

National Council on Independent Living

Summer 2022 Board Reports

July 24, 2022

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# Interim Executive Director’s Report

Submitted by: Darrell Lynn Jones, Interim Executive Director

Executive Summary

NCIL continues to be an organization in transition with seven staff changes (incoming and outgoing) occurring this year. Below is a summary of the highlights and lowlights. Details for each of these items can be found within the body of the report.

*HIGHLIGHTS*

* Achieved 562 confirmed registrations for the annual conference (in-person and virtual).
* Membership is trending upward with a 16% increase over 2021.
* Secured $165,000 in conference sponsorships for 2022 - $5,000 over target.
* Secured a co-working office space in the DC area for less than $4K / year.
* Hired a new Director of Advocacy and Public Policy, Jessica Podesva.
* Signed on / supported at least 30 bills and legislative actions since March 2022.
* Partnered with University of Kansas in federal grant application to create an Advancing Equity in Community Living Center.

*LOWLIGHTS*

* Decrease in conference revenue.
* Two Board positions remained vacant ahead of 2022 election.
* Loss of Ford Foundation funding for 2022.
* Four staff position changes in four months.

I. Governance: Board and Committee Activities

The priority of the NCIL Interim Executive Director and Operations Director since coming on the staff has been learning NCIL’s complex Standard Operating Procedures, committee and subcommittee structure, policy agenda, funders, programs and projects, and organizing the first ever hybrid annual IL conference; and stabilizing day to day operations. It has been possible to navigate these complexities and obligations with the support of key NCIL leaders who have immense historical knowledge about NCIL and the Bylaws and SOPs. NCIL’s dedicated and experienced administrative support staff have also played a vital role in moving the organization forward.

*ORGANIZATIONAL ASSESSMENT*

At the March Board meeting, the Board voted to undertake an organizational assessment that will culminate in a virtual Strategic Planning meeting scheduled for August 25-26. The report / results from the organizational consultant, Ellen Karcsay, will be forthcoming soon with an in-depth analysis of the information and feedback that she has gathered from surveys and individual interviews. Some trends and preliminary insights have been shared with the Assessment Resource Team (Lou Ann Kibbee, Larry Wanger, Suzy Gamez, John Herring, Darrell Jones, and Lindsay Baran - until her departure May 3). Ms. Karcsay has kept individual names and opinions confidential, but has made the following preliminary observations and recommendations:

Business Model

* Refocus the organization’s mission and purpose as an organization that exists to build the capacity and capability of CILs and SILCs first and foremost, in order to advance independent living and the rights of people with disabilities, regardless of race, religion, gender, sexual orientation, or type of disability.
  + Reevaluate the membership structure and function.
  + Identify opportunities for additional revenue (e.g., training, technical assistance).

Governance

* Redefine the organization's purpose, role, and function to reflect the connection to CILs and SILCs.
  + Drive accountability and discipline in board structure and function in a way that supports the mission, vision, and purpose of the organization.
  + Restructure bylaws to better support the organization's focus.
* Review Board onboarding, management, and offboarding processes as a means to strengthen the governance model.
* Build leadership capabilities and opportunities within the Board of Directors in order to fill governance positions.

Tools and Systems

* Evaluate processes and tools to ensure they are fit for a remote work environment, including legislative tracking, communications systems, and membership database.
* Reduce the cost and improve the efficiency of current tools and systems.

Observations made from day-to-day management are consistent with these findings. NCIL’s policy and advocacy work often minimizes the CILs and SILCs and expands on a wide range of disability issues. A fresh look at how each year’s priorities are chosen and how they impact staff and financial resources is needed.

There are additional recommendations made about day-to-day management and staff roles that were already underway when the assessment began, including identifying staff skills and strengths and realigning certain job responsibilities.

*COMMITTEES*

There are currently 5 standing committees, 10 functioning subcommittees (18 listed in posted Organizational Chart), and 1 task force (4 listed on Organizational Chart). There are currently no functioning caucuses, but the SOPs provide for an unlimited number: “Caucuses can be established by any NCIL member(s) focusing on concerns of a particular marginalized or underrepresented population of individuals with disabilities to strategize and guide NCIL on these issues.” Caucus chairs are selected by each caucus and activities are reported to the Diversity Committee chair. Each committee and subcommittee require a staff member to serve as liaison and support to the chairpersons.

*ANNUAL IL CONFERENCE*

Until recently, it was unknown to what extent the pandemic would impact the room block utilization at the Hyatt, potentially causing costly financial penalties. After the two previous years of cancelled contracts, the Hyatt was unwilling to either cancel or renegotiate the terms of this year’s contract. That’s why a hybrid conference was chosen by the previous leadership. The Executive Committee elected to appeal the terms of the contract as a reasonable accommodation under the ADA. NCIL’s disability rights attorney believed that the ADA did apply because of the increased risk of conference attendees due to disability and agreed to write a letter to the Hyatt to that effect. Not only did we meet the minimum room reservation requirements, we surpassed them. Since this report is written in advance of the conference, actual turn out remains to be seen.

As of this writing, there are 562 total registered for this hybrid conference, with 223 being for the virtual conference, 214 for in-person only, and 125 for both virtual and in-person. By contrast, there were 1,014 registered for the previous onsite conference in 2019, In 2020 there were 1,215 registered for the first virtual conference. In 2021 there were 873 registered for the second virtual conference. Room nights booked are 1140 (1046 were required in the contract).

*VIRTUAL OFFICE*

NCIL now has workspace / meeting space through WeWork, a national office space / workspace company with locations in DC as well as other cities such as Boston that provides NCIL with solutions to several situations that have arisen since the closing of the physical offices in DC. First, it gives NCIL the physical address that our banks and other legal entities require. It also provides desk space / Internet access for NCIL staff who may need to travel to DC for Congressional or organizational meetings. It also provides a conference room where group meetings can be held. This is a month-to-month agreement which can be cancelled at any time and costs less than $4,000 on an annual basis.

II. Staff

Despite significant turnover in the past 7 months, the staff remains committed to the organization and to the members. Their hard work, dedication, and extra efforts have allowed NCIL to remain viable through the transitions. As of July 18, 2022 there will be 8 full-time staff.

Below is a list of the staff changes that occurred from January 2022 – Current:

* Departure of Executive Director Reyma McCoy McDeid on January 31.
* Onboarding of Darrell Lynn Jones, Interim Executive Director, on February 1.
* Departure of Operations Director, Tim Fuchs, on February 28.
* Onboarding of new Operations Director, Jenny Sichel, on March 1.
* Departure of the Engagement Associate, Cara Liebowitz, on March 24.
* Departure of the Director of Advocacy and Public Policy, Lindsay Baran, on May 3.
* Onboarding of the new Director of Advocacy and Public Policy, Jessica Podesva, on July 18.

Current Staff and Positions:

Sarah Blahovec………….. Civic Engagement and Voting Rights Director

Sylena Campbell............... Administrative Coordinator / Bookkeeper

Eleanor Canter…………… Communications Coordinator

Darrell Jones……………… Interim Executive Director (beginning 2/1/ 22)

Denise Law……………….. Member Services Coordinator

Jessica Podesva…………. Director of Advocacy and Public Policy (beginning 7/18/22)

Jenny Sichel……………… Operations Director (beginning 3/1/22)

Rie Terashima.................. Staff Accountant

III. Finances and Financial Management

As the Finance Committee report indicates, the conference revenues will be important as we go through this year. The NCIL Staff have been working tirelessly to make sure the conference is as successful as possible financially. Here are some preliminary figures that we are monitoring closely:

As of July 7:

|  |  |  |
| --- | --- | --- |
| CATEGORY | TO DATE RECIEVED / COMMITTED | PROJECTED / BUDGETED |
| INCOME |  |  |
| Registrations | $138,787 | $250,000 |
| Ads | $2,745 | $4,755 |
| Exhibits | $4,000 | $35,955 |
| Sponsors | $165,000 | $160,000 |
| TOTAL CONFERENCE INCOME | $310,532 | $450,710 |
| PROJECTED EXPENSES |  | $393,127 |
| NET PROJECTED REVENUE |  | ($82,595) |

IV. Resource Development

*CONFERENCE SPONSORSHIPS*

Sponsorships for the 2022 IL conference were received or pledged in the amount of $165,000, surpassing the goal by $5,000. Sponsors are:

Ability360

Airbnb

Anthem, Inc.

The Boston Foundation

CareSource

Centene

Christopher & Dana Reeve Foundation

Disability Resource Center

Humana Healthy Horizons

Microsoft

Tusk Philanthropies

EMILY’s List

PhRMA

United Healthcare

Verizon

Waymo

*CURRENT RESOURCES*

Amazon Smile

Amazon Smile customers who select NCIL as their organization of choice, make small donations when making a purchase through the Amazon Smile platform. There is currently no way to track who has donated on Amazon Smile, but the revenue is recorded under other income.

Centene Corporation – Sponsorship of Organizational Assessment and Strategic Planning Process consultant

Centene has pledged $5,000 to provide support for the independent consultant to conduct an organizational assessment and facilitate a strategic planning process for NCIL.

Ford Foundation

Ford Foundation provided NCIL with a $200,000 grant for general operating support that ends July 31, 2022. $133,333 of those funds were allocated to 2022. An additional award of $160,000 was withdrawn upon the departure of Reyma McCoy McDeid. There is no record of the second award in the NCIL files.

Voting Rights

The $36,000 grant from the Aid Association for the Blind of the District of Columbia received in August 2021 to continue the organization’s voting rights work ended February 28, 2022.

