

Slide 1 >> The National Council on Independent Living presents –

NCIL's 2021 Policy Briefing

July 14, 2021

3:00 – 4:30 p.m. EDT



Slide 2 >> Agenda

- Welcome and Logistics Tim Fuchs
- NCIL priorities Tim Fuchs
- Rehab Act / ILA Ann McDaniel & Dan Kessler
- Healthcare & LTSS Ami Hyten & Lisa Hayes
- Housing Brian Peters & Gloria Garton
- ADA / Civil Rights Steve Higgins & Kimberly Tissot
- Transportation Peter Johnke
- Preparing for Virtual Hill Visits Lindsay Baran
- Questions & Answers



Slide 3 >> Overview of NCIL's Legislative & Advocacy Priorities

- Rehabilitation Act / Independent Living Funding
- Healthcare and Long-term Services & Supports
- Housing
- Civil Rights and the Americans with Disabilities Act
- Transportation



Slide 4 >> Rehab Act / IL Funding

Ann McDaniel & Dan Kessler, Rehab Act / IL Funding
Subcommittee Co-Chairs

- NCIL is very thankful for the nearly \$32 million in additional funding for Independent Living (\$29 million for Part C and nearly \$3 million for Part B) in President Biden's Budget proposal however, NCIL has grave concerns about the authorities requested to use part of independent living funding to do employment demonstration projects and believes centers doing employment demonstration projects should be funded from employment programs like RSA, ODEP or NIDILRR.
- While this is the largest increase for IL in any President's budget, the request is still completely overshadowed by the request for aging programs and the budget remains incredibly lopsided toward aging.



Slide 5 >> Rehab Act / IL Funding

- And current funding is not adequate to implement the Statewide Network of CILs outlined in SPILs nation wide
- CILs are the only entities required by federal law to transition people out of institutions – as part of the required Core IL Services – and funding is needed to provide transition services



Slide 6 >> Rehab Act / IL Funding

- Systems Advocacy is a required Core Service – in addition to individual outcomes, CILs (& SILCs with the new Authority) are also about ***changing communities***
- The FAQ on Advocacy issued by ACL in June 2019, aimed at limiting systems advocacy, has not been rescinded or revised despite the legal opinion acquired and provided by NCIL
- CILs provide services to hundreds of thousands of individuals with disabilities every year
- Most recent data on services and outcomes still not available from ILA / ACL though a new platform is projected to be available next month for submission of FY 2020 PPRs
- Increased funding (for both Part C and Part B) is necessary to build the capacity & network of CILs to provide IL services statewide in every state and the capacity of SILCs to fully represent all people with disabilities & conduct the advocacy necessary to improve service systems and protect civil rights



Slide 7 >> Healthcare / Long-Term Services & Supports

Ami Hyten & Lisa Hayes, Healthcare / LTSS Subcommittee Co-Chairs

Institutional Bias – COVID-19 Edition

- Hospital discharge to rehabilitation facilities instead of community
- Lack of investment in community infrastructure meant people using HCBS were left to find ways to social distance and get supplies when there were shortages
- Facilities received billions of dollars to respond to COVID but death rates were still the highest, and new spikes are happening back at these facilities
- CILs have transition as a core service but facilities denied our people entry and access to support people's escape to the community
- The institutional bias reinforces other structural biases: Black people, in particular, are institutionalized at higher rates, and in the community, receive fewer services, and have higher death and infection rates



Slide 8 >> Healthcare / Long-Term Services & Supports

Investment in Home and Community Based Infrastructure

- Biden Administration Proposal
- \$400 Billion Investment
- Budget Reconciliation Process
- Supported by Union Groups

Talking points:

- Addressing workforce issues are critical to supporting the system that keeps disabled people in their own homes and communities
- “Infrastructure” includes the human capital necessary to support long term service and support systems



Slide 9 >> Healthcare / Long-Term Services & Supports

Better Care, Better Jobs Act

Provides funds through continuation of the enhanced FMAP for

- State Plans for Addressing LTSS
- Implementation of Plans

Money Follows the Person as a Permanent Program

- Definition of community

Talking Points:

- This Bill will support states to look at their community based systems to develop comprehensive, effectively-working plans for community based services and supports
- This is a long term investment in LTSS that will be more necessary as the population ages
- Money Follows the Person is wildly successful and needs to be permanent
- The Bill needs to specifically include the roles of CILs in supporting community living for disabled and aging people



