



National Council on Independent Living

# **Summer 2023 Board Reports**

July 25, 2023

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# EXECUTIVE DIRECTOR REPORT

Prepared by: Theo Braddy, Executive Director

## STATEMENT FROM EXECUTIVE DIRECTOR

Much has been accomplished since starting February 1, 2023. I am pleased with a few things as I continued to implement the vision of NCIL. The NCIL Board has welcomed my leadership and offered tremendous support. The staff has also welcomed my leadership and is joining me as we re-establish and re-energize NCIL on a national level.

In this report are just a few of the activities that are highlighted. Some of activities are producing immediate benefits and others will yield benefits in the near future. I hope you are please and look forward to your continued comments and guidance.

## HIGHLIGHTS

### WHITE HOUSE

I have visited the White House on several occasions. One involved a delegation of advocates during the NCIL board meeting in February. I was invited back again during a Black History event. On April Tuesday, April 18th I had a special invitation to the White House to participate in the signing ceremony of the President 's executive order to help families access care and support care workers and family caregivers. I will continue to build this relationship.

- Biden-Harris Administration Announces Sweeping Set of Executive Actions to Improve Care: <https://advocacymonitor.com/biden-harris-administration-announces-sweeping-set-of-executive-actions-to-improve-care/>
- POTUS Tweet: <https://twitter.com/POTUS/status/1648676728552792067?s=20>

### MANAGED CARE ORGANIZATIONS (MCOS)

I am representing NCIL on the United Healthcare Services Advisory Committee (UHC). A fee of \$1,500 is paid to NCIL for every in-person meeting or \$325 per virtual meeting. Attended first meeting on March 16, 2023.

I am representing NCIL on the Centene National Disability Advisory Council. A fee of \$4,000 is paid to NCIL for participation.

Jeff Hughes introduced me to Merrill A. Friedman, Regional Vice President of Anthem. I am developing a meaningful relationship with them. Met with Merrill on several

occasions. Merrill represent Anthem / Elevance and is providing a \$20,000 sponsorship level for the IL Conference.

Met with Carmen Jones from United Health Care to determine other possible projects that can benefit NCIL. Discussions are ongoing.

Developed a contractual agreement with CareSource that resulted in a \$20,000 engagement fee paid to NCIL upfront that will allow NCIL to further work with CareSource.

I have just begun a conversation with Humana Healthcare, hoping to develop an ongoing relationship.

## CORPORATE BUSINESS INVOLVEMENT

**Cruise:** NCIL is a member of the Cruise Advisory Council. Cruise is on a mission to make transportation more accessible, equitable, and inclusive. Over 61 million Americans live with a disability, yet often lack reliable, affordable transportation access, compounding barriers to education, employment, healthcare, and wellbeing.

Cruise's Self-driving technology has the potential to alleviate transportation barriers that many with disabilities face, but that reality cannot be achieved in a vacuum - it has to be done with direct input from those with lived experience.

In developing the Origin Mobility, our wheelchair-accessible autonomous vehicle, and incorporating more accessibility features into our product, Cruise has partnered with a number of disability-led organizations and conducted user testing with people with disabilities to inform our product design.

**Lotus Labs:** NCIL is working with Lotus Labs in an effort to introduce new technology to assist people with disabilities. Lotus, a startup that's developed a new approach to home automation that is optimized for disability, and usable by everybody. Over the past two years the company has been developing a wearable ring that allows users to control objects like lights, fans and TVs by pointing. All without the need for apps, internet, or rewiring. Unlike traditional approaches that rely on smart speakers, Lotus uses infrared technology, providing a more affordable, private, and portable solution. Lotus is interested in working with CILs and SILCs to 1) educate staff on the technology, and 2) facilitate small scale pilots of the technology in end users' homes. I am planning to participate in a pilot and encourage others to do so as well. The technology is still at an early stage, so Lotus is eager to gain as much feedback from NCIL members as possible. For more details on the technology, please watch this [one-minute demonstration video](#).

**Airbnb Disability Roundtable 2023:** NCIL takes part on the Airbnb Disability Advisory Roundtable Meetings to provide accessibility advice on Air BNB sites. Airbnb sponsored a \$10,000 sponsorship for NCIL Conference.

**Rutgers's Self Driving Wheelchair Technology:** We are currently working on a research proposal titled "Pioneering Autonomous Wheelchair Navigation: Ensuring Safety and Reliability Across Indoor and Outdoor Environments". I will get paid \$125 per hour for approximately 40 devoted to this project.

**Verizon:** I've met with Zachary Bastian, from Verizon on several occasion to further develop an ongoing working relationship. We are particularly excited about working to promote the Affordability Connectivity Program that provide low-cost broadband internet services to many recipients who are Medicaid and Medicare eligible, many living with disabilities. Verizon is providing a \$15,000 sponsorship.

**Human Services Research Institute (HSRI):** HSRI is in development of a proposal for federal funding from NIDILRR that focused on improving remote data collection on people with cognitive disabilities. As part of this proposal, HSRI is looking to partner with NCIL who could serve as an advisor and help support recruitment of people with lived experience to participate in interviews and research activities. More to come on the amount of revenue that will be generated.

**Amazon:** Met with representatives from Amazon. They are interested in partnering with NCIL to be testers of line of products designed for persons with disabilities. Possible funding.

**Joyce Bender Consulting:** I am scheduled to appear on her podcast on July 11, 2023. Joyce Bender and Associates, along with Partners for Youth with Disabilities want to partner with NCIL for an Office of Disability Employment Policy (ODEP) grant.

