



NCIL Board & Committee Report Packet

Virtual Annual Conference

July 17, 2020

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NATIONAL COUNCIL ON INDEPENDENT LIVING
Human Resource Committee
Annual Membership Report

TO: NCIL Governing Board

FROM: Human Resource Committee
Lou Ann Kibbee, Chair
Secretary

DATE: July 2020

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 2019 Annual Meeting (since July 23, 2019):

- Reviewed the NCIL Personnel Policies and made recommendations to the Board for extensive changes, including reasonable accommodations, bonus day a month, paid leave for medical purposes, reducing vacation accrual quantity, and bereavement days.
- Made recommendation to the Board for a Bylaw amendment titled "Suspension of Annual Conference Specifications to Respond to Restrictions Related to the COVID-19 Pandemic" which was then affirmed by the membership.
- Reviewed the NCIL SOPs and made recommendations to the Board for changes regarding NCIL staff as majority people with disabilities; Region Reps ability to reduce or waive membership dues if needed; Non-Disclosure Policy & forms for Board and staff; designated representative defined under eligibility of office; policies and procedures needed to hold a virtual Annual Council Meeting and Conference, which the Board approved.
- Developed a flow chart for the process for Committee, Subcommittee, Task Force, or Caucus Chairs and Region Reps to follow when opening a NCIL Social Media account. Narrative will also be available for access.
- Completed changes to the Board Skills & Diversity form along with input from the Diversity Committee
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- Participated on PAS Subcommittee calls

- Participated on Executive Committee calls
- Participated on Rehab Act/IL Funding Subcommittee calls
- Participated on Annual Conference Subcommittee calls.
- Sent the applicable Board position descriptions, Bylaws, and SOPs to each Board member after 2019 Annual Council Meeting.
- Committee has begun reviewing NCIL 's grievance procedure, as well as several other current policies.

Summary of progress on Strategic Plan responsibilities (if applicable): The HR Committee oversees the Membership & Nominating Subcommittee and the Annual Conference Subcommittee which are the leads on the following goals and activities.

Goal Category: Mobilize & Strengthen NCIL's Capacity

Goal 3: Increase NCIL membership. (Membership & Nominating Subcommittee)

Goal Category: Strengthen the IL Network

Goal 2: Educate CILs on the new core services. (Annual Conference Subcommittee)

Matters requiring action by the Board/Members: No action at this time.

Committee goals and objectives for the next year: These are some of the things that the HR Committee has been directed to work on:

- Review the process of the Caucuses in policies under the Diversity Committee
- President send something to the Board members requesting what Committee, Subcommittee, Task Force, or Caucuses they serve on and/or Chair.
- Review the Vice Chair position under the Vice President in the bylaws and SOPs.
- Review the Annual Council Meeting and voting policies and procedures.
- Look at a possible Whistleblower form to go with our policy
- Review policies regarding harassment
- Coordinating all membership recruitment
- Leadership development activities for the Board
- Identifying and recruiting members to run for NCIL board positions each year

Other: I am going off the NCIL Board after serving since 1999 in the positions of Region VII Representative, Secretary, Vice President, and President in various terms. It is time for change for the NCIL Board and there are a list of great candidates this year. NCIL has come a long way in growth in the last 20 years but there is still a great deal of work to be done. The disability community as a whole has allowed racism to not only exist but continue to reproduce. As a major segment of the disability community, NCIL has the opportunity to make real change within the membership and beyond to the community at large. NCIL has been very successful in making change happen in many ways, so I have confidence that we will be successful as an organization in fighting for true inclusion for everyone. It will not be easy and will be painful, as it has for people of color who have disabilities have experienced forever. But we will be a stronger organization and community to support our CILs, SILCs, and people with disabilities in the Independent Living Movement. I want to thank everyone that has supported me through the years, including my husband, my boss Shari Coatney, Board members that I worked with through the years, and the membership that voted for me. I would especially like to thank the NCIL staff for all of their hard work and support through the years. You are some of the hardest working and most committed people in the IL movement that I know. I will continue working on multiple committees and this is my last Board report! Thank you all!!! Cheers!!!!

NATIONAL COUNCIL ON INDEPENDENT LIVING
Annual Conference Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Ann McDaniel, Chairperson
304-766-4624
ann.meadows@wvsilc.org

DATE: July 2020

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 2019 Annual Meeting (since July 23, 2019):

- Monthly meetings
- Debrief on 2019 Annual Conference and review Evaluations submitted and developed recommendations for 2020
- 2020 Annual Conference dates set for July 20-23rd
- 2020 will be the 30th Anniversary of the ADA – planning for a large dinner celebration in conjunction with NDLA similar to what we did in 2015
- Discussed the need to get information out about why the listening session was held at the 2019 conference to increase understanding
- Reviewed conference finance report – income exceeded goal and profit projected
- Discussed ways to use YouTube to engage youth but captioning is an issue
- Discussed how and whether to live-stream any of the 2020 conference and access issues, costs, etc.
- Established theme for 2020 “Evolution of Our Revolution” and approved logo

- Conducted conference access survey and reviewed responses
- Workshop RFP released and deadline extended
- Proposals reviewed and workshops selected
- COVID-19 impact on 2020 conference
- Discussed all options:
 - Postponing to a later date
 - Offer a reduced, mini conference
 - Hold a virtual conference
 - Cancel
- staff researched options
- Concerns about the scale of our event – concerns that sponsors won't be willing if we go virtual – how to have an exhibit fair on-line
- Will need significant technical assistance to have a virtual conference
- Established work plan for moving forward
 - Made recommendation to board that we move forward with a virtual conference, which the board approved
 - Worked with hotel to cancel for 2019 in exchange for adding one more year to current contract
 - Angela taking a 6 week course to be certified as a virtual conference planner
 - Revised conference budget
 - Adjusted registration rates for virtual conference
 - Bylaw and SOP amendments required to hold virtual Annual Meeting
 - Revised conference schedule to accommodate all sessions and activities within limits of staff capacity
 - Revised sponsorship structure and benefits

- ADA 30th Anniversary Celebration is moving forward virtual event with Angela as coordinator

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

Matters requiring action by the Board/Members: None

Committee goals and objectives for the next year:

- Review lessons learned from 2020
- Identify ways to provide conference access to those who cannot travel to DC
- Continue to improve the Annual Conference

Other: The committee would like to thank Tim Fuchs and Angela Elman for the stellar support they provide to our work and to the implementation of a successful Annual Conference. The committee could not do the work it does – and the conference would not be the outstanding resource and successful event it always is, without their expertise, dedication and support.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Membership & Nominating Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Membership & Nominating Subcommittee
Charlotte Stewart
Subcommittee Chairperson

DATE: July 2020

Description of Committee: Coordinates with NCIL staff and the members of the Regional Representatives Committee matters related to membership in the organization. Also coordinates the nomination and election of officers and at-large board members with NCIL staff.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019): Met on a monthly basis via teleconference to review and approve membership applications for new and renewing CILs and SILCs.

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

Paid Memberships as of 7/13/20
CILs: 170 - \$238,657.00
SILCs: 36 - \$13,800.00
Organizations: 13 - \$8,175.00
Individuals: 483 - \$16,635.00
Youth: 62 - \$410.00
Total: 764 - \$277,677.00

Matters requiring action by the Board/Members: None.

Committee goals and objectives for the next year: Continue striving to increase the number of paid CIL and SILC members.

Other: None.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Legislative & Advocacy Committee
Annual Membership Report

TO: NCIL Governing Board

FROM: Legislative and Advocacy Committee
Clifton Perez
Vice President

DATE: July 2020

Description of Committee: The Legislative and Advocacy Committee consists of the chairs of the Legislative and Advocacy Subcommittees and the chair of the Regional Representatives. The Legislative and Advocacy Committee undertakes activities as directed by the President and selecting a recipient or recipients for NCIL's annual advocacy awards. The Vice President serves as chairperson of the Legislative and Advocacy Committee. It is also our responsibility to provide necessary information for the development of NCIL's Legislative and Advocacy booklet. This year we have stream lined the L&A booklet and we increase the font size to 14 font to facilitate easier reading and as such, greater accessibility. As result of the COVID-19 Pandemic, we have made additional changes such as more specific information as to how our committees work and it will also be in electronic format, via email and on the NCIL website. The book will not be printed this year- online only. We discussed a new plan; instead of updating the old one, each committee chair should put a 1-2 paragraph description of what their subcommittee's current legislative priorities are and what our members should focus on in their advocate to the Hill. Can include talking points. The goal of the document should be to make it relevant to what the subcommittee is focusing on now and usable for our members on Hill Day. Since we are a membership controlled organization, they determine what are our legislative priorities and they are:

Rehab Act/IL Funding,
Housing,
Healthcare/LTSS,
Civil Rights/ADA,
Transportation,
Mental Health,
Social Security/Employment,
Voting Accessibility,
Violence and Abuse,
Education,
Emergency Preparedness,
Technology,
Veterans,
ADRC, and,
International Civil Rights).

