

# MOBILIZE

RESISTANCE THROUGH ACTION

2018 Annual Conference on Independent Living

## Conference Guide



JULY 23-26, 2018  
GRAND HYATT  
WASHINGTON, DC

Presented by the National Council on Independent Living

## A Message from the Executive Director

Dear Advocates and Friends,

NCIL's 2018 Annual Conference theme is *Mobilize: Resistance through Action*. For over a year now, members of Congress and aggressive ideologues have tried their hardest to strip people with disabilities of their health and liberty. We have met these challenges head-on and will continue to do so.

Some battles have been won, others lost. We are powerful, and 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.

In 2018, NCIL will focus heavily on mobilization and advocacy. This has always been the core of our work, but we must challenge ourselves to stay focused, strategic, and proactive. We cannot make progress without you. We need you to join us in Washington to show our power, take to the streets, and share our message of independence and empowerment.

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 this July for what is sure to be one of the most exciting Independent Living conferences in history.



Kelly Buckland



## Agenda

Sunday, July 22

- Registration Open: 12:30 - 5:00 p.m.
- Board Meeting: 9:00 a.m. - 1:00 p.m.
- Pre-Conference: 2:00 - 5:30 p.m.
- Youth Orientation: 6:00 - 7:00 p.m.

Monday, July 23

- Registration Open: 8:00 a.m. - 5:00 p.m.
- Opening Plenary: 9:00 - 10:00 a.m.
- Legislative & Advocacy Update: 10:15 - 11:30 a.m.

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- Preparing for the Day on the Hill: 11:30 - 11:45 a.m.
- Lunch (on your own): 11:45 a.m. - 1:00 p.m.
- Concurrent Workshops I: 1:00 - 2:15 p.m.
- Demo: Do It. Make It. Fix It - Assistive Technology You Control: 1:00 and 3:00 p.m.
- Regional Caucuses (Regions I-V): 2:45 - 3:45 p.m.
- Regional Caucuses (Regions VI-X): 4:15 - 5:15 p.m.
- Diversity Mixer: 6:00 - 8:00 p.m.

#### Tuesday, July 24

- Organize for the March: 9:30 - 10:00 a.m.
- March to the US Capitol: 10:00 - 11:00 a.m.
- Distribute Bag Lunches: 11:00 - 11:30 a.m.
- 2018 Rally at the US Capitol: 11:30 a.m. - 12:30 p.m.
- Hill Visits: 1:00 - 5:00 p.m.

#### Wednesday, July 25

- Registration & Exhibits Open: 8:00 a.m. - 5:00 p.m.
- Concurrent Workshops II: 9:00 - 10:15 a.m.
- Exhibit Fair: 10:15 a.m. - 12:00 p.m.
- Film Screening - *The Sensitives*: 10:30 a.m. - 12:00 p.m.
- American Health Policy 102: Understanding Medicaid and Recent / Current Policy Changes: 10:30 - 11:45 a.m.
- Awards Luncheon: 12:00 - 2:00 p.m.
- Annual Meeting: 2:30 - 5:30 p.m.
- Closing Social - NCIL@Nite: 8:00 - 11:00 p.m.

#### Thursday, July 26

- Registration & Exhibits Open: 8:00 - 5:00 p.m.
- Concurrent Workshops III: 9:00 - 10:15 a.m.
- Concurrent Workshops IV: 10:30 AM – 11:45 AM
- Lunch (on your own): 11:45 - 1:00 p.m.
- Concurrent Workshops V: 1:30 - 2:45 p.m.
- Film Screening - *Invalid Corps*: 1:30 - 2:15 p.m.
- Legislative Debriefing: 3:00 - 4:00 p.m.
- Closing Plenary: 4:15 - 5:00 p.m.

#### Friday, July 27

- Board Meeting: 9:00 a.m. - 12:00 p.m.

## NOTES

**Questions:** Contact us at [conference@ncil.org](mailto:conference@ncil.org)

### Registration

You may register multiple people in one transaction by using our online store. Visit [ncil.org](http://ncil.org) for:

- online registration
- printable registration forms
- personal assistant registration

Contact [cara@ncil.org](mailto:cara@ncil.org) for sponsor registration.

