



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



Today's webinar is:

*Expanding Disability Advocacy  
by Working Together:  
Successful Practices and  
Outcomes in Coalition Building*

*Please introduce yourself in chat*



# Agenda

- Introductions, welcomes, and logistics from the project team
- Presentations from coalitions
  - The Disability Policy Consortium – Massachusetts
  - Disability Public Health Task Force – ABLE South Carolina
  - The Ohio Olmstead Task Force
- Facilitated 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. Urgent individual concerns should be directed to [alulinski@hsri.org](mailto: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.

# Grassroots Project team at HSRI



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## 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 is not monitored during the webinar.* For urgent matters contact [alulinski@hsri.org](mailto: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>

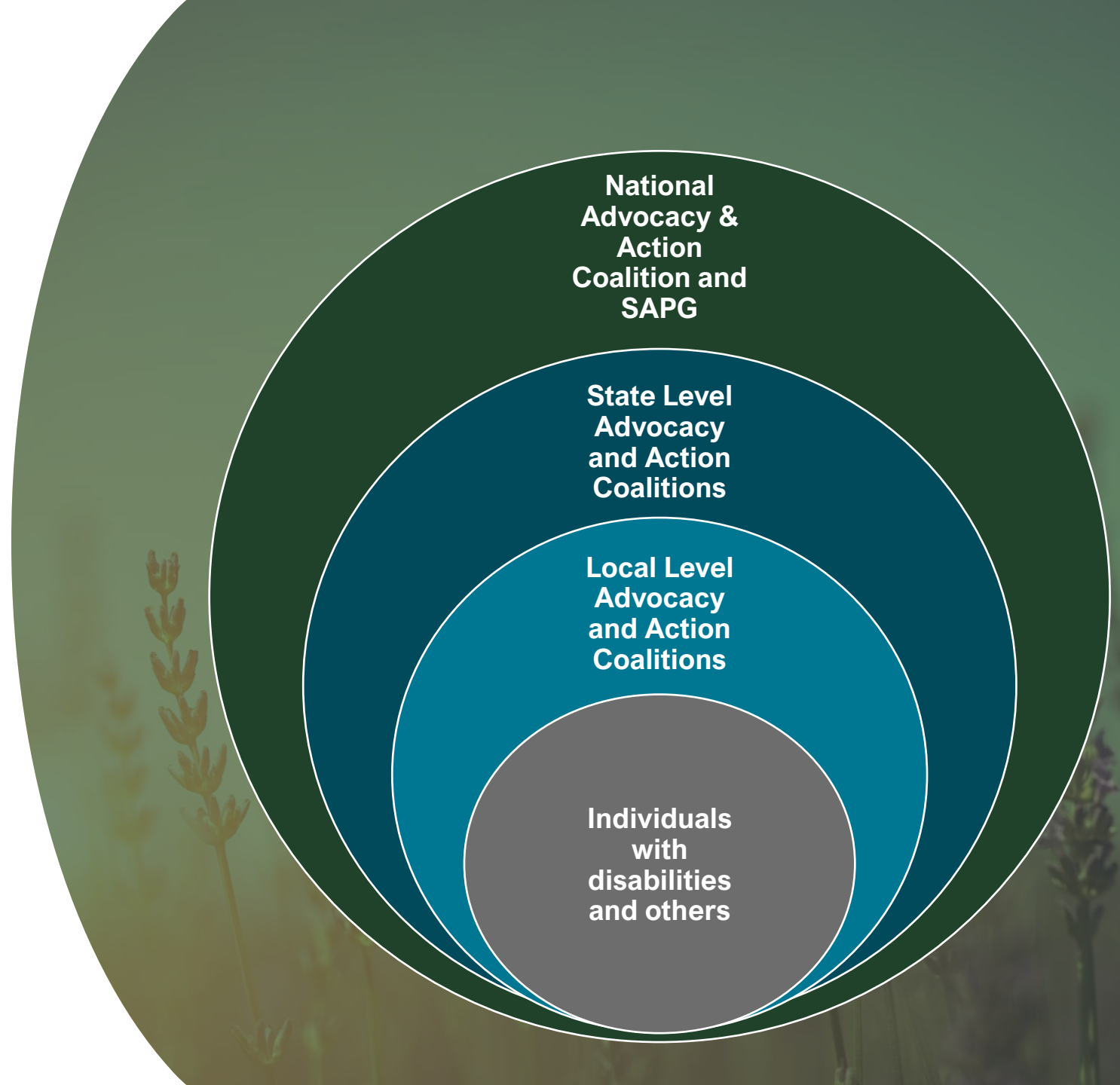
# Who's here?

