



IGNITE

2019 Annual Conference
on Independent Living

Conference Guide



Presented by the National Council on Independent Living

July 22-25, 2019 • Grand Hyatt • Washington, DC



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. NCIL regularly hosts over 1,000 people, including grassroots advocates, CIL and SILC leadership, members of Congress, government officials, and representatives from other major organizations that work for justice and equity for people with disabilities.

Please join us in Washington this July to show our power, take to the streets, and share our message. Together, our individual sparks will ignite a flame that cannot be ignored.

Your Partner in Disability Rights,

Kelly Buckland
Executive Director



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NOTES

Questions: Contact us at conference@ncil.org

Registration

You may register multiple people in one transaction by using our online store. Visit ncil.org for:

- online registration
- printable registration forms
- personal assistant registration

Contact cara@ncil.org for sponsor registration.

Participants must register for the Conference before being eligible for a discounted rate at the hotels.

See Pages 17-19 for complete registration details.

Reservations: Identify yourself as a NCIL Conference attendee to receive the discounted rate.

Grand Hyatt: 800.233.1234

Deadline: June 21, 2019

Accessible rooms are reserved on a first-come, first-served basis.



Schedule

Sunday, July 21

NCIL Board Meeting: 9:00 a.m. - 1:00 p.m.

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

Registration Open: 12:30 - 5:00 p.m.

Pre-Conference Sessions: 2:00 - 5:30 p.m.

The Pre-Conference is an opportunity to focus on pressing advocacy issues. Registration for the Pre-Conference is included with full Conference registration. The topics for this year's Pre-Conference Sessions will be announced shortly.

Monday, July 22

Registration Open: 8:00 a.m. - 5:00 p.m.

Opening Plenary: 9:00 - 10:00 a.m.

Join us for an opening keynote address to kick off a week of movement-building and advocacy! Complete details will be available in the Conference Program. Don't miss this exciting 2019 Annual Conference opener!

Legislative & Advocacy Update: 10:15 - 11:30 a.m.

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.

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 8-9 for workshop details.

- DIA Today: A Better Way
- Queer Disabled Justice
- Advocacy and Organizing: Using These Tools to Create Power and Change
- Running for Office 101
- REAADI in Disasters: Igniting Community and Political Power to Save Disabled Lives in Disasters

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

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 at www.ncil.org/regions.

Diversity Reception: 6:00 - 8:00 p.m.

The Diversity Committee will 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

March & Rally at the U.S. Capitol: 10:00 a.m. - 12:30 p.m.

This annual tradition is your opportunity to take grassroots advocacy to the streets! Participants will march from the Grand Hyatt to Capitol Hill carrying signs and chanting for disability rights. Then, marchers will converge in front of the Capitol for an empowering rally. Complementary Do-It-Yourself Sign Kits will be provided to Conference registrants.

Capitol Hill Visits: 1:00 - 5:00 p.m.

The key to a successful Hill Visit is planning! It is very important that meetings with legislators are scheduled 4-6 weeks in advance. Contact the legislator's Appointment Secretary / Scheduler to schedule a meeting for the afternoon of July 23 (after 1:00 p.m.). Explain your purpose and who you represent. It will be easier for Congressional staff to arrange a meeting if they know what you wish to discuss. Direct requests for interpreters and other accommodations to Congressional staff.

Wednesday, July 24

Registration and Exhibits Open: 8:00 a.m. - 5:00 p.m.

Concurrent Workshops II: 9:00 - 10:15 a.m. See Pages 10-11 for workshop details.

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

Film Screening and Panel Discussion: *Parenting Without Pity - Empowering the Next Generation*: 10:15 – 11:00 a.m.

- 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.

- 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 US 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.

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.

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.

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.

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

Registration and Exhibits Open: 8:00 a.m. - 5:00 p.m.

Concurrent Workshops III: 9:00 - 10:15 a.m. See Pages 11-12 for workshop details.

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

Concurrent Workshops IV: 10:30 - 11:45 a.m. See Pages 12-13 for workshop details.

