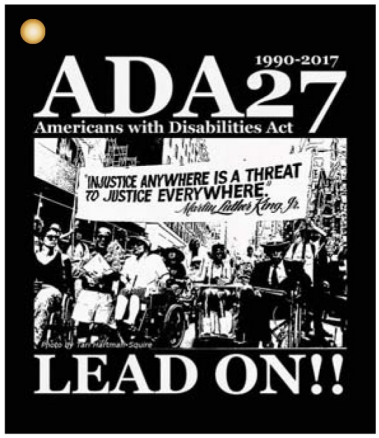
National Council on Independent Living

2017 Annual Report

NOTHING ABOUT US WITHOUT US

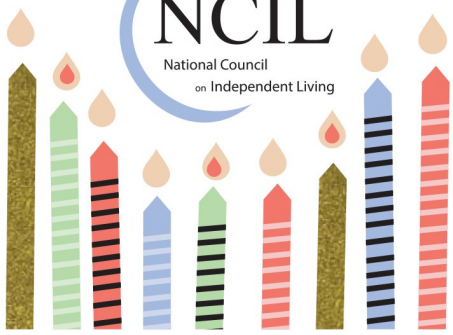


Celebrating

35

Years of Advocacy

NCIL
National Council on Independent Living



NOT DEAD YET
The Resistance
notdeadyet.org

#IAMAPREEXISTINGCONDITION

REVOLUTION

A GLOBAL INDEPENDENT LIVING MOVEMENT

DISABILITY RIGHTS ARE CIVIL RIGHTS

DON'T

ROLL BACK

OUR RIGHTS

WIN
WORLD INDEPENDENT LIVING CENTER NETWORK

United in Love AND Justice.

About NCIL

The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. NCIL represents people with disabilities, Centers for Independent Living, Statewide Independent Living Councils, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

» NCIL advances independent living and the rights of people with disabilities.
» NCIL envisions a world in which people with disabilities are valued equally and participate fully.

A Message from the Executive Director

2017 was an extraordinary year for the Independent Living Movement. We were tested on every front. Some battles were won, and others lost, but we rose to every challenge, demonstrating the strength, commitment, and resiliency of the disability community.

We joined forces to defeat attacks on healthcare. We fought attempts to weaken the Americans with Disabilities Act and erode our civil rights. We forced disability rights to the forefront of debates led by people who had no intention of including us. We worked diligently to initiate a global Independent Living network in order to create a world in which people with disabilities are truly valued equally and participate fully.

Nevertheless, many members of our community are paying the price for misguided and discriminatory policies on immigration, policing, access to healthcare and in-home services, and segregated workplaces and classrooms.

Helen Keller said, “It is in the most trying times that our real character is shaped and revealed.” We are humbled to be part of a community that displays such bravery and commitment to the principles of justice and equality. NCIL members have carried us through a difficult year with grace, determination, and grit.

2018 will be another critical year for our Movement. Frightening changes threaten programs and services for people with disabilities. NCIL will fight back when the mechanisms that enable our freedom are threatened. We’re not giving up and we know you won’t either. We will move forward, relying on Independent Living principles, to overcome these challenges together. We will, as always, become the heroes of our own story.

NCIL continues to provide first class member benefits, including training and technical assistance, insurance benefits, and a world class Annual Conference. Most importantly, NCIL provides its members with representation on Capitol Hill, ensuring that our voices are heard by those with the power to enact our priorities. I hope you will join us as we build a future of independence for all.

