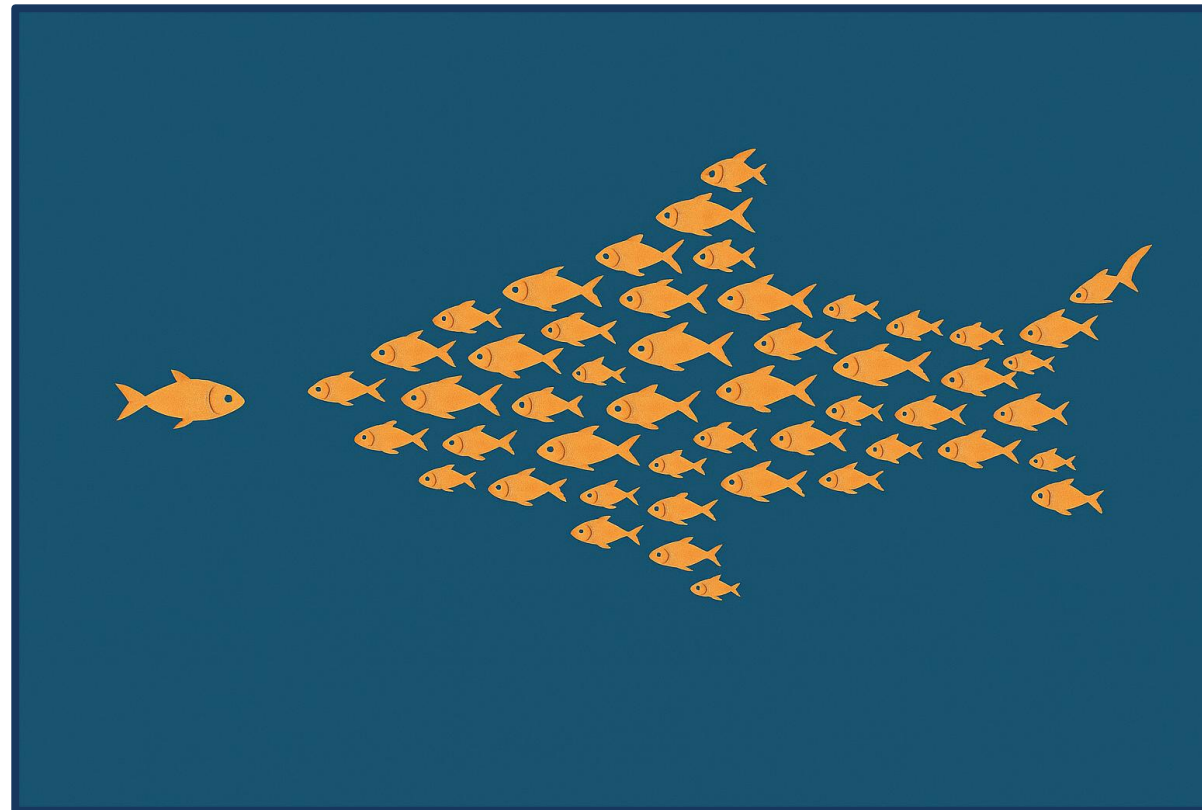
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## A Vision for NY Medicaid in 2026

Jan 5, 2026 | News, Policy & Budget Agenda

## Strength in Numbers



ALASKA | News

## Alaska disability advocates praise progress and push for more at state Capitol

GOV & POLITICS, HEALTH CARE, COURTS & JUSTICE | Mar 20, 2026 | 8:19 pm ET | By Corinne Smith

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Judy and Eric Edwards pose for a photo at a ribbon cutting ceremony for a new universal changing station installed on the first floor of the Alaska State Capitol on Mar. 19, 2026. (Photo by Corinne Smith/Alaska Beacon)

- **Attend public meetings**
- **If the state is hosting listening sessions- attend!**
- **If your state has public comment periods open for your changes to your Medicaid state plan or Medicaid Waivers, make comments.**

# State Committees and Councils

## Independent Living Systems

- Statewide Independent Living Council
- Centers for Independent Living (CILs)

## Developmental Disabilities Programs

- Council on Developmental Disabilities
- University Centers for Excellence in Developmental Disabilities
- Disability Rights

## Medicaid Program

- Medicaid Advisory Committee (MAC)
- Beneficiary Advisory Council (BAC)

## Traumatic Brain Injury Programs

- TBI State Partnerships

# Medicaid Advisory Committees and Beneficiary Advisory Councils

- **Medicaid Advisory Committee (MAC)**
- **Beneficiary Advisory Council (BAC)**

Bring questions and/or concerns about things you've encountered or things you are hearing about in the community. (Ex. Medicaid denials)

# What's Your State Doing?

## Ask your Medicaid State Agency what process they are putting in place to:

- Define those who are exempt from work requirements
- Validate (or confirm) exemption from work requirements
- What definition is the state using for “Medical Frailty?”
- Are any optional Medicaid benefits or home & community-based services being reduced or capped?

## Do you know how to find or contact your state's:

- Medicaid Director
- Medicaid Deputy Director
- Director of Developmental Disabilities
- Director of Mental Health
- Aging and Disabilities Director

# Medicaid Program and Waiver Names

**Medicaid and Medicaid Waiver Programs have different names in every state:**

## Waiver Names:

- Physical Disability Waiver
- Aged & Disabled Waiver
- Community First
- Intellectual Disability Waiver

## Medicaid Programs:

- Nebraska: Heritage Health
- Oklahoma: SoonerCare
- California: Med-Cal

**Do you know the name of your state's Medicaid program and the Home and Community Based Services Waiver that is important to you?**

# Discussion Panel

Ben HsuBorger

#ME Action

Erin Prangle

NACDD

Jessica Podesva

NCIL

# Contact Us:

[Grassroots@HSRI.org](mailto:Grassroots@HSRI.org)

## Stay tuned for ...

- The recording and PowerPoint for this webinar will be available for download at:

<https://www.hsri.org/projects/the-grassroots-project/>



# Thank you

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**Please Complete Our  
Engagement Survey:**

[https://qualtricsxm6vjvbs97z.qualtrics.com/jfe/form/SV\\_81x758iFuEqIGce](https://qualtricsxm6vjvbs97z.qualtrics.com/jfe/form/SV_81x758iFuEqIGce)