Advocacy Award – The Corey Rowley National Advocacy Award: Our recipient for the Corey Rowley National Advocacy Award this year is: Penny Shaw.

Penny Shaw, 77 has been living in Braintree Manor Nursing Home since 2002 because she can't get the level of personal care she needs in the community approved by Massachusetts Medicaid. Undaunted, she took on a new fight in 2011; she's been fighting for basic human and civil rights as a "patient" and for appropriate staffing.

Penny was recently appointed to the White House Coronavirus Commission for Safety and Quality in Nursing Homes. She continues her advocacy and is presently bringing media attention to her situation and continually pointing out that this is playing out nationally in every state.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019): A full report from each of the NCIL L&A Subcommittees have been submitted. Here are some highlights from the past year:

The NCIL L&A Committee continues to promote and advocate for the elimination of the "institutional bias" by supporting bills which will serve to advance the; economic independence, comprehensive health care, Long-Term services & Supports, Community-Based-Services and full inclusion in every aspect of community life for all Americans with disabilities. We also fight to strengthen existing laws and bills such as; health care, Money Follows the Person (MFP) accessible housing, transportation and the Americans with Disabilities Act, as well as continuing with our struggle to eliminate the institutional biased and fighting for legislation which will maximize the probability of securing Long-Term Services and Supports (LTSS). However, even within this toxic environment, we still have been very effective in our efforts toward addressing many of these attacks on our freedom, community integration and our independence. As such, we are still advancing and leading the way toward improving the lives of people with disabilities, our civil rights and, the IL Movement!

Summary of progress on Strategic Plan responsibilities (if applicable): Throughout the year, the Subcommittees have placed much attention toward legislation and other efforts which serve to strengthen the Centers on Independent Living (CILs) network, including seeking an increase in IL funding. Fortunately, within the COVID 19 stimulus legislation, we were able to secure an additional 85 million dollars for the Centers. The CIL money will be distributed the same way it always has been. Money will be held off for T/T&A so IL-NET should get a boost, too. The money is available through September 30, 2021.

Region Rep Chair Report: In May the committee Welcomed their new Region 2 Rep, Aaron Baier and unfortunately Candie Dalton resigned (from Colorado) so they are not at 100%; need to decide whether to take nominations or appoint someone. The Committee spent some time talking about CARES Act funds; still some questions about what they will and will not approve (they have been asked to contact their specific Program Officer); a lot of people are putting it towards technology. A lot of agencies are doing wellness checks; many are responding to the needs of financial assistance trough rent relief, utilities assistance, medical assistance, high amount of food insecurity. Quite a lot of federal focus on food insecurity but much of the programming is focused on age 60 or 65 and older. There hasn't been enough

money made available for younger disabled and chronically ill people- many CILs are trying to partner on this.

Housing: they have been reviewing the President's budget; CDBG funds, HOME program funding and other housing programs which were eliminated or reduced. Maintaining or increasing funds for housing remain a priority. There's a great deal of housing-related pieces in the HEROES Act (~\$100M). The National Low Income Housing Coalition has great information on the HEROES Act and the CARES Act with a lot of details. There is a legislative tracking group that follows federal legislation and the visit-ability website group follows the website and ensures that the information is constantly updated. As for the three priority bills the committee has been tracking have not changed. In an overview of the HUD money in the COVID-19 bill. There is \$12.4B for HUD.

As for the homelessness group, they have been doing action alerts, providing awareness, promoting shelter accessibility, data gathering and action plan development. Unfortunately, regarding emergency preparedness, there are ongoing concerns with FEMA and Red Cross, as it pertains to people with disabilities. The Emergency Preparedness committee decided not to renew an MOU with FEMA and they let the Red Cross one expire as well. The CILs in NY actually sued them and won. Just because we're having a pandemic doesn't negate the need to follow the ADA. It also doesn't put Mother Nature on hold and it's going to be hurricane season and fire season soon. A lot of what we're seeing shows us why we need READI and DRMA have to pass. They're going to pull out language to show if they had been in place how much support could have been provided. A survey is being developed with the Partnership for Inclusive Disaster Strategies and they are looking for institutional demographics, which will be used for READI and DRMA advocacy. There has been some pushback on DRMA (specifically the Medicaid portability). Marcie Roth (with the Partnership) pointed out that it makes no sense to link the 2 bills when the issue is with an issue in 1 bill. This is being looked into currently. NCIL has an intern working with Emergency Preparedness subcommittee, gathering best practices of CILs during COVID—stories.

Health Care/LTSS: New Bills were introduced of interest to the committee. Sen Casey has introduced S. 3277 which is an HCBS infrastructure bill, addressing community capacity and workforce barriers to community integration. There have been companion bills introduced on allowing HCBS to provide paid supports for people in acute care settings (HR5443/S3220). The CARES Act authorized Medicaid to pay for direct support workers to accompany people into hospitals or acute care facilities and continue to be paid for those services, which was great. But now we're seeing the disconnect between that and how that's playing out and other visitor policies, and actually being able to exercise that right. No plainer reminder of the discrimination and the institutional bias in our country than what we are seeing unfold as a result of COVID-19. Obviously, in keeping with our goal to eliminate institutionalization We want to keep people out of institutions and congregate environments. We may have an opportunity to make some permanent changes to how CMS does this. This pandemic can give us the chance to point out some of the glaring missteps that aren't paid attention to throughout the remainder of the year. We continue to work on issues around 1135 Waivers, which opens the door for institutions and has nothing for HCBS. States are allowed to do this.

Example, during hurricane Harvey in Houston, they filled their NF's, then shipped to facilities out of state. Currently, of the census in facilities—over half of the deaths are in facilities. People are being sent to where a person has just died, which has opened up that bed to them. Kaiser Family Foundation and other entities are tracking the Appendix K's which allows states to do emergency changes to HCBS.

NCIL is working on an action alert for Package 4. There is a push around Nursing Facilities collecting data and we are pushing for disability data to be included. Package 3.5 states that Nursing Facilities have to report, but it does not specify that disability data needs to be included in the report. Unfortunately, this does not include psychiatric facilities, even though many stories are being reported about deaths, about people who have roommates who have been forced to stay in a room with someone who died of COVID for hours and even days. We have done lots of sign-on's to letters spearheaded by other organizations. Some involving funding like the Defense Procurement Act regarding getting PPE's into the hands of homecare workers. We wrote a letter regarding COVID Package 4 and the need to include HCBS, inclusion of DSP workforce, create parity.

Fortunately, Money Follows the Person (MFP) received another funding extension through November and within the final CARES Act, it allowed people to have their PCAs and DSPs assist them in hospitals.

As for the EVV Task Force the group has continued to pursue options for pushing back against EVV implementation, including amendments to Cures 2.0, which has shifted legislative focus after finding out there's no interest in getting rid of EVV completely. Now they want to focus on consumer direction, but the board does not want to change their position to not support carve-outs. The legislation they're pushing is the prohibition of GPS and biometric data collection. S. 3740 includes another EVV delay. They did not get the exact language they want but it includes a delay until 6 months after the end of the pandemic. The focus of the committee is on what can be done to get this in the next package.

As for the Chronic Pain/ Opioids Task Force the CDC has been putting together a group of people to change their rules limiting access to chronic pain and opioid medication. NCIL's Chronic Pain/ Opioids Task Force nominated Kate Nicholson to be a member of such a group. Kate Nicholson is one of the co-chairs of the Task Force. Regarding access to medication or telehealth within the CARES Act, there was a provision only for Medicare (and Medicare Advantage) that addressed the 90-day refills. The DEA also relaxed (some) requirements for controlled substances (separately, not in the bill) related to 90-day prescriptions and telehealth, but this is subject to other regulations, like state law and insurance rules.