Stock Donations

NCIL is now able to receive stock as a charitable contribution to the organization. Stock received in 2021 was liquidated for a total of $16,767.53.

*POTENTIAL RESOURCES*

CareSource

Conversations are underway with CareSource concerning their interest in sponsoring curriculum and training that could be developed for CILs to use with consumers who are preparing for transition from institutions to community-based living.

University of Kansas

NCIL has partnered with KU in a federal grant application to NIDILRR to establish a Rehabilitation Research & Training Center at KU on Advancing Equity in Community Living. The project would be for five years and provide NCIL with a $110,000 subcontract for each of those years. The proposed budget includes a full-time project manager for NCIL and administrative and indirect support. KU has also partnered with four other universities that will bring diversity expertise / perspectives (Black, Native American, LGBTQ+, and rural). NCIL’s role would be:

* Advisory Panel
* Assistance with analysis of data / findings
* Assistance with analysis of CIL Program Performance Report data to assess disparities among CIL staff and consumers
* Recruiting CIL participants
* Conducting focus groups with CIL staff and consumers
* Assistance with developing resources, materials, and activities to support CILs
* Assistance with training workshops held in conjunction with the annual IL conference
* Assistance with dissemination of information, including key findings and products

V. Membership

NCIL’s 2022 membership performance up to July 11th steadily climbed back to pre-2021 levels. We have raised $238,272 through July 8th, which represents 89% of our annual membership revenue goal. This is solid performance for the first half of the year.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | As of July 11, 2022 | 2021 | 2020 | 2019 | 2018 | 2017 |
| CILs - wo satellite offices | 171 | 159 | 172 | 184 | 188 | 189 |
| CILs – including satellite offices\* | 314 |  |  |  |  |  |
| SILC | 36 | 23 | 37 | 39 | 44 | 41 |
| Organization | 13 | 13 | 14 | 15 | 15 | 14 |
| Individual | 558 | 480 | 578 | 672 | 674 | 647 |
| Youth | 24 | 18 |  |  |  |  |
| Total Members | 802 – wo satellite; 937 with member satellite | 693 | 801 | 910 | 921 | 891 |
| Total Income | $238,272.18  (thru 06/30) | $268,289.14 | $255,274.04 | $293,246\*\* | $279,253 | $291,229 |

\*CIL satellite offices except in one instance are considered part of a single organization. They are not separate members that pay dues apart from their main CIL. However, we list them here in the breakdown to show the expanded reach of the CIL membership. Many satellite offices are hundreds of miles from their main headquarters and have their own staff and territories.

\*\*In 2019 NCIL stopped counting memberships received from September through December as unearned income for the next calendar / fiscal year. Beginning in 2020 the membership year started January 1 and ended December 31.

VI. Programs and Projects

ADvancing States

Contract Period: 8/1/21 – 7/31/22

ADvancing States continues to 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 2022.

American Association on Health & Disability

Contract Period: 8/1/21 – 6/30/22

AAHD has completed their contract with NCIL for the first year of the AAHD *All of Us* grant. This grant involved meetings, conducting general dissemination activities, and conducting at least four specific dissemination opportunities to promote *All of Us* to NCIL’s community. This was the first year for this project.

NCIL will receive $13,000 in 2022.

American Association on Health & Disability

Contract Period: 10/1/ 21 – 9/30/22

AAHD has contracted with NCIL for the 3rd year to participate on the HILA Advisory Council, participate in the HILA focus group meetings, as needed, assist in the reviewing and revising the HILA training curriculum, assist in dissemination of HILA products via appropriate channels, and participate in recruiting CIL staff to participate in the HILA pilots and full trainings.

NCIL will receive $3,000 in 2022.

Anthem – Know Your Rights

Anthem contracted with NCIL to create a *Know Your Rights* video series for people with disabilities during the COVID-19 pandemic. NCIL created and produced the series and will disseminate the series after final approval from Anthem. NCIL worked with a variety of partners on this project.

NCIL received $25,000 to coordinate this work and produce the video series.

Centene Corporation – Barrier Removal Fund

Grant Period: 2/2/20 – 2/2/23

Contact: Kait McCormick and Matthew Schmitt, Centene

Centene has contracted 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, and Louisiana. We are currently conducting the BRF in Michigan, Georgia, and once again in Texas.

NCIL will receive $500,000 in 2022, with most of that money passing through for grants and subcontracts. NCIL will retain $120,000 for its time and effort coordinating the BRF.

IL-NET National Training & Technical Assistance Center for CILs

Contract Period: 9/30/21 – 9/29/22

Contact: Richard Petty, ILRU

NCIL continues its subcontract with Independent Living Research Utilization to provide training, technical assistance, and other education and management resources to Centers for Independent Living. This year’s project includes webinars and the first biennial IL Institute which is scheduled for September 7-9. NCIL has been involved in the CIL National T&TA Center (previously IL-NET) since its genesis in 1994. This partnership operates under a cooperative agreement from the Administration for Community Living to ILRU. This is a 3-year project. A new subcontract with ILRU is required each of the three years. We are currently in year two of a three-year grant cycle.

NCIL is contracted for $180,481 during the current contract year.

IL-NET National Training & Technical Assistance Center for SILCs

Contract Period: 9/30/21 – 9/29/22

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 are currently in year two of a three-year grant cycle.

NCIL is contracted for $31,477 during the current contract year.

IL-NET Launchpad

Contract Period: 8/2/21 – 9/15/22

Contact; Richard Petty, ILRU

NCIL provides logistical support to this advanced learning collaborative of CILs that have participated in one of the previous business acumen collaboratives. Launchpad builds on the outcomes of the prior collaboratives to provide hands-on peer support to CILs in the actual launch and first year of operating their new revenue-generating programs. The collaborative is sponsored by ILRU and facilitated by Lehigh Valley Center for Independent Living and The Independence Center.

NCIL has received $64,000 for the contracted period.

University of Kansas (KU) Research & Training Center – Community Living Summit

Contract Period: 9/30/21 – 9/29/22

Contact: Kelsey Shinnick Goddard, KU

KU’s Research & Training Center for Promoting Interventions for Community Living and NCIL are partnering to create a Community Living Summit to take place on August 17, 2022. The webinar-format event will share information and resources, including the National Community Living Resource Center website, Home Usability Program website, Out and About website, and CIL home modification program fact sheet which are aimed at CIL staff, board members, and consumers as well as SILC staff and council members.

NCIL will receive $7,380 for summit creation and execution.

VII. Advocacy and Public Policy Activities

2022 Policy Briefing PowerPoint Slides are available at [2022 Policy Briefing (ncil.org)](https://ncil.org/2022-annual-conference/2022-policy-briefing/)

2022 Advocacy Priorities Guide is available at [NCIL Documents](https://ncil.org/press-room/)

NCIL Internship Program

NCIL’s Policy Internship Program was put on hold as we re-evaluated the program’s structure and our capacity to maintain it during COVID and beyond. We also wanted to explore the potential for compensating interns (via a salary or stipend) before bringing the program back. With the departure of the Director of Advocacy and Public Policy on May 3, the re-evaluation and exploration have been on hold. However, it is worth renewing discussions when resources permit because, overall, the Internship Program has been a successful addition to NCIL’s policy efforts over the years. It has given young individuals from across the country (and several other countries) the opportunity to work for a national organization at the forefront of disability policy in DC. The remote format of NCIL may give us an opportunity to explore ways to expand the opportunity to young people who may otherwise not be able to participate. Over the years, the internship program has opened opportunities for increased funding and collaboration with universities and organizations such as the Washington Center for Internships and Academic Seminars, Jewish Federation, HSC Foundation, Mitsubishi Electric Foundation, the Religious Action Center, the Ruderman Foundation, AAPD, SARTAC, and others.

Policy Work

Since May 3, in the absence of a Director of Advocacy and Public Policy, the Interim Executive Director has been managing as much of NCIL’s policy agenda, and attending Legislative & Advocacy committee and subcommittees meetings, as time allows. Priority has been given to the work of the Rehab Act / IL Funding Subcommittee and the Long-Term Services & Supports (LTSS) / Healthcare Subcommittee, and to the IL appropriations and funding for Home and Community Based Services (HCBS). A list of policy sign-ons and other policy work over the past year are included below.

The new Director of Advocacy and Public Policy, Jessica Podesva, is scheduled to begin July 18. She served as a Senior Community Organizer at the Boston Center for Independent Living for almost three years, leading several systemic policy efforts. Prior to working at BCIL, she worked at the Greater Boston Legal Services in the Elder, Health, and Disability Unit and also as an Equal Justice Works Fellow and an American with Disabilities Act Transportation Advocacy Fellow. She has a Juris Doctor degree from New England Law | Boston.

Congressional staff have continued to be available remotely to NCIL staff and Legislative & Advocacy committee / subcommittees chairs. The first in-person meeting since the pandemic began will be held on July 27 during the Hill visits segment of the conference program. We have continued to work on many of the same priority issues. Before and after the departure of Lindsay Baran, we conducted a significant amount of advocacy around the institutional bias, particularly in light of the pandemic and the Administration’s proposed investment in HCBS and the direct support workforce, including the HCBS investment in the reconciliation package. While we maintained focus on some ongoing issues such as equitable vaccination distribution, boosters, medical rationing / crisis standards of care and other healthcare discrimination, particularly as COVID began to surge again with the Delta and Omicron strains, more focus was given to reopening policies, relaxing of mandates / protections, and sustaining support as the pandemic continues. These efforts included direct advocacy and engaging with partner organizations around these efforts.

