A Message from the Executive Director

Dear Advocates and Friends,

NCIL’s 2019 Annual Conference theme is IGNITE.

The Independent Living Movement ignites action and empowerment. When there is work to be done, we do it. When bad policy threatens our independence and rights, we fight back. When we know we have a better way, we take action to influence policy and pass laws. We are organized, we are powerful, and we know what we want.

We must share resources, strategize, and train new advocates if we want to succeed in our efforts to protect our programs and secure the independence of people with disabilities.

NCIL’s Annual Conference is the largest Independent Living event of the year. This week, we will show our power, take to the streets, and share our message. Together, our individual sparks will ignite a flame that cannot be ignored.

I would especially like to thank our sponsors: Centene; Anthem; Verizon; Walmart; Uber; Waymo; WITH Foundation; Pharmaceutical Research and Manufacturers of America; Motor Coach Industries; Center for Disability Rights; Airbnb; Ability360; United Healthcare; Pride Mobility; Molina Healthcare; Portlight Inclusive Disaster Strategies; the National Coalition for Assistive and Rehab Technology; and the Mitsubishi Electric America Foundation.

Your Partner in Disability Rights,

Kelly Buckland
Executive Director

Download NCIL’s conference app! Search for NCIL in the Apple Store or Google Play and download the app to access all of the conference details from your smart phone!

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Agenda

Sunday, July 21
- 9:00 a.m. - 1:00 p.m. — NCIL Board Meeting (Lafayette / Farragut)
- 12:30 - 5:00 p.m. — Registration Open (Independence Foyer)
- 2:00 - 5:30 p.m. — Pre-Conference Sessions (Constitution AB)

Monday, July 22
- 8:00 a.m. - 5:00 p.m. — Registration Open (Independence Foyer)
- 9:00 - 10:00 a.m. — Opening Plenary (Independence A)
- 10:15 - 11:30 a.m. — Legislative & Advocacy Update (Independence A)
- 11:30 - 11:45 a.m. — Preparing for the Day on the Hill (Independence A)
- 1:00 - 2:15 p.m. — Concurrent Workshops I (See Pages 12-14)
- 2:45 - 3:45 p.m. — Regional Caucuses: Regions VI through X (See Page 5 for locations)
- 4:15 - 5:15 p.m. — Regional Caucuses: Regions I through V (See Page 5 for locations)
- 6:00 - 8:00 p.m. — Diversity Committee Forum & Reception (Independence A)

Tuesday, July 23
- 9:30 - 10:00 a.m. — Organize for the March (11th & G Streets NW)
- 10:00 - 11:00 a.m. — March to the U.S. Capitol
- 11:00 a.m. - 12:30 p.m. — Lunch and Rally at the U.S. Capitol (West Front Lawn)
- 1:00 - 5:00 p.m. — Hill Visits

Wednesday, July 24
- 8:00 a.m. - 5:00 p.m. — Registration and Exhibits Open
- 9:00 - 10:15 a.m. — Concurrent Workshops II (See Pages 14-16)
- 10:15 – 11:00 a.m. — Film Screening and Panel Discussion: Parenting Without Pity - Empowering the Next Generation (Lafayette / Farragut)
- 11:15 a.m. – 12:00 p.m. — Film Screening and Roundtable Discussion: Ignite the Global IL Network! How to Best Disseminate IL Philosophy Locally and Globally (Lafayette / Farragut)
- 10:15 a.m. - 12:00 p.m. — Exhibit Fair (Independence Foyer)
- 12:00 - 2:00 p.m. — Awards Luncheon (Independence Ballroom)
- 2:30 - 5:30 p.m. — Annual Council Meeting (Independence Ballroom)
- 7:30 - 11:00 p.m. — Closing Social and Piss on Pity Film Screening (Independence Ballroom)

Thursday, July 25
- 8:00 a.m. - 5:00 p.m. — Registration and Exhibits Open (Independence Foyer)
- 9:00 - 10:15 a.m. — Concurrent Workshops III (See Pages 16-19)
- 10:30 - 11:45 a.m. — Concurrent Workshops IV (See Pages 19-22)
- 1:30 - 2:45 p.m. — Concurrent Workshops V (See Pages 22-24)
- 3:00 - 4:00 p.m. — Legislative Debriefing (Independence Ballroom)
- 3:00 - 4:15 p.m. — Film Screening Double Feature - The Invalid Corps and Union (Franklin)
- 4:15 - 5:00 p.m. — Closing Plenary (Independence Ballroom)

Friday, July 26
- 9:00 a.m. - 12:00 p.m. — NCIL Board Meeting (Lafayette / Farragut)
Schedule of Events

Sunday, July 21

NCIL Board Meeting

9:00 a.m. - 1:00 p.m. / Lafayette / Farragut

NCIL Board meetings are open to the public. If you plan to attend and require an accommodation, please contact tim@ncil.org by July 18, 2019.

Pre-Conference Sessions

2:00 - 5:30 p.m. / Constitution AB

The Pre-Conference is an opportunity to focus on pressing advocacy issues. Registration for the Pre-Conference is included with full Conference registration. See Pages 9-10 for more information about the Pre-Conference Sessions, “NCIL & ILA / ACL – The Good, the Bad, and the Ugly” and “A Dialogue on Accessible Voting: U.S. Election Assistance Commissioners and NCIL Members”.

Monday, July 22

Opening Plenary

9:00 - 10:00 a.m. / Independence A

Join us for an opening keynote address to kick off a week of movement-building and advocacy! Details will be announced at the conference web page. Don’t miss this exciting 2019 Annual Conference opener!

Legislative & Advocacy Update

10:15 - 11:30 a.m. / Independence A

Get up-to-date information on the progress of NCIL’s advocacy efforts from Chairs of NCIL’s Legislative & Advocacy Subcommittees. The Chairs will review and answer questions about NCIL’s advocacy talking points so participants are fully prepared for their Congressional visits on Tuesday.

Preparing for the Day on the Hill

11:30 - 11:45 a.m. / Independence A

Learn the ABCs of NCIL’s March & Rally, including where to meet, what to bring, important information about our route, what to do in case of an emergency, and how to get back to the hotel after your Capitol Hill Visits.

Concurrent Workshops I

1:00 - 2:15 p.m. / See Pages 12 - 14 for workshop details.
- DIA Today: A Better Way (Independence A)
- Queer Disabled Justice (Independence BC)
- Advocacy and Organizing: Using These Tools to Create Power and Change (Independence DE)
- Running for Office: the Final Frontier for the IL Movement (Independence FGHJ)
- REAADI in Disasters: Igniting Community and Political Power to Save Disabled Lives in Disasters (Lafayette / Farragut)

Regional Caucuses

Regions VI through X: 2:45 - 3:45 p.m.
Regions I through V: 4:15 - 5:15 p.m.

- Regions 1 and 6: Independence BC
- Regions 2 and 7: Independence FGHJ
- Regions 3 and 8: Independence A
- Regions 4 and 9: Independence DE
- Regions 5 and 10: Lafayette/Farragut

This is your opportunity to strategize for your Capitol Hill Visits. Each state decides who will attend which meeting to ensure that every legislator is visited. Please note the separate times listed for Regions I - V and VI - X. A list of Regions by state is available on Page 26.

Diversity Committee Forum & Reception

6:00 - 8:00 p.m. / Independence A

The Diversity Committee will host a discussion related to diversity and disability and also present awards to NCIL members who have committed themselves to centering people of color, LGBTQIA, young people, and other communities underrepresented in IL. Light snacks and non-alcoholic beverages will be available, accompanied by a cash bar.

Tuesday, July 23

Organize for the March

9:30 - 10:00 a.m. / 11th & G Streets NW

Participants should assemble at 9:30 a.m. at G and 11th Streets, NW. The March will begin promptly at 10:00 a.m.

March to the U.S. Capitol

10:00 - 11:00 a.m. / See Pages 31-34 for more information

NCIL members march from the Grand Hyatt to Capitol Hill demonstrating support for the independence of people with disabilities! Complimentary Do-It-Yourself Sign Kits will be available on the conference floor the afternoon of Monday, July 22. See page 27 for a list of ideas! Directions to and from the Hyatt are available on page 31 and a map of the Rally location is available on page 34.
2019 Rally at the U.S. Capitol

11:00 a.m. - 12:30 p.m. / West Front Lawn of the U.S. Capitol Building

Marchers will converge in front of the Capitol Building for an empowering Rally featuring a number of speakers, including leaders in the Independent Living Movement and elected officials working on the issues we care about most. Box lunches will be provided to conference registrants upon arrival.

Capitol Hill Visits

1:00 - 5:00 p.m.

Participants are encouraged to meet with their elected officials and their staffs to discuss issues important in their districts. Congressional contact information is available at house.gov and senate.gov, or you can call the U.S. Capitol Switchboard at 202-224-3121 or 202-224-3091 (TTY) and ask for your Senators’ and / or Representative’s office. Participants must arrange their own accommodations, including interpreters, for Hill Visits ahead of time. Direct requests for interpreters and other accommodations to Congressional staff. Contact angela@ncil.org with any questions.