“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.





# 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 area that the national, state, and local advocacy and action coalitions affiliated with the Grassroots Project can be engaged in.

# Webinar aim:

This national webinar – the third hosted by the Grassroots Project – brings together state and local advocacy and action coalitions discussing best practices for establishing common goals and collaborating to achieve them, and for ensuring disabled people are leading the charge to drive change. We will hear from ABLE South Carolina, Disability Policy Consortium Massachusetts, and the Ohio Olmstead Task Force on how working in cross-disability, disability-led, and community driven frameworks propel disability advocacy forward and create momentum for advancing disability rights.





# Meet the Coalition Representatives

- Noel Martin Rubio
- Sierra Royster
- Kimberly Tissot
- Brittanie Maddox
- Jennifer Kucera




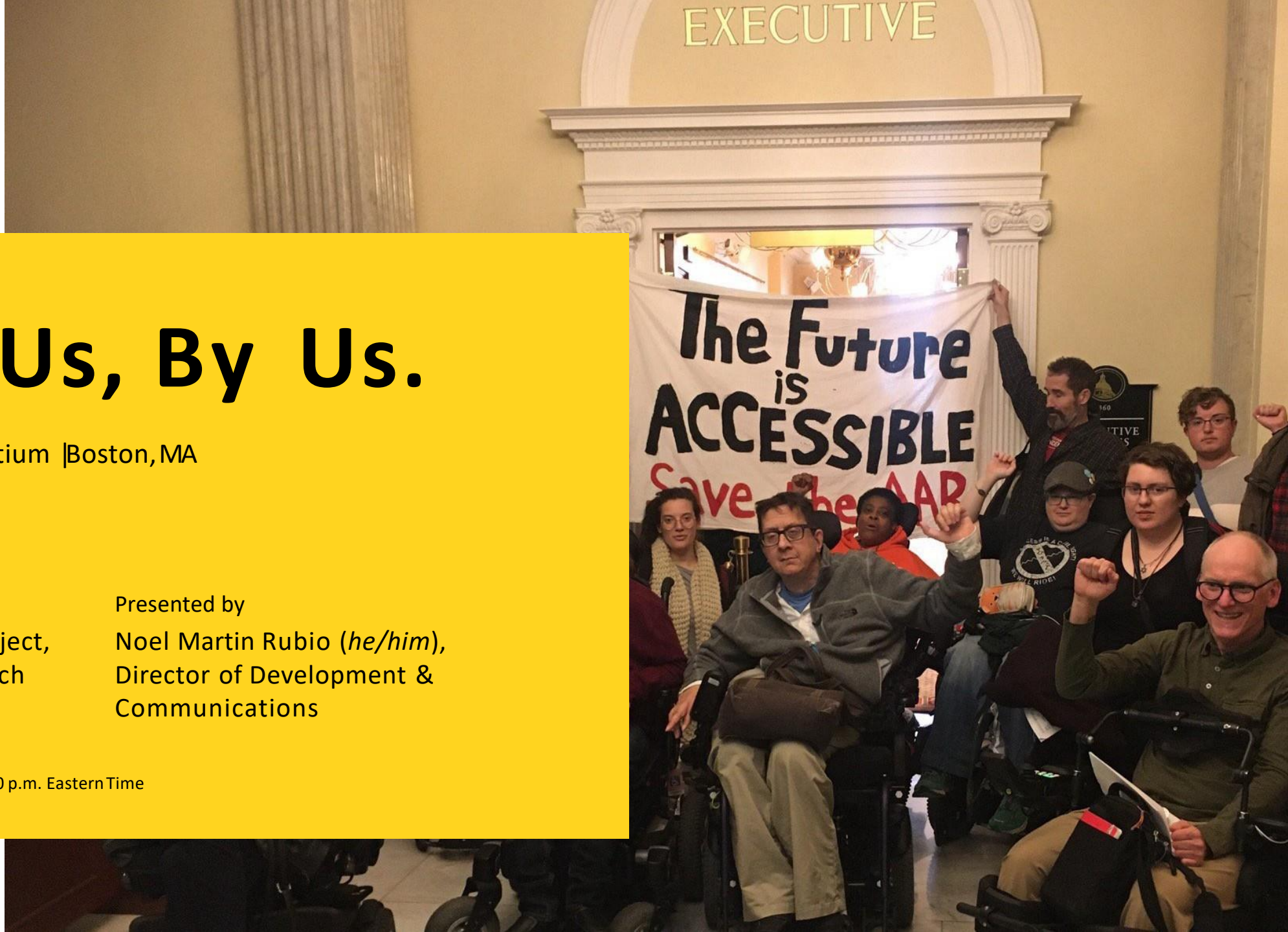
# About Us, By Us.