Kelly Buckland

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The Resistance
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JUSTICE
NOT
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Advocacy

In 2017, NCIL worked to advance the social, economic, and political equality of people with disabilities by:

- securing introduction and co-sponsors of the Disability Integration Act in both the House and Senate;
- supporting increased funding for Independent Living, Money Follows the Person, and other community integration efforts;
- opposing sheltered workshops, subminimum wage employment of people with disabilities, and Social Security work disincentives;
- advocating against H.R. 620 and other ADA notification efforts;
- actively engaging daily in disaster recovery and response efforts during the 2017 hurricane season, working with disability organizations serving the affected areas, and participating in community-wide engagement with national emergency management stakeholders;
- advocating in support of parental rights for people with disabilities;
- successfully fighting Congressional attacks on the Affordable Care Act and Medicaid through call-in days and support for nationwide and local advocacy efforts and direct actions;

- continuing to oppose assisted suicide legislation in many states and at the national level, including testimony at a Congressional hearing;
- engaging 68 CILs and SILCs to advocate for accessible sample ballots and voter education information in their counties and states, engaging the U.S. Election Assistance Commission to amplify the voting experiences of people with disabilities, and conducting outreach to candidate training programs to educate and engage them on improving their inclusion of prospective candidates with disabilities;
- working with the Independent Living Administration on regulations, rules, and the transition of the Independent Living Program, including expressing concerns around the final rule for Independent Living Programs, comments on the redesign of the 704 Part II Report, and a Freedom of Information Act Request for more information about funding levels and cuts to CILs;
- fighting cuts to Independent Living, including successfully stopping Congress from implementing Trump's PIII proposal to combine disability programs, which would result in major cuts to programs and services;
- conducting exploration and research for a non-partisan political candidate training program for people with disabilities, including interviewing current and former political candidates with disabilities across the country to provide feedback based on their experiences;

- strategizing and collecting input about the implementation of Electronic Visit Verification (EVV) nationwide;

- opposing unqualified and dangerous nominees and providing questions for several nominees' hearings; and

- collaborating on new creative efforts, including working with Rooted in Rights on the #IAmAPreexistingCondition video.

Strategic Plan Priorities

Political Power

- Build a strong Bipartisan Disabilities Caucus
- Pursue legal action against violators of disability rights laws
- Build an effective action alert and response system
- Hire Director of Public Policy
- Develop IL champions in Congress

Strengthening the IL Network

- Provide Training and Technical Assistance for CILs and SILCs
- Lead the development of sustainability of CILs and SILCs
- Develop a mechanism for providing legal assistance to CILs and SILCs
- Increase diversity and representation in NCIL and IL
- Increase IL Funding

Communications & Membership

- Create powerful NCIL marketing & branding campaign
- Increase media coverage to achieve legislative goals
- Increase membership

Resource Development

- Research endowments from corporations and foundations
- Access new funding through NCIL's Governing Board & Corporate Development Council
- Obtain new revenue from new grants

NCIL Accomplishments

In 2017, NCIL was increasingly effective in expanding the work of our members and advocating their issues nationally.

- NCIL received a major grant from the Ford Foundation to partner with ADAPT on the National Organizing Project.
- A record number of youth were awarded Youth Scholarships to attend the Annual Conference on Independent Living.
- NCIL Youth members collaborated to create the Disability Pride Toolkit, a resource that can be used to encourage and foster disability pride.
- Through two separate grants from the Craig Neilsen Foundation, NCIL passed through $202,500 to 9 Centers for Independent Living for 11 different projects that served 1,997 people all around the country.
- NCIL was awarded a grant from the Japan Foundation - Center for Global Partnership to assist 58 Japanese IL advocates to visit 9 CILs as part of a CIL Exchange Program.
- NCIL hosted the Global Independent Living Summit in Washington, DC with 200 advocates from 19 countries all over the world. The Summit produced the Washington Declaration, which established the World Independent Living Network.
- United Healthcare provided NCIL with a sponsorship to host webinars for CILs on current and emerging trends in long-term services and supports and explore how CILs can contract with managed care organizations.

Governing Board

- Bruce Darling, President
- Sarah Launderville, Vice President
- Darrel Christenson, Treasurer
- Lou Ann Kibbee, Secretary
- Dustin Gibson, Diversity Committee Chair

Regional Representatives: Steve Higgins, Chad W. Underwood, Jamey George, Kent Crenshaw, Maureen Ryan, Julie Espinoza, Roger Frischenmeyer, Candie Dalton, and Sheri Burns.