Wednesday, July 24

Concurrent Workshops II

9:00 - 10:15 a.m. / See Pages 14 - 16 for workshop details.

- Taking it to the Streets - How to Mobilize Your CIL (Independence A)
- Partners in the IL Network: Roles & Responsibilities (Independence B)
- How to Go From Being the Best Kept Secret to the Best Known! (Independence DE)
- Advocacy - It’s Not Just A Reaction (Independence FGHI)
- Fueling Business Acumen: How CILs are Securing Contracts with Health Plans and Payers (Lafayette / Farragut)

Film Screening and Panel Discussion: Parenting Without Pity - Empowering the Next Generation

10:15 – 11:00 a.m. / Lafayette / Farragut

- Ignite Our Political Power Track
- Presented by: Emily Ladau and Anna Zivarts
- Appropriate for all audiences and knowledge levels.

How many of us raised in isolation from other disabled people wish we could have built connections with the disability community earlier in our lives? What if we could change that for the next generation? In this session, you will hear from disabled parents and children within the disability community and view a new storytelling resource for disabled parents to educate parents of disabled children. This presentation will share insights into how we can create ties between disabled and non-disabled parents to share resources, discuss identity, and create a greater positive community of support and belonging for kids with disabilities. Participants will come out of the screening and panel discussion empowered to build relationships between disabled parents, and with parents of disabled children. Please note: this event is scheduled
concurrently with the Exhibit Fair.

Film Screening and Roundtable Discussion: **Ignite the Global IL Network! How to Best Disseminate IL Philosophy Locally and Globally**

11:15 a.m. – 12:00 p.m. / Lafayette / Farragut

- Ignite the IL Network Track
- Presented by: Kozo Hirashita and Bruce Darling
- Appropriate for all audiences and knowledge levels.

This workshop will contain a film screening (Japanese documentary about transition from institutions to the community) followed by a roundtable discussion among both U.S. and Japanese advocates. Presenters and participants will discuss how the IL Movement impacts our lives and how we could best disseminate our practices across borders, race, gender, etc. Sharing promising practices around the world will become a trigger to further “ignite” our global IL network! Please note: this event is scheduled concurrently with the Exhibit Fair.

Exhibit Fair

10:15 a.m. - 12:00 p.m. / Independence Foyer

Spend some time browsing the products and services offered by our exhibitors, many of which are your fellow NCIL members. The NCIL Conference would not be possible without the generous support of our exhibitors and sponsors. Exhibits will be open all day Wednesday and Thursday.

Awards Luncheon

12:00 - 2:00 p.m. / Independence Ballroom

Join us to celebrate and honor this year’s national award winners! Awards will be presented over lunch. Admission to this event is included in full Conference registration.

Annual Council Meeting

2:30 - 5:30 p.m. / Independence Ballroom

Attend the Annual Council Meeting to vote for Governing Board members and resolutions that will guide NCIL in the coming years. This year, elections will be held for: President, Treasurer, and three Members-At-Large. Elections for Representatives of Regions I, III, V, VII, and IX will be held prior to the Annual Conference and the winners will be announced at the meeting. CILs and SILCs must pay their 2019 dues in full by June 24 (30 days prior) to be eligible to vote in person or by proxy.

Closing Social and **Piss on Pity** Film Screening

7:30 - 11:00 p.m. / Independence Ballroom

Join us as we celebrate the 2019 Annual Conference on Independent Living. Come ready to join your fellow advocates in merriment and don’t forget your dancing shoes! Light snacks and non-alcoholic beverages will be available free of charge, accompanied by a cash bar.
This year, we will premier *Piss on Pity: We Will Ride* from 7:30 - 8:30 p.m., during NCIL’s Closing Social. This film documents the origins and early history of ADAPT. Through civil disobedience and political savvy, ADAPT has fought discrimination and segregation for over 35 years, playing major, if little-known, roles in key U.S. laws and policies, including the Americans with Disabilities Act and Money Follows the Person. *Piss on Pity: We Will Ride* covers ADAPT’s roots beginning with the liberation of people with disabilities from nursing homes to the fight for accessible transportation. With over 40 interviews, never-before-seen footage and stunning images from Tom Olin, *Piss on Pity: We Will Ride* gives voice to activists, old and new, who are on the front-lines of disability rights history.

**Thursday, July 25**

**Concurrent Workshops III**

9:00 - 10:15 a.m. / See Pages 16 - 19 for workshop details.

- Centene Corporation and NCIL Address Gaps in Disability Access – An Award-Winning Idea (Independence A)
- SILC Mentorship that Leads to Successful Engagement (Independence BC)
- Using the Minimum Data Set (MDS) to Fuel System Change (Independence DE)
- Reproductive Justice as Part of Independent Living (Independence FGHJ)
- Chronic Pain and the Opioid Crisis 102: Mobilizing for Chronic Pain and Substance Use Disorder Advocacy In Your Community (Lafayette / Farragut)

**Concurrent Workshops IV**

10:30 - 11:45 a.m. / See Pages 19 - 22 for workshop details.

- Housing: How Screwed Are We? And What Can We Do About It? (Independence A)
- One Voice, One Vision: Raising the Bar for Statewide Collaboration (Independence B)
- Improving Independent Living Services to Alaska Natives (Independence DE)
- How to Strengthen the IL Network in Your State (Independence FGHJ)
- Difficult Conversations: How the #LiveOn Campaign Challenges Ableism and Confronts Suicide in the Disability Community (Lafayette / Farragut)

**Concurrent Workshops V**

1:30 - 2:45 p.m. / See Pages 22 - 24 for workshop details.

- Intersections in Healthcare Accessibility and Business Acumen (Independence A)
- Building A Strong Board of Directors (Independence BC)
- Moving Out: Preparing and Empowering Young Adults in Transition (Independence DE)
- Unheard Screams - Human Trafficking (Independence FGHJ)
- Acting B-A-D: A Patient Advocacy Strategy (Lafayette / Farragut)

**Legislative Debriefing:**

3:00 - 4:00 p.m. / Independence A

This session will summarize the advocacy accomplished during the week and serve as a springboard for the development of a plan of action that can be implemented at the national, state, and local levels during the coming year.
Film Screening Double Feature - *The Invalid Corps* and *Union*

3:00 - 4:15 p.m. / Franklin

- Ignite Our Political Power Track
- Presented by Day Al-Mohamed and Julia Myers Neill
- Appropriate for all audiences and knowledge levels.

This is a double-feature of two 30 minute films: *The Invalid Corps* and *Union*, and each film will be followed by a brief Q&A session. *The Invalid Corps* is a documentary and *Union* is a narrative film. Both are set in the Civil War and revolve around Invalid Corps and disability during the 1860s. There is not a significant amount of scholarship on this area and it is a history that has not been widely explored or shared among the disability community. Civil War historians and disability studies academics are only just beginning to scratch the surface of this time period and of the actions of these men. Their stories shouldn't just be relegated to journals and classroom texts. This is disability history that belongs to everyone. *Please note: this event is scheduled concurrently with the Legislative Debriefing.*

Closing Plenary

4:15 - 5:00 p.m. / Independence Ballroom

Invited guests will deliver a closing keynote on pressing advocacy issues important to the NCIL membership and energize the crowd before we return home and prepare to make change.

**Friday, July 26**

NCIL Board Meeting

9:00 a.m. - 12:00 p.m. / Lafayette / Farragut

NCIL Board meetings are open to the public. If you plan to attend either of these events and require an accommodation, please contact tim@ncil.org by July 18, 2019.

Pre-Conference Sessions

NCIL & ILA / ACL – The Good, the Bad, and the Ugly: Sunday, July 21; 2:00 - 3:30 p.m.

- Location: Constitution AB
- Ignite the IL Network Track
- Appropriate for all audiences and knowledge levels.

This Pre-Conference session is presented by the NCIL Rehabilitation Act / IL Funding Subcommittee and will give you an understanding of NCIL’s relationship with the Independent Living Administration (ILA) and the Administration for Community Living (ACL) – the good, the bad, and the ugly. Presenters will review the successful advocacy efforts NCIL has implemented to get the ILA / ACL to comply with the law and the progress that has been
made, as well as the many tasks ILA / ACL has yet to complete and target dates that have been missed. Details of the Reorganization of ACL will be provided, along with the impact it has had on the ILA and on CILs and SILCs.

**Ann McDaniel** is the Executive Director of the West Virginia Statewide Independent Living Council (SILC). She has Master’s and Bachelor’s Degrees from Marshall University and has worked in the Independent Living and advocacy field since 1985. Under her direction, the SILC has developed seven State Plans for Independent Living (SPIILs) and sponsored, organized, and conducted multiple WV Disability Caucuses and Youth Disability Caucuses. Ann has served as a mentor to many other SILCs, provides training & technical assistance, and teaches online courses and webinars through the national IL Net training project.