**Ford Foundation:** Met with Rebecca Cokley to reconnect and improve relationship. So far we have maintained contact and she agreed to be a speaker at our IL conference.

## LETTERS OF SUPPORT FOR FUNDABLE PROJECTS

Letters of Support have been written for three of ACL's IDIQ funding opportunities in which NCIL can benefit. These include [Altarum](#), [NORC](#), and [Brandeis University](#).

## SPECIAL MESSAGES FROM EXECUTIVE DIRECTOR

I have written and disseminated widely 5 messages that focused on communicating my thoughts on important issues. These messages were crafted to communicate vision, restore and repair NCIL's missteps – to bring healing and a platform to move in a unified, collective direction. Message topics included: A Message from Theo Braddy, New Executive Director, National Council on Independent Living; A Brief Message from Theo Braddy, Executive Director of NCIL: 5 for 5 Campaign; A Message from Theo Braddy: Why We Are Stuck; A Message from Theo Braddy on Diversity, Equity, Inclusion, and Accessibility; and A Message from Theo Braddy: An Invitation to Join NCIL's March and Rally on July 26! All can be located at <https://ncil.org/ed>.

## CONVERSATIONS WITH SIGNIFICANT LEADERS

I have reached out or individuals reached out to me to re-connect. These include, Maggie Shreve, Tom Olin, Marcie Roth, Tony Coelho, Mark Johnson, Bob Kafka, and a host of other leaders.

## FEDERAL AGENCIES

Administration of Community Living (ACL): NCIL meets monthly with ACL and continue to fight for improvements.

Federal Emergency Management Agency (FEMA): Conducted several meetings with FEMA to improve real-time funding for disaster relief for persons with disabilities by working with centers. This is ongoing.

National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR): I have met on several occasions with NIDILRR with the plan to create a mutual benefiting relationship.

## SPEAKING ENGAGEMENTS

**University of Pittsburgh:** Spoke on the topic of community-based waiver services.

**Center for Independent Living of Central PA:** 2-day training on Cultural Competency at Hershey Hotel.

**Chambersburg:** Keynote speaker at Franklin County Human Services on the topic of Embracing Adversity.

**Penn State University (PSU):** Spoke on Disability Inclusion on Friday March 10th from 12pm-1pm at PSU.

### **Upcoming:**

In September, 2023 will be speaking on Disability Awareness at the Department of Justice's Diversity Forum.

In October, 2023, will be speaker at Capital Blue Cross's Diversity Forum.

In October, 2023, will be a judge for Mrs. Wheelchair Pennsylvanian. Don't particularly endorse this but, I was promised an opportunity to promote NCIL for youth.

## OTHER IMPORTANT ITEMS

**Collaborative:** NCIL is currently working with APRIL and NASILC to develop a working collaborative charter spelling out how we can work together on policy and high-level advocacy issues. So far, it looks promising.

**ILRU:** Spoke with ILRU to continue grant application with them.

**Judy Heumann Wheelchairs:** Judy's husband, Jorge, donated 2 of Judy's wheelchairs. One is also donated to the Smithsonian. I picked up the other two and NCIL has them in storage.

**Senator Casey:** Participated in a press call with U.S. Senator Casey and Representative Dingell to Join Protect Our Care to Call on States to Protect Medicaid Coverage for People with Disabilities.

## STAFFING

**New Program Manager:** Conducted several interviews with Operations Director and hired a new Program Director in June 2023.

**Staff Meetings:** Meet with individual staff members weekly on an ongoing basis. Meet with Operation Team weekly as well. Also, all staff meetings are conducted on every Monday, when possible.

**401 K:** I have been looking at alternative options to improve staff 401 K plans.

**Banking:** NCIL is switching to Capital One Bank for primary checking. We are continuing our local bank as well.

## CURRENT PROGRAMS AND PROJECTS

Prepared by Jenny Sichel (Operations Director) and Mary-Kate Wells (Programming Director)

## ADVANCING STATES

Grant Period: 8/1/22 – 7/31/23 (new contract in August)  
Contact: Nanette Relave, Advancing States

Advancing States has chosen to continue their contract with NCIL to support aging and disability Information & Referral / Assistance (I&R/A) programs and systems to enhance the quality, professionalism, and effectiveness of their services to older adults, people with disabilities, their families and caregivers through training, technical assistance,

information resources, and access to promising practices and innovations. NCIL will receive \$20,000 in 2023. NCIL will receive a new contract to review in late August or September.

## AMERICAN ASSOCIATION ON HEALTH & DISABILITY

Grant Period: 8/1/22 – 6/30/23  
Contact: Michelle Sayles, AAHD

AAHD has chosen to continue their contract with NCIL for the second year of the AAHD All of Us grant. This grant involves meetings, conducting general dissemination activities, and conducting at least four specific dissemination opportunities to promote All of Us to NCIL's community. This is the second year for this project. As part of this contract, NCIL will be posting and disseminating information relating to the All of Us Program. We are contracted to post 1x/week on Facebook and 1x/month on Instagram. Additionally, we disseminate information via Advocacy Monitor, NCIL's Membership Listserv, and extra social media postings. NCIL will receive \$15,000 for this contract. NCIL will be renewing this contract for Year 3 for a total of \$15,000.