Disability Policy Consortium | Boston, MA

Presented to  
The ACL Grassroots Project,  
Human Services Research  
Institute

Presented by  
Noel Martin Rubio (*he/him*),  
Director of Development &  
Communications

 Wednesday, August 28, 2024, 2:00 p.m. Eastern Time



# Our Why

**Our mission** is to ensure the voices of people with disabilities are heard on key issues, to support the health of the community through participatory research and expert policy analysis, and to empower grassroots disability leaders to transform their communities.

**Our vision** is a redefined role of government in the lives of people with disabilities, resulting in a Commonwealth, country, and world in which equity, access, and justice are centered and in which independence, inclusion, and empowerment are secured and promoted for all.

**Our credo** is *About Us, By Us*—the belief that when decisions are made about people with disabilities, people with disabilities must play a leading role in making them.



*Participants, Hosts, and Facilitators of the Inaugural Paul W. Spooner Generational Leadership Summit, Co-Hosted by DPC in September 2023*

# Our History

**1996**

DPC was established in response to a proposal to merge three state disability agencies. 240+ members of the disability community, united in a common cause, came together to successfully defeat that proposal.

**1999**

A DPC-led coalition won a \$22M increase in funding for three disability agencies. This increase ended ten years of level funding, enhancing resources for disability services and was instrumental in the creation of the DeafBlind Community Access Network.

**2008**

DPC identified over 500 violations of sidewalks and curb cuts in Boston, leading to a \$40M investment in sidewalk ramp repair and construction. DPC also negotiated an agreement to improve accessibility at the State House, resulting in an annual appropriation of more than \$200,000 for accessibility improvements.

**2009**

DPC held threestatewide public forums called the Olmstead Initiatives to co-develop solutions to gaps in home and community-based services for elders and people with disabilities.

**2012**

The Disabled Advocates Advancing Our Healthcare Rights (DAAHR), co-founded by DPC and comprised of over 20 community-based organizations, helps to ensure Massachusetts' place as the first state to implement the dual-eligible program for disabled Medicare and Medicaid members.

**2018**

DPC and Boston Center for Independent Living won a \$1.15M increase to the Alternative Housing Voucher Program through our jointly-led Housing Advocacy Leadership team. Over the last ten years, we have increased AHVP funding from \$4M to over \$26M, enabling hundreds of disabled people to access affordable, accessible housing.

**2016**

DPC contracted with Uber to develop accessible ride share options for people with disabilities in Massachusetts.