Members At Large: Amity Lachowicz, Jessie Lorenz, Brian Peters, Emet Tauber, Vilissa Thompson, Doug Toelle, and Emily Ladau.

Annual Conference on Independent Living

REVOLUTION

A GLOBAL INDEPENDENT LIVING MOVEMENT

Annual Conference on Independent Living 2017

NCIL's 2017 Annual Conference on Independent Living was an extraordinary experience. This year's theme, *Revolution – A Global Independent Living Movement* brought leaders from across the world. During the International IL Summit, disability advocates from 19 countries drafted, delegated, and announced the World Independent Living Network (WIN).

Attendance went above and beyond our expectations with 1,053 Conference participants and over 2,000 people at the March & Rally. The voice of the Independent Living community thundered throughout the streets of Washington, D.C. as we made our way to the U.S. Capitol. Once at the Rally, we heard from disability rights advocates, Members of Congress, and other influential speakers who spoke about their commitment to disability and civil rights – and the need for action.

The NCIL Youth Caucus raised over $20,000 to support travel and lodging for 40 youth with disabilities to attend this year's Conference, which featured several powerful youth speakers. We are proud that the 2017 Annual Conference on Independent Living served as a platform to amplify the voices of youth within the IL Movement.

We want to thank each and every one of the advocates in attendance. This year's Conference was outstanding because of your presence and participation.

Award Recipients

National Advocacy Awards:

- Max Starkloff Lifetime Achievement Award: Judith Heumann
- President's Award: Michael Gamel-McCormick
- Corey Rowley National Advocacy Award: Patricia Puckett
- Frank Harkin Memorial Award: Senator Charles Schumer
- Diana Viets Award: Kay McMillan
- Women's Caucus Award: Lou Ann Kibbee and Yvonne Smith

Regional Advocacy Awards:

- Region 1: Sadie Simone
- Region 2: Aileen Martin
- Region 3: Rosemary Ciotti
- Region 4: Carrissa Johnson and Jennifer Johnson
- Region 5: Ann Ford
- Region 6: Breggett Rideau
- Region 7: Don Dew
- Region 8: Bridging Communication
- Region 9: HoLynn D'Lil
- Region 10: Todd Holloway

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AUTISTICS
AGAINST BCRA
PLEASE SAVE OUR
HEALTHCARE
SO WE CAN STOP
MAKING PHONE CALLS

Independent Living Training and Events

NCIL provides a wealth of training and information to our members each year. In addition, NCIL is a partner in the IL-NET national training and technical assistance project for Centers for Independent Living (CIL-NET) and Statewide Independent Living Councils (SILC-NET), which focuses on:

- Deinstitutionalization / Community Services and Supports
- Outreach to Unserved and Underserved Populations
- Consumer Control
- Peer Mentoring of CILs and SILCs
- Systems Advocacy
- Data Collection and Reporting

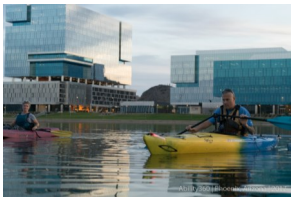
In 2017, NCIL presented 2 national onsite trainings and 10 webinars, reaching more than 1000 people. The IL-NET program also provided technical assistance to hundreds in the Independent Living community.

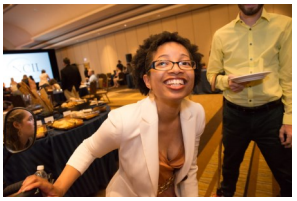
National Onsite Trainings:

- Community Integration - A Holistic Approach to the New Core Services for Transition & Diversion *
- Youth Transition: The Growing Role of Centers for Independent Living *

National Teleconferences and Webinars:

- Building an Inclusive Statewide Independent Living Council *
- The DSE, SILC Roles and Responsibilities, and the Regulations: Parts I and II *
- Get to the Core of It - Best Practices in the CIL Core Services: Information & Referral *
- Independent Living Skills Training for Transition to the Community *
- SILC Member Recruitment & Orientation *
- Virtual Town Hall to Gather Input on the New SPIL Instrument and Instructions *
- NCIL Presents: A Call with Senator Bob Casey on Threats to Healthcare, Medicaid, and Community Living for People with Disabilities †
- Medicaid Advocacy 101 Part IV: Exploring New Collaborations & Partnerships †
- The 2017 NCIL Policy Briefing †