NCIL has also continued to work on many of our other priority issues including: voting rights and accessibility (see below Voting Rights), housing and homelessness, healthcare access, education rights and access, immigration, guardianship reform and alternatives, mental health and school safety issues, employment and unemployment, SSI modernization, EVV, chronic pain and opioids, transportation issues (particularly Amtrak and air travel), assisted suicide, and more.

NCIL staff have attended and watched relevant hearings, provided testimony, comments, and other input, met with members of Congress and staffers, and collaborated with other disability rights groups and other partners. The Interim Executive Director, Rehab Act / IL Funding Subcommittee co-chairs, and NCIL’s Vice President meet regularly with the Administration for Community Living and the Office of Independent Living Programs on various ACL efforts. NCIL staff continue to engage with events in Congress, attend meetings and events put on by and with partners, work with committees and the NCIL membership to submit comments on legislation, rules, and regulations, and communicate with representatives from the Administration and Congress on our positions. NCIL staff have also worked with subcommittees and NCIL members to discuss legislative proposals with Congressional and committee staff and discuss and evaluate current legislation.

NCIL staff have worked with a number of other national organizations to build relationships and have been part of several strategic and collaborative efforts related to the issues listed above. In addition to the formal coalitions listed below, NCIL has been participating in formal and informal coalitions and working groups to address the COVID-19 pandemic response, medical rationing, mental health advocacy, guardianship, accessible transportation, and community integration. NCIL staff have participated on the Consortium for Citizens with Disabilities (CCD) task forces, the National Disability Leadership Alliance (NDLA), the Disability and Aging Collaborative, the Coalition to Advance Competitive Integrated Employment, the HCBS Advocacy Coalition, the Leadership Conference on Civil and Human Rights, and serve on several advisory boards including the National Organization on Disability, the National I&R Support Center, United Health Care, and Airbnb.

NCIL has also been engaging with other formal, informal, and ad-hoc coalitions that have been formed to address the COVID-19 pandemic. Some of these coalitions are disability-specific and others are not. These have proven to be useful groups for collaborating on strategies for Congressional advocacy. There have also been opportunities to collaborate on days of action and other ways to engage the NCIL membership with larger grassroots efforts.

*SELECT LIST OF PARTNERS*

NCIL partners with dozens of national organizations in its advocacy work. These are four of the most prominent:

Consortium for Citizens with Disabilities (CCD) – The Consortium for Citizens with Disabilities is a coalition of over 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. Staff is involved in several CCD taskforces including health care, long term services and supports, housing, civil rights, and employment / social security.

National Disability Leadership Alliance (NDLA) – NDLA is a coalition of disability-led organizations and allies which NCIL is a member of and on the 15-member steering committee. The coalition was formed to build a strong and unified cross-disability movement so that individuals with disabilities would have the power to shape national policies, politics, media, and culture. NDLA is guided by its values of self-determination, participation, choice, involvement, consumer control and people with disabilities having a voice. The coalition has developed a disability policy agenda and is working on its own infrastructure. NCIL staff has been very active in working with NDLA on many issues such as healthcare, Medicaid, community integration, voting and employment.

Disability and Aging Collaborative (DAC) – The DAC is a coalition of national aging and disability organizations working to advance long-term services and supports for older adults and individuals with disabilities. The coalition is now focused primarily on enhancing access to home and community-based services (HCBS), rebalancing, and Money Follows the Person reauthorization.

The HCBS Advocacy Coalition – This is a group of national organizations that supports the full inclusion of people with disabilities and aging populations in the community. We work collaboratively to help states fully comply with the HCBS Settings Rules and assist stakeholders in understanding the rule. These efforts are essential to achieving systems change that enables truly integrated settings, where people with disabilities can live, work, receive services, and fully engage in community life.

*APPROPRIATIONS FOR IL PROGRAM*

In late April we were given an opportunity to submit appropriations request for the IL Program. The full text of the request is available at [Independent Living Appropriations Request (advocacymonitor.com)](https://advocacymonitor.com/independent-living-appropriations-request/). NCIL requested a total appropriation of **$249,980,000 in funding for the Independent Living line item, which is an increase of $131,797,000.**

*VOTING RIGHTS*

Over the last year, NCIL has engaged in the following, coordinated by Voting Rights and Civic Engagement Director Sarah Blahovec:

* Developed and facilitated Elevate: Campaign Training for People with Disabilities. This consisted of seven 90-minute webinars in October and November of 2021, in which we trained 50 people with disabilities to run for office for the first time.
* Collaborated / will collaborate with other organizations in the campaign training space, including:
  + She Should Run event on disabled women’s political representation (July 2021)
  + Run for Something event on running for office with a disability (July 2021). We will once again partner with Run for Something in July 2022 for another event on running for office with a disability.
  + AAPD event on campaigning with a disability and learning to run for office in March 2022
  + EMILY’s List Brown Bag Lunch training on making campaigns accessible and inclusive in April 2022
  + Ballot Initiative Strategy Center later in July of 2022 to provide a training on campaign accessibility and inclusion
* Facilitated the National Coalition for Accessible Voting and facilitated moving NCAV from being solely controlled by NCIL to controlled by a steering committee of six disability rights organization.
* Responded to the National Institute on Standards and Technology’s request for information around access barriers to voting and submitted comments in response to the first draft of a report.
* Advocated for a carve out to the restrictive paper ballot mandate in the For the People Act and Freedom to Vote Act.
* Supported state-level advocacy efforts to expand electronic absentee voting to voters with disabilities.
* Analyzed and categorized states where voter suppression is likely to cause greater challenges in voting in the 2022 Midterms.
* Shared resources provided by VoteRiders so that voters can receive accurate information on Voter ID.
* Met with organizations such as the Apolitical Foundation, NIST, Congressional offices, The Office for Democratic Institutions and Human Rights for the Organization for Security and Cooperation in Europe, and various disability rights and civic engagement organizations looking for subject matter expertise around disability, voting, and running for office.

*PARTIAL LIST OF SIGN-ONS AND OTHER ADVOCACY WORK*

Sign-ons (since 10/28/21)

7/15/22 – BILL – International Children with Disabilities Protection Act of 2022 (Menendez, not yet introduced)

7/1/22 – BILL – Removing Access Barriers to Running for Elected Office for People with Disabilities Act (Casey, not yet introduced).

6/23/22 – DREDF letter in support of nomination of Jamal Whitehead for appointment to the U.S. District Court for the District of Washington.

6/20/22 – SILVER (Saving Institutional Lives Via Emergency Relocation) letter to President Biden asking him to shift the Administration’s focus from improving health and safety in institutions to transitioning individuals to the community with supports and services.

6/20/22 – Comment submitted to CDC regarding Providing Mail-Back Envelopes and Education on Safe Disposal with Opioid Analgesics Dispensed in an Outpatient Setting.

6/15/22 – Arranged for participation of a panelist (Peter Johnke) for BikeWalkNC during Pedestrian Safety Month, October 24, 2022, to provide perspective on safer more accessible communities.

6/10/22 – Distributed info on “Internet for All: The Affordable Connectivity Program and the Need for Digital Connectivity” at the request of the White House.

6/7/22 – BILL – Support local governments for jurisdictions that elect persons with a disability in providing the accommodations needed for the elected official to carry out their official work duties. (Casey, not yet introduced)

6/2/22 – BILL – Website and Application Accessibility Act (Duckworth, not yet introduced)

6/2/22 – National Disability Rights Network statement reaffirming that accessible voting systems are required by federal law (in response to counties threatening to discontinue use of their accessible voting equipment with no plan for replacement).

5/31/22 – CALL TO ACTION – Alert to IL Network to continue pushing for funding for HCBS.

5/30/22 – Paralyzed Veterans of America priority statement for 2023 FAA Reauthorization Act of 2018.

5/27/22 – US Access Board request for input on standards for height adjustable medical and diagnostic equipment, which includes examination tables and examination chairs – social media alert.

5/24/22 – BILL – SSI Savings Penalty Elimination Act (S. 4102), which would raise the amount of assets Supplemental Security Income (SSI) recipients can save without jeopardizing their vital SSI benefits. (S. 4102, Brown / Portman).

5/18/22 – Letter joining with 200+ advocates for seniors, people with disabilities, family caregivers, direct care workers, and allies to urge funding of home and community based services. <https://bit.ly/3NpYCme> #CareCantWait #HCBSCantWait.

5/16/22 – NCIL quoted in Government Accountability Office statement regarding funding needed for home modifications for those younger than 60.

4/27/22 – Coalition on Human Needs letter seeking an adequate share of funding for Labor-Health and Human Services-Education appropriations in FY2023.

4/26/22 – National Low Income Housing Coalition asking Congress to provide the highest possible funding amounts for affordable housing and community development programs.

4/20/22 – Leadership Conference on Civil & Human Rights letter to Congress urging them to vote no on extending Title 42, the public health law that has been used since the Trump Administration to expel immigrants seeking entry into the US, including those seeking asylum.

4/15/22 – CCD letter to Secretary Becerra urging him to issue updated regulations on Section 504 of the Rehabilitation Act.

4/1/22 – PVA letter in support of the Disabled Access Credit Act, asking Senate Finance to include it in any tax package they put forward.

3/31/22 – BILL – Promoting Responsible Emergency Protocols for All Students Act or the “PREP for All Students Act of 2022.” (S. 4259, Casey; H.R. 7859, Wild).

3/30/22 – Provided expert panelist at the [Alliance for Health Policy](https://www.allhealthpolicy.org/) virtual public webinar exploring lessons learned from COVID-era Medicare and Medicaid policy changes.