ADA/Civil Rights: The Parenting Task Force has put together a position paper opposing guardianship, while favoring supportive decision-making. The committee is also looking at, and reviewing ICE solitary confinement rules and class action lawsuit. Still waiting for news of the class action piece against ICE. ACCESS Act- no movement and we don't expect it to go anywhere, which is a good thing. Seems to be no support outside of the cosponsors and no support for tort reform during this session, but still watching in case they try to attach it to something else.

The subcommittee have been concerned with some issues related to the erosion of civil rights during COVID-19. One of the major things is voting rights and accessibility. They have sent an email looking to have a joint meeting/discussion with the voting rights subcommittee to discuss collaborative efforts. Also in preparation for the 30th Anniversary of the Americans with Disabilities Act (ADA), it was recommended that a booklet, highlighting the history and passage of the ADA, should be developed to be an educational teaching piece that can be used to educate members of Congress about the history and passage of the ADA as well as also teaching others. Unfortunately, people don't learn about the ADA in school so they also started looking at what can be done to explore methods whereby such a booklet could be provided to schools. The primary focus of the ADA booklet will be on members of NCIL and the Independent Living movement, and the role that such individuals played toward passage of the ADA. The subcommittee will be reaching out to collect personal stories. Dan volunteered to provide info about Justin Dart's cross-country tour to support passage of the ADA. Cliff mentioned reaching out to ILRU.

Transportation: The committee has been working on preparing responses to proposed rules on service animals. The group is using the 2016 letter from CCD as a foundation. The group is expanding on that letter to address the current proposals. They are also working on developing and distributing information and materials to help people comment and build support in addressing the access issues the proposed rules would create. Sen. Langevin has released a bill promoting transportation for people with disabilities which would allow for paratransit to be more accommodating. Kelly Buckland, as part of a panel provided testimony at the Air Carrier Access Act Advisory Committee. They talked about seating, and that included seating for assistance animals. Kelly also updated that the CARES Act has a bunch of money for transportation. He also provided testimony at the Access Board hearing about the feasibility of people flying in airplanes using either their own or manual chairs. It will be interesting how either one of those will continue to have meetings now.

Employment/SS: The committee has been focused on getting the Medicaid Buy-in age limit removed and adult disabled children reaching age of retirement bills introduced. The Medicaid Buy-in legislation looks like it has the support to pass. Unfortunately, other priority pieces of legislation, in light of COVID-19, will likely not be moving for quite a while. However, the subcommittee believes we should push to get the ABLE Age Adjustment Act in Phase 4. Social Security issues seem to have been largely resolved with the exception of those who have dependent children. We wrote a letter in opposition to the very quick turnaround deadline for filing in order to receive this support.

The Senior Care Act is sitting there, we are trying to talk to Congressional offices about getting the CDB bill added in there. Everything is pretty much on hold right now but Senator Casey's office has been talking with us. Discussed the short deadlines for the stimulus payments and the people who were left out of the package. There was an invitation for a roundtable on MBI put on by the Bipartisan Policy Center. People can still send feedback to them about what's working and what's not, and we need to go around and get more organizations to get involved with us.

The Department of Labor announced that five organizations were chosen to do an employment initiative to competitive integrative employment and at least two of them are sheltered employment orgs/providers. WID is planning to offer their expertise. Also some discussion about VR funding- had been some discussion about a request to waive pre-employment funding.

Watching what's going to happen with so many people working from home; it supports the position that more people could work from home- but big concerns (last hired, first laid off)- it will be hard for people to get back into the workforce when the economy is so bad. WID is looking to support people working from home and Mathematica is collecting data.

Rehab Act/IL Funding: President's budget, Part B cut, \$5 Million added to Part C on competitive employment. ACL to use IL funds to directly do training, cutting out IL-NET and the system that has worked for years. Eliminating annual on-site reviews. They plan on talking to appropriations committee regarding this ACL issue. NCIL commented on the new SPIL which can be viewed, along with all other comments, on the ACL site. The Subcommittee also has a work group that is developing a lobbying FAQ. The first draft has already gone out. They have also been focusing on stimulus money for CILs, most CILs will be able to see a full year of Part C dollars and need to think about how they will be using it. ACL mentioned that they want to collect stories on how CILs are using this money. They want to create a positive perception. They are putting together a template for CILs to use—NCIL is going to send this out and the Regional Reps will help.

Voting Rights: Within the voting provisions in the CARES Act, there is \$400M for grants to states for the election cycle. The difficulty is some states are going to use all mail-in voting or the combination of all mail-in and vote centers. Unfortunately, mail-in is not accessible to some people, and transportation is a major problem and vote centers mean people will have further to travel. It has been recommended that some of the money be used for accessible electronic voting, or as a second option ballot delivery systems. NCIL, ACB, NY State IL folks have filed a complaint with DOJ regarding all mail-in ballot system with no alternative access option. Stressed that every option must be accessible. NCIL is forming a coalition to work on this issue—ACB, NFB, NDRN and 3-4 more. We are drafting a statement of principles and will send it to everyone. We are looking to expand the legal stuff.

The subcommittee created a new third co-chair, Larry Moore. He is a long-time technology professional, has been involved with several successful companies that make various voting processes. He is creating a team of computer security experts. He thinks computer voting can be done safely, accessibly, and securely. They will be talking to someone in Estonia (said that about 45% of people in Estonia vote electronically and the Russians have not been able to hack them). Another thing the committee discussed was the deadline for the draft standards Voluntary System Guidelines – they need to flood the EAC with comments saying why it won't work and that they need to be accessible. They put flowery language about how things need to be accessible but when you get into the weeds they put in stuff about how everything has to be paper, which of course is not accessible to everyone. They've been getting negative and concerned feedback from election officials around the country about how they're not hearing from the disability community. If we go to mail, there has to be another accessible alternativ

Education: There is language within the CARES Act that requires the Secretary of Education to recommend waivers to IDEA within 30 days. The Subcommittee will monitor and comment on that. Additionally one big concern is the provision of a FAPE to students while schools are closed. How does the IEP get implemented? The Subcommittee will be discussing practices that can be put in place. CARES Act required Secretary DeVos to make a recommendation about waivers to IDEA and Section 504 of the Rehab Act – the recommendations for IDEA (2) dealt with funding for training and early intervention (not having to move on if not ready)- this was a tremendous and surprising outcome with a statement that FAPE was expected to be enforced and abided by. Congress still has to decide what to do regarding this. In some states there had actually been waivers and schools have asked parents to sign waivers for the remainder of the schoolyear. Something that came up that young people who would normally be going to school but are in institutional setting, nothing is happening for them. Some prep is being given to parents for students in the community. Nothing is being done to educate students in institutional settings. There's basically been an agreement that the schoolyear is over for them. This adds insult to injury. We don't know what will happen next year so it's important to work on this and the group agreed to work on a letter to the Department of Education about this issue.

Matters requiring action by the Board/Members: It has been brought to my attention by many individuals interested in participating in NCIL and in particular regarding participating and attending the NCIL Annual Conference that we strongly need to consider the possibility of providing our Annual Conference via Zoom or some other virtual format, thereby allowing many interested individuals whom, for whatever the reason, are unable to physically attend our Annual Conference. We should be able to hold our usual Conference in Washington but at the same time, provide the Conference workshops on line or a virtual format. Some of it could be provided in real time while others could be recorded. We should be able to sell such a package to those interested members who cannot attend the Conference, Everyone benefits, NCIL can earn more revenue and more people will have access to the Conference.

Committee goals and objectives for the next year: NCIL needs to begin the process of thinking and planning for the future. We need to be more proactive rather than to respond to negative legislation, policy and/or situations, action or events that can have a negative impact on Americans with disabilities. Toward that end we need to be more proactive in reaching out to young people. We need to develop a plan that will serve to engage young people to become involved and participate with NCIL and even consider a mechanism whereby young people could serve on the NCIL Governing Board, pursue mechanisms or strategies that will serve to engage Older Americans to become more involved with NCIL and the larger disability community as a whole, toward raising their awareness regarding their own "functional limitations" of which NCIL, working together with groups such as AARP and others who advocate on behalf of Older Americans could join forces and maximize their effectiveness. Many of the programs and services designed to increase autonomy, freedom and independence for Older Americans are very much the same as what is needed for Americans with disabilities. Clearly one substantial program/service which benefits both groups is health care and in particular, Long-Term Services and Supports. If the disability community could unite and work together with Older Americans, while simultaneously reaching out and involving young people, we would be the strongest political block in the country.