* IL-NET † NCIL / Other Partners

ABILITY360

A Sampling of Member Accomplishments

In every state and territory, NCIL's member Centers for Independent Living and Statewide Independent Living Councils lead efforts to secure civil rights and gain an equal playing field for people with disabilities in their communities. This is a small sampling of their accomplishments.

The Blue Ridge Independent Living Center in Roanoke, **Virginia** assisted 26 individuals to remain or become independent by completing home modifications.

Southern California Resource Services for Independent Living in Alhambra, **California** partnered with the Columbia Memorial Space Center to launch the first ever STEM program designed to empower youth with disabilities to become the innovators of the future.

REACH of Plano, **Texas** organized a vigil to honor the lives of the 19 Japanese people with disabilities murdered on the Anniversary of the ADA.

ABILITY360 in Phoenix, **Arizona** helped 11 consumers move out of nursing homes so they may enjoy less restrictive, more independent living arrangements.

Able South Carolina in Columbia, **South Carolina** successfully advocated for the creation and passage of the Persons with Disabilities Right to Parent Act, which eliminated language from a state law that allowed termination of parental rights on the basis of disability alone, and added language requiring accommodations and appropriate supports for parents with disabilities.

The **Vermont** SILC successfully advocated for employment incentive enhancements within the State Medicaid for Working People with Disabilities program, which will allow more people with disabilities to work and work more while retaining their necessary Medicaid coverage and personal assistant services.

Atlantis Community in Denver, **Colorado** launched a Mobile Independent Living Unit - a fully operational, wheelchair accessible, mobile office, which allows them to serve rural locations and people experiencing homelessness.

The **Idaho** SILC helped provide disability awareness and etiquette training to 400 Hewlett Packard employees through activities, role play and conversation with individuals with a wide array of disabilities.

Western New York Independent Living in Niagara Falls, **New York** saved taxpayers over $77 million by helping individuals leave or avoid institutionalization.

The Center for Accessible Living in Murray, **Kentucky** assisted Parks and Recreation in securing funds and establishing an accessible playground, the second of its kind in the area.