**Maureen Ryan** has been the Executive Director of the Wisconsin Coalition of Independent Living Centers, Inc. for the past seventeen years. She is a registered lobbyist for the state association of CILs in Wisconsin. She provides training and technical assistance nationally on Systems Advocacy, Facilitating a Quality Peer Review (QUILS), Providing and Documenting Quality Services within a CIL, and Developing and Implementing a Statewide IL Network. Ms. Ryan is a member of the NCIL Board and NCIL’s Region V Representative.

**A Dialogue on Accessible Voting: U.S. Election Assistance Commissioners and NCIL Members:** Sunday, July 21; 4:00 - 5:30 p.m.

- Location: Constitution AB
- Ignite Our Political Power Track
- Appropriate for all audiences and knowledge levels.

As the federal government’s independent, bipartisan commission on election administration, the United States Election Assistance Commission (EAC) plays a major role in encouraging election officials to make our elections accessible. In this dialogue session presented by the NCIL Voting Rights Subcommittee, the EAC wants to hear from voters with disabilities about their experiences with voting. EAC Commissioners will speak to participants about voting rights and accessible elections, and all participants will be invited to share their experiences and feedback on the voting process to help the EAC understand the needs and priorities of voters with disabilities. The EAC has guaranteed that at least three of the four EAC commissioners will be in attendance.

**Kathy Hoell** is Executive Director of the Nebraska Statewide Independent Living Council (NESILC), past president of The Arc of Nebraska, and past Board member of Disability Rights Nebraska. She is Co-Chair of the NCIL Voting Rights Subcommittee.

**Jim Dickson** has 30 years of experience with nonpartisan voter engagement issues. He is Co-Chair of NCIL’s Voting Rights Subcommittee. Mr. Dickson played a central role with the Leadership Conference on Civil and Human Rights (LCCRH) effort to pass the Help America Vote Act (HAVA). He was part of the leadership team that passed the National Voter Registration Act.

**Poster Sessions**

A poster session is the presentation of research information with an academic or professional focus. Posters are displayed throughout the NCIL Conference space at the discretion of the presenter.
**Under the Red Umbrella: CILs Should Start Supporting Sex Workers in Their Communities**

- Ignite the IL Network Track
- Poster by: Yolanda Vargas and Parker Glick

Sex workers are part of the disability community. Sex work is one of the most common forms of employment for people with limited access to support and disabilities that make holding socially acceptable jobs difficult. Presenters will compile information from people who either have experience directly with sex work or serving people in the sex work industry. This will allow discussion of concrete examples of the things that work and the things that don’t. It will also create a space where people can talk about the common misconceptions people have about sex work.

**CILs and Healthcare Contracting: Assessing Progress**

- Healthcare Track Sponsored by the WITH Foundation
- Poster by: Richard Petty, Brooke Curtis, and Elizabeth Blair

Centers for Independent Living have a critical role in in managed long-term services and supports and other delivery system reforms taking place around the country. The core services that CILs provide can help to improve health and quality of life outcomes for individuals with disabilities in these programs, and CILs have increasingly been marketing these services to health plans and other healthcare organizations. This poster, based on research conducted by the Aging and Disability Business Institute and by ILRU, will explore the progress that CILs have made in contracting with healthcare entities, and the role that the core services play in those contracts.

**About Workshop Sessions**

Workshops are classified by target audience: Front Line Staff & Consumers, Advocates & Project Directors, or Executive Directors & Board Members. Workshops are also classified as Newcomer, Experienced, or Appropriate for all levels.

**Workshop Tracks**

- **Ignite Our Political Power Track**: Workshops addressing the political power of the disability community, including voting rights, running for office, and systems advocacy.

- **Ignite the IL Network Track**: Workshops addressing innovation and promising practices in the core services of Centers for Independent Living, especially the new core services of youth transition, transition from institutions to the community, and avoiding institutions.

- **Healthcare Track Sponsored by the WITH Foundation**: Workshops related to healthcare, including healthcare policy and advocacy, along with the healthcare landscape and contracting with Managed Care Organizations and other healthcare providers.

- **Ignite Our SILCs Track**: Workshops covering best practices and innovation in operations and programs of Statewide Independent Living Councils.
DIA Today: A Better Way

- Location: Independence A
- Ignite Our Political Power Track
- Appropriate for all audiences and knowledge levels

The Disability Integration Act (DIA) is a civil rights, bipartisan and bicameral legislation in the 116th Congress. S. 117 is sponsored by Senators Schumer (D-NY) and Gardner (R-CO) and H.R. 555 is sponsored by Representative Sensenbrenner (R-WI). This presentation will discuss the reintroduction of DIA and the campaign taken on by thousands to move it towards becoming law. Since 2015, there has been collaborative and inclusive activism to get over 100 national and 500 local and state organizations to support DIA. In this session, presenters will discuss the political and organizing leadership of disabled people to move the next civil rights law in disability.

Bruce E. Darling is co-founder and President/Chief Executive Officer of the Center for Disability Rights, Inc. (CDR), a Rochester-based disability rights organization and Independent Living Center. Bruce is proud of his work as a community organizer with ADAPT and being part of the team that created and wrote the Disability Integration Act (DIA).

Dara Baldwin was born in Torrejon, Spain to parents involved in serving their country, the desire to serve has continued through her education and current career journey. Currently, she is the Director of National Policy for CDR. In her position, she will lead the DC policy outreach for the passage of the DIA.

Anita Cameron is a disability rights activist and has been involved in social change activism and community organizing for 36 years. Anita has been an ADAPT member for 31 years, serving as a national organizer, strategist, and police negotiator. Anita is very proud of the fact that she has been arrested 124 times with ADAPT doing nonviolent civil disobedience after the style of Dr. Martin Luther King, Jr. and Mahatma Gandhi.

Dawn Russell was born in the Mississippi Delta and institutionalized at the age of three. Dawn spent six months in Crippled Children’s Hospital in Memphis before the being released. In Dawn’s own words, “For almost a decade, I believed my eventual return and length of stay depended on my progress and performance. Today I understand it was not about me at all but about an empty nursing home bed”. Dawn is a proud ADAPT member and part of the team who created and wrote the Disability Integration Act (DIA).

Queer Disabled Justice

- Location: Independence BC
- Ignite Our Political Power Track
- Appropriate for all audiences. Knowledge level: Experienced

The purpose of this workshop is to engage the intersection of disability and LGBTQ identity from a social justice perspective. Discussion shall include ways to make the disability advocacy movement, including the IL field, more inclusive of LGBTQ people with disabilities and more social justice-minded.

Victoria M. Rodríguez-Roldán, J.D. is the Director of Disability Justice for the National LGBTQ Task Force.
Talila Lewis, Esq. is representing Helping Educate to Advance the Rights of Deaf Communities (HEARD).

Ma'ayan Anafi serves as Policy Counsel for the National Center for Transgender Equality.

Lydia X. Z. Brown is a Fellow at Bazelon Center for Mental Health Law.

Advocacy and Organizing: Using These Tools to Create Power and Change

- Location: Independence DE
- Ignite the IL Network Track
- Target audience: Advocates and Project Directors. Appropriate for all knowledge levels.

Advocacy and organizing are both important tools for Centers for Independent Living. Both can help us create the change we want to see in the world. However, it is important to know how these methods of change are different and how to successfully utilize both to achieve the outcomes you want. In this session, the facilitators will discuss power and how it works and give you some basic tools to see power shift in your community through the use of advocacy and organizing!

Chris Worth is the organizing team manager at Paraquad Inc. in St. Louis. Chris has fifteen years of experience in the field of community organizing. Chris organized his own grassroots initiative, known as the ENABLE Project. Based in West Virginia, the ENABLE Project was composed of a group of twenty people with disabilities interested in and passionate about making their communities a more accessible place for the disabled.

Derek Wetherell is the Systems Organizer at Paraquad. Derek heads up organizing initiatives around voting / civic engagement and campaign building. He also helps to design trainings and materials for a number of Paraquad initiatives, including Tuscher institute, Paraquad’s training institute on community organizing and civic engagement.

Running for Office: the Final Frontier for the IL Movement

- Location: Independence FGHI
- Ignite Our Political Power Track
- Appropriate for all audiences and knowledge levels.

One in five people in the US are disabled, yet only a fraction of a percentage of elected officials - at any level - identify as being a member of the community. This presentation discusses how the disparity of disabled elected officials impacts effective representation of disabled Americans at the legislative level, personal experiences regarding being a disabled candidate for office, and the importance of supporting disabled leaders, via the IL movement, to gain a seat at the legislative table.

Reyma McCoy McDeid is the both Executive Director of Central Iowa Center for Independent Living in Des Moines and the first openly autistic candidate for office in the US. She has carved out a unique career in employment services, disability advocacy, and education and she works to engage voters with disabilities into the political process and educate elected officials on the issues that impact the nation's largest marginalized community.