3/25/22 – Lyft Class Action Amicus Brief.

3/24/22 – Letter asking Congress to conduct hearings to document the ongoing harms resulting from the misapplication of the 2016 CDC Opioid Guideline, and to consider pain management more broadly.

3/24/22 – Department of Transportation hearing on air travel for wheelchair users – provided written and oral testimony.

3/11/22 – CCD Letter to federal partners on the need for a coordinated public campaign on ABLE accounts

3/4/22 – CCD letter in support of Stop Unfair Medicaid Recoveries Act

3/2/22 – Disability community letter to the CDC in response to masking guidance changes

2/25/22 – ACB, AFB, NDRN, NFB letters to Asst AG Clarke (1) and Senators (2) advocating for DOJ to finalize a rule on web and app accessibility

2/18/22- Letter to Senator Blumenthal with guardianship alternatives / reform recommendations + DOJ guidance outline

2/15/22 – APRAIS letter for the record (Ed & Labor hearing) re: restraint & seclusion, discipline, KASSA

2/14/22 – Via letter re IIJA implementation and paratransit

2/11/22 – Klinger Amicus Brief (assisted suicide)

2/11/22 – CCD letter to Congress urging them to pass appropriations bills and not a full-year CR

1/31/22 – Updated HCBS investment sign-on letter (CCD, DAC, etc.)

1/28/22 – NCIL COMMENTS- to HUD on their Draft FY22-26 Strategic Plan Focus Areas

1/27/22 – CCD Health TF sign on re: Notice of Benefit and Payment Parameters for the 2023 proposed rule

1/24/22 – Justice in Aging and Medicare Rights Center sign-on to urge the Biden-Harris Administration to expand access to COVID tests and other services for people with Medicare and clarify Medicare guidance

1/14/22 – Disability community letter of support for the nomination of Nancy Abudu to the Eleventh Circuit Court of Appeals

1/14/22 – Sign on comments to DOT re: the reopening of the comment period for the NPRM concerning accessing lavatories of single-aisle aircraft related to the design of the onboard wheelchair (OBW).

1/13/22 – Disability community letter to CDC re: remarks about disabled deaths being “encouraging.”

1/10/22 – NDRN letter to Amtrak re: narrower aisle widths.

1/3/21 – Joint letter opposing EAGLES Act (S. 391 / H.R. 1229) to reauthorize National Threat Assessment Center.

12/27/21 – Public Citizen – letter to HHS in support of their proposal to repeal / withdraw Trump’s SUNSET rule.

12/23/21 – CCD Ad Hoc guardianship alternatives priorities letter.

12/21/21 – BILL – Congresswoman Bush’s Bus Rapid Transit Act (and submitted suggestions).

12/20/21 – Coalition letter to CFPB to protect consumers from scams, errors, and inappropriate use of their data in tech payment apps and bank-to-bank payments.

12/17/21 – CCD letter to OCR re state / district compliance with Section 504.

12/15/21 – NLIHC and Enterprise letter in support of the Reforming Disaster Recovery Act.

12/15/21 – Medicare Oral Health Coalition letter to the Senate supporting the addition of a Medicaid adult dental benefit to the BBB package.

12/6/21 – Collaboration to Support Self-Determination and allies letter opposing provisions in the NDAA to expand or protect AbilityOne.

12/2/21 – CCD and allies letter to Senators re: absence of judicial nominees with disabilities.

11/29/21 – BILL – Safe Equitable Campus Resources and Education (SECuRE) Act (Casey).

11/29/21 – Families USA, Community Catalyst, The National Partnership on Women & Families, and Protect Our Care- letter thanking the House for passage of Build Back Better and urging swift passage in the Senate.

11/23/21 – LCCHR and Declaration for American Democracy letter to Senators urging them to commit to reconsideration of the Freedom to Vote Act and the John R Lewis Voting Rights Advancement Act immediately or cancel recess.

11/23/21 – People’s Action, Drug Policy Alliance, National Harm Reduction Coalition, and VOCAL-NY- letter to Congress to enact legislation to address the overdose epidemic through a public health lens focused on harm reduction and expanded access to treatment.

11/19/21 – National Women’s Law Center amicus in Adams v. School Board of St. John’s County re Andrew Adams, a trans student who was denied access to the boys’ restroom.

11/19/21 – Women Enabled submission to the UN Special Rapporteur on Minority Issues.

11/17/21 – Access Living letter re ASAP Act- thanking Senator Duckworth & office for their leadership and urging them to restore a provision that was lost to instruct DOT to privilege grants with plans to become 100% ADA accessible.

11/17/21 – BILL – Transformation to Competitive Integrated Employment Act (S. 3238, Casey).

11/15/21 – Disability groups letter(s) to Senators Murphy and Cassidy in response to their call for feedback on specific issues and thoughts on behavioral health policy and to Senate Finance Committee’s similar questions.

11/3/21 – LCCHR letter in support of the John Lewis Voting Rights Advancement Act.

11/3/21 – CCD Paid Leave Letter to Senator Manchin.

10/28/21 – BILL – Pell Grant for Students with Disabilities Act (H.R. 5739, Rep Morelle).

# Human Resources Committee

Submitted by: Kim Conner, Secretary

Description of Committee: The Human Resource Committee shall be responsible for coordinating membership recruitment, identifying and recruiting prospective board members, leadership development activities, reviewing grievances made against the organization, the executive director or board members and providing the Governing Board with recommendations. This committee shall also be responsible for the regular review of the NCIL by-laws, personnel policies and standard operating procedures.

Summary of activities conducted since the Spring Board Meeting:

Committee met in March, April, and June of 2022. The committee created a matrix of goals to accomplish assigning priorities. Committee accomplishments:

* Legislative & Advocacy and Employment & Social Security subcommittees; submitted to Board for review and approval, approved March 2022
* Updated Bylaws & SOPs contingent on full approval by membership, approved Spring 2022

Summary of progress on Strategic Plan responsibilities (if applicable): None at this time

Matters requiring action by the Board / Members: None at this time

Committee goals and objectives for the next year:

Address numerous goals as set by the Board of Directors and Executive Committee including:

* Reviewing and updating Personnel policy and procedures
* Aligning SOP’s with the Bylaws
* Reviewing policies:
  + Whistleblower form
  + Removal of Chairs
  + Position Papers
  + Fiscal SOP
* Streamline membership recruitment with Membership Committee and Regional Reps work

Other: A big thank you to Lou Ann Kibbee, Darrell Jones, Ann McDaniel and Sylena Campbell for their support of the HR Committee and me. Although my time on the NCIL Board has been short, I have appreciated the opportunity to support the great work you all have been doing.

## Annual Conference Subcommittee

Submitted by: Ann McDaniel, Chairperson

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 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 2021 Annual Meeting (since July 21, 2021):

* Monthly meetings
* 3 members left the committee and 2 New members added to committee
* 2 new staff were assigned to the committee
* Reviewed evaluation results from 2021 conference and considered in planning for 2022
* 2022 Annual Conference dates set for July 25-28, 2022 with virtual workshops on August 1-3, 2022
* Established theme for 2021 “Forging Justice” and approved logo
* 2022 Workshop RFP released and 49 proposals received
* All proposals reviewed and 25 workshops accepted
* Discussed COVID-19 impact on 2022 conference and negotiations with the Grand Hyatt to reduce or cancel our liability as an ADA accommodation.
* Registration opened.

Summary of progress on Strategic Plan responsibilities (if applicable): NA

Matters requiring action by the Board / Members: None

Committee goals and objectives for the next year:

To conduct a successful, productive, and beneficial Annual Conference for CILs, SILCs, and other IL stakeholders.

Provide 2023 conference as a hybrid of in-person and virtual and develop a plan that will best serve NCIL members based on the evaluation feedback received from the 2022 conference.

Continue to consider potential venue options for the Annual Conference going forward and identify the venue that best meets the needs of the membership.

Consider any changes to the conference format and consider new options to provide better access to all members and to best meet the needs of the membership.

Other:

The committee would like to recognize the years of support provided and the extraordinary expertise of Tim Fuchs during his tenure at NCIL. We must also express our sincere gratitude for the continuing support provided to the committee by Angela Elman and her skills and understanding. Our thanks to Eleanor Canter for listening to our ramblings and capturing our thoughts to develop logos that reflect our conference theme. And lastly to welcome Jenny Sichel as the new staff to the committee and thank her for her patience as she learns more about the committee and how we roll!

## Membership & Nominating Subcommittee

Submitted by: Charlotte Stewart, Chairperson

Description of Committee: To strengthen the organization by retaining existing members and recruiting new members through the development of strategies and incentives in collaboration with NCIL staff and the members of the Regional Representatives Committee. The Subcommittee will strive to have all CILs and SILCs in the United States as paid members each year. The Subcommittee with staff support will also solicit nominations from the membership for board positions and develop a slate of candidates for election at each annual council meeting.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

The Subcommittee met on a monthly basis via Zoom to review and approve membership applications of new and renewing CILs and SILCs.

Summary of progress on Strategic Plan responsibilities (if applicable):

* CILs with Satellite offices – 314
* CILs without satellite offices – 168
* SILCs – 36
* ORGs – 13
* INDs – 553
* Youth – 24
* Total with satellite offices – 940
* Total without satellite offices – 794

Matters requiring action by the Board / Members: None at this time.