Slide 10 >> Healthcare / Long-Term Services & Supports

Healthcare Access

Warren/Pallone Request for Information – Universal Healthcare Proposal

Managed Care and Healthcare Access

- States still have to meet Olmstead obligations
- Add requirements to work with local CILs

Talking Points:

- Long Term Services and Supports must be included as part of universal healthcare plans
- Non-discrimination and equity must be core features of any program; use of discriminatory standards to authorize services, treatment, or equipment cannot be allowed, and accessibility must be a requirement for all providers



Slide 11 >> Healthcare / Long-Term Services & Supports

Additional Issues

- Electronic Visit & Verification
- Physician Assisted Suicide/Healthcare Rationing
- Chronic Pain/Opioid Access

Talking Points:

- Congress needs to support efforts to restrict/repeal EVV requirements such as the CURES 2.0 proposal
- Much of the response to COVID-19 has demonstrated that disabled and aging lives are not valued; efforts to limit care or use discriminatory standards to determine priority of care are unnecessary, immoral, and illegal
- People who live with Chronic Pain and other disabilities should have access to palliative and pain treatments and medications necessary to support their health, safety and well-being



Slide 12 >> Housing

Brian Peters and Gloria Garton, Housing Subcommittee Co-Chairs

Background

- President Trump's 2021 budget request (submitted before COVID-19) had DEEP cuts.
- Advocacy and bipartisan support in Congress negated the cuts and many housing programs saw increases.
- President Biden called for affordable housing investment, but Senate is split in half (50-50) with the Vice-President as tie-breaker, and not a big margin in House (220-211). Bipartisanship is mandatory.
- There will be pressure to cut back on spending as the pandemic numbers improve.



Slide 13 >> Housing

Housing and COVID

- Enormous amount of money – at least \$46.55 Billion! - from emergency pandemic bills flowed to emergency rental assistance, and additional amounts for other housing assistance. Local gov'ts and state can also use their share toward housing.
- CDC Eviction Moratorium extended & now ends on July 31.
- Huge spike of evictions possible!
- Essential that emergency rental assistance funds get to people who need them.



Slide 14 >> Housing

Housing Fairness Act of 2021 (S. 769/H.R. 68):

- Additional funding for fair housing enforcement
- Over half of housing discrimination complaints were disability-based

Repeal the Faircloth Amendment Act (H.R. 659):

- PHAs are limited to the # of units they had in 1998 when law was passed
- Eliminates artificial cap on # of units PHAs can have

Homelessness:

- Talk to Congress about need for additional funding for homelessness assistance and prevention
- Share stories about housing crises and inability of shelters to serve people with severe disabilities

Other Issues:

- Eleanor Smith Inclusive Home Design Act (federal Visitability)
- Chemical, Electrical & Environmental Sensitivities



Slide 15 >> Civil Rights / ADA

Steve Higgins & Kimberly Tissot, NCIL ADA / Civil Rights Subcommittee Co-Chairs

- ADA Notification “ACCESS Act”
- Alternatives to Guardianship
- Immigration
- Parenting Rights



Slide 16 >> Transportation

Peter Johnke, Transportation Subcommittee Chair

- Advocate for accessibility & equity in all modes of transportation (including e-bikes and boats)
- Advocate for a strong “Bill of Rights” for air travelers with disabilities including passage of the Air Carrier Access Amendments Act - H.R. 1696 (Rep. James Langevin - RI) and S. 642 (Sen. Tammy Baldwin - WI)
- Advocate for equity (equivalent service) from Ride Hailing Service / Transportation Network Companies (TNCs)
- Advocate for accessible rail service ASAP ACT All Station Accessibility Program) Act S1680 (Sen. Tammy Duckworth – IL) and H.R. 3317 (Rep. Marie Newman – IL)
- Work with a broad spectrum of stake holders to develop a *sustainable* transportation funding mechanism for transportation infrastructure and all modes of transit



Slide 17 >> Preparing for the Virtual Day on the Hill

- Virtual Hill Day: Thursday, July 22
- March: send signs to Eleanor@ncil.org
- Rally: 10:00am at the conference site and NCIL's YouTube page
- Hill Meetings: make sure your Virtual Hill Meetings are scheduled!
 - Meetings can be by phone, Zoom, or another virtual format
 - Accommodation requests are made directly to the Congressional offices
 - You can coordinate with other people in your State



Slide 18 >> Questions & Answers

Use the Q&A feature in the Zoom toolbar to type your question. You may also submit your questions via email to the event host.



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