

The background of the top half of the page is a dark blue field filled with various data visualization elements. There are several line graphs with different colored lines (green, yellow, blue) and data points. A prominent pie chart is visible on the right side, divided into several segments. Various numbers are scattered throughout, including 16256, 8329, 27579, 33242, 9232, 9%, 3276, and 1000. A green arrow points from left to right across the middle of the background.

# Annual Report on Centers for Independent Living

*Funded under Part C of Title VII of the Rehabilitation Act, as amended*

#### **Submitted by**

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#### **Submitted to**

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**[www.acl.gov](http://www.acl.gov)**

ACL is an operating division of the U.S. Department of Health and Human Services.

# Background

## Independent Living Programs

The Rehabilitation Act, as amended, (the Act) authorizes funding for two independent living grant programs that collectively support independent living services in the United States. Together these programs:

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*Promote a philosophy of independent living including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.*

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The first grant program – Independent Living Services (ILS) program – is authorized Under Title VII, Chapter I, Part B of the Act. Initially authorized in the Act’s 1978 amendments as “Comprehensive Services for Independent Living,” the funding supported demonstration projects that created 11 centers for independent living. In 2019, appropriations for the ILS program provided \$25,378,000 to 56 states and territories in formula grants to provide, improve, and expand statewide independent living services.

The second grant program – the Centers for Independent Living (CIL) program – was authorized under Title VII, Chapter I, Part C in the Act’s 1992 amendments. The 1992 amendments established direct funding for discretionary grants to consumer-controlled community-based organizations: Centers for Independent Living.

A Center is defined as:

“A consumer-controlled,<sup>1</sup> community-based, cross-disability, nonresidential private nonprofit agency for individuals with significant disabilities (regardless of age or income) that—

- (A) Is designed and operated within a local community by individuals with disabilities; and
- (B) Provides an array of independent living services, including, at a minimum, independent living core services.”<sup>2</sup>

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### In 2019, appropriations for the CIL program

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provided	to support	managed by
<b>\$90,805,000</b>	<b>354 grants</b>	<b>284 CILs<sup>3</sup></b>

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The Act’s 1992 amendments also set standards for CILs and created the Statewide Independent Living Councils (SILC). For states to be eligible for the ILS or CIL grants, they must develop and implement a State Plan for Independent Living (SPIL). The SILC is responsible for the creation, review, and monitoring of each SPIL. CIL representation is a requirement of the SILCs and CIL program activities must be consistent with the SPIL.

## Requirement and Purpose of this Report

The Workforce Innovation and Opportunity Act of 2014 amended the Act to require the Director of the Independent Living Administration (ILA) to provide to the Administrator of the Administration for Community Living (ACL), and publish publicly, a report<sup>4</sup> on the administration and performance of the programs during the prior fiscal year.<sup>5</sup> The report must address:

- » The extent to which CILs receiving funds under Part C have complied with the standards and assurances in section 725 of the Act;
- » The identification of individual CILs in the analysis contained in that information; and
- » Results of onsite compliance reviews, identifying individual CILs and other recipients of assistance under Part C.

## Standards and Assurances

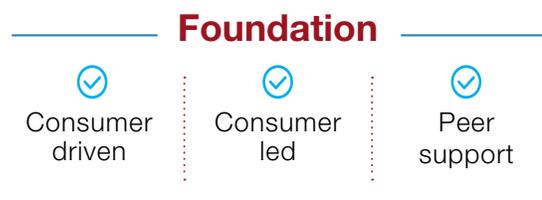
The Act sets forth standards and assurances for all programs and activities that are planned, conducted, administered, and evaluated in a manner consistent with the purposes of Title VII, Chapter I, Part C of the Act, and the objective of providing assistance effectively and efficiently. The Act requires that a CIL prepare and submit a report to the Administrator at the end of each fiscal year that contains information regarding the extent to which the CIL complies with the standards.<sup>6</sup> ACL utilizes the CIL Program Performance Report (CIL PPR) to collect the necessary data and information from grantees for each award a CIL receives. The review of CIL PPRs by federal staff is a critical component to ensuring compliance and providing ongoing monitoring and oversight.