## CENTENE CORPORATION – BARRIER REMOVAL FUND

Grant Period: 2/2/2020 – 12/21/2024  
Contact: Kait McCormick and Matthew Schmitt, Centene

Centene contracts with NCIL to provide support for its Barrier Removal Fund (BRF) project. The BRF is a competitive RFP opportunity for healthcare providers in Centene's network to receive grants to remove access barriers in their offices / buildings. NCIL subcontracts with Centers for Independent Living (CILs) or other ADA experts to provide on-site disability accessibility reviews to providers to assess their proposed improvements and recommend other access improvements. NCIL and Centene have completed the project in Florida, Illinois, Kansas, Texas, New Mexico, Ohio, Indiana, Pennsylvania, California, Hawaii, Iowa, Louisiana, Michigan and Georgia. In 2022, NCIL had over 120 applicants in the three states and provided grants to approximately 35 applicants. In 2023, NCIL will work with providers in Nebraska, Delaware, and once again New Mexico. NCIL will again receive \$500,000 in 2023. \$380,000 of those funds pass through NCIL for grants and accessibility surveys, but NCIL does retain \$120,000 for its time and effort coordinating the BRF.

## IL-NET NATIONAL TRAINING & TECHNICAL ASSISTANCE CENTER FOR CILS

Contract Period: 9/30/2022 – 9/29/2023  
Contact: Richard Petty, ILRU



NCIL continues its subcontract with ILRU to provide training, technical assistance, and other education and management resources to Centers for Independent Living. NCIL has been involved in the CIL National T&TA Center (previously IL-NET) since its genesis in 1994. This is a 3-year project. A new subcontract with ILRU is required each of the three years. We just finished year two of a three-year grant cycle and have started into year three. In 2022, NCIL coordinated 5 webinars, a three-day long Institute on IL, and other presentations during both NCIL's Conference and SILC Congress. In 2023, we are going to produce between 7-9 webinars on topics ranging from Core Services, to Transitions, to Intersectionality. Additionally, NCIL will help with coordinating presentations at the SILC Congress in March and the NCIL Conference in July. NCIL will receive \$233,470 during the FY23 contract period (an increase of \$52,989 over anticipated). NCIL will continue with this contract with ILRU for an additional year pending ACL contract.

## IL-NET NATIONAL TRAINING & TECHNICAL ASSISTANCE CENTER FOR SILCS

Contract Period: 9/30/2022 – 9/29/2023  
Contact: Richard Petty, ILRU

NCIL continues its subcontract with ILRU to provide training, technical assistance, and other education and management resources to Statewide Independent Living Councils. This is a 3-year project. A new subcontract with ILRU is required each of the three years. We just finished year two of a three-year grant cycle and have started into year three. As part of SILC-NET, NCIL will aim portions of all multiple webinars towards SILCs and additionally integrate 1-2 presentations at the NCIL Conference about SILCs. Finally, as part of this contract, NCIL will provide logistical back-up support for ILRU at SILC Congress. NCIL will receive \$26,754 in the FY22 contract period. NCIL will continue with this contract with ILRU for an additional year pending ACL contract.

## USAGING – DIAL PROGRAM

Contract Period: 9/1/2022 – 8/31/2023  
Contact: Sara Tribe Clark, USAging

New this year, NCIL has been awarded funding from USAging for work on their DIAL Project. NCIL has been helping out with the DIAL project for a few months, but without any funding. We will receive \$25,000, once the contract is finalized, for the contract period to continue the work that we had been doing. The DIAL program was created in response to the need to increase the support of people with disabilities during the COVID-19 pandemic and ensure that they receive information pertaining to COVID-19, receive assistance for vaccine registries, and get other support needed to increase the amount of COVID-19 vaccines distributed. This scope of work includes participation in monthly DIAL Partner meetings, participation in period DIAL marketing Workgroup meetings, promotion of DIAL to NCIL's network, assisting USAging in development of

disability trainings for Call Center staff, and facilitation of new informal partnerships with disability organizations. NCIL will receive \$25,000 during the contract period.

## USAGING – AGING AND DISABILITY VACCINATION COLLABORATIVE

Contract Period: 12/22/2023-5/18/2024  
Contact: Deborah Stone-Walls, USAging

NCIL has been selected, along with 21 other organizations, to partner with USAging on a recently received ACL grant to increase the COVID-19 and Influenza Vaccine Uptake amongst older adults and people with disabilities. This contract will be in addition to the DIAL Program, and NCIL's work on it will include serving as a liaison between CILs, SILCs, and associations of CILs and USAging to help USAging achieve its goal of developing a collaboration between Area Agencies on Aging, No Wrong Door Systems/Aging and Disability Resource Centers, Centers for Independent Living, other ACL funded disability networks and other aging and disability organizations to increase the number of older adults and people with disabilities who receive the COVID-19 and influenza vaccines. NCIL will receive \$75,000 during the contract period.

## USAGING – HOUSING AND SERVICES RESOURCE CENTER

Contract Period: 5/1/2023- 9/1/2023  
Contact: Molly French, USAging

NCIL has contracted with USAging to provide expert and technical services to support the development of services and products for the Housing and Services Resource Center (HSRC). The HSRC is a partnership between ACL, USAging and HUD to foster collaboration and cross-sector partnership among organizations that provide housing resources and services to help people live in the community. NCIL will provide expertise and technical assistance on HSRC webinars to ensure representation of the disability and IL communities. We will provide feedback on educational material on Centers for Independent Living. NCIL will also disseminate HSRC material to our membership network. NCIL will receive \$10,000 during the contract period.