**2020**

DPC co-founded a coalition of 20 disability and elder rights organizations working to fundamentally reform the nursing home and long-term care industries.

**2021**

DPC overturned discriminatory COVID-19 crisis standards of care and secured the creation of in-home vaccination programs and ASL interpretation services at community vaccination sites.

# Our Present



**26** Full- and Part-Time Employees

**\$2.7M** Annual Budget for Fiscal Year 2024

**15** Community Members Serve on the Board of Directors

**4 K +** Medicaid Members Served by My Ombudsman

**>75%** Employees and Directors Identify as Disabled

**7x** State Funding Increase Won Since 2014 for Affordable, Accessible Housing

## Key Issues

- Wheelchair Warranty and Repair Reform
- Disabled Parents' Rights
- Medicaid Estate Recovery
- Healthcare Non-Discrimination
- Independent Living Supports





# Our Model

A multi-pronged approach to systemic change, rooted in meaningful community partnership

## Individual

Healthcare mediation, patient advocacy, and case management services to 4,000+ Medicaid members through the state-funded My Ombudsman program

## Institutional

Education, training, and technical assistance services that enhance Massachusetts organizations' accessibility and inclusivity

## Community

Participatory research that centers the voices of people with lived experience of disability and sheds light on key issues facing the disability community

## Systems

Grassroots organizing and advocacy for public policy reform and intergenerational knowledge transfer and leadership development

# Our Impact

ADVOCACY

ACCESS

ACTION



INPUTS	OUTPUTS	OUTCOMES	GOALS
<ul style="list-style-type: none"> <li>• Dedicated, representative, and effective <i>staff, Board, and volunteers</i></li> <li>• Deep <i>subject matter expertise</i> and <i>credibility</i></li> <li>• Strategic, diverse, and trust-based <i>network of partners</i> to mobilize stakeholders and drive systemic change</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Community Outreach:</i> meeting communities “where they’re at” through accessible materials and campaigns</li> <li>• <i>Technical Assistance:</i> training workshops, consulting engagements, and advisory committees</li> <li>• <i>Actionable Thought Leadership:</i> publications, speeches, testimony, public letters, and webinars</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Civic Engagement:</i> People with disabilities are equipped to fully participate in the public policymaking process</li> <li>• <i>Inclusive Institutions:</i> schools, workplaces, care providers, residential facilities, and State Houses</li> <li>• <i>Public Awareness of Disability Policy Issues:</i> legislators, regulators, family members, caregivers, and allies</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Independence:</i> The ability to lead full, dignified, and self-determined lives</li> <li>• <i>Inclusion:</i> Closing the education, employment, healthcare, and housing gaps experienced by people with disabilities</li> <li>• <i>Empowerment:</i> People with disabilities are well-represented in positions of public trust, leadership, and authority at every level</li> </ul>

# Our Coalitions

Smart Partnerships: Led by Community, Driven by Trust, Focused on Systemic Change



# Our Partnerships in Action

## CODA: Commissions on Disability Alliance



### Formation

Established in 2013 by leaders from Newton, Boston, Cambridge, and Brookline Commissions on Disability, CODA facilitates knowledge sharing, mentorship, and coordination among members to avoid redundant problem-solving efforts. DPC's senior community organizer leads monthly CODA meetings via Zoom.



### Representation

CODA promotes the inclusion and integration of people with disabilities, advises municipal officials on federal and state disability laws, reviews municipal policies affecting persons with disabilities, provides information, advocacy, and technical assistance, and enables coordination with other local disability groups.



### Transformation

Volunteer members from Commissions on Disability, municipal employees, and ADA coordinators co-developed uniform accessible pedestrian signals for interconnected cities, enhancing safety for Blind and low-vision individuals, as well as practical guides on fundraising, communications access, and advocacy.