Generally, these self-reported data reflect that CILs collectively comply with the standards and assurances set forth in the Act. The following sections reflect an overview of the standards and assurances set forth in the Act as captured in the CIL PPRs. The report concludes with ACL's additional oversight activities, including those to directly address noncompliance.

# Centers for Independent Living Annual Performance Reports

## Independent Living Philosophy

As reported in CIL PPR data, CIL services, programs, and activities consistently meet and exceed program requirements to be consumer led, consumer driven, and include peer support.



## Consumer Driven and Consumer Led

Consumers of IL services, who are individuals with disabilities, set goals and receive services to increase their independent living and self-advocacy skills.

Americans with disabilities are also the leaders of the CILs across our nation. Program Year (PY) 2018 PPR data reflects 70% of board members and 64% of staff were individuals with significant disabilities. Of the staff with significant disabilities, 73% were in decision-making roles. This percentage is consistent with the requirement that a majority of CIL board members, staff, and decision-makers are individuals with disabilities.

## Disability and Diversity

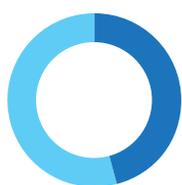
CILs serve individuals with a variety of disabilities across the lifespan including people with mental health-related disabilities, visual or hearing impairments, physical disabilities, and intellectual or developmental disabilities. Historically, more than half of all consumers receiving services in a given year have a physical disability. **Approximately 17% of people served by CILs are individuals with intellectual and developmental disabilities.**<sup>7</sup>

In PY 2018, the data demonstrate the diversity of individuals being served. These data are consistent with data reported in PY 2016 and PY 2017.



**54%**

female



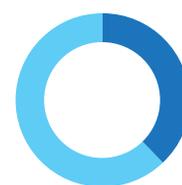
**46%**

identifying as a  
minority



**44%**

25–59 years old



**38%**

60 years old or over

This data is consistent with data reported in PY 2016 and PY 2017. CILs also report on outreach to unserved and underserved populations. Identified in the SPIL, unserved and underserved populations will vary by state as assessed by community needs. This assessment can, but does not always, include minority populations. CILs report 46% of consumers represent minority populations, an increase over the national minority population level of 42%.<sup>8</sup>

Section 21 of the Act contains a 1% IL funding set-aside requirement for conducting outreach to traditionally underserved populations. ACL identified the Native American population as underserved by the IL program and funded the Independent Living Demonstration (NAILD) project between PY 2016 to PY 2020 to better serve this population. Five CILs<sup>9</sup> received NAILD funding to:

- » Gain an understanding of service needs of Native Americans with disabilities living in Indian Country;
- » Improve cultural competence in regard to the needs of specific tribal organizations targeted by current CIL grantees; and
- » Capture lessons learned and best practices for outreach and service delivery for Native Americans with disabilities.

A final report on outcomes achieved for the NAILD project will be developed by ACL in FY 2021 after the conclusion of the demonstration project in FY 2020.

## IL Core Services

CILs provide services that enable people with disabilities to live in their community of choice with the supports they need. At a minimum, every CIL is required to provide the core services outlined in the Act.

### Core Services Include:



Information and referral services



Independent living skills training



Peer counseling



Individual and systems advocacy



Services that facilitate the transition from institutions to community living, diversion from institutions to community living, and transition of youth from secondary education to post-secondary life

In PY 2018, CILs reported providing more than 834,000 core service activities. The most significant growth reflected in annual CIL PPR data was a 31% increase in transition of youth from secondary education to post-secondary life. This increase likely reflects the passage of the Workforce Innovation and Opportunity Act of 2014 (WIOA) which added transition of youth from secondary education to post-secondary life to the core services.

While preventing institutionalization and transitioning individuals with significant disabilities from nursing homes or other institutions into their own homes has always been a focus of CILs, WIOA also added transition from institutions to community living and diversion from institutions to community living as core services. Since PY 2016, CILs reported a 5% growth in services preventing individuals from going into an institution and a 17% growth in services to individuals transitioning from an institution to community-based living. Data show, nationwide, 25,000 core service goals were achieved in transition and diversion services.