Other: We need to consider advocating for legislation which will serve to mandate that schools develop a disability curriculum, designed to educate students about the history of the disability civil rights movement.

We also might want to consider having all of the subcommittees put a conference workshop template together to make it easier for any committee interested in submitting a workshop for consideration at the NCIL Annual Conference.

NATIONAL COUNCIL ON INDEPENDENT LIVING
ADA / Civil Rights Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: ADA / Civil Rights Subcommittee
Steve Higgins, Kimberly Tissot
Co-Chairs

DATE: July 2020

Description of Committee: The Americans with Disabilities Act and Civil Rights Subcommittee (ADA/CR) educates NCIL members of all developments that impact the rights of people with disabilities. The Subcommittee develops and presents testimony about laws and regulation. They work with NCIL members to assist with making changes to laws that impact our community. There are work groups within the ADA/CR Subcommittee as well. These groups work on other civil rights issues, like disabled parenting rights. The Subcommittee works with other subcommittees on issues with shared concerns.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019): 2020 marks the 30th anniversary of the ADA. But direct threats against our rights continue. For example, the ACCESS Act (H.R. 4099), a proposed bill, that could weaken the ADA. This bill would set our rights back many years. The bill doesn't look like it will pass this year, but we can't ignore this. Lawmakers continue to introduce similar bills year after year. These bills may pass if we don't speak up and let our voices heard.

The ACCESS Act does not increase access. In fact, it creates more barriers to enforce the ADA. For example, before a disabled person can challenge a barrier in court, the burden is on them. They must educate the business about the issue. They would have to provide the business with a clear written statement of the problem. They would have to wait 60 days for the business to write a plan to correct the issue. Then waits another 60 days for the business to fix the issue. The bill would also weaken access requirements for websites.

The ADA/CR subcommittee encourages NCIL members to contact their legislators to help protect the ADA. Legislators need to hear from our community about how bills could impact us. Bills like the ACCESS Act are created about us, WITHOUT us. Lawmakers must work with us to better protect and respect our rights.

Guardianship: This year, the ADA/CR subcommittee worked to develop a position statement on guardianship. NCIL opposes the use of guardianship for disabled people. Guardianship deprives freedoms and choice for people with disabilities. Guardianship goes against everything the independent living philosophy stands for. We believe that all disabled people must control the decisions about their lives. Guardianship takes those rights. CILs and SILCs can and should help people avoid guardianship.

Lastly, the Pandemic has highlighted how the healthcare system discriminates against disabled people. Especially, disabled people who identify as black or a person of color. The ADA/CR committee is working with the healthcare committee on several issues.

The subcommittee recognizes that implicit bias is real even in the disability community. We are seeking members from communities that are not being represented to help us with being inclusive.

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

Matters requiring action by the Board/Members: Position Paper on Guardianship reviewed/approved

Committee goals and objectives for the next year:

- Follow and respond to any legislation which rolls back the rights of people with disabilities.
- Work to remove issues of Implicit Bias within the communities we engage and assure all persons with disabilities are treated equal.
- Educate our community around guardianship.
- Continue to promote development and use of plain language in all materials.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Education Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Education Subcommittee
Maureen Hollowell
Chair

DATE: July 2020

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 2019 Annual Meeting (since July 23, 2019): During Subcommittee conference calls the following were discussed:

RISE Act regarding higher education;
Restraint and seclusion;
Presidential candidates' disability agendas related to education;
Inclusion in schools;
CARES Act requirement for the Secretary of Education to make recommendations for waivers to requirement of the Individuals with Disabilities Education Act; and
How education is related to other NCIL efforts to address the institutional bias.

Summary of progress on Strategic Plan responsibilities (if applicable): not applicable

Matters requiring action by the Board/Members: none

Committee goals and objectives for the next year: Complete a set of statements regarding transition and students with disabilities. Advocate for strong federal language that will forbid the use of restraint except in emergencies threatening physical safety. Monitor USDOE policy development and advocate to ensure school accountability is not diminished. Review. Support the RISE Act to improve access to college. Monitor the impact of COVID-19 school closures and virtual education to determine if advocacy and/or awareness is needed regarding any problems.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Emergency Preparedness Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Emergency Planning Subcommittee
Todd Holloway
Disability Integration Adviser and Chair of the Subcommittee

DATE: July 2020

Description of Committee: The Emergency Planning Subcommittee is a body of Independent Living (IL) and Disability Rights (DR) advocates and members of the National Council on Independent Living (NCIL). Our mission is to assist all IL/DR advocates in making a place at the planning table with local, State and National emergency management and public health officials.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019): The NCIL EP Subcommittee continues to support the implementation of the REAADI-DRMA Act in coordination with the Partnership for Inclusive Disaster Strategies (PIDS) and all of the partner organizations involved.

REAADI S-1755 and HR-3208 DRMA S-1754 and HR-3215 can be researched at:
<https://reaadi.com/>

Monthly calls/meetings have consistently occurred to address a long list of issues related to disaster preparedness by the NCIL EP SC. We coordinate with PIDS to share information and activities that include weekly calls to maintain a national readiness posture throughout the year. Together, NCIL EP and PIDS have held daily calls to strategize responses to the COVID 19 pandemic.

Much more information and resource material are available at <https://disasterstrategies.org/> and <https://ncil.org/covid-19/>

Summary of progress on Strategic Plan responsibilities: Our strategic plan has expanded and progress on existing goals has been widely supported and achievements are occurring at a comfortable rate. Since the inception of the COVID 19 pandemic we have shifted our priorities to support a broader platform of services to assist IL Nationally on all core services and State Plan for Independent Living (SPIL) issues.

Matters requiring action by the Board/Members: The NCIL Board has received several sign-on opportunities for organizational support that is in line with NCIL's mission. Currently there is only one support document in process. The document is a call to action initiated by a coalition of IL organizations focused on reducing the rate of "loss of life" in congregate settings during the pandemic.

Committee goals and objectives for the next year: The NCIL EP Subcommittee's goal for this coming year is to have a written strategy for addressing emergency and disaster preparedness, response and recovery while living with the effects of the Global pandemic. More peer organizations are being included in this goal and strategy by the day.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Healthcare / LTSS Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Healthcare / Long Term Services & Supports Subcommittee
Lisa Hayes, Co-Chair lhayes@rollingstart.com
Ami Hyten, Co-chair ahyten@tilrc.org

DATE: July 2020

Description of Committee: The Healthcare / LTSS Subcommittee monitors and advocates on long term services and supports and healthcare issues impacting people with disabilities, including durable medical equipment, disability discrimination in healthcare, assisted suicide and euthanasia.

Summary of activities conducted since the fall report (since March 2020): After CMS Director Verma issued guidance outlining the process for States to pursue Medicaid block grants, NCIL signed on to a statement with CCD opposing the guidance.

And then, COVID-19 happened.

Since mid-March, collaboration with outside advocacy organizations has been intense, including: signing on to legal briefs, developing and issuing formal statements, petitions, and distributing action alerts on issues related to the impact of healthcare discrimination and the institutional bias for disabled people during the COVID-19 pandemic. Activities have included:

Signed onto CCD letter to Congress in support of measures to expand Sick Leave to Caregivers for People with Disabilities and Older Adults (ultimately, these issues were included in part in some of the first three COVID relief bills);

Passage of Three Rounds of Federal COVID Relief packages which included:

- Funding Extension for federal Money Follows the Person through November 2020
- Leave benefits for workers
- Expansion of Medicaid “settings” where direct support workers would be paid for their time while providing care to their client in a hospital setting

Signed on in support of Coronavirus Relief for Seniors and People with Disabilities Act S. 3544;

Joined request for temporary policy changes to CRT assessment and prior-authorization process to accommodate telehealth and provide access during shelter-in-place restrictions;

Crisis Standards of Care & Concerns about Healthcare rationing, including distribution of NCIL Statement on Medical Rationing and COVID-19: Information and Resources;
National Health Law Program Sign-on Urging Pres. Trump to Fully Invoke Defense Procurement Act;

Distributed “talking points” for Congressional advocacy related to COVID relief packages;
Sent out a Survey for NCIL Members from VetsFirst/United Spinal Association;

Signed on to ASAN Letter that would allow accompaniment of a support person in the hospital;

Signed onto Amicus brief supporting California’s defense of the Affordable Care Act in California v. Texas,/Texas v. U.S.;

We continue to monitor efforts to legalize assisted suicide / euthanasia, doing significant work in fighting efforts to legalize assisted suicide in the states through the involvement of local CIL advocates. NCIL continued to support the work of Not Dead Yet, the Patients’ Rights Action Fund (PRAF) and DREDF which secured bi-partisan introduction of a Sense of Congress resolution rejecting assisted suicide as dangerous public policy - H. Con. Res. 79. The resolution details the reasons why it is a grave mistake to legalize assisted suicide. We are specifically seeking cosponsors to ensure that this is recognized as a bipartisan effort. We monitored possible legislation addressing HCBS systems, including community direct support worker shortages, recruitment, and retention through HCBS infrastructure grants and legislation.

