



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



Today's webinar is:

*Coalition Building:
Strategies and
Perspective in Disability
Advocacy*

Please introduce yourself in chat



Webinar logistics

- Participants will be muted during this webinar. Please use the chat feature in Zoom to ask questions and communicate with the hosts. Urgent individual concerns should be directed to alulinski@hsri.org
- Toward the end of the webinar, panelists will have an opportunity to respond to questions that have been entered into chat.
- 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.
- Due to a recent Zoom update, full accessibility including ASL interpretation may not work if you are joining with a mobile device ASL interpretation, and slides can no longer be viewed simultaneously via phone or tablet. Swipe on your mobile device to find the ASL interpreter if you need to.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- Follow-up questions and feedback about the webinar can be addressed to grassroots@hsri.org. *This email is not monitored during the webinar.* For urgent matters contact alulinski@hsri.org
- 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 one day after the webinar.
- Grassroots Project webinars and associated materials such as plain language summaries and transcripts are archived on the Grassroots Project website at <https://bit.ly/3U5SYvW>

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

Project Goal & Purpose

ACL's Grassroots Project: Engage. Connect. Advocate. was launched in 2023 to support national, state, and local disability advocates in building networks to stay informed about the policies that affect people with disabilities. The Grassroots Project will also support disability advocates to work together to ensure their perspectives, priorities and preferences are reflected in disability policies and service systems.



Webinar aim:

This national webinar – the second hosted by the Grassroots Project – provides an opportunity to hear from community organizers and disability advocates on how they build and collaborate in local, state, and regional coalitions. This webinar will give attendees greater insight into the strategies and tools for, and challenges in coalition building, sustainability, and adaptability.



Agenda

- Introductions, welcomes, and logistics from the project team
- Presentations from coalitions
 - Going Home Coalition
 - Southern Disability Justice Coalition
- Facilitated Discussion

Grassroots Project team at HSRI



Alixe Bonardi

Grassroots Project Co-Director
Vice President, HSRI

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Kate Brady

Grassroots Project Co-Director

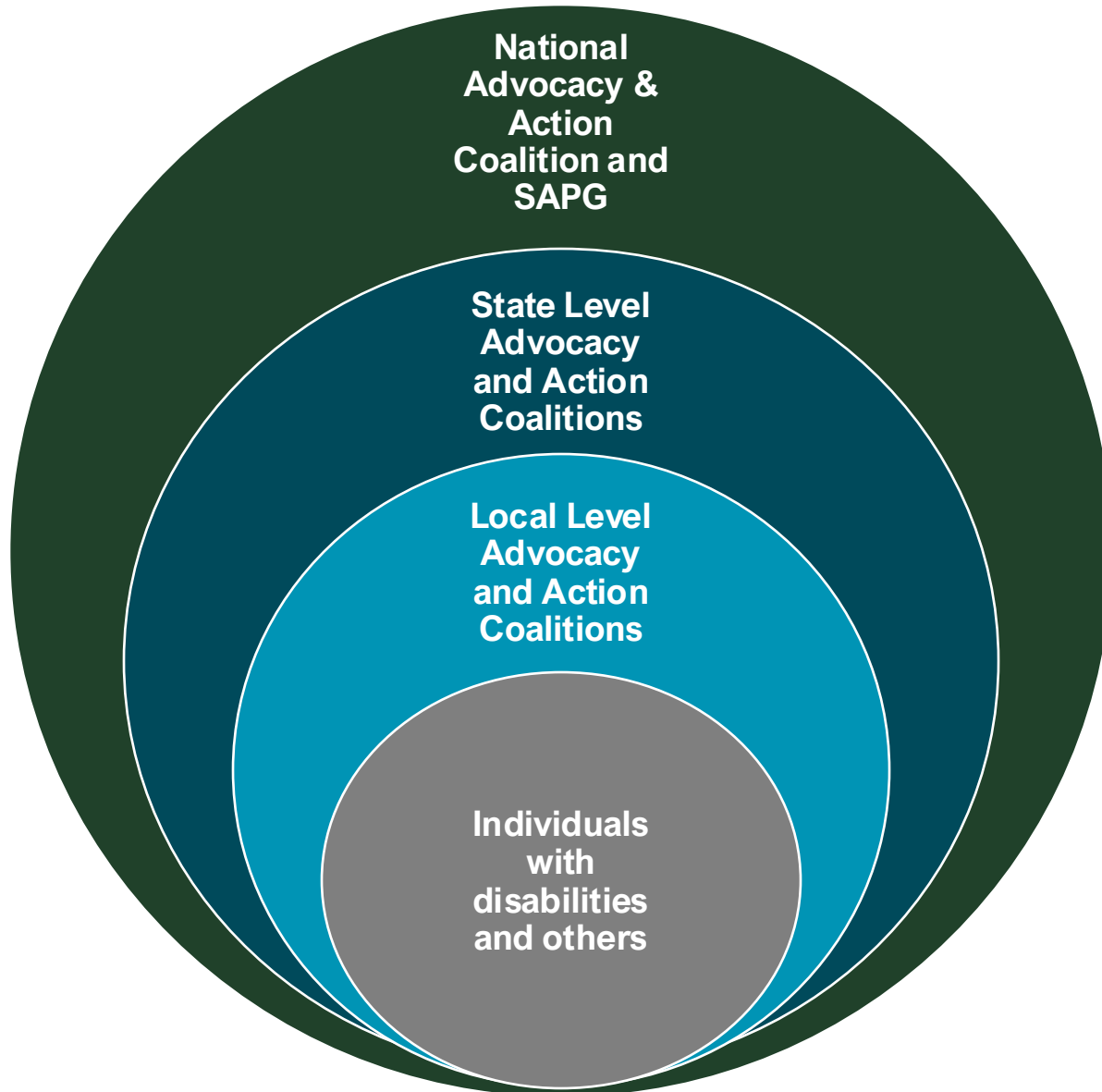
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Laura Bernas