## Daily Cost for a Shared Room in a Nursing Home

As of October 2019

Medicaid nationwide average

**\$247**

Range across the country<sup>10</sup>

**\$150-\$1,000+**

People with disabilities can live successfully in their community of choice when provided the supports they need. Community living not only provides the best pathway to independence, but also is far less costly.

Examples provided by CILs in annual PPR data of services that help people successfully live in their community of choice include:

- » **Able South Carolina** (Columbia, SC). Recognizing the role of employment as critical to a person's ability to live in the community of their choice, Able South Carolina provides services that increase the competitive integrated employment of young people, ages 16 to 30, who have developmental disabilities. These services include: (1) empowering educators, providers, and families to support systems change that is centered on the premise that everyone, including

individuals with significant disabilities, is capable of full participation in integrated employment, and community life; (2) leading a statewide employment coalition of public educators, disability networks, and employers; (3) equipping young people with the skills and confidence to succeed; and (4) supporting employers who recruit and employ individuals with disabilities in competitive, integrated work environments.

- » **Walton Options for Independent Living** (Augusta, GA). Many CILs provide durable medical equipment and home modifications to make community living possible. With the average cost under \$1200, home modifications such as the ramps and grab bars provided by Walton Options for Independent Living are representative of durable medical equipment and modifications provided by CILs to transition individuals with significant disabilities from nursing facilities and other institutions to a community setting.
- » **Atlantis Community** (Denver, CO). Transportation supports are vital to successful community living. Atlantis Community is collaborating with the Regional Transit District (RTD) to educate all RTD drivers about the individuals with disabilities, proper disability etiquette, and ADA protections and mandates relating to transportation access for individuals with disabilities. Because of the partnership between Atlantis Community and the RTD, the number of rider issues resulting in barriers to transportation for individuals with disabilities continues to decline in the Denver area.

## Grantee Objectives and Other Services

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*In addition to core services, many CILs provide an array of other independent living services. Additional services may include securing housing or shelter, mobility training, personal assistance services, or transportation, including training in the use of public transportation. Annual and three-year program and financial planning objectives are required to manage the diverse services a CIL may provide.*

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Examples of achievements reported by CILs include:

- » **Liberty Resources Inc.** (Philadelphia, PA). Many CILs provide services to assist with securing affordable, accessible, and integrated housing. Liberty Resources Inc. was able to expand its housing services by hiring a housing specialist in May 2017. This staff member assists people with disabilities to identify available housing and complete housing applications, and provides support during apartment viewings and lease signings. As a result of expanded services, Liberty Resources Inc. transitioned 31 individuals into the community and reduced their nursing home transition wait list from an average of 100 consumers to 60 consumers.
- » **Alliance of Disability Advocates** (Raleigh, NC). Emergency preparation, response, and recovery is an emerging area addressed by CILs nationwide. Alliance of Disability Advocates worked alongside federal, state, and local partners to prevent the unnecessary institutionalization of people with significant disabilities during and after Hurricane Florence. Staff helped facilitate the transition of 54 individuals with disabilities from post-hurricane medical shelters to community living.
- » **Wyoming Services for Independent Living** (Lander, WY). The ability to self-identify helpful resources encourages self-advocacy. Wyoming Services for Independent Living developed an online comprehensive resource guide where individuals can locate services within the CIL's service area (10 western counties in Wyoming). The tool prompts searches by keyword and filters by selecting the county, type of service, and age group. The search result produces the name and contact information for the organization that provides the service searched by the individual.

## Challenges

Progress on program and financial objectives is reflected in the annual PPR through descriptions of services, activities, and achievements, as well as challenges encountered throughout the reporting year.