The Electronic Visit Verification and Chronic Pain and Opioids task forces have continued their high level of work. They have filed separate reports. We greatly appreciate the work of the members of these task forces.

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:

Inclusion of HCBS funding and support for individual community-based and consumer-controlled services, workforce issues, and personal protection equipment.

Permanent re-authorization of the Money Follows the Person program, with CIL carve-in language and support from ACL.

Establish a strong NCIL presence and support CILs in participating in efforts to end the institutional bias in long term services and supports by demonstrating to policymakers how the institutional bias discriminates against people with disabilities, by expanding community capacity through program development, funding, and vigorous efforts to resist policies that restrict community integration.

Frame healthcare access issues as disability discrimination issues.

Delay the implementation of Electronic Visit Verification and limit the scope of EVV measures to exclude geo-tracking and other obtrusive features, oppose efforts to legalize assisted suicide, and add the perspective of people with disabilities and chronic pain to the public discussion about opioid use.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Electronic Visit Verification Task Force
Annual Membership Report

TO: NCIL Governing Board

FROM: EVV Task Force
Charlie Carr and Kendra Scalia
Co-Chairpersons

DATE: July 8, 2020

Description of Committee: The EVV Task Force is comprised of between 25-30 NCIL members nationally who oppose the use of geo location and biometrics in the use of EVV. It is a blatant privacy rights violation and has a lead to severe personal care services worker shortages nationally. Our work driven by the grassroots in concert with NCIL leadership and priorities.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019): We have built strong coalitions with a variety of local, state and national organizations that intersect with our commonalities of privacy protection and disabled people controlling our own personal care services programs.

The Task Force administered a survey of NCIL members and our allies to get a better understanding of how EVV is impacting individuals and states on the ground in real life situations. The results are compelling and an indictment of EVV. They will be published very soon on the NCIL webpage. The findings can be used as an advocacy tool and public policy document.

We were successful in working with Congress to include language in pending legislation S3740 that delays the implementation of EVV “until six months after the end of the national emergency.” We were also successful in getting language included in the 21st Century Cures Act 2.0 Concept Paper which is the working blueprint for the legislation that will clarify and make technical corrections to the original Act passed in 2016.

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

Matters requiring action by the Board/Members: The Task Force is preparing a rationale and statement of facts for the NCIL board to consider to formally support S3740.

Committee goals and objectives for the next year: We will push hard after the July 4 recess to pass S3740 and have that serve as a bridge for implementation into 2021. Concurrently, we'll work with Congress to pass Cures 2.0 which will prohibit the use of GPS and biometrics in the provision of EVV nationally

NATIONAL COUNCIL ON INDEPENDENT LIVING
Housing Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Housing Subcommittee
Brian Peters and Darrel Christenson
Co-Chairs

DATE: July 2020

Description of Committee: The work of the Housing Subcommittee is to promote the principles of affordable, accessible, healthy/non-toxic, decent, safe and integrated housing for person with disabilities.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019):

- The subcommittee updated the Housing Position Paper
- Contacted HUD to attempt to set up a meeting to discuss two issues
- Established workgroups on legislative tracking, Visitability/Universal Design, and Homelessness
- Tracked federal legislation

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

Matters requiring action by the Board/Members: N/A

Committee goals and objectives for the next year:

To monitor and respond to the housing related federal legislation affection persons with disabilities/affordable housing.

To promote the NCIL Housing Position Paper and the issues identified within.

To educate policymakers on the housing needs of persons with varying disabilities.

To monitor regulatory changes affecting persons with disabilities in programs.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Rehab Act / IL Funding Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Committee Name: Rehab Act/IL Funding
Chair Name(s): Ann McDaniel & Dan Kessler
Title / Position: Co-Chairs

DATE: July 2020

Description of Committee: The Rehab Act/IL Funding 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, and voluntary support of sharing in the cost of conference calls.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019):

- Monthly meetings
- Reviewed membership to ensure all members are Individual NCIL members
- Work group established to develop “best practices” to be shared with the membership on the new ability to change CIL service areas and/or redistribute Part C funds through the SPIL
- Monitoring the confirmation process for Julie Hocker’s appointment to the Department of Labor – has come out of committee and is now before the Senate
- Developed a format to gather CILs’ stories about uses of CARES Act funds to benefit individuals with disabilities – shared with all CILs with an e-mail address to send the stories which are being shared with ACL and which will be compiled by NCIL and used to advocate for CILs
- Monitoring stimulus bills for IL funding and other funding to benefit individuals and programs serving people with disabilities including:
 - FMAP increase by 14% July 1, 2021 – June 30, 2021
 - \$85 million for CILs that receive Part C funds
 - Individual stimulus payments
 - 15% increase in the maximum SNAP benefit

- Unemployment benefits increased \$600 per week and extended into January 2021
- CARES Act funding – Thank you to Corrina Stiles for ensuring funding is retroactive to January 20, 2020 – questions for ACL identified
- Monitoring federal budget process and funding for IL
- Work groups on Reauthorization, CIL Workgroup, SILC Workgroup, and Administration Workgroup, have been meeting and developing recommendations for amendments to Title VII in Reauthorization
- Work group established to develop CIL Indicators to submit to ACL as a recommendation
- Review of Compliance and Outcomes Monitoring Protocol (COMP) documents
- Detailed review of the proposed SPIL Instrument and Instructions – comments submitted to ACL
- Wrote and sent letter to ACL regarding accessibility of proposed SPIL Instrument and Instructions – inadequate response received October 21st (deadline to submit comments was October 11th) – so no accommodation was made to ensure individuals who use screen reader were able to access the document and submit comments
- Recommendation submitted that the 2020 Pre-Conference be a Q&A with the Independent Living Administration
- IL Program section of the NCIL policy booklet updated and 704/PPR Report aggregated data for 2016, 2017, and 2018 included (which is now available on the ACL website)
- Work group established to develop a communication to membership based on NCIL attorney’s opinion regarding the ACL FAQ on Advocacy. The work group has met and work on this continues.
- Recommendation submitted to CCD for Budget Principles: Would like federal IL program (CILs & SILCs) specifically mentioned in Principle #2 *Funding for federal programs that promote the independence, inclusion, and community living for people with disabilities must be increased through revenue increases*
- Meetings with ILA/ACL, APRIL & NCIL halted after September 2019 but resumed in April 2020. Concerns about FY 2020 SPILs not being approved (some for things not require in current SPIL and some because they include establishing CIL satellites). Resumed meetings include agenda items generated by this subcommittee.
- Quarterly IL Network WebEx’s – not giving enough notice to ensure IL entities can attend – would like to have input into the agenda

- One Co-Chair participated in training for committee & subcommittee chairs
- Drafted alert regarding OIG Report.