Committee goals and objectives for the next year:

* To develop strategies and incentives to enhance / improve membership recruitment and collaborate with NCIL staff and the Regional Reps Committee on same.
* To review CIL and SILC membership applications and approve same.
* To receive nominations for board positions from the membership and develop a slate of candidates for the annual council meeting elections with NCIL staff support.
* To work with the Regional Reps Committee on outreach to existing and potential
* CIL and SILC members.

Other: None at this time.

# Diversity Committee

Submitted by: Larissa Martin, Chair

Description of Committee: Our goal is to bring diversity in all its forms together moving forward. So that we create, give space and opportunities for those most marginalized which are typically people of color with disabilities and other Underrepresented marginalized groups. To ensure more of them are heard and are able to have the necessary tools needed so they can become the next generation of leaders in the independent living movement.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

We have welcomed new members to this Committee to complete the work we hope to achieve. We are also still discussing possible funding opportunities to support NCIL’s commitment to diversity and NCIL as whole.

Summary of progress on Strategic Plan responsibilities (if applicable):

For the past several months the diversity Committee has worked on restructuring this Committee and has worked with staff and its members of this Committee to figure out how our work can best benefit NCIL and the work it does going forward.

Matters requiring action by the Board / Members: None

Committee goals and objectives for the next year:

* To increase knowledge of NCIL to under-represented communities and the work we do.
* To help this organization try and understand what diversity really is and what that looks like for NCIL for the future.
* Create a survey for the membership to really get a grasp of what diversity looks like to them and what tools we can provide them as an organization so that they can better help their communities and The center they are a part of.

# Finance Committee

Submitted by: Jeremy Morris, Chairperson and 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 2021 Annual Meeting (since July 21, 2021):

The Committee has regularly been reviewing financial statements and activities of the organization.

The Committee has reviewed and approved an initial operating budget, as well as an amendment. There was an issue that arose on missing approval of the budget that was rectified after NCIL staff became aware of the issue. Board members voted electronically on the operating budget which was a revised version from the initial budget approved by the finance committee and executive committee.

The conference budget will be important as we go through this year. Maintaining revenue and limiting as much potential loss has been a key financial concern, but the Staff of NCIL has worked diligently to make sure we are as successful as possible financially.

The Committee has also completed a comprehensive review and revision, with major help from the NCIL staff, of the fiscal policies. Many things were very outdated, and some needed to be amended to fit the virtual operations. These revisions are being presented to the Board as part of the Treasurer’s Report. (See Appendix I: NCIL Fiscal Policies.)

Matters requiring action by the Board / Members:

Review and approval of amendments to fiscal policies

Committee goals and objectives for the next year:

Work with NCIL staff to improve the financial operations and strength of NCIL

Other:

A REMINDER TO THE GOVERNING BOARD:

The NCIL Standard Operating Procedures (SOPs) state that:

Board Member Responsibility

“It is the policy of the NCIL board that all board members secure contributions to NCIL either through giving themselves or securing gifts from others. This policy is known as “give or get” and $300 (in gives or gets) is required annually. The resources needed by NCIL are “unrestricted” funds, meaning cash assets that can be used for any purpose the organization desires. 'Gives' are direct donations made by board members to NCIL. 'Gets' are donations by others directly secured by board members. Signing up new members – either individual or organizational – does not qualify as a “Get” because this is a duty of all board members and requires an investment of NCIL resources (primarily staff time) to serve those members.

“Gives, or direct donations made by board members, and Gets will be tracked by staff and reported to board members at board meetings. Board members must report all Gets to staff in order for them to be tracked. Board members who do not meet the $300 annual Give or Get amount will be reminded by the President to meet their obligation. Any board member who is not able to meet the $300 requirement should contact the President to negotiate a lesser amount. All board members are expected to Give or Get unrestricted funds donations for NCIL annually.

“Please note that cash given at board meetings is not easily verified since we do not know which board member gave what amount. If a board member chooses to give cash, a receipt book will be available at all board meetings so that a receipt for the donation can be provided.

"Examples of ways to secure 'Gets' include:

* Ask 10 friends to donate $30
* Ask a wealthy friend or colleague to donate $300
* Issue a challenge to friends and colleagues that you will donate $2 for every $1 they donate or you will match their donations dollar for dollar

"As a 501(c)(3) non-profit corporation, all donations to NCIL are tax deductible."

# Regional Representatives Committee

Submitted by: Steve Higgins, 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 (since Oct 27, 2021):

The Regional Reps committee meets monthly on the second Monday.

In the last quarter the committee has been working on mentoring and development. Committee members have been encouraged to form and begin regular regional leadership groups. They have been forming as we mentor each other in the roles and responsibilities of a regional rep. Regional reps have been encouraged to include NCIL State Representatives and other NCIL Board members from their regions as part of the regional leadership groups.

This has resulted in several regions having regular meetings Via zoom.

Regional reps have also been asked how the Regional rep chair and staff can support them best as we go through a time of transition.

Regions 1 & 5 have also held meetings inviting NCIL members and potential members from through their areas to participate. Congressman James Langevin (RI) was the guest speaker at the Region 1 meeting.

Regional reps will be presenting at the 2022 annual NCIL conference in a session titles Building Regional Leadership teams.

Matters requiring action by the Board / Members:

Several regional reps have asked that updated letters to new or renewing members be sent in a timely basis which include and re-enforce the benefits of being a NCIL member.

Committee goals and objectives for the next year:

Teaching other and building the NCIL Community

# Legislative & Advocacy Committee

Submitted by: Lou Ann Kibbee, Chair and Vice President

Description of Committee: The function of the L & A Committee is to develop and implement NCIL’s legislative and advocacy agenda. The Legislative and Advocacy Committee shall consist of the Chairs of the legislative and advocacy subcommittees and the Chair of the Regional Representatives. The Legislative & Advocacy Committee shall undertake activities as directed by the President and selecting a recipient or recipients for NCIL’s annual advocacy awards. The Vice President shall Chair the Legislative and Advocacy and monitor the activities of the legislative and advocacy subcommittees.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

* Dealt with issues with some of the subcommittees and task forces through the year.
* Accepted resignations from some Chairs for a variety of reasons.
* Either appointed some subcommittee Chairs in absence of a President for a few months or made recommendations to the current President to appoint numerous Chairs, including Mart Musser as Co-Chair of ADA / Civil Rights; Kristi McGarity and Liz Steckler as Co-Chairs of the Opioids / Chronic Pain Task Force; Jeff Hughes as Co-Chair of the Rehab Act / IL Funding and the LTSS / Healthcare; Meg Coffin as Co-Chair of Voting Rights.
* Participated in as many L & A Subcommittee meetings as my schedule allowed.
* Respond to many emails from Policy Director with sign on requests from other organizations to advocacy letters.
* Respond to Policy Director on comments submitted by NCIL on various issues in conjunction with the applicable subcommittee.
* Participated in an ACL / CDC call with stakeholders around Booster Rollout in place of the Executive Director.
* Maintained communication with the NCIL Executive Director, NCIL Policy Director, and the L & A Subcommittee Chairs.
* Met with the Region Rep Chair at beginning of his term.
* Searched for potential Interim Director candidates.
  + Provided input to questions for a survey for all committee chairs that Executive Director and the Board Treasurer developed. Then worked with staff to get it online for the chairs to complete.
* Working with L & A Subcommittee Chairs to follow policies and responsibilities.
* Participated in a NCIL Interim Director Darrell Jones Meet & Greet requested by Michael Gamel McCormick from Senator Casey’s office. Attendees were Michael, Darrell, Kent Crenshaw, Lindsay Baran, and myself.
* Participated in meeting with ACL.
* Participated in meetings to work on a Return On Investment study of CILs which we have been pushing for years. This work will continue.
* Maintained communication with the NCIL Executive Director, NCIL Policy Director, and the L & A Subcommittee Chairs.
* Participated as part of the Resource Team working with the Karcsay consulting on the complete organizational assessment.
* Met with and worked closely with the Interim Executive Director and staff as needed around processes and procedures and historical content.
* Participated in Board meetings
* Participated in the Human Resource Committee meetings.
* Participated on the Annual Conference Subcommittee meetings.
* Chaired Monthly L & A Committee meetings.
* Participated in monthly Executive Committee meetings.

Acting President activities for several months:

* Chaired the Board meeting after the conference.
* Presented the History, Roles, & Responsibilities of NCIL Board with staff to the board members.
* Chaired the Executive Committee meetings.
* Maintained communication with NCIL Executive Director.
* Accepted the resignations of Shaylin Sluzalis and German Parodi from the NCIL Board.

Summary of progress on Strategic Plan responsibilities (if applicable):

The L & A Subcommittees have continued the advocacy work of NCIL.

Matters requiring action by the Board / Members:

None at this time.

Committee goals and objectives for the next year:

1) Evaluate the subcommittees as to where they currently are in regard to their purpose and responsibilities to determine what needs to be done with each group. (The evaluation was completed.)

2) Move each Legislative and Advocacy Subcommittee to meet their purpose, duties, responsibilities, and requirements as laid out in the NCIL SOP’s and Chair manual.

3) Committee members will work in partnership with each other and staff to further NCIL Legislative and Advocacy priorities.

Other:

When I came back on the Board last year to finish a term as Vice President, I had planned to work with the Legislative & Advocacy Subcommittee Chairs to make sure they knew what their duties and responsibilities are in this position. It became clear that some of the chairs needed some training and guidance. We did develop a survey for all committee, subcommittee, and task force Chairs to complete to evaluate where their knowledge of Chair duties and responsibilities are. We did discuss some of the duties and responsibilities during L&A Committee meetings. After the Board has their strategic planning completed, it would be good to review the Chair Manual for needed changes then assure that a complete training is done with all Chairs. It will also be necessary to review which committees, subcommittees, and task forces need Co-Chairs at that point and do some recruiting.

