



# 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 is:

*Finding One's Advocacy  
Community – Stories and  
Insights from the  
Disability Community*

*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.
- 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.
- 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](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 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

*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.*

# Webinar aim:

*In this first national webinar, we seek to learn from disability advocates and hold a conversation about how advocates stay informed, work together, and mobilize to make change in their communities and services systems.*

# Agenda

- Introductions and welcomes from the project team – ACL and HSRI
- Project overview
- Introduction of Panelists
- Facilitated Discussion



# Grassroots Project team at HSRI



**Alixe Bonardi**

Grassroots Project Co-Director  
Vice President, HSRI

[abonardi@hsri.org](mailto:abonardi@hsri.org)



**Kate Brady**

Grassroots Project Co-Director

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**Laura Bernas**

Grassroots Project Coordinator

[lbernas@hsri.org](mailto:lbernas@hsri.org)



## **Jennifer Johnson,** Acting Commissioner of the Administration on Disabilities



Dr. Jennifer Johnson is the Acting Commissioner of the Administration on Disabilities (AoD), part of the U.S. Department of Health and Human Services' Administration for Community Living. The Administration on Disabilities' 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 wellbeing, and independence and self-determination.

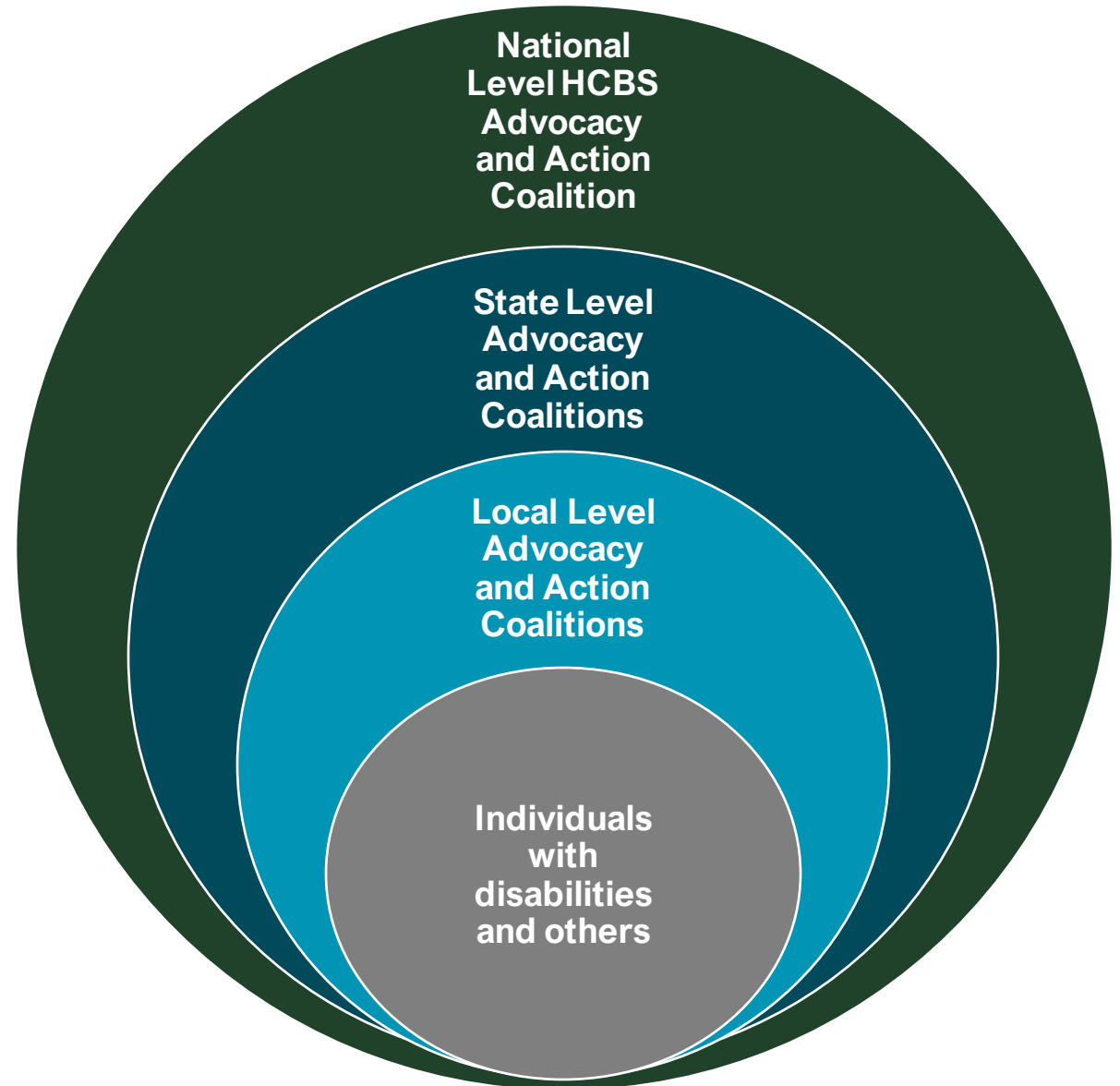
Dr. Johnson previously served as the Deputy Commissioner since September 2019, with a focus on improving the quality, accountability, and evidence base of the Administration on Disabilities' programs and initiatives. She supports planning and oversight of the Administration on Disabilities' \$355 million 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 local school systems demonstrates a clear commitment to improving opportunities for people with disabilities to lead full lives in the community, with emphases on diversity, inclusion, and advancing a diverse array of programs for underserved and unserved individuals and communities.