# Our Partnerships in Action

Thought Leadership Publications, Co-Created with Public Health and Policy Experts

**DPC**  
DISABILITY POLICY CONSORTIUM

## LEGISLATIVE ACCESS AGENDA

DPC's mission is to bring the perspectives of people with disabilities to the table on key issues, empower our community through healthcare support and advocacy, participatory research, and expert policy analysis, and lead grassroots campaigns that make Massachusetts more accessible and inclusive. Our credo is "About Us, By Us" – the belief that when decisions are made about people with disabilities, people with disabilities should be the ones making them.

**DPC**  
DISABILITY POLICY CONSORTIUM

## ACCESSIBLE EVENTS GUIDE FOR ORGANIZERS

NOVEMBER 2023

**Protect Disabled Parents' Rights**

**H.1601/S.1037:**  
An Act prohibiting discrimination against adults with disabilities in Family and Juvenile Court proceedings

**PARENTS WITH DISABILITIES SHOULD NOT BE DENIED THE RIGHT TO PARENT THEIR CHILDREN.**  
Parents with disabilities, especially psychiatric or intellectual disabilities, inappropriately lose custody or parenting time at alarming rates due to disability discrimination.

**H.1601/S.1037 will require courts to...**

- Determine if a parent's disability causes actual harm to a child based on evidence, not assumptions.
- Explain in writing if a parent's disability is a negative factor in custody and parenting time decisions.
- Assess if the harm can be avoided with adaptive equipment or supportive services for the parent

**H.1601/S.1037 will not cost the state money and may even save taxpayer dollars by preventing unnecessary foster care placements.**

**FEDERAL LAW IS NOT ENOUGH.**  
The US Departments of Justice and Health and Human Services entered into a settlement agreement with Massachusetts Department of Children and Families (DCF) to address disability discrimination.

- Parents with disabilities are **significantly more likely to stay in abusive relationships** out of fear of losing their children.
- **Nearly one in 10 children** in the U.S. are at risk of being removed from their home by a child welfare agency simply because their parent has a disability.
- While 6.7% of parents in the U.S. have a disability, families with a parent with a disability are **disproportionately involved** in the child welfare system.
- Stereotypes and biases about military service and mental health disabilities can **deter veterans** from seeking treatment and lead to errors in custody cases.

**H.1601/S.1037 is sponsored by Rep. Khan, Rep. Livingstone & Senator Lovely; and co-sponsored by:**  
Sens. DiDomenico, Eldridge, Keenan, Miranda, Moore and Rausch  
Reps. Cutler, Domb, Hawkins, Higgins, Howard, Gentile, Kushmerek, Jack Lewis, Montano, Murray, Robertson, Sabadosa and Vitolo

**Supported By:**  
The Arc of Massachusetts • The Asperger/Autism Network • Boston Center for Independent Living  
Boston Resource Center • Center for Living and Working • Citizens for Juvenile Justice • DEAF, Inc.  
Disability Law Center • Disability Policy Consortium • Disability Resource Center, Inc.  
Easterseals Massachusetts • Health Law Advocates • Justice Resource Institute • Kiva Center  
Lurie Institute for Disability Policy (Brandeis) • Massachusetts Association for Mental Health  
Massachusetts Law Reform Institute • Massachusetts State Association for the Deaf  
Mental Health Legal Advisors Committee • MetroWest Center for Independent Living  
NAMI Massachusetts • Southeast Recovery Learning Community • Stavros  
United Arc, Inc. • Veterans Legal Services • Wildflower Alliance

# Our Partnerships in Action

Of the Community, By the Community, For the Community



**LEGISLATIVE BRIEFING**  
THURSDAY, FEBRUARY 29  
10 AM - 12 PM

JOIN US FOR AN UPDATE ON OUR ACCESS AGENDA AND LEARN ABOUT THE DISABILITY COMMUNITY'S LEGISLATIVE PRIORITIES IN 2024!