On a personal note, I want to thank everyone that has supported me through the years as a NCIL Board member. NCIL has had some bumps in the road recently, but these things happen with organizations. Change is a common occurrence for entities, and they get through it. NCIL is already on the right track moving forward. The full organizational assessment that the NCIL Board decided to do was a great step forward. I have every confidence that the results will give the Board some directions needed to take. NCIL has always been a strong advocacy organization fighting for the rights of all people with disabilities alongside our Congressional partners and others with similar goals. This work has and will continue!

## ADA / Civil Rights Subcommittee

Submitted by: Steve Higgins and Marty Musser, Co-Chairs

Description of Committee: 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.

The Subcommittee also develops and presents testimony regarding Federal rulemaking efforts, and works in concert with the NCIL membership regarding changes to federal laws and regulations governing accessibility. The Subcommittee provides input on Independent Living activities to the NCIL membership through newsletter articles and action alerts. Ad hoc Working Groups within the ADA / CR Subcommittee focus on issues specifically brought forth by the NCIL membership, and follow Statements of Purpose of their own. The Subcommittee will work with other subcommittees on issues of mutual concern.

Pending Legislation:

H.R. 77: ADA Compliance for Customer Entry to Stores and Services Act or the ACCESS Act

* Rep. Ken Calvert (R-CA)
* Co-Sponsors: Rep. Tom Rice (R-SC), Rep. Glenn Grothman (R-WI)
* Assigned to Judiciary
* 03/01/2021 Referred to the Subcommittee on Crime, Terrorism, and Homeland Security. Not moving at this time.
* 6/21/ 2022 No New Updates since being introduced in the house on 1/4/21 over a year ago.

This bill addresses access to public accommodations for persons with a disability. The bill requires the Department of Justice (DOJ) to develop a program to educate state and local governments and property owners on strategies for promoting access to public accommodations for persons with a disability.

The bill authorizes an aggrieved person, after taking specified actions, to commence a civil action based on the failure to remove an architectural barrier to access an existing public accommodation. Specifically, the aggrieved person must have provided the owners or operators a written notice specific enough to identify the barrier and specify the circumstances under which public accommodation access was denied. The owners or operators must have (1) failed to provide the person a written description outlining improvements that will be made to improve the barrier, or (2) failed to remove the barrier or make substantial progress after providing such a description.

The Judicial Conference of the United States must develop a model program to promote alternative dispute resolution mechanisms to resolve claims involving architectural barriers to access for public accommodations.

Finally, the bill requires DOJ to complete a study of whether certain web content standards or information services for individuals with disabilities provided telephonically provide the same accommodations as would be available on a website.

S. 2658: REAADI for Disasters Act

* Sen. Bob Casey (D-PA)
* Co-Sponsors: Richard Blumenthal (D-CT), Tammy Duckworth (D-IL), Amy Kloubuchar (D-MN), Kristen Gillibrand (D-NY), Chris Van Hollen (D-MD), Elizabeth Warren (D-MA), Bernie Sanders (D-VT), Sen Lahey (D-VT)
* 08/05/2021 Read twice and referred to the Committee on Homeland Security and Governmental Affairs
* Tool Kit page: <https://ncil.org/disability-equity-during-disasters/>
* Companion Bill
* 8/5/2021 Assigned to Senate Homeland Security and Governmental Affairs. Read twice.
* No new updates 6/21/2022

This bill establishes programs and requirements to assist individuals with disabilities and older adults (age 50 or older) with disaster preparedness. Among other provisions, the bill:

* requires the establishment of an advisory committee that includes disabled individuals and older adults to oversee the use of funds made available by this bill;
* allows states to contract with Centers for Independent Living to provide services and support to disabled individuals in preparing for hazards;
* requires the Department of Health and Human Services to award grants to carry out projects of national significance that, among other things, create opportunities for disabled individuals and older adults to directly contribute to disaster preparedness, recovery, and mitigation;
* modifies and expands the membership of the National Advisory Committee on Individuals with Disabilities and Disasters to ensure that it represents the diversity of the disabled and older adult communities; and
* Establishes the Disability and Disaster Preparedness Advisory Commission to review settlement agreements involving potential violations of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

The Government Accountability Office must study the compliance of federal agencies with such enactments in expending funds to support disabled individuals and older adults in responding to, recovering from, and mitigating disasters.

H.R. 4938: REAADI for Disasters Act

* Rep. James Langevin (D-RI)
* Co-Sponsors: Christopher H Smith (R-NJ), Jimmy Panetta (D-CA), Albio Sires (D-NJ), Eleanor Holmes Norton (D-DC At large), Derek Kilmer (D-WA), Brian Fitzpatrick (R-PA), Jammal Bowman (D-NY), Jerry McNerney (D-CA), Jared Huffman (D-CA), Connor Lamb (D-PA), Elaine Luria (D-VA), Val Butler Demings (D-FL), Chellie Pingree (D-ME), Andy Kim (D-NJ), Jared Huffman (D-CA), Connor lamb (D-PA), Elaine Luria (D-VA), Val Butler Demings (D- FL), Chellie Pingree (D-ME), Andy Kim (D-NJ), Earl Blumenauer (D-OR) Mondaire Jones (D-NY), Andre Carson (D-IN)
* Bipartisan support in house from beginning very important.
* House - 08/06/2021 Referred to the Committee on Transportation and Infrastructure, and in addition to the Committees on Education and Labor, and Energy and Commerce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned.
* 6/21/22 No new updates.

Among other provisions, the bill:

* requires the establishment of an advisory committee that includes disabled individuals and older adults to oversee the use of funds made available by this bill;
* allows states to contract with Centers for Independent Living to provide services and support to disabled individuals in preparing for hazards;
* requires the Department of Health and Human Services to award grants to carry out projects of national significance that, among other things, create opportunities for disabled individuals and older adults to directly contribute to disaster preparedness, recovery, and mitigation;
* modifies and expands the membership of the National Advisory Committee on Individuals with Disabilities and Disasters to ensure that it represents the diversity of the disabled and older adult communities; and
* Establishes the Disability and Disaster Preparedness Advisory Commission to review settlement agreements involving potential violations of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

The Government Accountability Office must study the compliance of federal agencies with such enactments in expending funds to support disabled individuals and older adults in responding to, recovering from, and mitigating disasters.

S. 2646: Disaster Relief Medicaid Act

* Bob Casey (D-PA)
* Co-Sponsors: Richard Blumenthal (D-CT), Sherrod Brown (D-OH), Chris Van Hollen (D-MD), Elizabeth Warren (D-MA), Patrick Lahey 10/21
* 08/05/2021 Read twice and referred to the Committee on Finance.
* Companion Bill
* No new updates 6/21/2022

This bill establishes a series of programs and requirements relating to Medicaid coverage of individuals affected by a federally declared major disaster.

In particular, the bill provides for specific disaster relief coverage under Medicaid for individuals who meet specified income eligibility standards and, during the seven-day period preceding the disaster, were either residents of the impacted area or were employed in the impacted area (and subsequently lost employment). Coverage is effective for two years after the date of the disaster declaration.

State Medicaid programs must provide disaster relief coverage that is at least as comprehensive as the state's Medicaid coverage and the Medicaid coverage of the individual's home state, as applicable. The bill applies a 100% Federal Medical Assistance Percentage (i.e., federal matching rate) to such coverage and related administrative expenses.

H.R. 4937: To provide Medicaid assistance to individuals and families affected by a disaster or emergency, and for other purposes.

* Jimmy Panetta (D-CA)
* Co-Sponsors: James Langevin (D-RI), Jennifer Gonzalez-Colon (R-PR)
* Bipartisan
* 08/06/2021 Referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned.
* Brian Fitzpatrick (R-PA), Derek Kilmer (D-WA), Andy Kim (D-NJ), Darren Soto (D-FL), Eleanor Holmes Norton (D-DC At large), Kailai Kahele (D-HI), Peter Welch (D-VT), Val Butler Demmings (D-FL), Conor lamb (D-PA), Lisa Blunt Rochester (D-DE At large), Albio Sires (D-NJ), Gwen Moore (D-WI) Mark DeSaulnier (D-CA)
* In House Ways & Means and also House Energy & Commerce
* No new updates 6/21/22

This bill establishes a series of programs and requirements relating to Medicaid coverage of individuals affected by a federally declared major disaster.

In particular, the bill provides for specific disaster relief coverage under Medicaid for individuals who meet specified income eligibility standards and, during the seven-day period preceding the disaster, were either residents of the impacted area or were employed in the impacted area (and subsequently lost employment). Coverage is effective for two years after the date of the disaster declaration.

State Medicaid programs must provide disaster relief coverage that is at least as comprehensive as the state's Medicaid coverage and the Medicaid coverage of the individual's home state, as applicable. The bill applies a 100% Federal Medical Assistance Percentage (i.e., federal matching rate) to such coverage and related administrative expenses.

H.R. 4545: Freedom and Right to Emancipation from Exploitation (FREE) Act

* Bipartisan and was introduced on 7/20/21 by Representative Charlie Crist (D-FL).
* Current co-sponsors are Nancy Mace (R-SC), Darren Soto (D-FL), Eric Swalwell (D-CA)
* Introduced in House; assigned House Judiciary Committee
* No new updates 6/21/2022

Summary

This bill establishes rights for individuals who are subject to legal guardianship or conservatorship.