## REGIONAL REPRESENTATIVE FORUMS AND IL SHOWCASES

NCIL Original Project: 11/2022 – 9/2023 (Has been extended through September 2023)  
Contact: Steve Higgins, Regional Representative Chair

In an effort to unite the IL Network and highlight different aspects of the CIL/SILC program, NCIL has started production of Regional IL Showcases. These Showcases take place once every two months and feature innovative programs and successful advocacy efforts at CILs across the US. Each month there are two regions represented and speakers in those regions are identified by NCIL's Regional Reps. So far NCIL has

completed two of these webinars, the first featuring Regions 1 and 10, and the second featuring regions 5 and 6. Topics presented thus far include a model program for transitioning individuals with disabilities out of prisons back into the community, a rural transportation program, and details on a CIL's journey to getting legislation passed. NCIL does not receive any grant funding for this initiative.

## UNIVERSITY OF KANSAS – HOME USABILITY PROGRAM

Contract Period: through June 2024 (pending)  
Contact: Jean Hall, RTC/PICL

Under a new contract agreement, NCIL will work with the University of Kansas's Research and Training Center on Promoting Interventions for Community Living (RTC/PICL) on the Home Usability Project. In 2022, NCIL hosted a Community Living Summit in partnership with the RTC/PICL. In this contract agreement, NCIL will conduct outreach and recruit CILs to participate in the Home Usability Program and community of practice. NCIL will host monthly peer-to-peer meetings and moderate an online platform for on-going support and information exchange between CILs. NCIL will receive \$20,198 during the contract period.

## SPAN – THE INDEPENDENT LIVING ADVOCATE'S TOOLKIT FOR MENTORING FAMILIES OF CHILDREN WITH DISABILITIES.

Contract Period: 3/29/2023-9/1/2023  
Contact: Dr. Josie Badger, RAISE Center

NCIL contracted with the SPAN Parent Advocacy Network to produce 12 one-pager toolkits and a webinar on how families can support the self-determination of youth with disabilities from the Independent Living perspective. The goal is to bridge the gap between disability-led and parent-led organizations and provide technical assistance on the Independent Living philosophy. NCIL will receive \$7,000 during the contract period.

## NATIONAL DISABILITY INSTITUTE – LEAD / WIOA POLICY DEVELOPMENT CENTER

Contract period: started 4/11/2023 (Multiyear project)  
Contact: Elizabeth Layman

NCIL was awarded funding through the National Disability Institute's LEAD/WIOA Policy Development Center as a Dissemination Partner on their DEIA efforts. This is a multi-year grant with the option to recommit annually. As a Dissemination Partner, NCIL will share LEAD material on a monthly basis with our membership network. NCIL will receive \$4,000 during the contract period.

# ADVOCACY AND PUBLIC POLICY REPORT

Prepared by: Jessica Podesva, Director of Advocacy and Public Policy

## I. COMMUNITY BUILDING / ORGANIZING

Over the last year, since I have joined the staff at NCIL we have shifted a significant effort to focus our advocacy efforts and bring our network together with the overall goal of strengthening the Independent Living Program and advancing consumer control in areas where policy and programmatic decisions about people with disabilities are being made.

In alignment with the strategic plan, one major effort over the last year was a deep look at NCIL's advocacy subcommittees and an overall look at our internal advocacy structure. The vice president and I met with the chair of each sub-committee and asked them the following questions:

1. Why did you sign up to be an NCIL subcommittee co-chair?
2. How many members are engaged in your subcommittee? How many attend meetings/how many do not?
3. What issues has your committee focused on in the last year?
4. What are the biggest challenges in your committee?
5. What are the biggest strengths of your committee?
6. How are the dynamics of your committee? Do you have any members you struggle with?
7. If you could design a dream structure for NCIL's advocacy, what would it be?
8. How many work groups or task forces does your sub-committee have?

These questions were not meant to be prescriptive but to provide a foundation for a conversation. In addition to the chairs, we also met with several subcommittee members and I made an effort to have 1:1s with NCIL members not engaged in NCIL's subcommittee or advocacy efforts.

Following these meetings and internal discussions with myself and both NCIL's former executive director Darrell Jones and current executive director Theo Braddy, the vice president made the recommendation to the executive board to consolidate our subcommittees into the following areas:

- Transportation
- Healthcare and LTSS
- Housing

- Civil Rights and ADA
- Rehab Act
- Create a new committee focused on Emergency Preparedness and Disaster Response
- Move the International Subcommittee from the Diversity Committee to the Legislative and Advocacy Committee

The executive committee approved the changes, and a notice was sent out to all membership from the president and vice president notifying them of the changes. These changes have now gone into effect.

Over the next year internally we will work with the chairs of each subcommittee to identify some focused advocacy goals and develop a loose work plan of priorities. We will also be looking at the role that regional representatives can play in our community organizing activities.

Additionally, we will work on building relationships with other national groups in the AOD network and making additional efforts to connect with offices on the hill and hosting more listening session and advocacy events to engage with membership.

## II. SUBCOMMITTEE ACTIVITIES

Since the subcommittee structural changes went into effect prior to the collection of information from the subcommittee chairs, this report will only reflect the activities of the subcommittees remaining after the consolidation. Additionally, because the Emergency Preparedness and Disaster Response subcommittee was only recently established this report will not include updates on that subcommittee as it is too soon to have any information to report on. This section is a summary of information that was submitted by chairs. If any board member would like a copy of the original update submitted by a L&A chair it can be provided upon request.