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

See Page 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: July 2, 2018

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

### \* NCIL Board Meetings

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](mailto:tim@ncil.org).

Sunday, July 22

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

**Pre-Conference Sessions**

**Integrating Disability Into Emergency Management – A Blueprint to Saving Lives in the Community:** 2:00 - 3:30 p.m.

Presented by: Christy Dunaway; Todd Holloway; Vance Taylor; June Kailes; and Marcie Roth

2017 was unprecedented in the number and severity of disasters in our country. The disability community was disproportionately impacted because we, and local and state emergency managers and society in general, have not acted upon the lessons we have observed from previous disasters by implementing practices, policies and procedures to better prepare our response. Natural disasters are more intense, and human-caused disasters more frequent. If people with disabilities are to survive these disasters with less damage to us and our community, we must take action now! To paraphrase Justin Dart, “we must get involved as if our lives depended on it.” The NCIL Emergency Preparedness Subcommittee will discuss promising practices regarding developing strategies to integrate disability into emergency management in your community.

**Resistance through Direct Action – How IL and ADAPT Work Together:** 4:00 - 5:30 p.m.

Presented by: Bruce Darling; Anita Cameron; Candie Dalton; Dawn Russell; Denise Figueroa; Lindsay Miller; and Mike Oxford

After the #SummerOfADAPT, there has been a renewed interest in organizing direct action throughout the Independent Living community and this organizing has been critically important. In fact, without the on-the-ground organizing done around the country, we would likely not have saved Obamacare or prevented the proposed draconian Medicaid cuts. The purpose of this pre-conference session is to provide participants with an orientation to ADAPT and disability-led direct action while helping participants understand the various ways that CILs can provide support to local ADAPT organizing and how states can leverage this in effecting systems change.

**Youth Orientation:** 6:00 - 7:00 p.m.

Youth (anyone age 26 and under) are welcome to attend this meeting. NCIL’s Youth Caucus will discuss the layout of the Conference, the function of the Youth Caucus, and setting goals for the Youth Caucus in the next year. Youth scholarship recipients are required to attend.

Monday, July 23

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

Join us for an opening keynote address to kick off a week of movement-building and mobilization through action! Complete details will be available in the Conference Program. Don’t miss this exciting 2018 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.

**Demo: Do It. Make It. Fix It - Assistive Technology You Control:** 1:00 and 3:00 p.m.

Presented by: John Flaherty and Brenda Dare

Assistive Technology is essential for independence, but ready-made devices are often expensive, difficult to trial and may not even meet the needs of users. The current climate of DIY and Maker efforts offer a range of options that can be tailored to the individual. Our presentation will speak to the effectiveness of two approaches, one on each end of the tech complexity spectrum: adaptive design work utilizing triple-ply cardboard to create custom answers and a 3D printing program that can generate individualized solutions external to the consumer marketplace. Attend the demo at either 1:00 or 3:00 p.m. to get hands-on assistance with your assistive technology questions! *Please note that the 1:00 demo is scheduled concurrently with Concurrent Workshops I and the 3:00 demo is scheduled concurrently with Caucuses for Regions I-V.*

**Regional Caucuses:** Regions I through V: 2:45 - 3:45 p.m.; Regions VI through X: 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](http://www.ncil.org/regions).

**Diversity Mixer:** 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 24

**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 24 (after 1:00p.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 25

**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.

**American Health Policy 102: Understanding Medicaid and Recent / Current Policy Changes:**  
10:30 - 11:45 a.m.

This training workshop will: 1) provide an overview of the evolution and current design of the US Medicaid program, 2) assess the growing role of Medicaid managed care; 3) discuss recent Congressional and Administrative proposals for Medicaid reform; 4) describe the variety of HCBS programs funded by Medicaid; and 5) explore implications of current / recent policy changes for Medicaid beneficiaries with disabilities. *Please note that this event is scheduled concurrently with Film Screening: The Sensitives.*