Grassroots Project Coordinator

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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

Project approaches

- Develop **structures, processes, and relationships** necessary to build the next generation of **cross-disability, cross generational, and culturally diverse leaders** within the advocacy movement.
-
- **Connect, grow, and strengthen networks of grassroots advocacy and action coalitions** supporting each other and with the skills and knowledge to advocate for improvements in the quality of community living.

Advocacy and advocacy*

Advocacy

- Direct action
- Lobbying
- Note the Byrd Amendment
 - *Second, Title 31 Sec 1352 of the United States Code, commonly referred to as the Byrd Amendment to the Federal Acquisitions Regulations (FAR), places lobbying restrictions on organizations that receive federal grants and federal contractors. These prohibit the use of federal funds for lobbying purposes, but generally allow those organizations to lobby provided they use non-federal funds.*

advocacy*

- Education
- Information dissemination
- Preparation
- Organizing

Lowercase “a” in **advocacy** is the work that local, state and advocacy and action coalitions affiliated with the Grassroots Project can be engaged in.



Meet the Coalition Representatives

- Carole Rosen
- Lila Zucker

Going Home Coalition

The Grassroots Project

0 7.18.24



Going Home Coalition - History

- LIFE Campaign
- Going Home Campaign
- Going Home Community Inclusion Coalition
- Going Home Coalition
 - Illinois Council on Developmental Disabilities - 3 Years
 - Coleman Foundation – Began 6.2023
 - Grassroots Project – Began 6.2024



Going Home Coalition

Redefining, Reimagining, Reinvigorating, Revitalizing

Carole Rosen

Advocacy Program Specialist

Going Home Coalition - 2021

REV UP Illinois - 2022

- Illinois Council on Developmental Disabilities
 - 2014 until 2020
 - Executive Committee
 - Community Housing and Inclusion Committee
- CSH IHDA SHPA
 - Permanent Supported Housing Institute
- National Disability Institute.
 - Financial Wellness Trainer
- PATH/MAPS Training
- Masters of Interior Design
 - Certified Aging in Place Specialist
 - Universal Design



Going Home Coalition

Vision

For people with disabilities in Illinois is to live in a truly individualized person-centered system with the supports and services they choose.


Everyone, no matter what challenges they may face, has the right to live a full life in the community. Community is strengthened by diversity, inclusion, and accessibility.

Mission

The Going Home Coalition is a diverse statewide network of self-advocates, families, community service providers and allies. We purposefully advocate to create systems change, transition institutional living through increasing community capacity, and empower fair and equal choices and opportunities for people with intellectual and developmental disabilities.