### 1. REHAB ACT COMMITTEE / IL FUNDING

The Rehab Act Subcommittee is responsible for analyzing, interpreting, and advocating for needed changes to the statute and regulations. Membership on this subcommittee requires consistent contribution by all members. This contribution involves routine attendance to monthly subcommittee meetings, participation in the meetings and e-mail discussions, assistance with research and planning efforts by the subcommittee. Over the last year the subcommittee has worked on the following:

- Worked on recruiting new members and updating membership list
- Worked on strategies for increasing IL funding resulting in \$10 million increase for FY 2023

- Met with Michael Gamel McCormick & Grace Hart (Sen. Casey staff), and Sarah Mueller (HELP Committee/Sen. Sanders staff) re: how to create a system to employ people with disabilities and the role CILs can play – potential innovation grants for CILs to provide employment
- Established and launched “5 for 5” drive to increase IL funding – requesting \$500 million for 5 Core Services – developed one-page fact sheets on What CILs are & do, and Data on Services Provided by CILs – worked with staff on advocacy event for February 2023
- Discussed potential restructuring of NCIL committees & subcommittees to focus on IL, CILs, & SILCs and what that could look like
- Discussed renaming this committee
- Discussed comments regarding revisions to the SPIL Instructions & Instrument & formed work group to develop
- Discussed potential response (and to whom) and strategies regarding the fact that RSA had to return \$550 million unused VR funds for 2021
- Followed status of 2024 Budget
  - New line item for IL Projects of National Significance - \$1.2 million
  - \$32 million increase for IL (\$29.7 million Part C and \$2.3 million Part B) for total of \$160 million
- Submitted comments on the update to the SPIL Instrument & Instructions including focus on an appeals process
- Established work group to develop and finalize amendment recommendations for the Reauthorization of the Rehab Act – plan to have draft ready for Fall Board Meeting
- Established monthly meetings with ACL & NCIL
- Discussed legislative priorities to focus on at Annual Conference
- Information about what NCIL supports will be on the new membership portal
- Discussed debt ceiling issues – NCIL part of a collaborative meeting with key Senators – working with APRIL to coordinate efforts
- Identified issues & questions for all OILP stakeholders meetings and for ACL& NCIL monthly meetings

Over the last year the subcommittee has met monthly with additional meetings as necessary and required by advocacy efforts. The subcommittee had two smaller work groups:

1. Reauthorization Work Group: This group has focused on SILC Issues- recommendations have been developed and shared with the full

subcommittee, CIL issues, Administration Issues. This work group will continue to meet and develop comments for the full subcommittee to review.

2. SPIL Instructions & Instrument Comments Work Group: Comments were developed and submitted for the first 60-day comment period. Comments will be shared with the full NCIL membership with a request that everyone submit comments in the upcoming 30-day comment period.

Goals of the Subcommittee over the next three months:

- Implement Advocacy Event in February re: 5 for 5 campaign for IL funding
- Finalize recommendations for Reauthorization – develop and adopt position paper.
- Provide training, information, and technical assistance to members of committee on specific areas of Titles VII, I, III and possibly V.

## 2. TRANSPORTATION

The Transportation subcommittee is responsible to promote and advocate for safe, affordable, and accessible transportation for people with disabilities of all ages in rural, urban, and suburban areas in the public and private sectors. Support for all modes of transportation so that they are inclusive of the disability community. Over the last year the subcommittee worked on the following:

- Federal Aviation Administration (FAA) Reauthorization bill was recently introduced and has been moving very fast. This is a must pass bill before the end of FY23. We have worked closely with Paralyzed Veterans of America (PVA) and other disability organization.

Many of the provisions of the Air Carrier Amendments Act have been incorporated into the FAA Reauthorization bill.

- DOT's activities regarding air travel for wheelchair users including efforts to promote technology that would enable wheelchair users to stay in their wheelchair when flying.
- Monitor Amtrak's accessibility improvements since the DOJ settlement.
- The effects of the pandemic on transportation services for people with disabilities and how to strengthen services in a post pandemic era.

Committee members have also regularly participated in monthly meetings with Paralyzed Veterans of America (PVA) for improved air travel; in quarterly meetings with disability advocates and Amtrak for improved accessibility and We Will Ride, a group from American Association of People with Disabilities (AAPD) advocating for universal design in autonomous vehicles,

Goals for the Subcommittee over the next three months:

- Develop a workplan
- Recruit new members
- Possible areas of focus:
  - Making Air travel safer
  - Accessible autonomous vehicles (AV)
  - Environmental barriers to transportation

### 3. HOUSING

The NCIL Housing subcommittee strives to promote the principles of affordable, accessible, healthy/nontoxic, decent, safe and integrated housing for persons with disabilities. The subcommittee works with the NCIL staff person to communicate with legislators, other organizations, and participate in collaborative efforts to further our goals. Over the last year the subcommittee worked on the following:

- Provided feedback to NCIL's Policy Director on Bill HR 7676 -the Home Modification Accessibility Act of 2022 (see attachment) for the meeting with Representative Crist.
- Provided feedback and signed a letter of support for the **Visitable Inclusive Tax Credits for Accessible Living (VITAL) Act**.
- Submitted comments to HUD regarding CDBG Disaster Recovery funds.
- Provided feedback to NCIL's Policy Director on the Affirmatively Furthering Fair Housing (AFFH) proposed rule.

The housing subcommittee also had 3 workgroups over the last year, consistent with our strategic plan, these workgroups will be consolidated into the broader subcommittee with smaller meetings taking place as necessary on specific activities. The work of the workgroups will be considered in developing a work plan for the subcommittee for the next year.

1. **Homelessness Workgroup:** This workgroup consisted of 4-5 members and was in the process of writing a position statement to address the lack of safe and accessible shelters. The position statement was also going to address the increased number of incidents across the country criminalizing the homeless. Many of these individuals live with disabilities and individuals with mental illness are frequently targeted. The position paper was not completed.