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

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

- Best Practices being developed regarding using the SPIL to change/redistribute CIL service areas and/or Part C funding
- CARES Act funding stories being gathered from CILs and will be used to demonstrate CILs' value
- Reauthorization work groups developing proposed amendments to the Rehab Act to increase the ability of CILs and SILCs to meet the needs of individuals with disabilities
- Work group developing recommendations for CIL Indicators to provide to ACL
- Subcommittee continues to advocate for NIDLRR to conduct ROI analysis of CILs.
- Subcommittee developing an FAQ on advocacy vs. lobbying, based on the NCIL attorney's opinion, which will be released to the membership
- Subcommittee drafted response to OIG report regarding on-site reviews
- Subcommittee continues to advocate for a PPR that will effectively demonstrate the value of CIL's

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

Committee goals and objectives for the next year:

- Finalize recommendations for CIL Indicators
- Finalize recommendations for amendments to the Rehab Act
- Finalize Best Practices re: changes to CIL service areas and/or Part C funding in the SPIL
- Continue to push ACL & NIDLRR for an ROI study of CILs
- Continue to participate in ILA/NCIL/APRIL/NASILC meetings to share concerns and issues and to provide input on solutions
- Continue to gather CARES Act funding uses stories

- Continue to monitor the federal budget process

- Monitor Congressional actions, federal budget process, federal regulatory processes, and ACL guidance processes regarding Independent Living, CILs, and SILCs

Other: The committee co-chairs and membership would like to thank Lindsay Baran for providing staff support and working tirelessly to monitor and share information regarding actions on the Hill and for drafting statements and responses that forward and/or protect IL. We also want to express our appreciation for Kelly Buckland for establishing a stellar reputation with Congress and staff and the positioning of NCIL, for representing us so well, and for supporting this committee in our work.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Technology Committee
Annual Membership Report

TO: NCIL Governing Board

FROM: Technology Subcommittee
Susan Tachau (Chair)
CEO, Pennsylvania Assistive Technology Foundation

DATE: July 2020

Description of Committee: The Technology Subcommittee has focused its attention on technology-related legislation and initiatives that are under discussion in the U.S. Congress. The Subcommittee has also learned about and supported the assistive technology (AT) maker's movement.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019):

1. Expanding membership of the Committee (currently 9 members).
2. Held 6 Committee meetings.
3. Supported the national AT Makers' Conference (held last fall, Pittsburgh). Submitted article to NCIL for inclusion of the newsletter.
4. Provided information to Committee members about 3-D printing advancements, state AT programs and Alternative Financing Programs.
5. Provided NCIL staff with information about the 21st Century Assistive Technology Act and requested support for amendments.
6. Monitored federal legislation (e.g., complex DME, including wheelchairs, access to augmentative communication devices.)
7. Participated in a national AgrAbility training – the topic was peer mentoring (connections with Centers for Independent Living) and assistive technology funding resources.

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

Matters requiring action by the Board/Members:

1. Support for a separate funding stream for Alternative Financing Programs (AFPs) within the Assistive Technology Act. For the past 8 years, Congress has appropriated \$2 m. for the creation and expansion of these programs – waiting for the reauthorization when it may be possible to include a separate funding stream, once again, for these programs.

Committee goals and objectives for the next year:

1. Make a connection (or a renewed contact) with Congressional members/staff and NCIL who have an interest with assistive technology (or technology, in general), including Senators Casey and Hassen and Representatives G.Thompson and Meuser.)
2. Work with Congress on legislation to reauthorize the Assistive Technology Act (a reintroduction of the 21st Century Assistive Technology Act) that includes a separate funding stream for Alternative Financing Programs (AFPs) and the inclusion of consumer control and direction in the activities that are conducted by the state AT programs.
3. Continue to expand membership on the Technology Committee.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Transportation Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Transportation Subcommittee
Peter Johnke
Chairperson

DATE: July 2020

Description of Committee: To promote and advocate for 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 2019 Annual Meeting (since July 23, 2019): The Transportation Subcommittee has struggled to maintain a viable committee. After the 2019 NCIL Conference a few new members expressed interest in transportation issues. However membership did not grow. The committee meets on the 4th Monday of odd numbered months. We were meeting at 2pm and switched to 11am in the hope this was increase participation. While the number of participants has still been low (3-4), it remains steady.

As chair of the committee, it seems to me that the work of removing transportation barriers, for people with disabilities is a 'slog through the trenches'. With the possible exception of the Air Carriers Access Amendments Act, which would remove substantial barriers to air travel, there are no 'sexy' issues. The committee works to continually monitor and advocate for improvements in all modes of travel including rail, air, autonomous vehicles, public transit, and transportation networking companies, bicycles and boats.

In the fall, the Department of Transportation proposed new rules on Service Animals in airline travel. The committee worked with other advocates to provide comments opposing many of the rule changes.

Recently, we have worked with other advocates to submit guidelines to the airline industry and the Transportation Safety Administration on how to improve air travel for people with disabilities in the midst of the COVID-19 pandemic.

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:

Continue working to remove barriers in all modes of transportation for people with disabilities. Monitor closely, the progression of HR 2, ('big transportation bill') toward becoming law.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Regional Representatives Committee
Annual Membership Report

TO: NCIL Governing Board

FROM: Regional Representatives Committee
Sheri Burns
Region 9 Rep and Regional Representatives Coordinator

DATE: July 2020

Description of Committee: This committee is comprised of the 10 NCIL Regional Representatives across the nation. Each Regional Rep is responsible for communication with their IL Leaders, State Coordinators and IL Advocates who live and work in the states within their respective region.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019):

- The RR Committee welcomed two new Representatives this year: Jill Jacobs (Region 2) and Aaron Beier (Region 1). We are also bid a fond farewell to Candie Dalton Burnham (Region 8) this month. Thank you for your many years of exceptional representation and advocacy work in Region 8!
- Encouraged more IL staff and advocates to join NCIL and become involved in one or more L&A committees.
- Discussed ideas and plans for use of COVID-19 stimulus funds to CILs.
- The Committee members and regional NCIL advocates worked to support NCIL's Legislative & Advocacy chairs on many national and federal advocacy issues including:
 - a. ADA/Civil Rights – Continue to monitor HR 4099, the latest ADA notification bill. No movement to date.
 - b. EMPOWER Care Act/MFP– There were many short-term funding extensions with the MFP program which is now extended to December 2020. IL advocates and other disability rights groups across the country are continuing to encourage Congress to pass a 5-year or permanent bill that includes CIL engagement.
 - c. DIA – Continue to meet with Congressmembers and Senators to encourage them to sign onto the bill; push for moving it forward in the Congressional Energy & Commerce Committee for a full hearing.

d. EVV – Since no bill has been forthcoming to delay EVV implementation further or modify the language in the CURES Act, advocates are pushing states to adopt policy and implementation language that mirrors that of CA – no GPS or other biometric data collection that violates the right to privacy.

e. DRMA & READDI for Disasters Acts

f. COVID-19 relief packages to include IL funding, housing rent assistance, PPE, expanded voting, emergency prep, food assistance, HCBS funding).

- Discussed specific state disability issues – calls and visits with local legislators to educate and advocate on LTSS, Healthcare, NF Transition Services, Housing, Transportation, and EVV implementation plan that includes disability stakeholders

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

- Weighed in on ideas/options for NCIL to capture 1) membership demographics, especially focusing on the make-up of the staff, board, and consumers in relation to local/regional communities, and 2) ideas, thoughts and recommendations for NCIL to address race and equity.

- Reps worked with the Membership Committee to encourage engagement of CILs, SILCs and IL Individuals to join NCIL and become involved in one or more committees, subcommittees or task forces and respond to Action Alerts on various national issues.

- Discussed various activities and personal invitations to secure new State Coordinators for each state in the RR regions. A few RR's have brought on one or two new SC's and a few previous SCs have retired.

- Assisted Membership Committee with input regarding changing NCIL membership dues from a standard calendar year to an anniversary date renewal.

Matters requiring action by the Board/Members:

- Nominees for new Region 8 Representative.

- Development of new methods to improve easy and fast communication with Congress members and Senators on issues affecting people with disabilities.

Committee goals and objectives for the next year:

- Assist the Membership Committee to increase NCIL membership, especially among racially diverse and multiply marginalized communities.

- Support passage and enactment of DIA.

- Support passage and enactment of long-term MFP funding that includes CILs.
- Oppose any ADA notification bills.
- Respond to future bills that are discriminatory or will injure persons with disabilities.
- Continue to build stronger relationships with our district Congress members and U.S. Senators to educate them on disability rights, healthcare needs, LTSS needs, and community concerns.
- Continue to build stronger relationships with NCIL members in our respective regions.
- Secure State Coordinators in as many states within our respective regions.
- Expand media contacts in our states/regions; develop relationships with media as “go-to expert” on disability justice issues.