ASL INTERPRETERS AND CART REQUESTED

STATE HOUSE ROOM 428

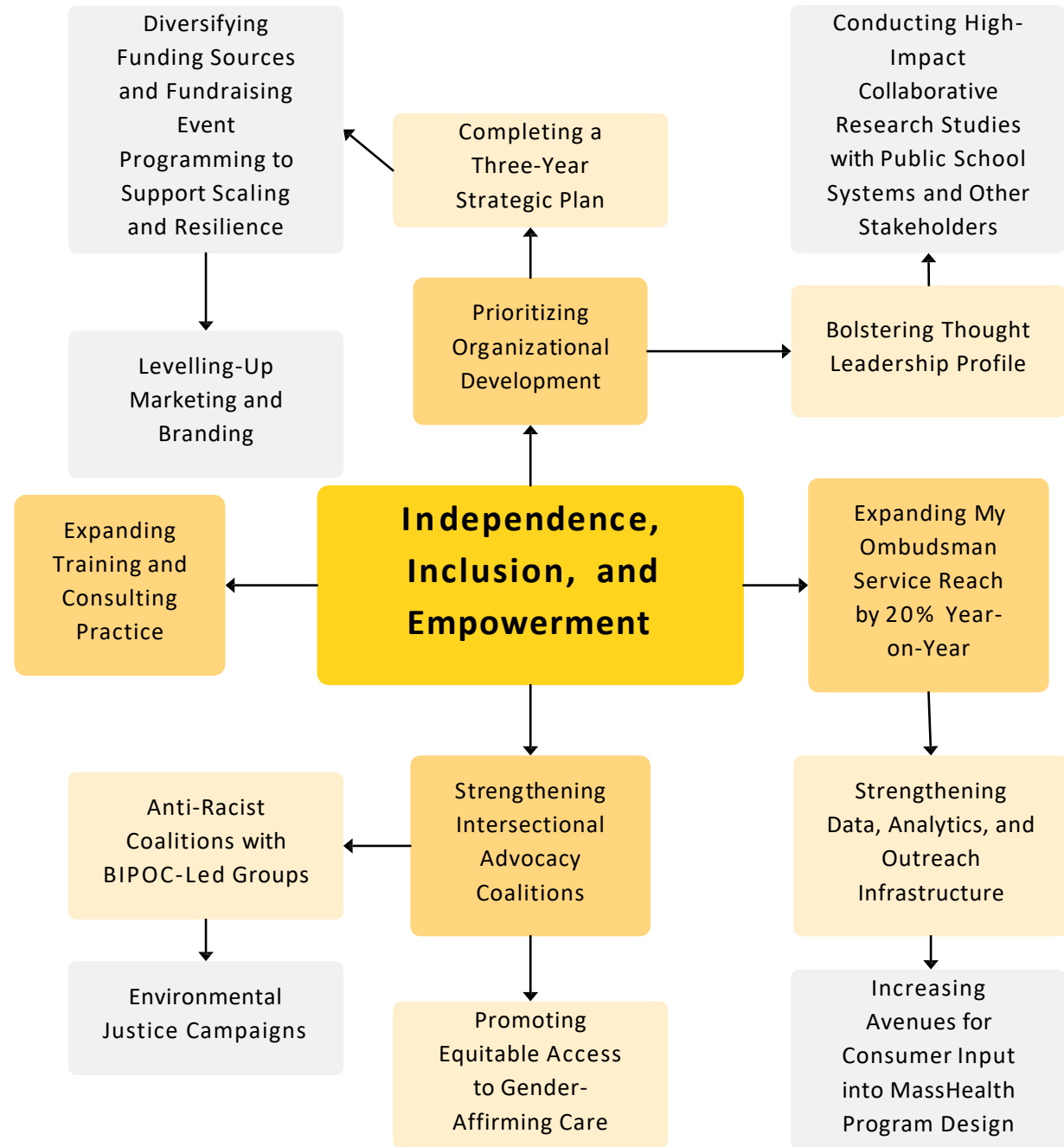
CONTACT:  
HARRY WEISSMAN  
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(617) 977-4084