2. **Visitability and Universal Design Workgroup:** This workgroup consisted of 5 members who met 7 times over the last year. The workgroup developed a brainstorm list of activities that the subcommittee could work on within this topic. This list of activities was completed and sent to the full subcommittee and will be considered when developing next year's workplan.



**3. Legislative Workgroup:** The legislative workgroup only had one member despite repeated requests for individuals to join the workgroup. No workgroup meetings were held. Instead, legislative updates are shared during our monthly subcommittee meeting, and committee members are encouraged to share information and updates via email in between our monthly meetings.

Goals for the Subcommittee over the next three months:

- Develop work plan for subcommittee
- To monitor and respond to pertinent housing-related federal legislation affecting persons with disabilities related to affordable, accessible, and integrated housing.
- To share information about the housing subcommittee with others in attendance at the NCIL Conference.
- To educate policymakers on the housing needs of persons with varying disabilities.
- To monitor regulatory changes affecting persons with disabilities in housing programs.
- To discuss with the NCIL Policy Director and Executive Director the feasibility of organizing a nationwide Housing Campaign for CILS, SILCS and individuals with disabilities to bring greater awareness to the myriad of issues related to housing and people with disabilities. The campaign would culminate in a special meeting with key members of HUD and Congress at next year's NCIL Conference.

## 4. ADA / CIVIL RIGHTS

The purpose of the Americans with Disabilities Act (ADA) /Civil Rights Subcommittee is to educate and inform the National Council on Independent Living (NCIL) membership of legislative and judicial developments that impact the rights of people with disabilities, and to develop appropriate and effective steps for the NCIL membership to implement in response. The Subcommittee provides referral of the NCIL membership to appropriate enforcement authorities concerning discrimination under the ADA and other civil rights laws.

Over the last year, the subcommittee reviewed and developed recommendations on several bills which is reflected in the legislative positions. Legislation reviewed:

- Text: H.R.241 — 118th Congress, Access Act
- [H.R.239](#) — 118th Congress (2023-2024) Same Day Registration Act of 2023
- H.R.68 — 118th Congress (2023-2024) Housing Fairness Act of 2023
- H.R.82 — 118th Congress (2023-2024) Social Security Fairness Act of 2023
- H.R.219 - No Patient Left Alone Act of 2023

As part of the subcommittee consolidation, this subcommittee has absorbed the employment subcommittee, the voting subcommittee, the technology subcommittee, the education subcommittee, and parts of the mental health subcommittee.

Goals for subcommittee over the next three months:

- Update and edit Committee statement of purpose to reflect consolidation changes
- Develop work plan for next year.
- Shift committee meetings into working meetings
- Steve Higgins will be stepping away a co-chair. Marty Musser will remain as interim co-chair while we search for a new chair. Once a new chair is identified she will switch to co-chairing the IL funding subcommittee. Steve will remain an active member of the subcommittee and assist during the transition.

## 5. HEALTHCARE / LTSS

The Healthcare / LTSS Subcommittee monitors and advocates on long term services and supports and healthcare issues impacting people with disabilities, including durable medical equipment, disability discrimination in healthcare, access to opioids and other therapies for individuals experiencing chronic pain, assisted suicide and euthanasia. Over the last year the subcommittee worked on the following:

- **Legislation:** BCBJ: S.100 / H.R.547; HCBS Access Act: S.762 / H.R.1493
- **Workforce Issues:** Challenges to get and maintain PCA services are being felt nationally and is threatening the independence of people with disabilities in epic proportions. Members of the H/LTSSSC have met with advocates from various states to learn how they are addressing this issue as well as with our federal partners in an effort to open the door to policy discussions. A smaller workgroup was formed and drafted a values statement that we hope to finalize for the board. With the understanding that there is no 'one-size-fits-all' solution, discussions suggest higher wages, benefits, paid time off & training for PCA's should be the springboard from where policy recommendations begin. Additionally, legislation such as EVV should be curbed to remove GPS and biometric provisions as they do more to discourage participation in consumer-controlled services.
- **5<sup>th</sup> Core funding:** We continue to advocate for permanent funding for Transition Meetings have occurred with CMS and ACL. We hope to develop policy recommendations.
- **Assisted Suicide / Euthanasia:** We continue to monitor efforts to legalize assisted suicide / euthanasia, doing significant work in fighting efforts to legalize assisted suicide in the states through the involvement of local CIL advocates. Monitoring current case in California that argues California's 7-year-old law that allows terminally ill people to choose to get lethal drugs to end their life — the

End of Life Option Act — puts disabled people at greater risk of being coerced into seeking assisted suicide.

- **Chronic Pain:**

- Submitted comments to the Food and Drug Administration, for the April 2023 meeting of the Anesthetic and Analgesic Drug Products Advisory Committee.
- Submitted comments to the Drug Enforcement Agency, on proposed rules for prescribing controlled substances by telemedicine.
- Led a new sign-on letter from NCIL, APRIL, and the disability community to the Department of Health and Human Services, regarding the DEA's proposed rules for telemedicine prescribing.
- Updated our previous sign-on letter to Congress, on legislation related to opioid prescribing, addiction treatment, and pain treatment.
- Met with Eastern Oregon Center for Independent Living about harms to people with pain in Oregon. Sent out a bullet-point summary and edited a sign-on letter to the Oregon Medical Board.