NATIONAL COUNCIL ON INDEPENDENT LIVING
Resource Development Subcommittee
Annual Membership Report

TO: NCIL Governing Board

FROM: Resource Development Subcommittee
Phil Pangrazio
Subcommittee Chair

DATE: July 2020

Description of Committee: The Resource Development Subcommittee, staffed by NCIL's Development Coordinator, advises on all matters related to resource development, including grants, individual fundraising, and conference sponsorship/advertising/exhibits/merchandise. The Committee brainstorms ways to grow NCIL's resources and revenue stream in a variety of ways.

Summary of activities conducted since the 2019 Annual Meeting (since July 23, 2019): We added several new members to our committee who have brought invaluable insight and input. We have made connections with new organizations, including Coca-Cola and May Mobility. When the COVID-19 pandemic hit, we talked extensively about the options available to NCIL under the CARES Act.

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

Goal 4: Increase NCIL's revenue (Page 4)

Goal 1: Provide pass-through funding opportunities to member CILs, SILCs, and IL Associations. (Page 7)

We have increased NCIL's revenue in a variety of ways. We received a \$15,000 grant from the Disability Inclusion Fund for COVID response work. We received \$30,000 from the Aid Association for the Blind of the District of Columbia. We also received both an Economic Injury Disaster Loan Advance (\$10,000) and a Paycheck Protection Loan (\$114,529.70). We have received a new grant from Centene to work with two CILs to develop an Emergency Personal Assistance Registry. Part of this grant has been passed through to two member CILs in Pennsylvania and Kansas, respectively. We are on track to meet or at least get close to our original sponsorship budget goal for the 2020 conference, even with the revised budget due to a virtual event.

Matters requiring action by the Board/Members: Pass the (virtual?) hat and donate to NCIL!

Committee goals and objectives for the next year:

- Promote and publicize recurring giving

- Continue to explore new fundraising opportunities, including year round partnerships with organizations
- Continue to grow our Committee membership

NATIONAL COUNCIL ON INDEPENDENT LIVING
Executive Director's Annual Meeting Report
Washington, DC
July 22, 2020

To: NCIL Board and Membership

From: Kelly Buckland, Executive Director
202-207-0334 (v)
kelly@ncil.org

I. Governance: Board and Committee Activities

A lot has happened in the past year. NCIL's work to support disability rights and independent living have continued and will continue as a matter of fact we had been busier than ever! The staff and I have been very busy with a host of policy priorities, projects, and programs. As you well know from your own experience, literally everything we do has been affected by the virus. We have had some major victories, such as the appropriation of 85 million in the CARES Act. And at the same time major challenges, and tens of thousands of people dying in congregate settings and discrimination in the provision of health care. I hope you'll keep reading for more details on that work.

Even our annual conference as you know is completely different this year. The entire world has changed, and we have had to adapt and even grow with the changes.

Staff remains actively engaged with the Board, Committee Chairs and members at virtually every level of NCIL. Communications between the staff, Governing Board, the committees and subcommittees remain very good, even with everything going virtual. As always, we are extremely busy.

Staff and board have been in contact with the ACL Leadership, Staff, as well as the Administrator of the Administration on Disabilities and the Director of the ILA on at least a week basis around issues with the COVID 19 virus response and implementation of the CARES Act.

We have also been in constant contact with Congress. In fact, I testified in front of the House Education and Workforce Committee on the effects of COVID 19 on people with disabilities and the response from centers for Independent living.

I have also been a speaker at Marca Bristo's memorial service, was a speaker at the US DOT Access and Mobility for all Summit, attended the Centene National Advisory Board meetings in St. Louis, Attended the RESNA ATAT Meeting on wheelchair stowage in aircraft, met with Mark Schultz the new RSA commissioner, attended the TracFone Accessibility Summit in Miami, Florida, attended the CCD annual meeting, testified in front of the National Academy of Sciences, feasibility study on securing wheelchairs on passenger planes and was a panelist at the Election's Assistance Commission "Elections Accessibility and Security Forum". I also

have been appointed by Centene to their Diversity Committee which will provide recommendations to the entire company.

NCIL's presence on various social media sites continues to be very strong! With 6,329 followers on Facebook and over 6,100 Twitter followers between the NCIL organization and NCIL director accounts, NCIL is able to quickly and easily communicate with a larger audience outside of our membership. Followers have reacted enthusiastically to being able to follow updates during hearings, online Q&A opportunities, and access alerts.

Facebook: www.facebook.com/NationalCouncilonIndependentLiving

Youtube: NCILtv

Twitter: twitter.com/NCILdirector and twitter.com/NCILAdvocacy

Instagram: [ncilgram](https://www.instagram.com/ncilgram)

II. Finances and Financial Management

NCIL's finances are strong. The Finance Committee and Governing Board have been following the budget closely and we ended 2019 in the black. We continue to manage a large number of grants and are adding more all the time. A project update is included with this report. The Finance Committee led by our Treasurer, Reyma, continues to be actively engaged in all aspects of NCIL's finances.

III. Resource Development

Cara Liebowitz is NCIL's Development Coordinator and working on growing NCIL's resources in a variety of ways.

Amazon Smile

When you make a purchase on Amazon Smile, NCIL gets a cut. There is currently no way to track how much we have earned on Amazon Smile.

Anthem

NCIL is finalizing discussions with Anthem on a "Know Your Rights" webinar series for people with disabilities during the COVID-19 pandemic. NCIL will be working with a variety of partners on this critical webinar series taking place this fall.

Corporate Development Council

NCIL's Corporate Development Council continues to meet and advise on development issues. We have members from a number of corporations and organizations serving on the council and are actively looking to grow the Council.

Ford Foundation – National Organizing Project

The National Organizing Project is now complete with some final changes to the project in light of the COVID-19 pandemic and reallocation of funds returned from CDR. The final report will be submitted at the end of July.

Centene – Barrier Removal Fund

We are well into our third year of the Barrier Removal Fund and Centene has committed to funding the project for another three years, through 2023.

Disability Inclusion Fund - COVID-19 Emergency Response

We have been awarded a \$15,000 grant from the Disability Inclusion Fund for general operating support/COVID-19 emergency relief.

Voting Rights

The Aid Association for the Blind of the District of Columbia awarded us \$30,000 to continue our voting rights work.

EIDL and PPP

We received both a \$10,000 EIDL advance and a Paycheck Protection Loan in the amount of \$114,529.70 to assist us during the COVID-19 pandemic.

Other Fundraising

We are still working on growing our individual fundraising. We introduced recurring fundraising but have had no traction with it thus far. We also continue to have success with Facebook fundraising, particularly with small “birthday” fundraisers. We are exploring the possibility of fundraising more for NCIL at the conference in a variety of ways. We are focusing on finding funding to restore our youth transitions fellow position and expand our policy staff. If you are interested in brainstorming ideas for NCIL’s fundraising and resource development growth, please contact Cara at cara@ncil.org or Phil Pangrazio, Resource Development Committee chair, at philp@ability360.org.

IV. Membership

NCIL’s 2020 membership performance is good. The following table shows our membership numbers through July of 2020. The other years show the full year total. We are on par with last year’s renewal pace and completing activities from the strategic plan to try to improve on recent performance. Our priority remains to improve the CIL membership numbers since our other categories are steady or growing.

2020 (As of July)

CIL: 172

SILC: 36

Organization: 13

Individual: 545

Total Members: 766

Total Income: \$278,577

2019

CIL: 184

SILC: 39

Organization: 15

Individual: 672
Total Members: 910
Total Income: \$285,317

2018
CIL: 188
SILC: 44
Organization: 15
Individual: 674
Total Members: 921
Total Income: \$281,815

2017
CIL: 189
SILC: 41
Organization: 14
Individual: 647
Total Members: 981
Total Income: \$284,160

2016
CIL: 197
SILC: 41
Organization: 13
Individual: 730
Total Members: 981
Total Income: \$263,092

2015
CIL: 196
SILC: 44
Organization: 20
Individual: 807
Total Members: 1067
Total Income: \$269,709

V. Grants & Projects

IL-NET

Grant Period: 10/01/2017 – 9/29/2020

Contact: Richard Petty, ILRU

NCIL continues its longstanding partnership with ILRU, APRIL, and Utah State University's Center for People with Disabilities to provide training, technical assistance, and other education and management resources to Centers for Independent Living and Statewide Independent Living Councils. This partnership operates under a contract from ACL,

Department of Health & Human Services. This is a 3-year project. A new subcontract is required each of the three years.