Specifically, these individuals have the right to:

* petition the court to replace their private legal guardian or conservator with a state guardian or other designated individual; and
* Communicate with a caseworker employed by the state, without the interference or objection of the individual's legal guardian or conservator.

Furthermore, the bill creates a private right of action for individuals whose rights have been violated.

The bill also authorizes the Department of Health and Human Services to provide grants to states to hire state-employed caseworkers, legal guardians, and conservators for legally incompetent adults.

S. 2881: Guardianship Accountability Act of 2021

* Bipartisan introduced by Senator Susan Collins (R-ME)
* Current Co-Sponsors: are Bob Casey (D-PA), Maggie Hassan (D-NH)
* Introduced in Senate on 9/28/21; Assigned Health Education Labor & Pensions Committee
* No new updates 6/21/2022

This bill requires the Department of Health and Human Services (HHS) to create a National Resource Center on Guardianship for the publication of resources and data relating to court-determined adult guardianships. Further, HHS must award at least 5% of certain grant funds for state programs related to overseeing the administration of court-appointed guardian arrangements.

NCIL Parenting Task Force, as noted above will begin reaching out to Parenting task force members. Have not had opportunity to do this as of yet 6/21/2022.

Alternatives to Guardianship / Conservatorship:

* 2/15/2022 Cross committee task force being formed. Looking for a couple of people who would be interested in serving. No updates at this time will reach out to others and share that Marty interested in participating
* No new updates 6/21/22

Immigration / Public Charge

* No major updates this month. There are still several things playing out in the courts.
* Other items
* New Policy Person, awaiting announcement and will be sharing soon.

Settlement: Giannaros v. Poly-Wood

A proposed settlement has been reached that would resolve the class action lawsuit Giannaros v. Poly-Wood, No. 1:21-cv-10351 (D. Mass.). The lawsuit alleges that Poly-Wood violated the Americans with Disabilities Act, 42 U.S.C. §§ 12101, et seq. by failing to take the necessary steps to ensure its Websites do not discriminate against blind or visually disabled consumers who use screen reader auxiliary aids to access digital content. Poly-Wood denies the allegations. Under the settlement, Poly-Wood agrees to take additional steps to make its websites, mobile apps, and any new website or mobile app it develops or acquires Accessible to screen reader users. For a more complete summary of the terms of the proposed settlement, please visit www.polywoodadasettlement.com.

Questions concerning the settlement should be directed to Class Counsel at the contact information below:

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Summary of progress on Strategic Plan responsibilities (if applicable): none

## Education Subcommittee

Submitted by: Maureen Hollowell, Chair

Description of Committee: The Education Subcommittee monitors and participates in the development and implementation of education-related federal legislation and policy. The Subcommittee encourages grassroots’ efforts to advocate for strong education policy and implementation at the federal, state and local level.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

The Subcommittee reviewed several letters sent by the US Department of Education (USDOE), Office for Civil Rights to state education agencies on the wearing of face masks as a COVID precaution. <https://www.ed.gov/news/press-releases/department-educations-office-civil-rights-opens-investigations-five-states-regarding-prohibitions-universal-indoor-masking>.

The Subcommittee discussed the use of face masks by students with disabilities and other students. While some students with disabilities need accommodations to wear face masks such as assistance with putting the masks on and off and frequent repositioning of the masks, other students with disabilities need students and school staff to wear masks to minimize exposure to illnesses others may have. The issue is complicated by the ongoing national debate about the wearing of face masks, pressure from other students and school staff, and variations in COVID transmission rates over the past six months. The Subcommittee drafted a statement about face masks in schools for the NCIL Board to consider.

The Subcommittee discussed the USDOE proposed Federal Learning Agenda. The Subcommittee recommended that NCIL sign onto a letter with comment on the proposed Agenda developed in collaboration with the Consortium for Citizens with Disabilities Education Task Force. Comment included the need to review and act on issues related to the impact of COVID on the education of students with disabilities, providing equity in resources and research, increasing postsecondary access, and improving student aid programs.

The Subcommittee reviewed the proposed All Students Act that would “create a Council on Emergency Response Protocols to ensure the establishment of accessible, developmentally appropriate, culturally aware, and trauma-informed emergency response protocols in public schools, early childcare and education settings, and institutions of higher education, and for other purposes”. NCIL staff draft comment regarding the draft legislation to address the inclusion of people with disabilities on the proposed Council. The Subcommittee discussed the comment, made suggestions and encouraged NCIL staff to discuss the comment with Senator Casey’s office.

The Subcommittee discussed plans announced by the US Department of Education to review the Department’s 504 regulation and promulgation of amended regulation in 2022-2023. The Department has stated it is their intention to move through this process quickly with a goal of final regulation approval in 2023.

Matters requiring action by the Board / Members:

Review draft statement on face masks in schools.

Committee goals and objectives for the next year:

Comment on NOIRA for US Department of Education 504 Regulation.

Advocate for strong federal language that will forbid the use of restraint except in emergencies threatening physical safety. Support the Keeping All Students Safe Act.

Monitor USDOE policy development and advocate ensuring school accountability is not diminished.

Support the RISE Act to improve access to college.

Monitor the impact of COVID-19 school closures and virtual education and advocate as needed.

## LTSS / Healthcare Subcommittee

Submitted by: Lisa Hayes and Jeff Hughes, Co-Chairs

Description of Committee: The LTSS / Healthcare Subcommittee monitors and advocates on long term services and supports and healthcare issues impacting people with disabilities which includes but is not limited to, Home and Community Based Services (HCBS), disability discrimination in healthcare, chronic pain / opioid advocacy, assisted suicide and euthanasia

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

1. It became apparent Build Back Better reconciliation pkg. (H.R. 5376) was not going to happen; shifted national advocacy efforts to HCBS.

2. Monitored FMAP bump; encouraged state advocates to participate in those discussions; know what your state planned with the extra funding;

3. Continue to monitor Better Care Better Jobs Act S.2210 / HR4131 that will establish programs and provides funds for state Medicaid programs to improve HCBS.

4. Followed issues around healthcare discrimination / resource rationing; monitored crisis standards of care activities, advocated to ensure people with disabilities are at the local table

5. Institutional Bias: Reviewed S.3417 / HR 6860- Latonya Reeves Freedom Act that prioritizes community living over nursing facilities. Addresses systemic bias; as of now cost was removed thinking it would be picked up in BCBJ; this may change.

6. We provided Public Option Health Insurance Recommendations

7. Provided input on the fact sheet: “Protecting Seniors and People with Disabilities by Improving Safety and Quality of Care in the Nation’s Nursing Homes from The White House”. Concerns that no HCBS referral path was mentioned; suggested actions, including a path out of Nursing home.

8. Advocating for accessible telehealth (added to Cures 2.0) beyond PHE.

Sign-On Letters; Support / Opposition:

1. Medicare coverage gap for COVID testing

2. Access strategies for Medicaid & CHIP specifically regarding LTSS;

3. Sign-on letter in support of "Stop Unfair Medicaid Recoveries" Act.

New Bill HR 6698:

4. March 23, 2022, Hearing: An Economy That Cares: The Importance of Home-Based Services

5. Letter to the CDC in response to masking guidance changes

6. letter with DREDF and Justice in Aging on a CMS rule re MMPs that could hurt thousands of persons with disabilities

7. Letter to Support Emergency Paid Leave

8. requesting that HHS / CMS provide at least 120 days (rather than the currently promised 60 days) before the end of the public health emergency

9. Sign on to Biden letter; thank you and push for HCBS

Matters requiring action by the Board / Members: None.

Committee goals and objectives for the next year:

1. Continue advocacy for HCBS funding for direct care workers, (recruitment, retention, etc.);
2. Permanent re-authorization of MFP;
3. Explore opportunities & make recommendations for 5th core Funding;
4. Eliminating the Institutional Bias – Next iteration of S.3417 / HR 6860- Latonya Reeves Freedom Act;
5. Advocate against disability discrimination in healthcare; encourage HealthPlan / CIL partnerships / contracts;
6. Continued advocacy to remove Geo tracking & biometrics in EVV;
7. Continued opposition to legalize assisted suicide.
8. Continue advocating with Congressional offices for / against legislation related to opioid prescribing, continue responding to calls for comment by federal agencies, add another letter to our state efforts in Oregon, publish talking points and fact sheets for the disability community to distribute to Congress, collaborate with the National Pain Advocacy Center and other disability justice organizations.

Other: N/A

## Rehab Act / Independent Living Funding Subcommittee

Submitted by: Ann McDaniel and Jeff Hughes, Co-Chairs

Description of Committee: 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. Co-Chairs participated in monthly L&A calls.

Summary of activities conducted since the Fall 2021 Report:

Workgroups continuing to develop recommendations for the Reauthorization of the Rehab Act. The House passed Reauthorization with no changes to the Rehabilitation Act. The Senate will not take up Reauthorization this year. The Co-Chairs and NCIL staff met with Congressional staffers regarding Reauthorization and priority issues and amendments.

The CIL Indicators workgroup was merged with the CIL Reauthorization work group and is working to finalize recommendations. The SILC Reauthorization work group finalized recommendations. A session at the 2022 Annual Conference will be led by the Co-Chairs and will focus on Reauthorization, current draft recommendations, and gathering input and feedback in order to finalize recommendations.

Co-Chairs attend regular monthly meetings with ACL staff to discuss issues and advocate for improvements. Committee members develop questions for each of these meetings which are submitted to ACL and are included on the agenda.