Goals for the subcommittee over the next year:

- Draft work plan for subcommittee
- Continued advocacy around passage of BCBJ and the HCBS Access Act to ensure permanent authorization of MFP, addressing workforce issues, ending the institutional bias, funding for HCBS.
- Develop policy recommendations and advocacy to provide 5<sup>th</sup> core funding directly to CILs nationally.
- Continue to oppose efforts to legalize assisted suicide, demonstrating how these efforts are discriminatory and devalue the lives of people with disabilities.
- Support access to opioids and other therapies for people dealing with chronic pain through education and advocacy.
- Ongoing framing of the importance of healthcare access as a civil right; monitoring changes and influence Crisis Standards of Care & QALYs to stop the devaluing of disability lives, and ill-will perceptions of our quality of life.

## 6. INTERNATIONAL SUBCOMMITTEE

A report was not submitted by the International Subcommittee. The current chair Doug Toelle has recently resigned and recommended another committee member to step in as chair.

# OPERATIONAL EXCELLENCE COMMITTEE

Prepared by: Jason Beloungy, Committee Chair and NCIL Secretary

Formerly the Human Resources Committee, the Operational Excellence Committee shall:

- Be chaired by the NCIL Secretary.
- Be responsible for the regular review, and review at the request of the Board, of the NCIL Bylaws, personnel policies, Board operating procedures, and other policies approved by the Governing Board, and making recommendations to the Board for revisions.
- Be responsible for nominating a slate of prospective Board members each year for the positions outlined in Article V, Section 6.
- Organize orientation for new Board members and training for full Board.
- Review grievances made against the organization, the executive director or board members and providing the Governing Board with recommendations.
- Review and resolve appeals for denied applications for NCIL membership.
- Monitor and report on the activities of its subcommittees which may from time-to-time request to be established.

Summary of activities conducted since the 2022 Annual Meeting:

- Reviewed and provided recommendations on changes to NCIL by-laws, including approval of new mission statement.
- Reviewed and provided recommendations on changes to NCIL Policies

Summary of progress on Strategic Plan responsibilities: The committee has been active in its role to revise, and recommend for approval, the organizational by-laws, and personnel policies. The bylaws set the foundational organizational structural changes as outlined in the strategic plan.

Matters requiring action by the Board / Members: Approval of personnel policies, as recommended by the committee.

Committee goals and objectives for the next year:

- Development of new administrative SOPs for recommendation to the full Board.
- Oversee workgroup progress on vision and values, which were not modified at the same time as the mission statement.
- Set goals and activities related to responsibilities of the committee as outlined in the new bylaws.

# ANNUAL CONFERENCE SUBCOMMITTEE

Prepared by: Lindsay Miller, Subcommittee Chair

Description of Committee: The charge of the Annual Conference Subcommittee is to develop and implement a conference program that, to the greatest extent possible, meets the educational and experiential needs of Centers for Independent Living, Statewide Independent Living Councils, and people with disabilities. The membership of this committee is open to an individual member of NCIL with an interest in assisting in the development of an educational and experiential national conference for CILs, SILCs, disability rights organizations, and people with disabilities and their families. The NCIL Board Secretary oversees and works with the chair of the Annual Conference Subcommittee and is responsible for ensuring that the subcommittee is working to fulfill their purpose.

Summary of activities conducted since the 2022 Annual Meeting:

- Monthly meetings held.
- Ann McDaniel stepped down as Chair, Lindsay Miller approved as new Subcommittee Chair.
- Reviewed evaluation results from 2022 conference and considered them in planning for 2023.
- Planning for the 2023 Annual Conference July 24-27, including:
  - Established the theme “Indivisible” and approved the logo.
  - Decided how best to accommodate the “hybrid” portion of the conference.
  - Review and approved sponsor packages; Discussed increased sponsorship goal and strategies for fundraising at the conference.
  - Established workshop tracks:
    - Community Organizing & Systems Advocacy
    - IL Workforce Development & Expansion
    - Core Service Track
    - Equity in Action
    - SILCs in the IL Network
  - Reviewed and approved workshop RFP
  - 2023 Workshop RFP released, and 58 proposals received. Committee reviewed all the proposals and made selection for final program.
  - Decided to bring back the March & Rally in 2023 and discussed plans for the day.

- Requested and discussed the Hyatt emergency evacuation plan – also discussed contacting fire department and other emergency responders about a plan, considering the size of our group and the number of individuals who cannot exit independently without elevators.
- Decided on speakers for the opening and closing general sessions.
- Discussed COVID protocol options for annual conference and decided to recommend testing and require masks.
- Discussed options for AV support and approved SmartSource once again as AV consultant.
- Provided feedback on the Diversity Committee's plans for a diversity mixer.
- Hyatt contract signed for 2026 & 2027.

Committee goals and objectives for the next year:

- To conduct a successful, productive, and beneficial Annual Conference for CILs, SILCs, and other IL stakeholders.
- Work toward 2023 Conference being a hybrid of in-person and virtual and develop a plan that will best serve NCIL members.
- To consider potential venue options for the Annual Conference going forward and identify the best options.

Other: The Annual Conference subcommittee would like to thank Jenny and Angela for their ongoing support and for their excellent work in carrying out the bulk of the load to implement the work of the committee.

# FINANCE COMMITTEE

Prepared by: Jeremy Morris, Committee Chair and NCIL Treasurer

Description of Committee: The Finance Committee guides and monitors the finances and accounting systems of NCIL to ensure accurate financial reporting, proper accounting practices, and financial solvency.

Summary of activities conducted since the 2022 Annual Meeting: Assisted in creating of annual budget, assisted in the new budget structure to align with strategic plan focus areas, review of 990 and audit report, review of monthly financial statements.