REAADI in Disasters: Igniting Community and Political Power to Save Disabled Lives in Disasters
Three Portlight Inclusive Disaster Strategies Fellows will provide an overview of existing emergency planning and their fellowship initiatives to build support for the Real Access for Aging and Disability Inclusion in Disasters Act (REAADI). Stephanie will lead a training so everyone is REAADI for powerful conversations with our representatives and communities for access to disaster planning, response, and recovery. Dustin will explore the intersection of disability, disasters, and the frontiers of technology. Valerie will discuss using policy and partnerships to address gaps in response efforts. Robbie Kopp of Able SC will discuss experiences in a CIL supporting disaster-impacted disability community through four disasters.

**Stephanie Hydal** is a recent Fellow with Portlight and Partnership for Inclusive Disaster Strategies and was housed in NCIL to organize for community and congressional support of the Real Emergency Access for Aging and Disability Inclusion in Disasters Act (REAADI).

**Valerie Novack** is completing a year-long Portlight Fellowship at Center for American Progress focusing on enhancing accountability in emergency management at federal, state, and local levels through education and legislation such as the REAADI Act. She previously worked in advocacy at The Ability Center in Toledo, OH.

**Dustin Snowadzky** is completing his Portlight Fellowship term at the American Association of People with Disabilities, where he focuses on technology to maximize nationwide engagement with disability inclusive emergency management initiatives.

**Robbie Kopp** is Able South Carolina’s Director of Advocacy & Community Access. Since 2015, South Carolina has had impacts or significant threats from severe weather, and Robbie has coordinated a group of CILs and other service providers to interface with state emergency management structures to address shelter access, communications, and unmet needs. When the weather is clear, he promotes policies that shift the spectrum of shelter services towards independence.

**CONCURRENT WORKSHOPS II: Wednesday, July 24, 9:00 - 10:15 a.m.**

**Taking it to the Streets - How to Mobilize Your CIL**

- Location: Independence A
- Ignite the IL Network Track
- Appropriate for all audiences and knowledge levels.

Learn about Atlantis Community Inc.’s answer to serving consumers they couldn't reach through traditional efforts. When consumers experience barriers to accessing the traditional IL services at the Center, the Center comes to them. The Mobile Unit allows Atlantis to serve the underserved populations such as consumers with psychiatric disabilities, rural consumers, consumers experiencing homelessness, or individuals who can't otherwise access services as a result of their disability.

**Robbie Roppolo** moved to Denver in 1996 and joined Atlantis Community, Inc. in 2016 as an
Independent Living Specialist. In 2017, he became the Mobile Independent Living Unit Manager while the program was still in its infancy with a newly awarded grant. He is an active member of Atlantis ADAPT.

**Candie Burnham** is the Executive Director of Atlantis Community, Inc. in Denver. She has extensive disability policy experience at the local and state level. Her years of hands-on work in disability program design and evaluation has allowed her to develop creative solutions to addressing various systemic issues and developing metrics to ensure programmatic sustainability.

**Partners in the IL Network: Roles & Responsibilities**

- Location: Independence BC
- Ignite Our SILCs Track
- Target audience: Executive Directors and Board Members. Appropriate for all knowledge levels.

This workshop will provide clarity on the roles and responsibilities of the partners in the IL Network – the CILs, SILC, and DSE. An overview of the duties and responsibilities in the law will be provided. The Indicators and Assurances for SILCs will be reviewed, as well as the Assurances for DSEs. Participants will be encouraged to share experiences, issues, and potential solutions – providing peer support for each other.

**Jeremy Morris** is the Executive Director Ohio SILC. Before joining the SILC in 2017, Jeremy had spent almost 10 years working in Independent Living. His background in Centers for Independent Living includes direct services, advocacy and community partnerships, and operations management.

**Ann McDaniel** is the Executive Director of the West Virginia SILC. Ann has provided national, state, and regional training on the history and philosophy of independent living, the roles and functions of SILCs, SPIL development, strategic planning, measuring consumer satisfaction, the legislative process, advocacy, parliamentary procedure, the Rehabilitation Act, and a variety of other topics.

**How to Go From Being the Best Kept Secret to the Best Known!**

- Location: Independence DE
- Ignite the IL Network Track
- Appropriate for all audiences and knowledge levels.

Learn how anyone associated with your CIL can promote what you do so your CIL will be known in your areas as the go-to place for people with disabilities!

**Michelle West** is the Marketing Communications Director for The Independence Center in Colorado Springs, CO. Michelle has been a director of marketing for a myriad of nonprofits over a decade.

**Advocacy - It’s Not Just A Reaction**

- Location: Independence FGHI
- Ignite Our Political Power Track
- Appropriate for all audiences and knowledge levels.
Advocacy is at the core of the Independent Living & disability rights movements. Yet with changes in staff, community, leadership, and laws, many are being told that we can no longer advocate or even mention the “A” word. The presenters in this workshop will not only be dispelling all of those myths but explore the many ways effective advocacy can and should take place at every Center for Independent Living across our nation through “igniting” our membership.

Steve Higgins is the Executive Director of Independence Associates, Inc. located in East Bridgewater MA. He currently serves on the NCIL Board as the Representative for Region I and as Co-Chair of the ADA / Civil Rights Subcommittee. Additionally, Steve has served several terms as a member of the Massachusetts SILC.

Kimberly Tissot serves as the Executive Director of Able South Carolina, which serves half the state. She currently serves as the Co-Chair of the NCIL ADA / Civil Rights Subcommittee and the NCIL Parenting Task Force, as well as many statewide boards and councils.

Fueling Business Acumen: How CILs are Securing Contracts with Health Plans and Payers

- Location: Lafayette / Farragut
- Healthcare Track Sponsored by the WITH Foundation
- Appropriate for all audiences. Knowledge level: Experienced.

Many CILs are seeking to expand their services by contracting and partnering with health plans, managed care organizations and other payers. But how do you build these relationships and why are these contracts important to meeting the needs of the disability community? Join us for a panel discussion with CILs who are leading the way in working with health plans and payers to learn more about how they got to “the table”, what services health plans and payers are most interested in, and about the growth and financial support their CILs have experienced through contracting with health plans and payers.

Richard Petty, M.B.A., is Co-Director of ILRU and Director of the National Center for Aging and Disability (NCAD) at TIRR Memorial Hermann. In addition to directing independent living and technical assistance programs at ILRU for twenty years, he leads training and technical assistance activities for disability-oriented community organizations with the Aging and Disability Business Institute with ILRU’s partners.

Patricia Yeager is the CEO of The Independence Center, a 30+ year old organization serving the Pikes Peak area. The Independence Center operates a $12 million skilled and nonskilled home health agency and a pilot hospital-to-home program helping people with disabilities transition home after an acute hospital episode, rather than to the nursing home.

Audrey Schremmer is Executive Director of Three Rivers, Inc. (3Rivers). 3Rivers achieved their goal of funding diversification using contracts with Managed Care Organizations (MCOs) as an important revenue stream. Ms. Schremmer has worked closely with current and prior MCOs to develop contracts to provide mission-based services to Kansans with disabilities.

CONCURRENT WORKSHOPS III: Thursday, July 25, 9:00 - 10:15 a.m.

Centene Corporation and NCIL Address Gaps in Disability Access – An Award-Winning Idea
To address disparities in disability access to healthcare, Centene and NCIL partnered in 2017 to implement a National Barrier Removal Fund (BRF). The program allows providers to apply for competitive funding to remediate priority disability access barriers. Grant recipients also receive tailored technical assistance and training from NCIL, local CILs, and Centene’s local health plans, including on-site Accessibility Site Reviews to verify disability access data in provider directories. Centene and NCIL will present the 2018 BRF results, talk about the current BRF implementation in Kansas, Florida, and New Mexico, and discuss the future of the initiative.

Sarah Triano is the national manager of LTSS Product Innovation and Development for Centene. Previously, Triano served in California Governor Jerry Brown’s administration as a disability policy advisor to the Secretaries of Health Care Services and Labor, was the Program Director at Access Living of Metropolitan Chicago, and the Executive Director of the Silicon Valley ILC.

Kelly Buckland is the Executive Director of the National Council on Independent Living. He is the former Executive Director of Living Independence Network Corp (LINC) and the Idaho SILC, both in Boise.

Theresa Lyons Flanders is a Provider Network Performance Manager with Centene Corporation, where she manages disability services, Foster Care, and (Long Term Services and Supports (LTSS) provider networks. Her work includes ongoing health plan interaction and provider engagement that result in awareness and increased compliance of federal and state disability access, improved child health and welfare, and enhanced network of services for LTSS members.

SILC Mentorship that Leads to Successful Engagement

- Location: Independence BC
- Ignite Our SILCs Track
- Target audience: Executive Directors and Board Members. Appropriate for all knowledge levels.

This workshop will provide participants with ideas and resources on how to create an individualized mentoring program to help new council or board members become confident, knowledgeable, and active participants. Participants will be introduced to two types of mentoring programs currently being used with success within two Statewide Independent Living Councils: one is a formal program adopted by the Virginia SILC and the other is an informal mentoring program being used by the Nevada SILC.