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Americans

Donors

- The Ability Center of Greater Toledo
- Access Living
- ADAPT of Texas
- APRIL
- Ashley Allen
- Missy Allen
- William Allan
- Julie Alexander
- Bevan Archer
- Melissa Argay
- Kathleen Artis
- James Baker
- Allegra Barnes
- Phyllis Bass
- Rachel Eva Bass
- Joan Bell
- Helena Berger
- Arthur Blaser
- Gary Bloch
- Mark Bourdon
- Rich Boyko
- Hazel Lee-Briggs
- Kathleen Brill
- Marca Bristo
- Kelly Buckland
- Sherisse Burns
- Shirley J Burton
- Allie Cannington
- Darma J. Canter
- John Cave
- The Center for Disability Rights
- CIL for Western Wisconsin
- Kate Chaz
- Susan Orr Checkla
- Tamim Chowdhury
- Darrel Christenson
- Cherie Clark
- Coalition for Barrier Free Living
- Jodi Tripp Perlman Cohen
- Jesse Cole
- Cheri Coleman
- Diane Coleman
- Deb Cotter
- Scott Crawford
- Kent Crenshaw
- Evie Curtis
- Richard Curtis
- Bruce Darling
- Sherri Darrow
- Yoshiko Dart
- Keith Murfee-DeConcini
- Shelley Davis De Marco
- Mark Derry
- Jan Derry
- JoAnne DeVries
- Mary Dillard
- Torrie Dunlap
- Laurie Elinoff
- Kim Elmore
- Endependence Center
- EOCIL
- Eunice Esomonu
- Julie Espinoza
- Mary Evilsizer
- Mark Farnsworth
- Jan Fender
- Denise Figueroa
- Dana Fink
- Merrill Friedman
- Ruth Fuller
- Robert Fuchs
- Tim Fuchs
- Mills-Gelardin Family
- Patricia Gill
- Laura George
- Marion Lisa Hayes
- Judith Herr
- Judith Heumann
- Steve Higgins
- Jeanne Hill
- Michael Hineberg
- Kathy Hoell
- Deborah Holden
- Judd Holzman
- Kathleen Danielle Hopkins
- Roger Howard
- HSC Foundation
- Jakob Hytken
- Independence Associates
- Karen Ireland
- Japan Council on ILCs
- Rhonda Jeter
- Jessica Jimenez
- Mark Johnson
- Marsha Katz
- Mary Lou Keller
- Kessler Foundation
- Douglas E. Kidd
- Lou Ann Kibbee
- Kenneth A. Klauck
- Kathleen Kleinmann
- Kyle Kleist
- Cristina Vaccaro Konkolewski
- Allison Lourash
- Ellen Ladau
- Emily Ladau
- Hannah Langlie
- Sarah Launderville
- Carlotta Lawson
- Cara Liebowitz
- Gwen Geller Liebowitz
- Josh Liebowitz
- Evelyn Fielding Lopez
- Barbara Linn
- Diane Lutz
- Helen Peterson Magill
- Dana Marlowe
- Martha Mason
- Nancy McCauley
- Christine McClelland
- Benjamin McMullan
- Tracy Miller
- Christina Mills
- Mary Margaret Moore
- Lindy Moran
- Michael Murphy
- Sharon Myers
- Dorothy Nary
- Carolyn Nash
- Ari Ne'eman
- Pam Nolan
- Joan Ostrove
- Nina Pan
- Jarron Paronto
- Shyla Patera
- Manda Peace
- Brian Peters
- Jorge Pineda
- Linda Pogue
- Kristen Potts
- Carolan Quenneville
- Sam Rasoul
- Carol Reynolds
- Margaret Roffee
- Neil Romano
- The Romano Group
- Eli Rosenberg
- Jodie Gray Rosenblum
- Maureen Ryan
- Mark Schmitt
- Lee & Julie Schultz
- Richard Schwalb
- Ellen Seidman
- Marty Senetra
- Robin Shaffert
- Sharon Shapiro
- Claudia Laken Sherr
- James E. Shirk
- Brian Silver
- Oliver Stabbe
- Cori Stell
- Step Out Families
- Wei En Soh
- Southwest Louisiana Independence Center
- Jamie Spritzer
- Susan Styles
- Kentaro Sugioyama
- Cathie Sunday
- Susan Tachau
- Annette Tashiro
- Douglas Toelle
- Three Rivers, Inc.
- Olivia Truland
- Carol Tyson
- Chad W. Underwood
- Yolanda Vargas
- Vermont CIL
- Walgreens Boots Alliance
- Sandra L Weber
- Diane Weiner
- Douglas White
- Glen White
- Bob Williams
- Faith Williams
- Despina Wilson
- Brian Wise
- Amanda Gaul Worboys
- Yomi Wrong
- Patricia Yeager

NCIL Staff

- Lindsay Baran, Policy Analyst
- Rachel Bass, 2017 Fall Policy Intern
- Raquel Bernstein, 2017 Summer Policy Intern
- Sarah Blahovec, Disability Vote Organizer
- Kelly Buckland, Executive Director
- Sylena Campbell, Administrative Assistant
- Eleanor Canter, Communications Coordinator
- Kings Floyd, Youth Transitions Fellow 2017
- Tim Fuchs, Operations Director
- Patricia Gill, Accountant (outgoing)
- Denise Law, Member Services Associate
- Cara Liebowitz, Development Coordinator
- Anna Phearman, 2017 Fall Policy Intern
- Matt Schwartz, 2017 Summer Policy Intern
- Rie Terashima, Accountant (incoming)
- Hindley Williams, Youth Transitions Fellow 2018