**Film Screening - *The Sensitives*:** 10:30 a.m. - 12:00 p.m.

*The Sensitives* is a documentary that premiered at NYC's Tribeca Film Festival this year. Drew Xanthopoulos filmed the material over a three-year period during which he stayed with (or near to) people with hypersensitivities. This film provides an up-close education about the barriers and adaptations common to people with this disability. Such an education is unlikely to be available elsewhere, and it is crucial to fulfilling our responsibilities as cross-disability advocates and service providers. *Please note that this event is scheduled concurrently with American Health Policy 102: Understanding Medicaid and Recent / Current Policy Changes.*

**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: Vice-President, Secretary, Diversity Chair, and three Members-At-Large. Elections for Youth at-Large and Representatives of Regions II, IV, VI, VIII, and X will be held prior to the Annual Conference and the winners will be announced at the meeting. CILs and SILCs must pay their 2018 dues in full by June 25 (30 days prior) to be eligible to vote in person or by proxy.

**Closing Social - NCIL@Nite:** 8:00 - 11:00 p.m.

Join us as we celebrate the 2018 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.

Thursday, July 26

**Film Screening - *Invalid Corps*:** 1:30 - 2:15 p.m.

Created in 1863, the Invalid Corps was made up of men who had been “disabled by wounds or by disease contracted in the line of duty” – men missing limbs, and eyes, those with rheumatism, epilepsy, bullet injuries, those with what we would now call PTSD, and many others. In this film, it is July 1864 and Confederate General Jubal Early is at the gates of Washington, DC. The city is in panic. Almost every able-bodied soldier from the Union has already been sent south with General Grant for the siege of Petersburg. The only defenders remaining are clerks, government officials, and the Invalid Corps. This is the story of men with disabilities, of men with honor, and of men whose place in history shouldn't be forgotten. Attend this film screening to learn about the Invalid Corps and the men who served in it. *Please note that this film screening is scheduled concurrently with Concurrent Workshops V.*

**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.

**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 27

**NCIL Board Meeting:** 9:00 a.m. - 12:00 p.m.



## **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.

### **Advocacy Anxiety: Don't Stress About It!**

- Presented by: John Morosky and Patrick Griffith

For people with disabilities whose independence relies on their ability to communicate and take action for themselves, anxiety can greatly diminish their chances for success. Our poster will be designed to invite conversation by graphically presenting solutions for those who find anxiety to be a barrier in their efforts to self-advocate.

## Workshop Tracks

- **Advocacy & Organizing Track:** Workshops related to systems advocacy, individual advocacy, and organizing.
- **Mobilizing New Leaders Track:** Workshops related to building new leadership by including and prioritizing the perspectives of youth, people of color, people who are LGBTQIA, and other advocates underrepresented in the IL Movement.
- **Core Services Track:** Workshops addressing innovation and best 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.
- **SILC Track:** Workshops covering best practices and innovation in operations and programs of Statewide Independent Living Councils.
- **General Track:** Workshops for staff, consumers, and other advocates in the Independent Living Movement that do not fit the other four categories.

## 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.

### CONCURRENT WORKSHOPS I

Monday, July 23, 1:00 p.m. - 2:15 p.m.



#### Advocating for our Rights; Adhering to the Rules

- Advocacy & Organizing Track
- Presented by: Ami Weidler-Hyten

This workshop will explore federal rules and regulations that might impact a Center's ability to participate in advocacy or lobbying activities, and how to fulfill Centers' advocacy purposes while abiding by applicable rules.

#### L&A Hot Topic: Organizing and Action to Advance the Disability Integration Act

- Advocacy & Organizing Track
- Presented by: Bruce Darling; Dawn Russell; Greg Beratan; and Laura Halvorsen

This workshop will help prepare participants to effectively advocate and organize for passage of the Disability Integration Act. Presenters will review the legislation, provide an update on

the status of the bill, explore answers to common questions about the bill and identify effective organizing strategies to use locally. Finally, participants will learn talking points targeted to both ends of the political spectrum that will help in securing allies and addressing potential opposition.