Lauren Snyder Roche is the Administrator of the Virginia Statewide Independent Living Council; a systems change advocate; professional artist; former art educator; and an individual with multiple disabilities.

Dawn Lyons, MPA, LMT is the Executive Director of the Nevada Statewide Independent Living Council; a Nevada Aging and Disability Services Program Specialist for the Commission on Services for Persons with Disabilities; a volunteer for homeless, disadvantaged and disabled youth; a single mother of two adult children with disabilities; and
an individual with a Traumatic Brain Injury.

Using the Minimum Data Set (MDS) to Fuel System Change

- Location: Independence DE
- Ignite the IL Network Track

The Minimum Data Set (MDS) collects a lot of information about the people living in nursing facilities in our states. As significant revisions were being made to the document, advocates were able to make a place at the table and make specific improvements to the MDS Section Q, relating to residents’ ability to return to their own homes. Learn about the MDS, changes made to the MDS, and how the information in the MDS can be used by advocates to promote systems change and community integration to free our people!

**Ami Hyten** is a licensed attorney and the Executive Director for Programs and Operations of the Topeka Independent Living Resource Center (TILRC) in Kansas. TILRC has provided Ami with the opportunity to merge her training as an attorney, her experience with public policy work, and her passion as an activist in working towards a fully integrated and accessible society for all people with disabilities.

**Mike Oxford** is the Executive Director for TILRC, a national organizer with ADAPT, and Past President of NCIL. Mike has dedicated his life’s work to building the partnership between consumer-driven community change agendas, direct action through non-violent civil disobedience, and public policy work to implement real systems change.

Reproductive Justice as Part of Independent Living

- Location: Independence FGHI
- Ignite Our Political Power Track
- Appropriate for all audiences and knowledge levels.

Given the experience of the Kavanaugh confirmation, the rape of the disabled Native American woman in Arizona, and ongoing and repeated attempts to use disability as a wedge issue in public policy spaces, there is a real need for a conversation at the intersection of disability rights and reproductive justice. How do we talk about issues of consent, access to reproductive healthcare, the right to bodily autonomy, within spaces both inside and outside of the disability community?

**Rebecca Cokley** directs disability policy at the Center for American Progress. She joined CAP after 4 years leading the National Council on Disability. Prior to 2013 Cokley worked in the Obama Administration at the Departments of Education, Health & Human Services, and the White House where she oversaw diversity outreach.

**Jamila Taylor** is a senior fellow at American Progress where she is an expert on women’s health and rights, leading the organization’s efforts to develop and advance policies that ensure women have an equal opportunity to live healthy and economically secure lives, centering the experience of women of color.

**Azza Altiraifi** is a research associate for the Disability Justice Initiative at American Progress. Prior to joining American Progress, Altiraifi worked at Georgetown University’s Center for Contemporary Arab Studies, where she managed public programming, developed improved
standards of disability access, and amplified underrepresented issues impacting the region.

Chronic Pain and the Opioid Crisis 102: Mobilizing for Chronic Pain and Substance Use Disorder Advocacy In Your Community

- Location: Lafayette / Farragut
- Healthcare Track Sponsored by the WITH Foundation
- Appropriate for all audiences and knowledge levels.

People with chronic pain continue to experience increasing barriers to accessing and maintaining adequate pain management. This interactive workshop will focus on gaining a deeper understanding of policies driving these barriers and strategies to increase awareness and advocate to increase access to the full spectrum of pain management options. Presenters will provide up-to-date information on federal laws and regulations, state legislation, and other efforts impacting people with chronic pain. Participants will share what's happening in their states and communities. A significant amount of time will be allocated for the group to discuss opportunities for advocacy, both national and locally.

Lindsay Baran is the Policy Analyst at NCIL, where she helps to implement NCIL's legislative and advocacy activities. Lindsay has lived with chronic pain for most of her life, and she has organized and facilitated chronic pain peer support groups. She has strong knowledge of disability and chronic pain policies, and she has written and presented on both issues.

Sarah Blahovec is the Disability Vote Organizer for NCIL and a chronic illness advocate with Crohn’s Disease. As a writer and individual advocate, Sarah has encouraged greater inclusion of people with chronic illness and chronic pain in the disability advocacy movement. She has advocated individually for her own pain management throughout the course of her illness, and is an advocate for policies and practices that are inclusive of and compassionate toward everyone, from pain management patients to people struggling with addiction.

Eiryn Griest Schwartzman focuses their disability advocacy on chronic pain, medical ethics, mental health, class issues, and the intersection of queer identity. Since 2015, they've dedicated their time to fighting for more equitable opioid policy and protecting our rights to life and liberty. The trauma they've faced as a direct result of being a disabled person with multiple rare diseases and intractable pain is the driving force behind their work.

CONCURRENT WORKSHOPS IV: Thursday, July 25, 10:30 - 11:45 a.m.

Housing: How Screwed Are We? And What Can We Do About It?

- Location: Independence A
- Ignite Our Political Power Track
- Appropriate for all audiences and knowledge levels.

NCIL’s Housing Subcommittee will cover the challenges facing people with disabilities who are seeking housing assistance. The shortage of accessible, affordable, healthy / nontoxic, decent, safe, and integrated housing in communities is well known. But how severe is this problem? Different aspects will be covered ranging from someone seeking an ordinary apartment, to a homeless individual, to a person transitioning from a nursing institution. The presenters will vary between providing national numbers and discussing brief case studies of
challenges encountered in local communities by CILs. Opportunities for advocacy will be outlined with each aspect of the numerous housing challenges faced.

**Brian Peters** is a Community Access & Policy Specialist at IndependenceFirst in Milwaukee, WI. Brian has been involved the NCIL Housing Subcommittee for the past 16 years. He has engaged in numerous housing advocacy efforts locally, on a statewide basis, and at the national level.

**Jeff Iseman** is the Public Policy and Outreach Coordinator for the Pennsylvania Statewide Independent Living Council. Jeff has been active with the NCIL Housing Subcommittee, the Housing Alliance of Pennsylvania and the PA Disability Budget Coalition on housing issues for people with disabilities along with other public policy concerns.

**Kimberly Meck** (Heymann) became the Executive Director of the Alliance of People with Disabilities in September of 2014. She has a Master’s degree and a history of working with a CIL as a board member for several years. Kimberly’s specialty is research.

**One Voice, One Vision: Raising the Bar for Statewide Collaboration**

- Location: Independence BC
- Ignite Our SILCs Track
- Appropriate for all audiences and knowledge levels.

This panel presentation sponsored by the SILC-NET (a part of the IL-NET) will expand upon the national conversation about collaboration among the CILs in a state, the SILC, and the DSE. One Voice, One Vision is about seeing collaboration as something more than just working together, as required, on writing the State Plan for Independent Living or any other activities the network might choose. It will broaden the conversation to the aspects of collaboration that create an integrated IL Program and unity within a statewide network and some proven strategies for how to achieve it. Representatives from two states will share their challenges and successes in moving their networks to the next level of collaboration.

**Paula McElwee** is the Technical Assistance Coordinator for ILRU / IL-NET.

**Jeremy Morris** is the Executive Director of the Ohio Statewide Independent Living Council.

**Kathy Foley** is the Executive Director of Services for Independent Living in Euclid, OH.

**Kathy Cooper** is the Executive Director of the Statewide Independent Living Council of Kansas.

**Improving Independent Living Services to Alaska Natives**

- Location: Independence DE
- Ignite the IL Network Track
- Appropriate for all audiences. Knowledge level: Experienced.

Lessons learned and best practices! Southeast Alaska Independent Living (SAIL), in partnership with the Administration for Community Living (ACL), National Council on Independent Living (NCIL), Association of Programs for Rural Independent Living (APRIL), Alaska Native Elders Care and strategic tribal partners, implemented the IL-STAND demonstration project. Attendees will gain from this workshop presentation: an increased
understanding of service needs of southeast Alaska Natives with disabilities; information about how SAIL increased cultural competency of staff, building capacity to deliver five core services in six communities; and ideas for replication across the country.

Joan Herbage O’Keefe is in her 17th year as Executive Director of Southeast Alaska Independent Living (SAIL) following 5 years in SAIL’s adaptive recreation program. SAIL’s service region is arguably one of the most geographically challenging in the nation, roughly the size of North Carolina, and comprised of dozens of small, remote communities and Native villages not connected by a road system.

Gail Dabaluz was hired by SAIL April 2017 to administer the Independent Living –Services to Alaska Natives with Disabilities (IL-STAND) federal demonstration project. She has over 20 years of federal, state and SBA contracting and tribal management administration experience and is an enrolled citizen with the Tlingit and Haida Indian Tribes of Alaska.

### How to Strengthen the IL Network in Your State

- Location: Independence FGHI
- Ignite the IL Network Track
- Appropriate for all audiences and knowledge levels.

Wisconsin Coalition for Independent Living and New York Association on Independent Living will provide information on what State Associations across the nation look like and discuss the components of a strong IL network.