# Project vision

The ACL Grassroots Project will position the next generation of cross-disability, cross generational, and culturally diverse grassroots advocates as leaders. Advocates will be supported to be catalysts of systems change who hold states and/or providers accountable and responsive to input.

HSRI will lead a national effort to support disability grassroots advocacy by partnering with national organizations to support state and local advocacy and action coalitions in leveraging the ACL disability networks in each state and territory to advance quality community living.



# The ACL Grassroots Project

- What is it?
- What do we seek to accomplish?



# 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.
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- **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.

# Key project activities

- Environmental Scan of gaps in advocacy, existing resources to support advocacy, and the infrastructure for advocacy
- Host web-based trainings and provide technical assistance that meet the needs of the advocacy and action coalitions
- Produce an Advocacy Resource Hub
- Generate a toolkit of innovative advocacy examples
- Support the growth of a new generation of advocates to engage across the following 6 ACL focus areas:
  - 1) Person-centered planning, consumer direction, and self-direction
  - 2) Caregiver crisis
  - 3) Health and safety in community living
  - 4) HCBS settings rule
  - 5) Civil rights
  - 6) Community integration

# Immediate outcomes

With special attention on **1) the formation of new grassroots advocacy partnerships, 2) the number of improved state and local policies, 3) the number of grassroots advocates who become trainers** (e.g., of the Center, train-the-trainers), and **4) advocates' increased ability to engage in state-level system advocacy**, we anticipate the following immediate outcomes:

## Increased knowledge for ...

- State and local grassroots advocates about state systems, policies, and funding for services and supports and the state and local agencies that oversee / fund them
- Support circles (parents, siblings, other family members, providers, teachers, etc.) about independent living philosophy and disability rights

## Increased number of ...

- State and local advocacy and action coalitions
- Peer networks to provide training on how to advocate in the six focus areas
- Advocates actively working to affect system and policy changes at the state in the six focus areas to improve quality of life and community living opportunities for people with disabilities

## Increased number and diversity of ...

- Individuals actively advocating and participating in coalitions
- Advocates serving in leadership roles and participating in leadership training
- Advocacy and action coalitions

# Intermediate outcomes

We anticipate the following intermediate outcomes for individual grassroots advocates and collectively on the national stage:

## **Grassroots advocates:**

- Gain knowledge of states' services and understand how to hold states / providers accountable and responsive to input from people with lived experience.
- Gain knowledge of state systems and funding streams; understand how to navigate to the correct state and local systems and advocate for changes in state and local policies and services
- Understand how to leverage state and other resources to create new coalitions / programs / organizations to do peer-to-peer outreach and training on community living advocacy
- Understand how services are funded, provided, and know the state and local agencies that funds services and supports
- Begin organizing in the state; have a strategy for how to identify areas where change is needed at the state or local level and taking action to effect that change

## **Nationally:**

- Establish processes and structures that ensure people with disabilities are supported (including by individuals in their support circle) to advocate and make their own choices
- State and local advocacy and action coalitions have a strategic plan for sustainability
- State coalitions have a strategic plan for building sustainable relationships with grassroots advocacy coalitions





# 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

# National Advocacy & Action Coalition

- National Association of Councils on Developmental Disabilities
  - National Disability Rights Network
  - Association of University Centers on Disabilities
  - Autistic Self-Advocacy Network
  - Self-Advocacy Resource and Technical Assistance Center
- Association of Programs for Rural Independent Living
  - National Council on Independent Living
  - National Paralysis Resource Center
  - National Associations of State Head Injury Administrators

# 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 can be facilitated by the NAAC.

# State Agency Partnership Group (SAPG)

**This advisory group will meet quarterly to support the effectiveness of the Grassroots Project in improving the systems that support community living for disabled people.**

**Engaging in 2024 with:**

- National Association of State Directors of Developmental Disabilities Services
- ADvancing States
- National Association of State Head Injury Administrators
- National Association of Medicaid Directors



# Meet our panelists

- Allilsa Fernandez
- Cody Drinkwater
- Eric Washington
- Lola Kernell
- Santa Perez



*Image description: Brown, latinx, nonbinary person with short black hair, wearing a red sweater with a dressy white undershirt and a red bow tie.*

## Allilsa Fernandez

[fernandezallilsa@gmail.com](mailto:fernandezallilsa@gmail.com)

Allilsa Fernandez is a mental health and disability advocate, activist, and consultant. They have worked with companies such as Facebook, Lionsgate, Verizon, and ReelAbilities Los Angeles. In addition, they have volunteered with Sylvia Rivera Law Project on shelter organizing, with Met Council on housing justice, and New York City mutual aid providing aid to people across the city.

Allilsa has also worked with diverse organizations, companies, and politicians such as Janos Marton, to create intersectional mental health policies. They graduated magna cum laude from Stony Brook University with a bachelor's degree in psychology and completed fellowships with the Coelho Center for Disability Law, Policy and Innovation, and Latino Justice Law Bound.

Their work has been featured in Forbes Magazine and the Laura Flanders show.



*Image description: Man with brown beard and glasses wearing black and white checkered shirt under a black jacket.*

## Cody Drinkwater

[cody.drinkwater@maryland.gov](mailto:cody.drinkwater@maryland.gov)

Cody Drinkwater is the Regional Self Advocacy Specialist for the Eastern Shore. He has a bachelor's degree from Towson University in history with a minor in English. He previously worked for the Wicomico County Public School System. In addition to his role at the Developmental Disabilities Agency, he works as the policy coordinator for People on the Go of Maryland.

He is on the autism spectrum and has executive functioning disabilities along with mild cerebral palsy. This makes the work he does for self-advocacy even more important. His job duties entail assisting individuals in the self-advocacy process, networking with providers, providing outreach and guidance to self-advocacy groups, and creating necessary trainings in the region. The main thing he likes about his work is helping and empowering people. He wants others to know they can always reach out to him. He's happy to help them.



*Image description: Man with dark beard wearing t-shirt in front of green grassy background.*

## Eric Washington

[ewash33@gmail.com](mailto:ewash33@gmail.com)

Eric Washington is a former football player for the University of Minnesota and the University of Kansas. His football career ended on Sept. 30, 2006, due to a concussion and spinal cord injury. After recovering from the injury, he returned to graduate with a bachelor's degree in applied behavioral sciences.