### **Achieve Success Through Partnership: Collaboration with CILs and other Organizations to Accomplish Goals**

- Advocacy & Organizing Track
- Presented by: Kim Lackey; Sarah Gentry; and Chris Worth

Recent years have resulted in a mix of positive and negative policy outcomes for the disability community in Missouri. This workshop will focus on the importance of coalition building with stakeholders within the disability community and across issue areas. Presenters will highlight recent successes, challenges, and the lessons learned in their state-level advocacy efforts. Participants will gain a better understanding of best practices for working with partners to impact policies that are important to the disability community, and how organizing and policy efforts can work together to accomplish goals in the current political climate.

### **Exploring SILC Authority to Conduct Systems Advocacy**

- SILC Track
- Presented by: Darrell Jones and Ann McDaniel

What does it mean that Statewide Independent Living Councils now have the Authority to “perform such other functions... as the Council determines to be appropriate...” and “... authorized in the approved SPIL?” This Authority provides SILCs with some latitude that was not previously available to them (consistent with the prescribed duties), most notably a more clearly stated opportunity to conduct systems advocacy. This workshop will explore the many forms that systems advocacy can take and be conducted by the SILC as a whole, SILC staff, and individual SILC members.

### **Lifting As We Climb: Empowering Young Leaders Through Peer Mentoring**

- Mobilizing New Leaders Track
- Presented by: Donna Fox and Tyler Levy

This workshop will be an interactive and lecture style discussion on how to engage youth and young adults with disabilities in your Center for Independent Living. The presenters will provide an opportunity to look at developing youth and young adult oriented peer groups and how an individual can start out as a peer mentor and end up as a community leader and advocate! It will discuss how to find, engage, and involve youth and young adults in your CIL and in the community.

## **CONCURRENT WORKSHOPS II**

Wednesday, July 25, 9:00 a.m. - 10:15 a.m.



### **Mobilizing Media Tools For Action**

- Advocacy & Organizing Track

- Presented by: Lawrence Carter-Long; Dominick Evans; Day Al-Mohamed; Anita Cameron; and Patrick Cokley

From traditional media to the ever-changing landscape of "new" and social media, disability activists have unparalleled options at our disposal to help get the word out about our work. But with so many choices, it can be difficult to decide which options are best for you and your organization. Here's your chance to learn from the pros, who will share firsthand examples of what they've learned in the field and lead participants in training exercises to help you decide which tools and techniques will work best for you.

### **Using Your CIL's Strong Foundation to Demonstrate Your Value and Fulfill Your Purpose**

- General Track
- Presented by: Erica Anderson and Lindsay Baran

Maintaining the consumer voice in your business is especially important when rapid change is required to maintain, expand, or grow your current operations. In this session, you will learn how to capitalize on the performance of your organization in your advocacy efforts. Receive resources from the HCBS Business Acumen Center along with stories and examples of promising practices from community-based organizations serving people with disabilities.

### **The New Role for SILCs Following WIOA and How It Relates to the IL Network**

- SILC Track
- Presented by: Stephanie Jensen; Matt Seeley, Esq.; and Paula McElwee

What has changed for your SILC since the passage of WIOA? What is your SILC's new role in the "IL network" in your state? The workshop will provide you with an overview of what should have / could have changed for your SILC based on the amendments to the Rehabilitation Act made by WIOA and the new IL Regulations. The new partnership between the SILC and CILs and how the SILC fits into the IL network will also be explored and all participants will be asked to share experiences, problems, and solutions.

### **Disability, Diversity and Intersectionality Project**

- General Track
- Presented by: Stanley Holbrook

Independent Living Research Utilization (ILRU) in collaboration with Public Research and Evaluation Services (PRES) conducted a three-phase research study entitled, Disability, Diversity and Intersectionality (DDI) project. This research study was designed to determine how Centers for Independent Living are designing, implementing and evaluating culturally and linguistically competent policies and practices to improve services, programs and outreach for racially / ethnically, culturally and linguistically diverse groups. The purpose of this workshop is to share best practice models implemented by Centers and provide a platform of knowledge and resource for Centers who want to become more inclusive in outreach and program service delivery.