Maureen Ryan has been the Executive Director of the Wisconsin Coalition of Independent Living Centers, Inc. for the past seventeen years. She is a registered lobbyist for the state association of CILs in Wisconsin. She provides training and technical assistance nationally on Systems Advocacy, Facilitating a Quality Peer Review (QUILS), Providing and Documenting Quality Services within a CIL, and Developing and Implementing a Statewide IL Network. Ms. Ryan is a member of the NCIL Board and NCIL’s Region V Representative.

Lindsay Miller is Executive Director of the New York Association on Independent Living (NYAIL), the statewide membership organization for Independent Living Centers. Ms. Miller has extensive experience implementing and managing statewide programs in collaboration with NYAIL’s member ILCs through various State and private grants.

### Difficult Conversations: How the #LiveOn Campaign Challenges Ableism and Confronts Suicide in the Disability Community

- Location: Lafayette / Farragut
- Healthcare Track Sponsored by the WITH Foundation
- Appropriate for all audiences and knowledge levels.

The #LiveOn Campaign is a project by and for disabled people showing how worthwhile life is, despite the heavy burden of living in an ableist society. Many of us are bullied, forced into nursing facilities by the institutional bias, or discriminated against at school and work. While it is not often discussed in disability rights spaces, oppression can and does lead to depression and sometimes suicide. This workshop will describe current efforts to confront this problem directly with #LiveOn: a multi-media campaign showing disabled people who choose to #LiveOn. It will train CIL staff about how to connect those at risk with resources they need, many of which are available through #LiveOn.
Leah Smith is a Media and Entertainment Advocate for the Center for Disability Rights in Rochester, NY. She has nearly a decade's worth of experience in the Independent Living Movement, first as a board member and then a Relocation Specialist for LifeRun in Lubbock, TX; and next as a Senior Marketing and Communications Specialist and Quality Management Specialist at Liberty Resources in Philadelphia, PA. She has also served two terms as the Director of Public Relations for Little People of America.

CONCURRENT WORKSHOPS V: Thursday, July 25, 1:30 - 2:45 p.m.

Intersections in Healthcare Accessibility and Business Acumen

- Location: Independence A
- Healthcare Track Sponsored by the WITH Foundation
- Appropriate for all audiences. Knowledge level: Experienced.

People with disabilities face well-documented disparities: We have twice the difficulty finding doctors who meet our needs as our non-disabled counterparts, and poorer access to key preventative-health screenings. However, promising developments are transforming the landscape: new standards for accessible medical-diagnostic equipment (MDE) were finalized in 2017; new Medicare payment policies promise improved preventative-care access for harder-to-serve patients; increased attention paid to social determinants of health by providers and managed care organizations is promoting the rethinking of accessible, culturally-competent care across-the-lifespan with an understanding that such innovations enhance quality-of-care in a cost-effective manner. This panel will address these innovations from an IL perspective, discussing how CILs have successfully identified opportunities and become involved in this work through business acumen and partnerships with hospitals, providers, and healthcare industry partners.

Patricia Yeager has spent her entire 35 year career in services and advocacy to improve the lives and communities of people with disabilities. She is the CEO of The Independence Center in Colorado Springs. She has served as a SILC coordinator as well as a SILC member.

Priti Pandya, LEAP’s Director of Community Partnerships oversees LEAP’s partnership with Centene’s Provider Accessibility Initiative and Barrier Removal Fund. Through this partnership, providers chosen for awards will receive an on-site disability accessibility review completed by LEAP and funding to remediate priority disability access barriers.

Dr. Stacy Jones is a Harvard Medical School graduate that helped form a national organization, NMAC, a group of about 50 people including medical students, but some nursing, pharmacy and occupational therapy, from about 40 different schools. The group advocates for better systems for people with disabilities in medicine, for more awareness across the field, and provides peer support.

Building A Strong Board of Directors

- Location: Independence BC
- Ignite Our SILCs Track
- Target audience: Executive Directors and Board Members. Appropriate for all knowledge
The workshop on how to build a strong board of directors will enable participants to develop a strategic plan to building a strong board. By analyzing what the needs are related to board member talents and skills that are already present, participants will develop a board matrix with clear and concise goals tying back to the mission statement. Participants will learn the importance of a vision statement that projects the future terms of the organization. Participants will understand the importance of best practices, while remaining relevant in meeting the needs of changing climate and defining key responsibilities of board members. Any participant in this workshop should bring their current board list indicating the diversity of the membership and have on hand a current strategic plan, if applicable. Facilitators will have these items on hand for the group interactive discussion.

**FranSha’ Anderson** is the Executive Director of the Arkansas Statewide Independent Living Council located in Little Rock, Arkansas. She is a member of NCIL and serves on the Voting Rights Subcommittee and the REV UP Advisory Committee. Her background includes advocacy, outreach, civil and disability rights, as well as project management and operational management of non-profits.

**Jeremy Morris, BSBA** is the Executive Director of the Ohio Statewide Independent Living Council. Before joining the SILC in 2017, Jeremy had spent almost 10 years working in Independent Living. His background in Centers for Independent Living includes direct services, advocacy and community partnerships, and operations management.

### Moving Out: Preparing and Empowering Young Adults in Transition

- Location: Independence DE
- Ignite the IL Network Track
- Appropriate for all audiences and knowledge levels.

In the IL community, young adults may experience transitions from a variety of settings: a family home, a college campus, an institution. Further, they may define independent living differently from previous generations. What are the challenges young adults with disabilities face when moving out on their own? What resources help them experience successful transitions and live as independently as they wish? We conducted interviews with six young adults to answer these questions. Come hear their perspectives on navigating a transition to community and independent living and join in a discussion about ways to empower other young adults on moving out.

**Hayley Steinlage** is a Research Project Coordinator at the Research and Training Center on Independent Living, at the University of Kansas. As a project coordinator, Hayley is currently working on the RTC for Promoting Interventions for Community Living, which addresses home usability and community participation barriers for people with physical disabilities.

### Unheard Screams (Human Trafficking)

- Location: Independence FGHI
- Ignite the IL Network Track
- Appropriate for all audiences and knowledge levels.

This workshop will cover the basics of human trafficking, what to look for if a person is being trafficked, what some Centers for Independent Living are currently doing to prevent trafficking...
of people with disabilities, what policies are currently in place and what is in the future. A designated safe space will be provided.

**Ericka Reil** works as a disability advocate for the Vermont Center for Independent Living. She has held this position for 16 years. She is the Chair of several boards dealing with protections and advocacy for people with disabilities. She serves on the Human Trafficking Task Force in Vermont. Ericka is successfully living with a disability, traveling around the state and country training and advocating others about disability rights and culture.

**Jan Derry** is the Executive Director for the Northern West Virginia CIL and has been addressing human trafficking in Morgantown, WV as CIL director and through her city's human rights commission. She also serves on NCIL Violence and Abuse Subcommittee.

**Jae Jin Pak** is a social justice advocate, educator, and ally with over 25 years of experience working on issues of domestic / sexual violence prevention, anti-trafficking, mental health, disability, anti-oppression, and cultural competency. He serves on the Statewide Independent Living Council of Illinois, IL Imagines Chicago Team, and the National Human Trafficking & Disability Working Group Steering Committee.

**Kim Colville** is a Peer Advocate at the Vermont Center for Independent Living. In addition to her counseling work, she teaches on various disability topics, including human trafficking. Kimberly is a member of the Vermont Human Trafficking Task Force Education Committee and has worked as a trainer at the Vermont Crime Victims Academy. She is a graduate of the Vermont LEND program and is currently working on a certificate in Disabilities Studies at the University of Vermont.

**Acting B-A-D: A Patient Advocacy Strategy**

- Location: Lafayette / Farragut
- Healthcare Track Sponsored by the WITH Foundation
- Appropriate for all audiences and knowledge levels.

Despite nearly three decades since the passage of the ADA, and five decades since the passage of Section 504, access to accessible healthcare for persons with disabilities remains elusive. The reasons for that range from ignorance, indifference, or outright discrimination by healthcare providers. With the possible dismantling of the Affordable Care Act, now more than ever, persons with disabilities and their advocates must be their own patient advocate, and that advocacy is enhanced when a person uses an organized strategic approach requiring them to Act Before – After – During their healthcare appointments.

**Andrés J. Gallegos**, Esq. is a disability rights and healthcare attorney, and founded and directs the Robbins, Salomon & Patt, Ltd. (RSP) national disability rights practice, which focuses primarily on improving access to accessible healthcare for persons across all types of disabilities. Andrés is the Chairman of the Board of Directors of Access Living in Chicago, IL and a member of the National Council on Disability.

**Jennifer M. Sender**, Esq. has over 25 years of experience litigating a wide variety of civil cases in state and federal courts. Jennifer joined RSP in 2013 works with Andrés in representing persons across all types of disabilities to address accessibility barriers at medical clinics, hospitals, and other healthcare facilities.
**Restrooms**

All restrooms on Independence Level (5B) will be gender inclusive for the duration of the conference.
Onsite Registration

Please note that rates are per person and include materials, workshops, and Awards Luncheon.