Illinois by the Numbers

Kathy Carmody, CEO
kathy@instituteonline.org
The Institute Online

**Illinois Services for People with Intellectual and Developmental Disabilities by the Numbers
2023**

- 7 = Number of Illinois state institutions
- 17 = Number of states with no state institutions
- 1,645 = Number of people living in Illinois state institutions
- 16 = Number of states with fewer than 200 people living in state institutions (1)
- 49 = Number of states with fewer people living in state institutions than Illinois (1)
- \$347,375/Yr. = FY22 Interim average annual Medicaid claiming rate for all Illinois state institutions (2)
- \$405,150/Yr. = FY22 Interim average annual Medicaid claiming rate for most expensive Illinois IDD state institution (2)
- \$90,728/Yr. = 2022 average topline CILA reimbursement for people receiving 24-hour care (3)
- 26% = Average topline CILA reimbursement compared to FY22 interim average annual Medicaid claiming rate for state institutions (2) (3)
- 2.5x = Number of people in CILA settings with total/extensive support needs compared to the entire population of Illinois state institutions (3)
- 36% = % of CILA residents age 60+
- 44% = Turnover rate for Illinois community Direct Support Professionals (DSP) (4)
- 58% = Illinois minimum wage increase since 2019
- 37% = Statewide CILA DSP reimbursement increase since 2019
- 31% = Difference between statewide CILA DSP reimbursement and statewide minimum wage
- 50% = Guidehouse recommended difference between CILA DSP reimbursement and statewide minimum wage
- 50th = Illinois ranking on percentage of people with I/DD in out-of-home settings who reside in a setting of 1 – 6 people (Illinois has a higher percentage of people in 7+ settings than any other state) (5)
- 46% = Illinois fiscal effort on IDD spending (\$2.87) compared to the national average of \$4.60
Fiscal effort is the amount of money spent by the state and federal government on ID/DD supports and services per \$1,000 of statewide personal income. In other words, how much a state spends on ID/DD services considering state wealth. The Fiscal Effort comparison lets us compare how much money different states spend on services and supports for people with ID/DD, even though states have different policies and state wealth. (5)
- 9% = Institutional services percent of national fiscal effort spending on IDD services (5)
- 35% = Institutional services percent of Illinois fiscal effort spending on IDD services (5)
- 6 = Number of years Illinois has been out of compliance with the Ligas Consent Decree (6)


1 2022 U/CP Case for Inclusion
2 9/1/22 IDDI Medicaid Rates for DHS State-Operated Facilities Memorandum
3 IDHS CILA Rates Annual Update 6/30/22
4 2020 NCI IDD Staff Stability Survey Report
5 University of Kansas State of the States in Intellectual Disabilities Report
6 Ligas Court Monitor 8th Annual Report to the Court

<https://www.instituteonline.org/wp-content/uploads/2023/08/Illinois-IDD-Services-by-the-Numbers-2023.pdf>

Accessed 07.05.24

Going Home Coalition Teaches Advocacy

Empowering Coalition members through teaching them advocacy skills and supporting self determination. Participants are advocating for inclusion, independence, individualized person-centered supports, employment opportunities, fair wages for support staff, affordable housing and accessibility to create systems change.