### **Supporting Independence for Veterans**

- General Track
- Presented by: Marsha Unruh

What role can a CIL play in working with veterans to promote independence? See how one program in Colorado Springs, The Independence Center's Veteran in Charge program (Veteran-Directed Home & Community Based Services or VD-HCBS), partnered with a VA Medical Center to operate a program where veterans have the freedom and flexibility to self-direct services to remain in their home and community. VA Medical Centers work directly with Aging & Disability Resource Centers, Area Agencies on Aging, and / or CILs to offer VD-HCBS. The VA has announced plans to expand the program in the coming years.

## CONCURRENT WORKSHOPS III

Thursday, July 26, 9:00 a.m. - 10:15 a.m.



### **Rev Up your Non-Partisan Voter Engagement for the 2018 Midterms**

- Advocacy & Organizing Track
- Presented by: Kathy Hoell; Don Dew; Cindy Walker; Zach Baldwin; and Sarah Blahovec

One in six American voters has a disability, and it is critical to mobilize our community to vote in the 2018 election. In this workshop, voting rights advocates will discuss the best ways to engage voters with disabilities to register to vote, become educated, and show up at the polls on November 6th. Topics will include how to get involved with National Voter Registration Day (September 25th), conducting non-partisan voter education through the AAPD REV UP Candidate Questionnaire and community voter education resources, conducting Get Out The Vote (GOTV) operations, using your voting rights, and reporting barriers at the polls.

### **Providing Culturally Competent IL Services in the Orthodox Jewish Community**

- Mobilizing New Leaders Track
- Presented by: Sheryl Grossman and Sharon Shapiro-Lacks

This workshop will explore what cultural competency and best practices look like in an Orthodox Jewish community. Participants will get an inside look at the unique challenges and opportunities facing disabled Orthodox Jews.

### **Policies & Procedures with the New SILC Indicators**

- SILC Track
- Presented by: Stephanie Jensen; Ann McDaniel; and Matt Seeley, Esq.

The role of the SILC changed significantly with the passage of WIOA. Have your policies and procedures been updated to reflect those changes? Have you considered the new SILC Indicators and Assurances and how they affect your policies and procedures? This workshop will give you an overview of the changes in the law, regulations, indicators, and assurances and provide some guidance on how your policies and procedures may be updated to reflect those changes.

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

- Advocacy & Organizing Track
- Presented by: Maureen Ryan and Lindsay Miller

This workshop is intended to be an interactive discussion on how to build and sustain a unified IL network in your state. Hear from two states that have strong IL networks about their successes, challenges, and lessons learned. Participants will learn about how to share resources and obtain quality and consistency throughout your IL network, hear strategies on mobilizing your IL network for resistance and systems advocacy, and learn how to obtain a unified message for your SPIL development. Presenters will also share results from the recent national survey on state associations. Let's hear from you what works in your state and what barriers you are still experiencing.

### **Participating (Not Just Living) in the Community!**

- Core Services Track
- Presented by: Hayley Burghart and Dot Nary

Transitioning to the community is one thing but PARTICIPATING in the community is another. The Promoting Interventions for Community Living (PICL) project seeks to facilitate a process of removing home barriers and teaching skills and community connections that CIL staff can use to assist consumers. The Home Usability Program increases the ability of consumers with physical disabilities to negotiate their homes while the Out and About Program provides resources and trains goal-setting skills that can facilitate community participation. Come learn how your CIL can teach consumers their rights and facilitate their participation in community change!

## CONCURRENT WORKSHOPS IV

Thursday, July 26, 10:30 a.m. - 11:45 a.m.



### **CILebrity Squares**

- General Track
- Presented by: Misty Dion

CILebrity Squares is a replica of the game show "Hollywood Squares" it is a fun and interactive way to learn IL Movement information. This workshop will consist of 9 'CILebrities' that will answer questions provided by conference presenters and / or experts in the disability field. The audience will be divided in to two teams, "X" and "O" and each audience member will have the opportunity to agree or disagree with the 'CILebrity'. The topics covered will be derived from the various workshops presented at the Conference, disability services and IL Movement-related information.