- NCIL Member Organization: $310
- NCIL Individual Member: $380
- Non-Member: $430
- Youth (26 or younger): $110
- Daily Rate: $210
- Luncheon Ticket: $75

Personal Assistant Registration Policy: Personal Assistants are not required to pay the registration fee but should fill out a form to receive a badge. Personal Assistants are welcome to attend all conference events, including scheduled meals and receptions.

Meals

- Luncheon tickets will be included in your registration materials and collected at the event. Unregistered guests may purchase Luncheon tickets for $75.
- Rally lunches will be available to all registered conference participants. Individuals not registered for the conference are not guaranteed a lunch at the Rally.

NCIL Regions By State


Region VI (6): Arkansas, Louisiana, New Mexico, Oklahoma, Texas. Region VI Representative: Julie Espinoza.

Region VII (7): Iowa, Kansas, Missouri, Nebraska. Region VII Representative: Ami Weidler-Hyten.


Region IX (9): Arizona, California, Hawaii, Nevada, American Samoa, Guam, Northern Mariana Islands, Trust Territory of the Pacific Islands. Region IX Representative: Sheri Burns.

Do-It-Yourself Sign Kits

Complimentary Do-It-Yourself Sign Kits will be available on the conference floor the afternoon of Monday, July 22. Please use this kit to create your signs for the March and Rally. This is your opportunity to speak truth to power! Feel free to be creative. Some examples include:

- Disability Integration Act Now
- Medicaid Saves Lives #SaveMedicaid #NoCutsNoCaps
- Disability Is a Natural Part of the Human Condition
- I AM INDEPENDENT LIVING
- Free Our People / Institutionalization Is No Way to Live
- Disability Rights Are Civil Rights #NCIL2019
- Don't Roll Back Our Rights!
- ADA: Making the Dream Live for ALL (Lead On) #ADA29
- Nothing About Us Without Us
- Full Community Integration Now
- Employment = Empowerment
- Equality Now! America for All
- Down with Nursing Home Lobby Pigs
- I Escaped a Nursing Home
- We Demand Freedom
- Justice Delayed is Justice Denied
- Our Homes Not Nursing Homes! #FreeOurPeople
- ADA: I Am Equal Too
- Civil Rights Are Not Special Needs
- The Future is Accessible
- Access is a Civil Right
- Cure Ableism #CheckYourPrivilege
- Disability Power! #DisabilityPride
- I Am A Pre-Existing Condition
- Disabled People Vote #CripTheVote
- Justice Not Just Us
- People Not Profits
- #IGNITE - Resist Injustice!
- What Do We Want? ACCESS! #ADA29
- The People United Shall Never be Defeated

What to Bring

Conference participants often brave blistering heat, massive thunderstorms, and even chilly workshop rooms, all to bring our message to Capitol Hill! Remember to bring along the following items to ensure your comfort and safety:

- large plastic bags to cover any batteries or electric devices that might be exposed to rain during the March and Rally, and duct tape to secure them;
- an umbrella to shield sun and rain;
- attire appropriate for both very hot and chilly temperatures;
- repair equipment / tools for your devices; and
- any medications or assistive devices you may need during strenuous activity.
Rules of Conduct for Annual Meetings

To ensure fair and orderly meetings that allow all NCIL members to participate, NCIL uses Robert’s Rules of Order for the conduct of annual meetings to the greatest extent possible. However, NCIL feels that under no circumstances should “undue strictness” be allowed to intimidate members or limit full participation.

The conduct of ALL business is controlled by the general will of the whole membership, with the right of the majority to decide. The following is a quick reference to the rules of order:

Anyone may obtain the floor (the right to speak) by being the first to stand or raise your hand or indicate in some way that you wish to speak, and wait to be recognized by the Board President before speaking.

A member may make a motion at any time after they have been recognized to speak. All motions must be seconded. Debate cannot begin until the President has restated the motion and asked if there is discussion on the motion.

Rules of order that members can invoke at any time during the meeting, including during discussion of a motion:

- **Point of Privilege**: Pertains to noise, personal comfort, etc. - may interrupt only if necessary, does not require a second or a vote

- **Point of Information**: Generally applies to information desired from the speaker: "I should like to ask (the speaker) a question." - does not require a second or a vote

- **Point of Order**: Infraction of the rules, or improper decorum in speaking. Must be raised immediately after the error is made, does not require a second or a vote

- Any questions regarding correctness of procedure will be referred to the independent parliamentarian secured by NCIL for that purpose.

Access, Accommodations, & Resources

Environmental / Chemical Sensitivities

Fragrance and chemicals can be access barriers. To help make this Conference accessible to participants for whom chemicals or fragrances are an access barrier, NCIL requests that you come fragrance free. Please refrain from wearing any scented products or washing with them. This includes clothing that has been laundered with fragranced detergent or fabric softening products. Additionally, please completely air out any dry-cleaned clothing before wearing it to the Conference.

Smoke can also be an access barrier. It is essential that we maintain a smoke-free environment. If you smoke, please use the designated smoking area located outside the Hyatt. Please refrain from smoking near any other doorways or paths of travel. The hotel entrance at 11th Street should be the least polluted with cigarette smoke and vehicle exhaust, although it unfortunately has steps.
Parking

The maximum vehicle height for the garage at the Grand Hyatt is 6’ 6”. Taller vehicles (up to 8’ 2") may park in the City Center complex, directly across the street from the Grand Hyatt. City Center offers an overnight parking rate of $24 / night, which is less than the rates at the Grand Hyatt.

Sensory Retreat

The McPherson room will be available throughout the entire Conference as a sensory retreat. This room is reserved for individuals that need a break from overstimulation and / or the large group environment of the Conference. Please help us maintain this accommodation. Do not use this space to hold conversations or meetings.

Auxiliary Aids & Services

Communication Access Realtime Translation (CART), sign language interpreters, assistive listening devices, personal assistants, accessible materials, and other services will be provided upon request for all NCIL Conference activities. However, participants must arrange their own services for Hill Visits on Tuesday. Congress is responsible for providing interpreters for Hill visits upon request. Email contact: interpreters@saa.senate.gov.

Local Service Providers: Personal Assistant Services

NCIL's Personal Assistants will be available during Conference hours only. Use the information below to arrange your own personal assistant service during non-conference hours.

ENDependence Center of Northern VA (CIL) - Arlington, VA

- Contact: Ruchika Lalwani, PAS Coordinator
- Phone: 703-525-3268
- TTY: 703-525-3553
- Email: ruchikal@ecnv.org

Local Service Providers: Wheelchair and Scooter Rental and Repair

The route of the NCIL March from the Grand Hyatt to the US Capitol is a little over one mile long. Many Conference attendees rent power chairs or scooters and have them delivered to their hotel to ensure they can participate.

ZASK Medical Supply - Alexandria, VA

- Phone: 703-354-1266
- Email: info@zaskmedical.com
- ScootAround
  - Web: www.scootaround.com
  - Phone: 1-888-441-7575

Express Mobility Services

- Phone: 703-346-8796
- Website: expressmobilitieservices.com

Scooterplus / Lenox Medical Supply

- Web: www.lenoxmedicalsupply.com
- Phone: 1-866 474-4356 or 202-387-1960
Advocate’s Guide to the Hill

Each year, the highlight of the NCIL Annual Conference is the convergence of members from across the nation, who unite on Capitol Hill to share stories of discrimination, institutionalization and segregation with their Senators and Representatives. Our message is loud and clear: Independent Living is a civil right we are willing to fight for!

March & Rally

Tuesday, July 23, 2019 has been set aside for NCIL’s March and Rally on Capitol Hill. We will be lining up outside of the Grand Hyatt Hotel along 11th & G Streets NW at 9:30 a.m. for the March. Participants will be divided up into their respective regions where signs will be distributed by state.

We will begin marching at 10:00 a.m. sharp.

The March route is a little over one mile long. We have an area designated on the West Front Lawn of the U.S. Capitol Building, near Constitution Avenue and First Street NW (see text directions below or page 34 for map). The Rally will begin at 11:30 a.m. Please feel free to join the Rally even if you are not able to participate in the March. Lunch will be provided to conference registrants.

The March and Rally will occur rain or shine so it is important to dress appropriately for the weather and be prepared to spend most of your day outdoors on Capitol Hill. Be sure your chair is fully charged and that you have enough medications, supplies, snacks, and drinks to get you through the day. As we learned in years past, it is imperative that people who use power wheelchairs or electric scooters bring plastic bags to protect batteries and controls in case of rain.

After the Rally, NCIL members are strongly encouraged to go and meet with their elected officials to discuss pressing legislation impacting people with disabilities and Independent Living nationwide.