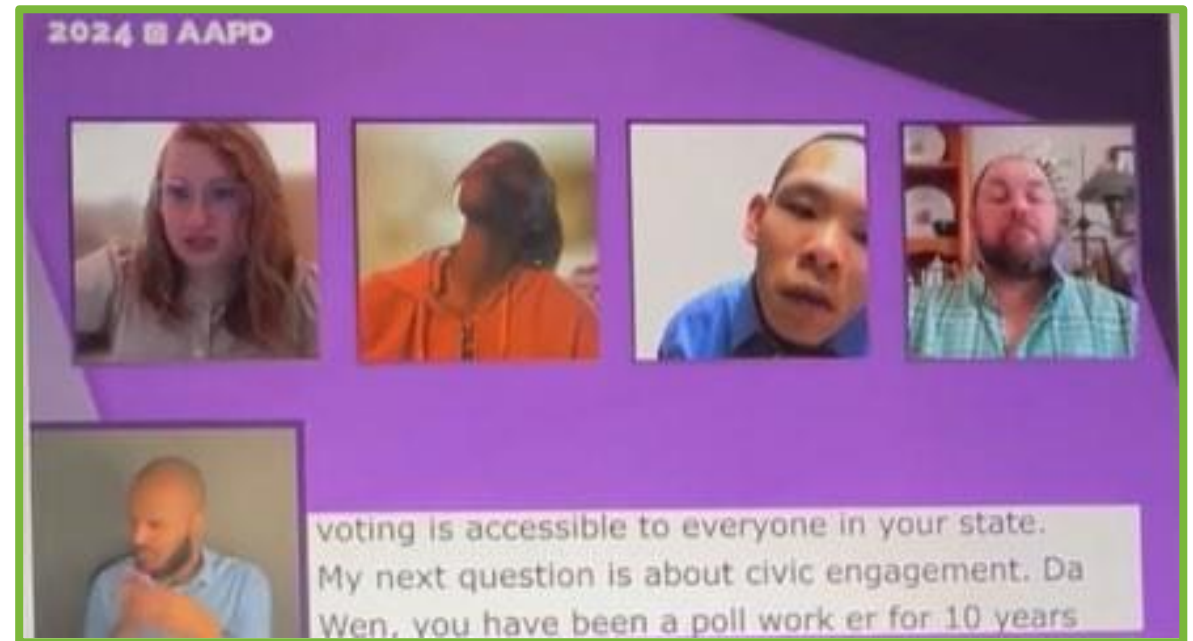
Action Steps

- Monthly Meetings
 - 9 Module Legislative Advocacy Series
 - Membership Directory
 - Legislative Meetings
 - Meetings with IDHS-DDD staff-Governor's Policy Staff
 - Regional Trainings
 - Diversify and Increase Membership Base
 - Tech Study
 - Support Coalition Members Calls to Action Events in State Operated Developmental Centers
 - Resource Events
 - Story Telling
 - Media Presentations
 - Website Refresh
 - Expansion of Social Media Platforms
 - Sustainability
 - Advocacy Day
-



Action Steps – Activating Advocates

- Self Advocate Co-presenters
 - Monthly Meetings
 - Presentations
- Board Appointments
 - Quality Care Board
 - SHPA Peer Development
 - Homelessness Task Force
 - Emergency Preparedness
 - DD Advisory Council
 - 708/377 Board
- AAPD – REV UP National Panel
 - Polling Place Accessibility Project
 - Disability Voting Rights Week
- Disability Pride Parade



Results



“Helped in being better advocate for all.”

"The number of people who attend the event provides strong motivation to follow up and take action."

“I assist in helping with our self advocacy meeting. We started the group during the pandemic and it’s an adjustment for many who have never advocated in a larger capacity before. It’s been life-changing for our members.”

“Participating in email action alerts; sending letters about various issues.”

“I acquired new ideas for advocacy.”

“It helped me assist individuals in our self-advocacy group to use their voices and actions to facilitate their own self-advocacy meeting. I’m learning how to let go of leading the meeting and assist members in leading their own meeting. Watching how your presenters lead with respect to one another and allow everyone to speak and take turns has been inspiring.”

Carole Rosen

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[Website](#)

[Facebook](#)

[Instagram](#)





**NEW
DISABLED
SOUTH**

Southern Disability Justice Coalition

Lila Zucker, Organizing Director (she/her)

About Us

New Disabled South (c3) and New Disabled South Rising (c4) are fighting for disability rights and disability justice in 14 states:

Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia



About Us, continued

Mission: to improve the lives of disabled people and build strong disability justice and rights movements in the South.

Vision: A South where liberation and justice for all disabled people is achievable

How do we get there?

We are **building** a coalition of disability justice activists, advocates, and organizations in the South.

We are **fighting** for policies at the state and local level that help improve the lives of disabled people in the South.

We are **researching** the most impactful issues disabled people in the South face and finding solutions that center justice.



The Reality of Being Disabled In The South

The majority of the 61 million disabled people in America reside in the South, and with a large number of them being Black, Indigenous, and other people of color, the intersecting issues at play increase those disparities.