Matters requiring action by the Board/Members: Possible budget revision  
Committee goals and objectives for the next year: Continue to work on revising budget format and improve financial position of organization.

# REGIONAL REPRESENTATIVES COMMITTEE

Prepared by: Steve Higgins, Committee Chair

Description of Committee: The NCIL Regional Representatives Committee is comprised of 10 NCIL members, one from each Federal Region, who are elected by NCIL members in their respective regions.

The Regional Representative is the pivotal position in NCIL's communication system with its membership. The Regional Representative is responsible for communicating at least quarterly with NCIL members regarding IL issues and working with any other group interested in pursuing NCIL's goals within his or her respective region. The Regional Reps will assist the NCIL board and committees in building and coordinating grassroots coalition to advance NCIL's advocacy activities. The NCIL Regional Representatives will also assist in the recruitment and retention of NCIL members. The regional representatives will disseminate information related to regional or state advocacy efforts to their regional members.

Summary of activities conducted since the fall board meeting:

The Regional Representatives Committee meets monthly on the second Monday.

In the last year, the committee has been working on mentoring and development.

During this year, the Regional Representatives hosted four regional showcase calls originally called Peer Sharing Forums as the committee developed the process.

## 1. PEER SHARING FORUMS

We reached consensus on rotating regional reps, pairing two at a time to reach out to CILs in their regions to identify CILs with success stories to share; and that rep could be given guidance on how to identify those CILs, if they are new and not yet networked, i.e., reach out to SILCs through the NASILC's regional representatives (NASILC has been seeking ways to collaborate with NCIL). New reps would always be paired with more experienced reps for each call. We would keep the calls to one hour. The CILs that share their success stories could also be asked to share what the national network (NCIL) means to them, as one way to encourage memberships. We could provide a link on the screen that takes participants directly to NCIL's membership application page. You and I (and next ED) could trade off co-moderating the calls, so extra work is not put on staff.

You said you are comfortable with suggesting that donations are appreciated to help defray costs (this can be stated in a way that does not strong arm anyone to pay). The goal of these forums are building relationships and memberships NOT advocacy organizing.



2. ADVOCACY NETWORK – Region reps are preparing to work under the newly approved Strategic plan which included changes to roles and responsibilities and committee structures as a whole within NCIL to promote DEAI and grow the participation of membership of the organization.

Matters requiring action by the Board / Members: Re-appointing members who had stepped aside during the executive search, Filling the Region 7 position, which has been open long term.

Committee goals and objectives for the next year: Teaching others and building the NCIL Community

Other: It has been a pleasure serving as chair of this committee during this year.

# DIVERSITY, EQUITY, ACCESSIBILITY, AND INCLUSION (DEAI) COMMITTEE

Prepared by: Larissa Martin, Committee Chair

Description of Committee: Our goal is to bring diversity and intersectionality together moving forward. So that we create, and give space and opportunities for those most marginalized, which are typically people of color with disabilities and other marginalized groups that are in the disability justice & independent living and, really focusing on DEAI work and how we can improve this NCIL and the independent living and disability justice as a whole.

Summary of activities conducted since the 2022 Annual Meeting:

- We have established DEAI definitions for NCIL.
- We have changed and implemented a new name for this committee.
- We have been continuing to rebuild this committee, and part of that work was creating an event at this year's conference to showcase the work we have done and the work we hope to accomplish moving forward.
- We created a mission statement for the committee.

Matters requiring action by the Board/Members: Approval of our mission/ purpose statement for this committee

Committee goals and objectives for the next year:

- keep building and establishing this committee.
- getting demographics on the NCIL application and starting tracking demographics for possible funding opportunities for not only this committee but as an organization

## MISSION

The Mission of the NCIL DEAI Committee is to empower every voice within the Independent Living and Disability Justice movements to be heard and validated, to move collectively as one network, and to foster accountability within our organization and society as a whole.

# MEMBERSHIP & NOMINATING COMMITTEE

Prepared by: Aaron Baier, Committee Chair and Region II Representative

Description of Committee: The Membership & Nominating Committee reviews NCIL's Membership policies, supports planning of ongoing Membership development, and supports NCIL Staff with matters related to NCIL's Membership and Nominations.

Summary of activities conducted since the 2022 Annual Meeting:

- Reviewed NCIL Member applications and renewals for CILs, SILCs, and Organizations
- Provided guidance on Member outreach, specifically in response to NCIL's Strategic Plan.
- Provided guidance for NCIL Bylaw revisions, specifically related to sections on Membership and Committee roles and responsibilities.
- Provided guidance to NCIL staff on development of new Membership Platform implementation and testing.
- Provided guidance to NCIL Staff on development of NCIL Member Benefits and Engagement.

Summary of progress on Strategic Plan responsibilities (if applicable): The NCIL Membership & Nominating Committee provided support on strategic review and changes to Bylaws, Member outreach and planning for Membership development and growth. Several initiatives are still in planning phase and will be implemented over the next year.

Committee goals and objectives for the next year:

- To set benchmarks and goals for annual Membership growth
- To formalize a set of Member Benefits that assist with development
- To develop a Member Outreach Plan that helps NCIL better engage with its Members
- To develop a New Member Outreach Plan that will support NCIL's ongoing growth.
- To support the ongoing enhancement and development of NCIL's Membership Platform.
- To support Regional Representatives in efforts to engage with Members and non-members in their regions.
- To support NCIL's Advocacy efforts through ongoing Member Development.