### **Disability Solidarity for Chronic Pain Advocacy**

- Advocacy & Organizing Track
- Presented by: Lindsay Baran and Sarah Blahovec

Millions of people with chronic pain face major barriers to accessing and maintaining adequate pain management, and new policies aimed at restricting opioid use are making it even more difficult. But despite chronic pain being a widespread issue in the disability community, we've been largely silent on these new challenges. This workshop will focus on explaining the current major issues facing people with chronic pain, why the disability community needs to be involved in conversations about both chronic pain and opioids, and

what tangible steps we can take to support chronic pain advocacy.

### **How to Establish a Productive Partnership between the SILC and DSE**

- SILC Track
- Presented by: Matt Seeley, Esq.; Stephanie Jensen; and Ann McDaniel

What is your SILC's relationship with your DSE? Do you have problems with SILC autonomy? SILC funding? Timely processing of funds to your SILC? Many SILCs have issues with working with their DSE. The West Virginia SILC has experienced all the above and will share how to build a strong partnership with the DSE. The Wyoming SILC has a long history of working well with its DSE and will share the DSE perspective to give an idea of what a state agency considers.

### **Intersectional Storytelling: Amplifying Your Voice for the Disability Rights Movement**

- Advocacy & Organizing Track
- Presented by: Emily Ladau and Vilissa Thompson

As the disability community contends with a political atmosphere that places little value on our human rights and a media landscape that often misrepresents us and ignores our intersecting identities, it's important to take control of our narratives. Developing skills and strength to share our stories is empowering, and allows us to be part of national conversations about issues that impact our lives. In this session, members of the Rooted in Rights team will discuss how to talk about what matters, how to fill gaps in disability representation, and how to push past barriers to speak truth to power.

### **How Guardianship Contradicts the IL Philosophy: The Role of CILs**

- Core Services Track
- Presented by: Jerri Davison

The number of guardianships in the US has tripled since 1995. This trend represents a drastic shift of power and control away from individuals with disabilities. Significant changes to disability rights have always come at the urging of and thanks to the collective strength of the disability community, so this session will focus on the role CILs can play in changing the culture surrounding guardianship and how to bring power back to the individual. Participants will receive tools and information about alternatives to guardianship and strategies to promote independence through Supported Decision Making.

## **CONCURRENT WORKSHOPS V**

Thursday, July 26, 1:30 p.m. - 2:45 p.m.



### **The Promise of WIOA for Independent Living: Where Are We Now?**

- General Track
- Presented by: Dan Kessler; Ann McDaniel; and Lou Ann Kibbee

With the passage of WIOA and the move from the Rehabilitation Services Administration (RSA) to the Administration for Community Living (ACL), CILs and SILCs across the country

had high hopes for the new Independent Living Administration. This session will provide an update on where we are in achieving our vision. We will explore what changes in Independent Living have occurred since the passage of WIOA and the move from RSA to ACL. The workshop will also focus on NCIL's concerns with the implementation of WIOA and ACL's response to those concerns. A listening session for participants to share what issues they are having that they would like to see NCIL address will close this session.

### **Different Strokes for Different Folks: Embracing and Recognizing the Spectrums of Gender Identity and Sexual Orientation**

- Mobilizing New Leaders Track
- Presented by: Katie Johnson; Anita Cameron; Yolanda Vargas; Parker Glick; and Don Dew

This workshop will be presented by members of the NCIL Rainbow Caucus. The disability community is diverse. Within our community and outside of it exists LGBTQ+ people with various types of disabilities that have issues, and concerns that align with the disability community at large. Unfortunately, there exists a barrier of miscommunication, misunderstanding, and distrust. We aim to erase that barrier by educating participants about the shared history and struggles that the two communities have, and how to bridge the gap created by unique terminology and dissecting challenges specifically faced by disabled queer /gender queer people to make them less intimidating. We will also touch on how to mobilize individuals in the LGBTQ+ community in organizing efforts to further the mission of the Independent Living Movement.