### The two most common challenges reported by CILs in PY 2018:



**Finding and utilizing affordable, accessible, integrated transportation for people with disabilities**



**Securing affordable, accessible, integrated housing for people with disabilities**

ACL is collaborating with other federal agencies to address these and other key issues affecting the people served by the agency. In 2019, that collaboration identified an opportunity for CILs to leverage funding from both ACL and the Federal Transit Administration (FTA) to increase community integration for people with disabilities. Specifically, CILs can use ACL funding as a match resource for FTA programs. For example, the FTA's Enhanced Mobility of Seniors and People with Disabilities program makes available federal resources to improve mobility for seniors and individuals with disabilities by removing barriers to transportation service and expanding transportation mobility options. If a CIL receives a grant from the FTA through that program, and also uses funding they receive from ACL to fund those services, the ACL grant funding can be counted toward the FTA match requirement.

## Resource Development Activities

*To support sustainability and expansion of services, the Act requires CILs to conduct resource development activities. A CIL must create sources of income in addition to the funding received through the CIL program award. Specific resource development activities vary from CIL to CIL.*

Examples of resource development activities reported by CILs include:

- » **Peninsula Independent Living Center** and **Southeast Alaska Independent Living Centers** (AK) participate in the Veteran Directed Care (VDC) program funded by the Veterans Administration. The VDC program funds services necessary to support community living for veterans with nursing home level of care or higher. Combined, the Peninsula Independent Living Center and Southeast Alaska Independent Living Center received \$281,736 in PY18 to provide VDC services.
- » **Ability360** (Phoenix, AZ) contracts with Medicaid and managed care organizations to serve individuals across the state by providing home modifications, nursing home reintegration, and over 1,800 homecare workers to support independent living in the home and community of the individual's choice.
- » **Active Re-Entry** (Price, UT) has a certified and trained Veteran Service Officer (VSO) on staff funded by the Utah Department of Veterans and Military Affairs. The program provides and locates long term care supports and services for veterans using a person-centered approach. The CIL's VSO travels the 27,000 square miles of service area to provide services to veterans.
- » **Spa Area Independent Living Services** (Hot Springs National Park, AR) received a grant from the Arkansas Development Finance Authority to provide Tenant Based Rental Assistance to people with disabilities. The funding is from the Home Investment Partnerships Program (HOME) that provides formula grants to states and localities, often in partnership with local nonprofit groups, to provide assistance for individuals to acquire housing.

- » **Alpha One** (South Portland, ME) received a Cumberland County Community Development Block grant for \$50,000 to support the Critical Access program, which funds building ramps for consumers' homes – preventing placement in a more restrictive setting.

In PY 2018, CIL resource development activities generated approximately \$673,384,490 in additional funds to supplement Part C awards that fund CILs.



## Oversight Activities

### Compliance and Outcome Monitoring Protocol

*ACL is committed to ensuring the proper use of federal funds and took significant steps in FY 2019 to improve oversight and compliance of the CIL program.*

ACL completed development and piloted a robust tool, the Compliance and Outcome Monitoring Protocol (COMP). ACL now conducts systematic and consistent reviews of key risk indicators for every CIL, every year.



1. **Standard Monitoring** is the ongoing annual review of each CIL grantee. Federal staff use a standardized approach to assess select program, operational, and fiscal management data. This monitoring includes, but is not limited to, the review of the program performance report, fiscal documents, and funds drawdown records. For example, program officers review the pace at which a CIL is drawing its grant funding. Drawing funds more quickly or more slowly than the norm would require additional follow-up. Although there are many legitimate reasons for either behavior, both can be indicators of risk.
2. **Comprehensive Review** is a more thorough review of a CIL's operations and includes a thorough examination of all the components ACL monitors. A team, led by an ACL program officer, conducts an onsite or remote review (the latter is also referred to as a desktop review). The Comprehensive Review is an interactive process between the review team and the CIL and may require additional document collection and review. On an annual basis, ACL conducts

comprehensive reviews on a subset of CIL grantees. The process to select CIL grantees for a comprehensive review involves a combination of (1) risk factors from monitoring by federal staff, (2) random selection, (3) federal staff recommendations, (4) geographic area considerations, and (4) requests from grantees.