NCIL has been involved in the IL-NET project since its genesis in 1994. We are currently in year three of this three-year project.

SILC T&TA

Grant Period: 10/01/2017 – 9/29/2020

Contact: Richard Petty, ILRU

NCIL has partnered with ILRU, APRIL, and Utah State University's Center for People with Disabilities to provide training and technical assistance to Statewide Independent Living Councils under ACL's new SILC T&TA grant.

NCIL is currently in year three of this three-year project.

UNIVERSITY OF KANSAS

Grant Period: 10/01/2019 – 9/30/2020

Contact: Jean Hall, KU

NCIL has been subcontracted by the University of Kansas Research & Training Center on Community Living to review research material, disseminate information, and provide workshop space at the Annual Conference.

NCIL is currently in year four of this five-year project. NCIL will receive \$25,000 in 2020.

US DEP'T OF HEALTH AND HUMAN SERVICES / NASUAD – NAT'L I&R SUPPORT CENTER

Grant Period: August 1, 2016 – July 31, 2021

NCIL has subcontracted with NASUAD to advise and improve the National I&R Support Center through the following activities: Collaborate with Support Center staff to support national training events, including the I&R/A Aging and Disability Summit and the I&R/A HCBS Intensive. Assist Support Center staff with the development, dissemination, and analysis of national surveys of aging and disability I&R/A agencies, and assist with reporting and presentation of findings. Assist with training and technical assistance for the Support Center, including assistance with development and review of disability-related training materials. Assist with identification of promising practices for serving consumers with disabilities of all ages, and development of profiles and issue briefs, with a focus on the use of technology. Collaborate with the Support Center on the work of, and participate as a member in, the National I&R Support Center Advisory Committee and the Technology Discussion Group. NCIL is currently in year four of this five-year project.

FORD FOUNDATION / ADAPT – NATIONAL ORGANIZING PROJECT

Grant Period: May 1, 2019 – June 30, 2020

Made possible by the generous support of the Ford Foundation, the National Organizing Project creates a formal partnership between NCIL and ADAPT to support ADAPT chapters, promote direct action, and analyze and create policy to support people with disabilities. NCIL and ADAPT have a long history of cooperation that was strengthened during the #summerofADAPT, where ADAPT and NCIL worked together to advocate against healthcare reforms that would have had a devastating impact on people with disabilities.

NCIL has recently completed its work and will be submitting final reports by the end of July.

CENTENE CORPORATION – BARRIER REMOVAL FUND

Grant Period: Feb 2, 2020 – Feb 2, 2021

Centene has contracted with NCIL to provide support for its Barrier Removal Fund (BRF). 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 also 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. The project will begin in Illinois, Texas, and Ohio, and likely continue in additional states in 2019.

Centene has committed to funding this project at \$500,000/year through 2023.

CENTENE CORPORATION – EMERGENCY DIRECT CARE WORKERS PROJECT

Grant Period: Feb 2, 2020 – Feb 2, 2021

Centene has contracted with NCIL and APRIL to support the creation of pilot emergency personal assistance programs at two CILs in Pennsylvania and Kansas. NCIL will also complete a nationwide survey and report on the status of CILs they have or are interested in creating emergency PAS programs or emergency registries of PAs.

NCIL will receive \$300,000 in 2020 for this project. Most of this money will pass through to the pilot CILs and APRIL.

AMERICAN INSTITUTES FOR RESEARCH (AIR) – CENTER FOR KNOWLEDGE TRANSLATION FOR DISABILITY AND REHABILITATION RESEARCH (KTDRR)

Grant Period: Nov 19, 2019 – Apr 20, 2020

AIR has contracted with NCIL to provide suggestions on their website, a survey, and other materials related to their KTDRR Center. NCIL will also help AIR disseminate and promote the survey to NCIL's network.

NCIL will receive \$5,000 for this five-month project.

THE ARC – PARTNERSHIP FOR 2020 CENSUS RESOURCES DISSEMINATION

Grant Period: Jan 8, 2020 – June 20, 2020

The ARC has contracted with NCIL to disseminate the census resources and materials to NCIL's network.

NCIL will receive \$1,000 for this six-month project.

VI. Advocacy and Public Policy Activities

NCIL Internship Program

Since the creation of the NCIL Policy Internship Program approximately nine years ago, NCIL has had dozens of interns from all over the country and internationally. The Internship Program has proven to be a very successful addition to NCIL's policy efforts, and has given young individuals the opportunity to work for a national organization at the forefront of disability policy in DC. Interns have been involved in a wide variety of tasks including organizing and staffing events, attending Congressional briefings and hearings, Congressional outreach and visits, participating in and providing support to NCIL subcommittees, writing for

the Weekly Advocacy Monitor, conducting research around key policy issues, attending networking events, and other activities with NCIL staff. The Internship Program continues to open opportunities for increased funding and collaboration with organizations like the Jewish Federation, HSC Foundation, Mitsubishi Electric Foundation, the Religious Action Center the Ruderman Foundation, AAPD, and others.

Policy Work

NCIL continued to do work on the hill on IL funding, the Disability Integration Act, Money Follows the Person reauthorization, healthcare, Clear2Connect, community integration and other key policy and advocacy issues. NCIL staff have attended and watched relevant hearings, met with members of Congress and staffers, and collaborated with other disability rights groups. NCIL staff were involved in efforts on the hill related to the Disability Integration Act, the Money Follows the Person and HCBS Spousal Impoverishment Protection extensions, the READI act, appropriations, and other issues as they came up. NCIL has continued to actively work with the Administration for Community Living and the Independent Living Administration on the transition of the IL program and NCIL has been actively working on how to address both the recent ACL restructuring efforts and the recent guidance put out by ACL on advocacy and lobbying.

NCIL staff have participated also conducted activities and participated in meetings and events regarding Medicaid, education, autonomous vehicles, the ACA, housing issues, mental health, chronic pain and opioids, HIPAA, transportation networking companies, assisted suicide, Social Security work disincentives, chronic pain and opioid use, transportation access, captioned telephone services, shock torture, immigration, Social Security work disincentives, Electronic Visit Verification, and assistance animals. Staff continue to participate in events in Congress as well as many meetings and events put on by and with partners, work with committees and the NCIL membership to submit comments on legislation, rules, and regulations, as well as to communicate with representatives from the Administration and Congress on our positions.

NCIL staff have worked with committees and the NCIL membership to submit comments on legislation, rules, and regulations, as well as to 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.

As part of the National Organizing Project grant from the Ford Foundation, the Community Living Advocate (CLA) has continued to increase collaboration with ADAPT and is working to strategically do so around the country. The CLA has actively engaged on the Hill regarding legislation impacting community integration including the Disability Integration Act, Money Follows the Person reauthorization, and HCBS Spousal Impoverishment protections. The CLA has participated regularly in the Disability and Aging Collaborative and related hill visits. The CLA has also worked to mobilize CILs and local advocates around community integration issues to ensure members of Congress hear from their constituents. The CLA and other NCIL

staff have continued to work on creating documents and put on two webinars to assist CILs and advocates with their advocacy.

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 voting rights, community integration and home and community-based services (HCBS), disaster management and recovery, EVV, transportation, housing, and assisted suicide. 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, and serve on several advisory boards including the Center for Benefits Access, the American Association for People with Disabilities, the National I&R Support Center, United Health Care, Centene and AT&T.

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, and planning the 25 Anniversary of the ADA.

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.

In addition to serving on the AAPD Board of Directors, the Executive Director is also one of the co-chairs of the CCD Employment and Training Task Force and chair of the AAPD Policy Committee.

VII. Staff

Lindsay Baran: Policy Analyst

Kelly Buckland: Executive Director

Sylena Campbell: Administrative Assistant/Bookkeeper

Eleanor Canter: Communications Coordinator
Tim Fuchs: Operations Director
Sheryl Grossman: Community Living Advocate
Denise Law: Member Services Associate
Cara Liebowitz: Development Coordinator
Rie Terashima: Accountant

I also want to recognize Angela Ellman, our conference coordinator. While Angela is a contractor, she is a critical part of our team and makes our annual conference possible each year!