CRIMINALIZATION

- Two thirds of the state and federal prison population are disabled
- In 44 states, a jail or prison holds more mentally ill individuals than the largest remaining state psychiatric hospital
- 50% of people killed by police are disabled
- 55% of Black disabled men are likely to be arrested by 28

VOTING

- As of 2016 only 17% of polling places in the US were accessible
- While people with disabilities voted at record numbers in the last election, there were more reported barriers to voting, and many of these barriers have been put into place in the South - many new voter suppression laws have been enacted recently
- 20% of all disabled voters faced barriers to in-person voting in 2022
- 1.5 million Americans are subject to legal guardianship; at least 32,000 individuals have had their voting rights stripped due to guardianship laws

POVERTY & CARE

- Half of the 30 million people without health insurance in the United States are BIPOC, and the vast majority of uninsured people reside in the South
- Seven out of the ten states that haven't expanded Medicaid are in the South. This leaves many disabled people without access to healthcare
- Disabled people live in poverty at more than twice the rate of nondisabled people
- More than 3/4 of all people on HCBS waiver waiting lists in 2023 live in the South
- The states with the highest poverty rates are in the South



What guides our work?

This work demands that we dream – [Disability Justice](#) is the center of everything we do. We believe in a world where full participation for disabled people in every facet of life is possible and we work toward that every day.

Disability Justice (as defined by [Sins Invalid](#)), centers on the wholeness of disability and all of its intersections. Disability Justice is framed around the necessity of community and interdependence, where those most impacted lead and cross-movement solidarity achieves collective liberation. Changemakers in our space too often work in silos, which limits our effectiveness.



Southern Disability Justice Coalition (SDJC)

Who we are

The SDJC is made up of 3-5 individuals or organizations from each of the 14 Southern states in our area. These are individual disabled leaders, staff at disability organizations and staff from community organizations that are not disability focused but have or want to bring a disability justice lens to their work.

Members include a number of the federally mandated Protection & Advocacy (P&A) organizations across the South, organizations with a focus on LGBTQ+ and reproductive justice work, civic engagement and voter turnout organizations, individual disabled activists who are leaders in their community, student activists and more.

To participate in the Coalition members must agree to incorporate or strive towards the 10 principles of Disability Justice in their own work and/or in their work with the Coalition.

There are no dues to participate.



Southern Disability Justice Coalition (SDJC)

The Southern Disability Justice Coalition aims to break down silos, align on regional strategy, lift up each other's work and create spaces for disabled Southerners to lead in creating a better world

Resource Sharing and Development

The SDJC is committed to enabling our members and their communities to acquire, sustain, and develop the necessary resources to continue doing the powerful work in their respective states/areas in a larger capacity. There is so much amazing work that has been happening on the ground across the South for generations, SDJC's goal is to uplift this work and to work together to build power and increased capacity.

So many of the struggles SDJC members are navigating are nearly identical to the struggles others have faced in different states and by sharing resources, information, strategies and connections we are able to focus on fighting for our communities rather than replicating what has already been created elsewhere.

Regional Interdependence

Operating as individual actors and moving in siloes limits the power and impact of our movements. United, we can go farther and have more sustained success for our communities and movements. So many Coalition members thought they were the only ones doing this type of work and discovering they're not alone has opened many doors for connection and collaboration.



Southern Disability Justice Coalition (SDJC), continued

SDJC meetings as a full Coalition once a month and provides updates, information and calls to action to members in between meetings through email and a private Slack workspace.

The Coalition currently has 4 active workgroups which meet about every 6 weeks:

- Voting & Elections
- Criminalization
- Home & Community Based Services (HCBS)
- Labor, employment + technology

New Disabled South staff are constantly reassessing the Coalition, the timing/number of meetings and the ways that we can support SDJC so that it's as useful and accessible as possible for our members



New Disabled South's Southern Disability Justice Coalition



Lila Zucker

Organizing Director

SDJC Facilitator

lila@newdisabledsouth.org

If you're an organization interested in working with
New Disabled South, please email organizing@newdisabledsouth.org

[Website](#)

[Facebook](#)

[Instagram](#)

[Twitter](#)



Discussion with the Coalitions & Questions from the Chat

Thank you & stay tuned for...

- The recording and PowerPoint for this webinar will be available for download at:
<https://bit.ly/GrassrootsProject>
- Contact us: Grassroots@HSRI.org



Scan me