- 3. **Targeted Review** employs remote and/or onsite reviews to identify and address concerns, including operations and financial management. Targeted Review involves focused monitoring of the grantee in specific areas of concern. This type of review is individualized based on the issue(s) with the program. For example, complaints that the CIL facility isn't accessible might begin with a request for additional information from the CIL. That information might be sufficient to address the issue – perhaps the front door was broken, but it has been fixed. In contrast, if the complainant stated that the CIL has fixed the door, but they still cannot navigate the site using a wheelchair, and the CIL insists there is a not a problem, a site visit may be needed to accurately assess the issue.

One key goal of COMP is to identify developing issues early so that ACL program officers can work with grantees to address situations before they become significant. There is no set frequency as to when a grantee could receive a compliance review. If concerns persist, grantees could receive more than one site visit and/or remote comprehensive review. COMP is designed not only to improve compliance but also to drive continuous improvement across the program so that more Americans with disabilities are living independently.

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## Pilot Remote Reviews

COMP was launched in June 2018 as a pilot with six CILs participating in remote reviews. The six CILs that participated were:

State	CIL
MD	Accessible Resources for Independence, Inc.
SC	ABLE South Carolina
MI	Metropolitan Detroit Center for Independent Living
TX	Panhandle Independent Living Center
CA	Dayle McIntosh Center
WA	Spokane Center for Independent Living

The pilot remote reviews provided a protocol and program officer training exercise, and the opportunity for volunteer CILs to strengthen their program and fiscal operations. CILs were strongly encouraged to work with the training and technical assistance provider to resolve findings in a timely manner.

## On-site Reviews

At least six on-site reviews will be conducted during FY 2020. Three on-site reviews were completed in December 2019. The remaining three planned reviews for FY 2020 (and any additional) will be scheduled prior to March 31, 2020. In future fiscal years, ACL will initiate the site visit plan for each fiscal year no later than 60 days after the start of the fiscal year.

Remote and onsite reviews supplement ACL's larger oversight efforts. Another key element of oversight is ensuring that grantees know and understand grant requirements. As a result of oversight activities, ACL identified non-compliance trends and issued FAQs to clarify grant requirements on the issues of lobbying and conflicts of interest. Additional FAQs are planned for the coming year. Grantees continue to provide positive feedback about the additional information and support they receive from federal staff, and ACL looks forward to continuing to improve our outreach, oversight, and quality improvement efforts.

# Endnotes

- 1 *A founding principle of CILs is consumer control, which means that each CIL “vests power and authority in individuals with disabilities, in terms of the management, staffing, decision making, operation, and provisions of services, of the center.”*
- 2 *Core services include: Information and referral, independent living skills training, peer counseling, individual and systems advocacy, services that facilitate transition for institutions to community-based living, assistance to those at risk of entering an institution, and transition of youth to post-secondary life.*
- 3 *Some CILs receive more than one CIL award.*
- 4 *The May 2019 reorganization of the Administration for Community Living designated the Commissioner of the Administration on Disabilities (AoD) as the Director of the Independent Living Administration. (The Director of ILA continues to report directly to the ACL Administrator, as required by statute.) Prior to this realignment, annual reports had not been submitted to the Administrator.*
- 5 *CIL programs are funded from September 30 of one year through September 29 of the following year, with appropriations for the fiscal year in which the program began. For example, Program Year (PY) 2018 ran from September 30, 2017 through September 29, 2018 and was funded with FY2017 appropriations. This report refers to program years, which correspond to the fiscal year in which the program’s activities took place.*
- 6 *Sec. 725(c)(8) and (13)*
- 7 *Data collection does not measure intellectual and developmental disabilities directly or exclusively. For purposes of this report, we include individuals reporting cognitive disabilities in the category of I/DD. It is reasonable to conclude data reported as “multiple disabilities” and “other” likely represent additional individuals with I/DD.*
- 8 *U.S. Census 2018 estimate*
- 9 *Western New York Independent Living; Southeast Alaska Independent Living, Inc.; North Country Independent Living in Wisconsin; Disability Services & Legal Center; and Superior Alliance for Independent Living*
- 10 *American Council on Aging, Nursing Home Costs by State and Region – 2019, <https://www.medicaidplanningassistance.org/nursing-home-costs/>*