ABOUT US BY US



# Our Future

Bold, Bright, and Brave





DISABILITY POLICY CONSORTIUM

# DPC | Disability Policy Consortium

**Thank you for your attention!  
Questions? Get in touch:**

Web

[dpcma.org](http://dpcma.org)

Email

[mail@dpcma.org](mailto:mail@dpcma.org)

Social Media

FB: [@dpcma](https://www.facebook.com/dpcma)

IG: [@dpcorg](https://www.instagram.com/dpcorg)

Call Us

+1 (617) 307-7775



# Status of South Carolina



- 56,753 people are living in institutional settings in SC
- Study from Boston Consulting Group and published in January 2024:
  - SC is only state among peers where majority of mental health treatment facilities are operated by the state
  - South Carolina has the most fragmented health and human services agency structure vs. all other states
- **In 2023, South Carolina had 41,078 people waiting for HCBS waivers** (Kaiser Family Foundation, 2023)
- **In 2022, South Carolina had 24,190 people on the waiting list for HCBS waivers** (Kaiser Family Foundation, 2023)
- Individuals and families do not know about EPSDT or how to transition to HCBS, causing children and youth with disabilities to be setup for failure.

# The why: The people.

## **Example Profile:**

Alex – an Autistic teenager with who also has significant seizures, suffered severe abuse and neglect at a residential facility. Initially, 90% potty trained, Alex regressed to wearing pull-ups 24/7. For more than a year, Alex had no teachers and he was deprived of essential educational and behavioral support. He went over five years without necessary ankle/foot orthoses, leading to severe physical deterioration. Still today, his ankles turn inwards to the point that he practically walks on them. Alex suffered from numerous injuries, including, but not limited to, lacerations, bites, falls (which resulted in the need for staples to the head), a broken collar bone, and a nail that was bitten off (which resulted in the dismissal of a member of personnel and a lifetime ban on working with children). Alex was taken to the hospital for treatment. After months in a hospital and treatment cycle, Alex's medical bills reached millions. Home and Community-Based Services via EPSDT would have allowed Alex to live with his family and thrive. Rather, lack of this option, has resulted in the state with a dramatically more costly health care option that restricts Alex's quality of life.

# Coalition

## Creation

- People who are on the SC Disability Public Health Coalition
- Families we had assisted with individual advocacy
- Partner organizations

## Makeup

- People with disabilities
- Families of disabled individuals
- Family Organizations
- Attorney Consultant

# Deliverables

- Letter to South Carolina Department of Health and Human Services from the disability community to express concerns and demand for them to improve.
- A fully accessible tool to walk families through securing appropriate EPSDT services as well as how to prepare for transition to adulthood utilizing HCBS.
- Media Press Release will be issued to inform the public of the concerns.

# Contact Us!

Kimberly Tissot, President & Chief Executive Officer

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803-779-5121 ext: 133

Sierra Royster, Director of Capacity Building

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803-779-5121 ext: 148



# The Ohio Olmstead Task Force

Who We Are, What We Do, And Why It Matters

2024



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## What is the Ohio Olmstead Task Force?

- The Ohio Olmstead Task Force (OOTF) is a statewide grassroots coalition of Ohioans with disabilities of all ages, family members, advocates and organizations advocating for the right to live, work and participate in their communities.
- Founded in 2002, OOTF consists of both individuals and those representing organizations across the state.
- OOTF works closely with Ohio departments and agencies, centers for independent living, disability rights organizations, and lawmakers, among many others, to advocate and facilitate change.

## Mission and Vision

### OOTF's Mission Statement:

To advocate, educate, and support change for all people with disabilities ensuring their rights to participate in a thriving community life.

### OOTF's Vision Statement:

Ohioans with disabilities shall have access to inclusive, integrated, and person-centered services and support tailored to their individual needs to live independently in the community.