Continue to monitor the federal budget development process. The FY 2022 budget included $2 million increase for Independent Living which ACL determined will be applied to Part C. Worked with NCIL staff and ACL to gather data and develop an appropriations request for FY 2023 of $250 million for the Independent Living line item – a $131.8 million increase.

Beginning a new initiative to increase the IL line item to $500 million - “Drive for 5!” Recruiting state coordinators to share information, raise alerts, and coordinate efforts at the state level.

Preparing for 2 workshops at the Annual Conference:

* “Independent Living 2050 and Beyond”
* “Rehab Act Reauthorization Updates”

Co-Chairs have reviewed the committee membership list to remove members who are not participating, reached out to some members to confirm their interest in continuing, and have recruited some new members. The membership list was submitted to NCIL staff and individual NCIL membership of each member is being ensured.

Co-Chairs participated in a meeting with the new director of NIDILRR, Dr. Anjali J. Forber-Pratt, to discuss strategies for getting a Return on Investment study of CILs, which was quite productive. Work will continue to ensure an ROI study is conducted.

Summary of progress on Strategic Plan responsibilities (if applicable):

Goal: To provide CILs and SILCs with the tools and resources they need to maintain quality and demonstrate their value.

* Advocacy for increases in IL Funding resulted in a $2 million increase to the Independent Living line item for FY 2022
* Developed recommendations for how states could make adjustments to Part C funding and / or service areas through the SPIL and submitted to ACL
* Continued to advocate for an effective PPR and an ROI study to provide information and data on the effectiveness of CILs to be used in advocacy efforts to increase funding
* Continue to meet with ACL to address issues and hold them to the requirements in the Rehab Act
* Continue to work with Congress on both Reauthorization and Appropriations

Matters requiring action by the Board / Members: None at this time.

Committee goals and objectives for the next year:

Finalize recommendations for the Reauthorization of the Rehab Act for board approval.

Work with Congressional staffers and law makers on amendments to the Rehab Act that will increase support and improve operations of CILs and SILCs.

Work with Congressional staffers and law makers to secure increased funding for Independent Living.

Develop draft CIL indicators of minimum compliance, for board approval, to be presented to ACL with recommendations for implementation.

Advocate for a PPR that effectively demonstrates the value of CILs and for a user friendly portal for the submission of the PPR which will provide data that demonstrates the effectiveness of the IL program.

Continue to advocate for a Return on Investment (ROI) study of CILs by NIDILRR.

Continue regular meetings with ACL to share concerns, discuss issues, and improve systems that support the Independent Living Program.

Other: The Committee and Co-Chairs express their gratitude for the years of amazing staff support provided to the committee by Lindsay Baran and her legislative advocacy efforts.

## Technology Subcommittee

Submitted by: Susan Tachau, Chair

Description of Committee: The Subcommittee, which focuses on technology-related legislative and regulatory initiatives, meets at least every other month (and often every month).

There were a couple of new members added to the Subcommittee this year and a few who left. We spent time getting to know each other.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

* Reviewed legislation related to complex rehab technology (wheelchairs) and hearing aids and sent comments to Lindsay Baran.
* Met with Lindsay several times to discuss the reauthorization of the Assistive Technology Act. Sent comments and met with Phoebe Ball, House Education and Labor Committee.

Matters requiring action by the Board / Members: None at this time.

The Subcommittee appreciates NCIL’s continued support for programs – including the Alternative Financing Programs – within the Assistive Technology Act. Additionally, the Subcommittee continues its commitment for the inclusion of language that emphasizes consumer-control and consumer direction.

Committee goals and objectives for the next year:

1. Working with Congress on the reauthorization of the Assistive Technology Act.
2. Introduction to the new CEO of National Coalition for Assistive and Rehab Technology (NCART). (The search is in progress.)
3. Recruiting new Subcommittee members.

## Transportation Subcommittee

Submitted by: Peter Jonke, Chair

Description of Committee: 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.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

The committee continues to advocate for accessibility in all modes of transportation. Specifically, we have been monitoring the following:

* DOT’s activities regarding air travel for wheelchair users including efforts to promote technology that would enabled wheelchair users to stay in their wheelchair when flying
* Monitor Amtrak’s accessibility improvements since the DOJ settlement
* Air Carrier Access Amendments Act of 2021 (HR1696 & S642)
* 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,

Summary of progress on Strategic Plan responsibilities (if applicable): N/A

Matters requiring action by the Board / Members: none

Committee goals and objectives for the next year:

Although we have made a little progress in recruiting new members. They have not shown up for meetings. More follow-up needs to be done.

## Voting Rights Subcommittee

Submitted by: Sha Anderson and Meg Coffin, Co-Chairs

Description of Committee: Our goal is for all people with disabilities to vote in all elections. All people with disabilities must be able to vote privately and independently. All voters must have access to both in-person and remote voting. Both must have accessible options.

Summary of activities conducted since the 2021 Annual Meeting (since July 21, 2021):

Below is a list of topics and discussions the committee had over the past year

1. Justice Dept. Guidance on Federal Statues Regarding Redistricting & Methods Electing Public Officials
2. [National Disability Voter Registration Week AAPD](https://www.aapd.com/advocacy/voting/dvrw/)
3. Update on Elevate: Campaign Training for People with Disabilities
4. Freedom to Vote Act
5. Election Day for local and State officials- what folks are doing what barriers folks are facing?
6. National Institute of Standards and Technology, Executive Order on Access to Voting Update – Public Comment period through November. Comment on report and link to it <https://www.nist.gov/itl/voting>
7. Recruitment of New Members
8. Represent Women Democracy Solutions Summit – Sarah is speaking at this event on March 8th
9. Upcoming AAPD event on running for office with a disability—Sarah currently working with Lilian to schedule a webinar for later in March about running for office with a disability.
10. Report out on meeting with Congressman Mondaire Jones’s office about SSI asset caps and civic engagement.
11. Action item: planning for the 2022 Midterms. How does the subcommittee want to engage ahead of the 2022 Midterm elections?

Things to think about include:

* engaging in civic holidays such as National Disability Voter Registration Week and National Voter Registration Day (and several others
* sharing pre-existing resources we’ve made such as the Plan Your Vote Guide and our GOTV toolkit, conducting outreach to NCIL member organizations and individuals to encourage them to do nonpartisan voter registration and GOTV, etc.
* subcommittee’s input on what they want to see Sarah doing and also how they would like the subcommittee to contribute.

1. NCIL’s Annual Conference: NCIL is now accepting proposals for presentations at the 2022 annual conference. Will the subcommittee be submitting any proposals this year?
2. NIST Report on Voting Access Barriers (link: <https://nvlpubs.nist.gov/nistpubs/SpecialPublications/NIST.SP.1273.pdf>)
3. White House Forum on Biden’s Executive Order on Promoting Access to Voting (VP Harris’s remarks and Fact Sheet summarizing agency updates [Links unavailable at time of publication])
4. Remote voting legislation in Alaska and DC
5. Continuing discussion on outreach to states impacted by voter suppression legislation leading up to Midterms: developed a two-tiered list of states that passed voter suppression legislation since 2020 and states that may pass voter suppression legislation soon, to target our outreach
6. New York Redistricting <https://news.yahoo.com/york-top-court-throws-district-184516218.html>
7. Sign-on letter opportunity from the Leadership Conference on Civil and Human Rights (see attached letter)
8. Plan for outreach to states that passed voter suppression laws
9. Sarah was quoted in Vox regarding some voting laws that are disenfranchising disabled voters: <https://www.vox.com/23043567/voters-with-disabilities-voting-barriers-restrictive-laws>
10. Sarah will be presenting with Rylin Rodgers of Microsoft at the Annual Conference about voting legislation.
11. Smartmatic would like to partner with us to write a voter guide
12. Voting Access updates

Summary of progress on Strategic Plan responsibilities (if applicable): N / A

Matters requiring action by the Board / Members: None at this time

Committee goals and objectives for the next year:

Develop information packet to send to ILCs and SILCs in states that have passed restrictive voting measures that details how to vote and what the new laws mean.

Participate in voter engagement activities leading up to the 2022 Midterms, including National Voter Registration Day, Disability Voting Rights Week (formerly National Disability Voter Registration Week), Voter Education Week, Vote Early Day, and other civic holidays

Continue to engage around state and federal-level legislation pertaining to voting accessibility, including outreach to states considering electronic ballot return. If new voting legislation is discussed at the federal level, we will be prepared to continue advocating for accessibility and voting rights expansion

# Task Forces:

## Chronic Pain / Opioids Task Force

Submitted by: Kristi McGarity and Beth Steckler, Co-Chairs

Presented comments to the Centers for Disease Control Board of Scientific Counselors on their Opioid Workgroup process.

Submitted comments to the Food and Drug Administration for the meeting “Morphine Milligram Equivalents: Current Applications and Knowledge Gaps, Research Opportunities, and Future Directions.”

Submitted comments to the Drug Enforcement Agency’s “Notice on Proposed Aggregate Production Quotas for Schedule I and II Controlled Substances.”

Collaborated with the National Pain Advocacy Center (NPAC) on a call to action asking the disability community to comment on the 2022 draft *CDC Guideline for Prescribing Opioids.*

Submitted extensive comments to the Centers for Disease Control, on the 2022 draft of the *CDC Guideline*.

Authored Community Letter to Congress, co-signed by 60 disability organizations, requesting hearings on harms from the *CDC Guideline*.

Submitted comments to the Food and Drug Administration on their FDA initiative “Providing Mail-Back Envelopes and Education on Safe Disposal With Opioid Analgesics Dispensed in an Outpatient Setting.”