March Route

Directions from the Grand Hyatt Hotel (1000 H Street NW / Washington, DC 20001) to NCIL Rally Site (West Front Lawn of the U.S. Capitol Building)

- Depart 10th & G Streets NW.
- Travel 1 block East on G St. NW.
- Turn Right on 9th St. NW, travel 3 blocks South.
- Turn Left on Pennsylvania Ave. NW, travel 4 blocks SE.
- Cross 3rd St. NW and move to the sidewalk along the Congressional parking lot.
- Proceed across 1st St. NW and enter the West Front Lawn of the U.S. Capitol.

The metro stations at Union Station and South Capitol are located just a few blocks away from the Rally site and the House and Senate office buildings. Union Station is to the North, closest to the Senate office buildings. Capitol South is located to the South, closest to the House office buildings. A map is located on Page 33. Cabs are also readily available near the U.S. Capitol. A limited amount of wheelchair accessible Uber vans are also available in DC. For more information, go to uber.com/ride/uberwav.

About Your Visit to Capitol Hill

Security Notice: In order to meet with your elected official, you will have to pass through a security screening in all House and Senate office buildings. You are encouraged to bring photo ID with you
on your Capitol Hill visit.

You will be required to pass through a body scanner. If you are unable to be scanned or uncomfortable, please request a pat down or wand screening.

All bags are subject to thorough search and security screening. If you have any of the following items with you on your visit to Capitol Hill, you may not be allowed to visit your representative. Prohibited items include:

- Mace and pepper spray
- Any sharp or pointed object
- Knives of any size, including pocket knives
- Cans and bottles
- Any bag larger than 14" wide x 13" high x 4" deep (per security discretion)
- Weapons of any kind
- Non-aerosol spray
- Aerosol containers
- Protest Signs

This is an abbreviated list. If in doubt, leave it at the hotel!

**Tunnels**

Both the Senate and the House Office Buildings are connected by a series of underground tunnels. Once you pass through security to either the Senate or the House Office Buildings, you can move about freely between buildings of that office without having to repeatedly go through security. The interconnecting tunnels can be found in the basements of both the Senate and House Office Buildings.

**Accessible Entrances**

- **Capitol Building**: Public tours enter through the Capitol Visitor Center; Official House business enters on the south side of the Capitol; Official Senate business enters on the north side of the Capitol.
- **Capitol Visitor Center (CVC)**: Main entrance at First and East Capitol streets. The CVC also offers an on-demand shuttle and other services.
- **Cannon House Office Building**: Entrance on New Jersey Avenue, SE, south of the terrace at the intersection with Independence Avenue.
- **Dirksen Senate Office Building**: First and C Street entrance.
- **Ford House Office Building**: Entrance on 3rd Street, SW or 2nd Street, SW.
- **Hart Senate Office Building**: Second Street entrance or Constitution Avenue entrance.
- **Longworth House Office Building**: Main entrance, Independence and New Jersey Avenues. Or the South Capitol Street entrance.
- **O'Neill House Office Building**: C Street SW between 2nd and 3rd Streets.

**Hill Cafeterias**

Have some down time in between appointments once you are in the House or Senate Office Buildings? Both offer a number of places to have everything from a quick snack, to a full meal. For
more specific information on directions to tunnels, eateries, or to your Representative’s office, feel free to ask Hill staff or security.

Senate Office Buildings:
- Russell Basement: Coffee and Sandwich Shop
- Dirksen Basement: Full Cafeteria - Your best bet on the Hill!

House Office Buildings:
- Longworth Basement: Cafeteria
- Rayburn Basement: Coffee and Sandwich Shop

There is also a cafeteria located inside the U.S. Capitol Building.

Services on Hill Visits

CART (Communications Access in Real Time), sign language interpreters, assistive listening devices, personal assistants, accessible materials, and other services will be provided upon request for all NCIL conference activities. However, participants must arrange their own services for Hill Visits on Tuesday, July 23. Congress is responsible for providing interpreters for Hill visits upon request. The following email contact is provided by the Capitol Visitor Center: interpreters@saa.senate.gov.

Directories of the 116th Congress: First Session

Directory of the Senate: To contact your Senator, use the directory at: www.senate.gov/senators/contact. Senators are listed alphabetically with their phone numbers, email addresses, and office locations available. You may also find information by calling the Capitol Switchboard at 202-225-3121 or 202-224-3091 (TTY).

Your Senator’s office will be in one of three “Senate Office Buildings” or SOB. They are Dirksen, Hart, and Russell. The room number of your Senator coincides with the floor his or her office is on. If your Senator is located in Hart 302, that office is on the 3rd floor; Dirksen 439, is on the 4th floor; Russell 238 is on the 2nd floor.

Directory of the House of Representatives: To contact your Representative, use the directory at: www.house.gov/representatives. Representatives are listed alphabetically with their phone numbers, email addresses, and office locations available. You may also find information by calling the Capitol Switchboard at 202-225-3121 or 202-224-3091 (TTY).

Your Representative’s office will be in one of three “House Office Buildings” or HOB. They are Cannon (CHOB), Longworth (LHOB), and Rayburn (RHOB). The room number of your representative coincides with the floor his or her office is on. If your representative is located in Cannon 328, that office is on the 3rd floor. If the office number is more than three digits, disregard the first number and the second number represents the floor your representative’s office is located on. For example, an office listed as Rayburn 2439, is on the 4th floor; Longworth 1721 is on the 7th floor.

Additional Resources

For more help with planning your visit to the Capitol please visit the Capitol Visitor Center's website: www.visitthecapitol.gov/plan-visit/visitors-disabilities
NCIL Rally Site: West Front Lawn of the U.S. Capitol Building
Sponsors

Soldier for Justice
- Centene Corporation
- Anthem

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Mover & Shaker
- Motor Coach Industries
- Center for Disability Rights

Activist
- Airbnb
- Ability360
- United Healthcare
- Pride Mobility
- Molina Healthcare

Catalyst
- Portlight Inclusive Disaster Strategies
- National Coalition for Assistive and Rehab Technology
- Mitsubishi Electric America Foundation

Donors: Tracfone Wireless, American Association for Homecare, Yoshiko Dart, American Association of People with Disabilities, and The Independence Center

EMAIL CONGRESS TO PROTECT ACCESS

Visit www.protectmymobility.org to learn how you can help protect access to Complex Rehab Technology for individuals with disabilities.
WITH Foundation is proud to support the National Council on Independent Living!

The WITH Foundation is a private foundation that promotes comprehensive and accessible healthcare for adults with developmental disabilities. To learn more about WITH's efforts, see: withfoundation.org

“Never bend your head. Always hold it high. Look the world straight in the eye.”
-Helen Keller

Bender Leadership Academy
Empowering Talent Together
Launching and accelerating career success for students with disabilities
www.benderleadership.org

Uber is proud to work with the National Council on Independent Living to develop solutions that support everyone’s ability to easily move around their communities.

Learn more about how we’re improving the Uber experience for riders in wheelchairs at ubr.to/uberwav, and about all of Uber’s accessibility work at accessibility.uber.com
When it comes to health, everyone matters.

As a person-centered company, Centene works with our members to access appropriate quality healthcare and resources needed to live healthy independent lives. We’re proud of our diverse and dedicated employees, who provide the perspectives, insights, and efforts to help us transform the health of our communities – one person at a time.
HASHTAGS

Together, we can create a strong presence on social media, so that the work we do during the Annual Conference on Independent Living reaches far and wide.

#NCIL2019

When you post to social media platforms such as Facebook, Instagram, and Twitter, just add the hashtag at the end of your post. Then, click the hashtag to see what others are posting about. Please caption any photos you post if possible, so they are accessible to the entire community.

#IGNITE
Supporting You and the People who are Important to You

Proud to sponsor the 2019 NCIL Annual Conference on Independent Living
The Research & Training Center on Promoting Interventions for Community Living Joins NCIL in Igniting Action and Empowerment!

We are exploring ways to increase and promote community participation among people with physical and other disabilities by addressing environmental barriers within and outside the home.

The Home Usability Program teaches people how to examine their home for possible usability problems and how to make sure their home fits their needs. Out and About encourages people with disabilities to overcome barriers to getting out in their community by practicing goal setting skills and connecting with community resources.

Find more information and resources at our site: www rtcil.org

Let’s get connected! Email us at rtcil@ku.edu

The Research and Training Center on Promoting Interventions for Community Living (RTC/PICL) is a project of the Universities of Kansas and Montana. Contact: RTC/IL at the University of Kansas 1000 Sunnyside Ave., 4089 Dole Lawrence, KS 66045-7561 785-864-4095 TTY: 785-864-0706 rtcil@ku.edu www rtcil.org

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YOUR SUPPORT IS VITAL
Access Ready Inc. is a nonprofit cross-disability education and advocacy organization promoting a policy of inclusion and accessibility across information technology through education and best practices. The Board of Directors of Access Ready has deemed inaccessible information technology to be a clear, growing and present danger to the civic, economic and social welfare of people with disabilities.

INCLUSION CAN'T WAIT

VOTEC Corporation is developing an accessible Voter Check-in Kiosk for the poll place. Visit our website at votec.net to experience our prototypes and provide us feedback.