# OOTF Organizational Structure

## **OOTF Membership**

- Officers:
  - Chair
  - Vice Chair
  - Treasurer
  - Secretary
- Members at Large
  - Voting members
  - Non-voting members

## **OOTF Sub-Committees**

- Steering Committee
- Standing Committees
  - Legislative
  - Public Relations
  - Finance
- Ad Hoc Committees
  - Direct Care Workforce Crisis
  - Housing Advocacy
  - Voting Advocacy

# What are the OOTF Sub-Committees?

## **Steering Committee**

- OOTF officers and committee chairs
- Determine OOTF operating policies, procedures, and advocacy priorities.

## **Legislative Committee**

- Monitor proposed and current federal and state laws and policies to determine the impact on the OOTF mission.
- Organizes educational activities as appropriate and make recommendations to the Steering Committee for advocacy activity.

## **Public Relations Committee**

- Develop and distribute OOTF materials and resources via social media, news media, and other formats
- Connect with other organizations and communities to facilitate recruitment of new OOTF members

## **Finance Committee**

- Drafts recommendations on how to effectively spend OOTF budget to advance advocacy priorities
- Oversee financial affairs and procedures and ensure they are enforced

# History of OOTF

- Created in 2002 by advocates from The Ability Center of Greater Toledo and the Disability Studies Program at The University of Toledo
- Medicaid expansion was the catalyst for the formation of OOTF
- Initial funding was made available through the Money Follows the Person Program
- Medicaid was unable to house the funding so advocates were able to get DD Council to be the financial management entity
- Eventually OOTF became a 501c3 so that advocates could manage their own funds
- Unlike other grassroots groups, OOTF provides mileage and PCA reimbursement so advocates can attend various events





# Grassroots Partnership Development

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- Initially membership increased through word of mouth
- Partner with Centers for Independent Living (CILs) and Ohio Statewide Independent Living Council (OSILC)
- OOTF has a diverse group of voices from self-advocates, disability organizations, state agencies, managed care companies (MCOs), aging agencies, housing and homeless organizations
- Increase partnership with legislators
- We continue to hold virtual open houses and participate in various events held throughout the state to increase membership

# Project Accomplishments

- Multiple Legislative Advocacy Days at the Ohio Statehouse
  - SB 202: anti-discrimination legislation for parents with disabilities
  - Increased funding for Direct Care Workers in the last budget cycle
- Carer Event 2023 at the Ohio Statehouse
- We provide public comments on various rule changes from state agencies, written and in-person testimony on disability related legislation
- Speaking engagements:
  - Accessible Housing Conferences
  - Disabled Women Make Art Event: Celebration of the Olmstead Decision





# Project Accomplishments: Continued

- Partner with Ohio's P&A and the CILs to host legislative town halls connecting advocates with their local and state policymakers
- REVUP funding to discuss voting at various Youth Leadership Forums (YLFs) to increase voting education among youth
- Working on policy around self-direction with the Medicaid and Aging Departments
- Working with legislators to create a long-term study commission on the care crisis and the elimination of sub-minimum wage for people with disabilities

# HCBS Advocacy Retreat 2024

- Over the last few years, there's been an increased need for advocacy surrounding HCBS and Waiver issues
- Plan to host around 20 individuals for a two-day retreat to discuss strategies and future projects to reimagine the HCBS system in Ohio
- The event will take place in September in Columbus, Ohio
- OOTF will develop session topics for the roundtable discussions, provide reimbursement for travel and PCAs, provide food and swag material
- Goal is to continue our coalition building and advocacy



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## Ways to Connect!

- Visit our website: <https://ohioolmstead.com/>
  - Jennifer Kucera: [jenniferkucera134@gmail.com](mailto:jenniferkucera134@gmail.com)
  - Brittanie Maddox: [bmaddox@disabilityrightsohio.org](mailto:bmaddox@disabilityrightsohio.org)
- Connect on social media:
  - Facebook: <https://www.facebook.com/OhioOlmsteadTaskForce/>
  - X: <https://twitter.com/OhioOTF>
  - LinkedIn: <https://www.linkedin.com/in/ohio-olmstead-task-force/>



# 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](mailto:Grassroots@HSRI.org)



*Scan me*