Today, Eric's life mission is to advocate for people like him—people with traumatic brain injury (TBI)—especially those who are also unhoused. He serves as a strong advocate in the high school athletic community, helping student athletes make educated decisions when accepting scholarships and helping their families to understand the importance of not rushing to return to activities after an injury. Eric was a faculty member for the NCAPPS Brain Injury Learning Collaborative. He is co-lead and member of the TBI TARC TAL-Group.





*Image description: Woman with brown glasses and long blonde hair.*

## Lola Kernell

[lola@kcdd.org](mailto:lola@kcdd.org)

Lola Kernell is a senior at Bishop Miege High School, where she is involved in theater, French club, National Honor Society, and campus ministry. She has been on the honor roll each semester, received awards in French and theology, and was awarded the Eric Druten Memorial Junior Scholarship. She is an active lector and server at Curé of Ars Catholic Church. Currently, she is working on her highest-level award for American Heritage Girls. She is also involved in Down Syndrome Innovations ACE program.

Lola works part time for the Kansas City Royals and the Kansas City Chiefs and has worked for Nautical Manufacturing and Fulfillment. Lola is a peacemaker who is friendly and outgoing. She loves public speaking and being an advocate for others. She also has great technical computer skills. She is living her dream by working as an intern for Kansas Council on Developmental Disabilities.

# About Me — à propos de moi



# How I Connected with KCDD



#WDSD at the Kansas Capitol



Down Syndrome Innovations and KCDD Employment Roundtable

# My Role at KCDD

- I am the Advocacy Coordinator at KCDD.
- I will be leading the Change Agent Program (CAP), a new training program to support individuals with IDD as they become self-advocates and share their experiences with Kansas legislators to drive change.
- The CAP Program is launching in September of 2024



# KCDD's Current Advocacy Issues

- **Kansas has the largest, historic waitlist in our state's history**
  - Advocating for Increased Funding to Eliminate our IDD Waitlist & Address Workforce Issues
- **Increasing competitive, integrated employment for the IDD community**
  - Kathy's Bill
  - Eliminated subminimum wage at federal level (via TCIEA) and at state level through a new grant program
- **Establishing a new grassroots advocacy program called the KCDD Change Agent Program to recruit and empower self-advocates and advocates around Kansas to be more effective advocates**



I got to introduce Governor Kelly with our KCDD Executive Director Sara Hart Weir

# IT TAKES COURAGE TO BE A SELF ADVOCATE!

You may...

- Be taking a risk
- Disagree with others
- Share something personal
- Feel like you are being judged
- Be afraid of getting in trouble



*Image description: Woman with long dark hair wearing purple beads and jacket.*

## Santa Perez

[Santa.Perez2762@outlook.com](mailto:Santa.Perez2762@outlook.com)

Santa earned a Bachelor of Arts in psychology from Cal State Northridge. Santa has been an advocate for people with developmental disabilities and intellectual disabilities for most of her life. Her ultimate goal is to promote inclusion for all people no matter who they are. All people need to be included to have a democratic society.

Santa is a founding member of People First of Nevada, and active president emeritus of the People First of Nevada. She believes that people with developmental and intellectual disabilities need to become active advocates in every aspect of their lives. They need to make their mark on the world. Along with People First of Nevada, Santa was instrumental in the passage of three laws: the People First Respectful Language Law, the Signature Stamp Law, and the Supportive Decision-Making Law. Santa is a former member of the Nevada Governor's Council on Developmental Disabilities and sits on many state and national committees. She was appointed to the President's Committee for People with Intellectual Disabilities. She is the chair of the sub-committee of Community Living. Santa is co-teaching at Virginia Commonwealth University in Disability, Diversity & Human Rights.

In her personal life, Santa has accomplished many things. She has her own home and is a part of her community—but in her eyes, her greatest accomplishment is her son, Noah. Santa is a published author and blogger and the author of “Sitting At Eye Level: My Life as an Advocate, a Professional, a Woman, a Mom, and a Person with a Significant Disability.”

Discussion  
with our  
Panelists  
&  
Questions  
from the Chat





# Stay tuned for ...

- The recording and PowerPoint for this webinar will be available for download at <https://bit.ly/3U5SYvW>





# Thank you

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**Contact us:**

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