Corporate Sponsors

Soldier for Justice Award Recipients: Centene and Anthem

NCIL also recognizes the following corporate sponsors for their support and partnership in 2017:

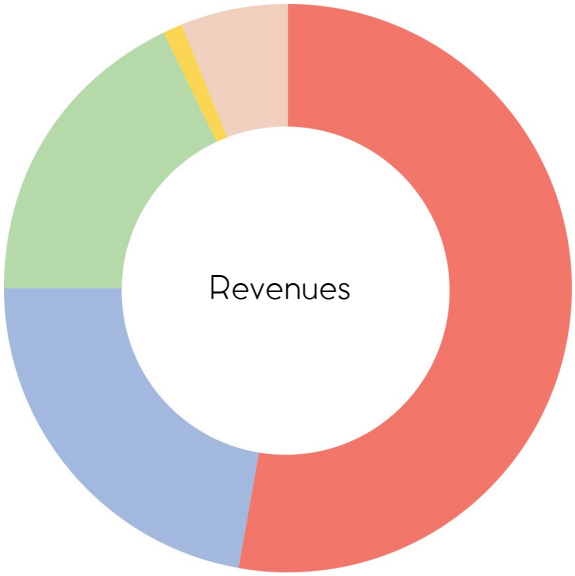
- Verizon
- United Healthcare
- Uber
- Ability360
- Walmart
- Waymo
- Independence*First*
- Center for Disability Rights
- National Disability Institute / The LEAD Center
- Pride Mobility
- Molina Healthcare
- Institute for Educational Leadership
- Independent Living Center of the North Shore and Cape Ann
- Microsoft
- HSC Foundation/Mitsubishi Electric America Foundation Conference Support Fund

Conference Donors: Shepherd Center; American Association for Homecare; Amtrak, Allen's Naturally, and AAPD.

Statement of Financial Position*

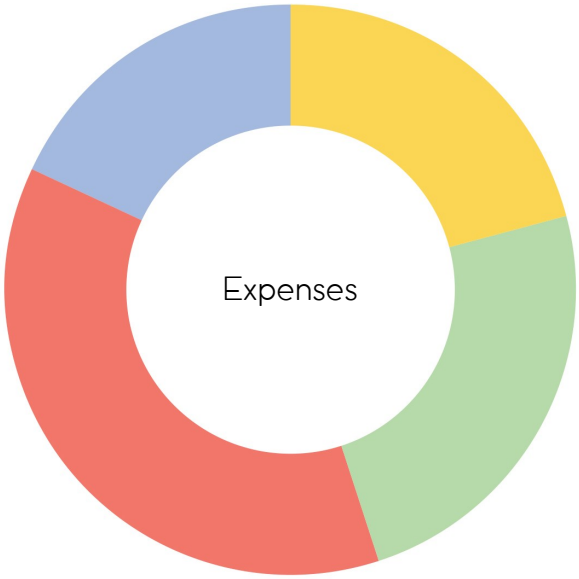
Revenues:

- Grants & Programs $825,610 (52%)
- Annual Conference $357,506 (23%)
- Membership Dues $292,229 (19%)
- Donations $22,150 (1%)
- Other Income $82,432 (5%)
- Total 2017 Income $1,579,928



Expenses:

- Administration & Finance $347,389 (21%)
- Training & Assistance $397,390 (24%)
- Advocacy & Programs $596,023 (37%)
- Annual Conference $293,014 (18%)
- Total 2017 Expenses $1,633,818



Assets:

- Current Assets $513,189
- Prepaid Expenses $43,593
- Prepaid Legal Expenses $16,427
- Fixed Assets $7,797
- Deposits $14,702
- Other Assets $16,377
- Total Assets $612,088

Liabilities and Fund Balance:

- Current Liabilities $494,033
- Unrestricted Reserve $171,918
- Total Net Income $53,864
- Total Liabilities & Net Assets $612,088

*All figures represented in this statement of financial position are unaudited. Final numbers may vary slightly. Please contact NCIL for an updated report.