### **How SILCs Can Be Good Partners to CILs in the Good, the Bad, and the In-Between Times**

- SILC Track
- Presented by: Kathy Cooper; Kim Conner; and Paula McElwee

Do people in your state think the CILs answer to the SILC? What is your SILC's relationship with the CILs? What are the CILs' relationships with each other like? With the changes in the law and regulations, the relationship between the SILC and CILs is clearer and more important than ever. This workshop will look at those relationships and discuss the SILC role in collaborating with, supporting, and assisting the CILs when things are good, when CILs are struggling, and all the times in-between.

### **Journey from Incarceration to Stability: Transitioning Former Inmates with Disabilities**

- Core Services Track
- Presented by: Christa Nuxoll

This workshop focuses on a specific population of transitioning people with disabilities: former inmates leaving correctional institutions and reintegrating back into society. Safe and stable housing, increased employment, access to healthcare, transportation. - all are integral to transition for people with disabilities, but for many former inmates, access to each may pose unique and enhanced challenges. This session seeks to improve former inmate outcomes with an emphasis on reduced recidivism, promoting independence and stability, and encouraging sobriety and healthful living.

### **Including Parents WITH Disabilities at your CIL**

- Advocacy & Organizing Track

- Presented by: Kimberly Tissot; Sarah Wendell Launderville; Susan Yuan; and Kelly Buckland

Parents with disabilities are often viewed as unfit based solely on their disability and are not provided with appropriate family preservation and reunification services and supports that are tailored to their needs. This session provides an overview of applicable laws and federal guidance followed by examples of systemic advocacy efforts and services that CILs can provide to support parents with disabilities.

## **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, 2018 at a special rate of \$254 single / double occupancy (plus tax of 14.5%). Triple and quadruple occupancy is available at \$279 and \$304, 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](http://ncil.org/hotels) or call the hotel at 800.233.1234 (voice / TTY). Be sure to identify yourself as a NCIL Conference attendee to receive the discounted rate. Reservations received after July 2, 2018 will be accepted on a space availability basis.

### **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 \$254 per night (plus tax of 14.5%). Reservations must be made by July 2, 2018. To make your reservations online, use NCIL's custom link at [ncil.org/hotels](http://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.

## **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.

## 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.



Fragrance  
Free

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-neutral 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 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

- Contact: Jabessa Daba (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



## **#ADAYouthPledge**

Due to a variety of barriers, most especially cost, youth with disabilities have been unable to fully participate in the national disability community. We are asking that your organization takes the #ADAYouthPledge through one of three ways:

- Pledge to financially sponsor 2 young people in your local area to attend the NCIL conference.
- Pledge to financially sponsor 2 young professionals on your staff to attend the NCIL conference.
- Contribute towards the Youth Scholarship Fund that will bring young people from across the country to the NCIL conference. Your donation will support plane tickets, hotel accommodations, personal assistance services, and registration costs for attendees.

Visit [ncil.org/youthpledge](http://ncil.org/youthpledge) to take action! With your help, we can bring youth with disabilities to the NCIL Conference and ensure that #GenerationADA is empowered, engaged, and supported to lead.



## **Registration**

Register by Mail or Fax: Sign up in minutes at [www.ncil.org](http://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 27, 2018.

## **Onsite Registration:**

Online registration closes Friday, July 13. Conference attendees who have not registered by July 13 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 877.525.3400 (voice / relay), or by email at [conference@ncil.org](mailto: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](http://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](mailto:conference@ncil.org)) by Friday, July 6, 2018. 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 6, 2018 are refundable less a \$50 processing fee.



RESISTANCE THROUGH ACTION

2018 Annual Conference on Independent Living

2018 Annual Conference on Independent Living Registration Form

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

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 2018 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 27, 2018):

Standard Registration (postmarked after April 27, 2018):

NCIL Member Organization: \$190

NCIL Member Organization: \$265

NCIL Individual Member: \$260

NCIL Individual Member: \$335

Youth Member: \$110 (26 & Under)

Youth Member: \$110 (26 & Under)

Non-member: \$310

Non-member: \$385

Subtotal: \$ [ ]

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

Monday, July 23

Wednesday, July 25

Thursday, July 26

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