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

Concurrent Workshops V: 1:30 - 2:45 p.m. See Pages 14-15 for workshop details.

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

Legislative Debriefing: 3:00 - 4:00 p.m.

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.

- 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 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.

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.

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.



Workshops & Poster Sessions

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.

Workshop Sessions

The following workshops have been selected by NCIL's Annual Conference Subcommittee. Great care has been taken to ensure that the workshops are, as a whole, relevant to this year's Conference theme and valuable to a cross-section of CIL, SILC, and IL Association staff, board members, consumers, and other advocates.

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.

CONCURRENT WORKSHOPS I: Monday, July 22, 1:00 - 2:15 p.m.



DIA Today: A Better Way

- Ignite Our Political Power Track
- Presented by: Dara Baldwin, Bruce E. Darling, Anita Cameron, and Dawn Russell
- 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.

Queer Disabled Justice

- Ignite Our Political Power Track
- Victoria M. Rodríguez-Roldán, Talila Lewis, Esq., Ma'ayan Anafi, Lydia X. Z. Brown
- 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.

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

- Ignite the IL Network Track
- Presented by: Chris Worth and Derek Wetherell
- 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!

Running for Office 101

- Ignite Our Political Power Track
- Presented by: Lianna Stroster
- Appropriate for all audiences and knowledge levels.

Thinking about running for office but don't know where to start? EMILY's List, the nation's largest resource for women in politics has helped Democratic women for the past three decades run and win races up and down the ballot, will guide you through the nuts and bolts of planning your run, teach you how to get your house in order, and get you ready to take the first steps toward running — and winning. You don't need to be a declared candidate or actively planning to run, attendees just need an interest in learning the basics of being a candidate.

REAADI in Disasters: Igniting Community and Political Power to Save Disabled Lives in Disasters

- Ignite Our Political Power Track
- Presented by: Dustin Snowadzky, Valerie Novack, Robbie Kopp, and Stephanie Hydal
- Appropriate for all audiences and knowledge levels.

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 4 disasters.



Taking it to the Streets - How to Mobilize Your CIL

- Ignite the IL Network Track
- Presented by: Robbie Roppolo and Candie Burnham
- 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.

Partners in the IL Network: Roles & Responsibilities

- Ignite Our SILCs Track
- Presented by: Ann McDaniel and Jeremy Morris
- 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.

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

- Ignite the IL Network Track
- Presented by: Michelle West
- 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!

Advocacy - It's Not Just A Reaction

- Ignite Our Political Power Track
- Presented by: Steve Higgins and Kimberly Tissot
- 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.

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

- Healthcare Track Sponsored by the WITH Foundation

- Presented by: Richard Petty, Bill Henning, Audrey Schremmer, and Patricia Yeager
- 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.



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

- Healthcare Track Sponsored by the WITH Foundation
- Presented by: Sarah Triano, Kelly Buckland, and Theresa Flanders
- Appropriate for all audiences and knowledge levels.

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.

SILC Mentorship that Leads to Successful Engagement

- Ignite Our SILCs Track
- Presented by: Lauren Snyder Roche and Dawn Lyons
- 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.

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

- Ignite the IL Network Track
- Presented by: Ami Hyten and Mike Oxford
- Target audience: Advocates and Project Directors. Knowledge level: Experienced.

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!

Reproductive Justice as Part of Independent Living

- Ignite Our Political Power Track
- Presented by: Rebecca Cokley, Jamila Taylor, and Azza Altiraifi
- 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?

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

- Healthcare Track Sponsored by the WITH Foundation
- Presented by: Lindsay Baran, Sarah Blahovec, and Eiryn Griest Schwartzman
- 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.

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



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

- Ignite Our Political Power Track
- Presented by: Brian Peters, Jeff Iseman, and Kimberly Meck (Heymann)
- 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.

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

- Ignite Our SILCs Track
- Presented by: Paula McElwee, Jeremy Morris, Kathy Foley, and Kathy Cooper
- 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.

Improving Independent Living Services to Alaska Natives

- Ignite the IL Network Track
- Presented by: Joan Herbage O’Keefe and Gail Dabaluz
- Appropriate for all audiences. Knowledge level: Experienced.

Lessons learned and best practices! Southeast Alaska Independent Living, 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.

How to Strengthen the IL Network in Your State

- Ignite the IL Network Track
- Presented by: Maureen Ryan and Lindsay Miller
- 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.

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

- Healthcare Track Sponsored by the WITH Foundation
- Presented by: Leah Smith
- 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.



Intersections in Healthcare Accessibility and Business Acumen

- Healthcare Track Sponsored by the WITH Foundation
- Presented by: Patricia Yeager, Priti Pandya, Dr. Stacy Jones
- 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.

Building A Strong Board of Directors

- Ignite Our SILCs Track
- Presented by: Sha' Anderson and Jeremy Morris
- Target audience: Executive Directors and Board Members. Appropriate for all knowledge levels.

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.

Moving Out: Preparing and Empowering Young Adults in Transition

- Ignite the IL Network Track
- Presented by: Hayley Steinlage
- 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.

Unheard Screams (Human Trafficking)

- Ignite the IL Network Track
- Presented by: Ericka Reil, Jan Derry, Jae Jin Pak, and Kim Colville
- 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.

Acting B-A-D: A Patient Advocacy Strategy

- Healthcare Track Sponsored by the WITH Foundation
- Presented by: Andrés J. Gallegos, Esq. and Jennifer M Sender, Esq.
- 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.



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; and
- any medications or assistive devices you may need during strenuous activity.



Hotels & Lodging

Grand Hyatt Washington

We will return to the Grand Hyatt Washington, located at 1000 H St. NW, one block from the Metro Center subway station in downtown Washington, DC. The Grand Hyatt is the official Conference hotel and virtually all events will be held here.

A block of rooms has been reserved for NCIL Conference attendees from July 21-27, 2019 at a special rate of \$259 single / double occupancy (plus tax of 14.5%). Triple and quadruple

occupancy is available at \$284 and \$309, respectively (plus tax). Regency Club rooms are available at a variable rate, based on availability.

You must be registered for the Conference to qualify for the NCIL room block and the discounted room rate. To make your reservations online, use NCIL's custom link at ncil.org/hotels or call the hotel at 800.233.1234 (voice). Be sure to identify yourself as a NCIL Conference attendee to receive the discounted rate. Reservations received after June 21, 2019 will be accepted on a space availability basis.

Overflow Accessible Guestrooms: Marriott Metro Center

Overflow accessible rooms are available at the Marriott Metro Center, 775 12th Street NW, just one block from the Grand Hyatt. The rate is \$259 per night (plus tax of 14.5%). Reservations must be made by June 24, 2019. To make your reservations online, use NCIL's custom link at ncil.org/hotels or call the hotel at 202.737.2200. Be sure to identify yourself as a NCIL Conference attendee to receive the discounted rate. Accessible guestrooms are reserved on a first-come, first-served basis.



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 11st Street should be the least polluted with cigarette smoke and vehicle exhaust, although it unfortunately has steps.

Restrooms

Accessible and gender-inclusive restrooms will be available.

Van 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 actually quite competitive for downtown DC.

Quiet Room / Sensory Retreat

The McPherson room will be available throughout the entire Conference as a quiet room / 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. Please 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.

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 slightly less than one mile. 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

Rentals only. Delivery available.

- Web: www.scootaround.com
- Phone: 1-888-441-7575

Express Mobility Services

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

Scooterplus / Lenox Medical Supply

Rentals only. Delivery available.

- Web: www.lenoxmedicalsupply.com
- Phone: 1-866 474-4356 or 202-387-1960



Registration

Register by Mail or Fax: Sign up in minutes at www.ncil.org! Online registrants do not need to complete a hard copy registration form. If you prefer to register by mail or fax, please use a separate form for each registrant.

Registration Rates

- NCIL Individual Member Registration: \$335 / person (Early Bird: \$260)

- NCIL Member Organization Registration: \$265 / person (Early Bird: \$190)
- Full Conference Non-Member Registration: \$385 / person (Early Bird \$310)
- Daily Rate: \$115 / day (NCIL Members); \$160 / day (Non-Members)

Early Bird registration rates end April 26, 2019.

Onsite Registration

Online registration closes Friday, July 12. Conference attendees who have not registered by July 12 must register onsite. Please note that onsite registration fees differ from standard registration fees and plan accordingly.

Onsite Registration Rates:

- NCIL Individual Member Registration: \$380 / person
- NCIL Member Organization Registration: \$310 / person
- Full Conference Non-Member Registration: \$430 / person
- Daily Rate: \$210 / day

Youth Registration Rate

NCIL offers a reduced youth registration fee of \$110 to all NCIL members that are 26-years-old or younger. We hope this special rate will allow young people to afford the Conference and organizations to sponsor young people to attend.

Registration Policies

- Full Conference registration fees are per person and include registration for all events and activities, including the Awards Luncheon, materials and workshops. If you have any questions, please contact NCIL at 1.844.778.7961 or conference@ncil.org.
- Confirmations will be sent to each participant at the email address listed on the registration form.
- Individuals must register for the Conference and pay in full before reserving a discounted hotel room.

Personal Assistant Registration

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. Personal Assistants may also register online at www.ncil.org. Look for the link to Register a Personal Assistant.

Replacement and Cancellations

Replacement and cancellation requests must be made in writing and sent to NCIL by fax (202.207.0341) or email (conference@ncil.org) by Friday, July 5, 2019. No refunds will be issued after that date.

- Registrant Replacement: If it becomes necessary for you to send someone in your place, please contact us as soon as possible.
- Cancellation: Cancellation requests received by Friday, July 5, 2019 are refundable less a \$50 processing fee.

2019 Annual Conference on Independent Living

Complete, save, and send this form to NCIL:

Email: sylena@ncil.org

Mail: 2013 H Street NW / Sixth Floor

Washington, D.C. 20006

Fax: (202) 207-0341

Registration Form

Prefix and Name: Title:

Organization:

Address: City, State, Zip:

Email: Phone: Fax:

Check this box if you are a personal assistant to a registered attendee and are therefore not required to pay registration fees.

I certify that I am providing personal assistance to:

Full Conference Registration: All rates are listed per person. The member organizations rate is available to all staff, board, and consumers of all 2019 NCIL member organizations. To claim the member organization rate, you must list an organization in your contact information so we can verify your membership.

Early Bird Rate (must be postmarked by April 26, 2019):

- NCIL Member Organization: \$190
- NCIL Individual Member: \$260
- Youth Member: \$110 (26 & Under)
- Non-member: \$310

Standard Registration (postmarked after April 26, 2019):

- NCIL Member Organization: \$265
- NCIL Individual Member: \$335
- Youth Member: \$110 (26 & Under)
- Non-member: \$385

Subtotal: \$

Daily Registration: Skip this section if you are registering for the full Conference

- Monday, July 22
- Wednesday, July 24
- Thursday, July 25

- NCIL Member: \$115 / day
- Non-member: \$160 / day

Subtotal: \$

Payment

- Please charge my: Visa MasterCard
 American Express Discover I'm sending a check

Total amount: \$

Name on Card: Card #: Expiration: CID / CIV:

If paying by credit card, consider mailing or faxing this form; email does not provide encrypted delivery of your personal information.
Please make checks payable to National Council on Independent Living (Federal Tax ID: 74-2291620).

Auxiliary Aids

- Materials: Standard Print Electronic Materials: PDF, Word, and plain text on USB Large Print
 Braille Program + other materials in Plain Text on USB Braille Audio on USB

Diet: Standard Fare Vegetarian Salt-Free Low Cholesterol Other:

Accommodations: American Sign Language Transcripts Contact Sign Personal Assistant
 CART Assistive Listening Device Other:



2013 H Street NW / Sixth Floor
Washington, D.C. 20006