

The background of the top section is a dark blue field filled with various data visualization elements. There are several line graphs with multiple lines, some showing upward trends. Pie charts of various sizes are scattered throughout, some with segments highlighted. Large, semi-transparent numbers are overlaid on the charts, including 16256, 8329, 27573, 33242, 97579, 9232, 9%, and 80%. The overall aesthetic is technical and data-driven.

Annual Report on Centers for Independent Living Program Years 2020 and 2021

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

Submitted by

Jill Jacobs
Commissioner, Administration on Disabilities
Administration for Community Living
U.S. Department of Health and Human Services

Submitted to

Alison Barkoff
Senior official performing the duties of the Administrator
Administration for Community Living
U.S. Department of Health and Human Services



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*Improving the Lives of Older Adults and People with Disabilities
Through Services, Research, and Education*

February 14, 2024

Alison Barkoff, Performing the duties of Administrator and Assistant Secretary for Aging
Principal Deputy Administrator
Administration for Community Living
U.S. Department of Health and Human Services
330 C Street SW
Washington, DC 20201

Dear Principal Deputy Administrator Barkoff:

I am pleased to transmit the Program Year (PY) 2020 and 2021 Combined Annual Report on the Centers for Independent Living (CILs) program in accordance with Title VII, Chapter I, Part C in the Rehabilitation Act, as amended. This report provides a summary of the tremendous accomplishments of CILs during this two-year period. CILs play a critical role in supporting independent living of disabled people across the United States. CILs delivered a total of an all-time high of 1,202,766 independent living services in PY 2021 to more than 200,000 consumers.

The report highlights how grantees quickly responded to innovate service delivery during the COVID-19 public health emergency. The Administration on Disabilities also continues to strengthen oversight and compliance, improve program performance, and identify and disseminate best and promising practices. To that end, this report also includes:

- Examples of how CILs receiving funds under Part C have complied with the standards and assurances in section 725 of the Act; and
- Results of onsite compliance reviews, identifying individual CILs and other recipients of assistance under Part C.

The Administration on Disabilities looks forward to continuing to serve the disability community.

Sincerely,

Jill Jacobs
Commissioner, Administration on Disabilities, Administration for Community Living

Note: In addition to yearly appropriations, as part of the COVID-19 pandemic response, centers for independent living (CILs) received supplemental funding from two sources. First, the Coronavirus Aid, Relief, and Economic Security Act of 2020 (CARES Act) provided \$85 million in supplemental funding. Second, CILs received funding from an interagency agreement between the Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC). These funds have been used to meet the urgent needs of individuals with disabilities, including food and meal delivery, access to personal protective equipment, housing, vaccine outreach, and transportation due to the pandemic. While this report will reflect some of these activities, ACL will receive final and complete data from CILs on their COVID-related activities in early 2024 that will be analyzed thereafter.

Executive Summary

The Administration for Community Living's (ACL's) Office of Independent Living Programs provides grants to more than 350 community-based nonprofit organizations called centers for independent living (CILs). Located in every state and territory, CILs provide a comprehensive range of services that each year help more than 200,000 people with all types of disabilities live and fully participate in their communities. A hallmark of CILs is that they are designed, operated, and led by people with disabilities. They provide training and peer support, assist with navigating systems that provide services and supports, including determining eligibility and applying for programs, and help connect people to local services and resources, such as housing, transportation, personal care attendants, food, and other important benefits. In addition, CILs support young people with disabilities who are transitioning to adult life following high school and provide a range of supports to help people who want to move from institutions to the community and to prevent institutional admissions for people currently in the community. The CIL program is authorized by Title VII, Chapter I, Part C of the Rehabilitation Act of 1973, as amended¹ (the Rehab Act).

This report shares how CILs filled gaps in services for the disability community over program years (PY) 2020 and 2021 (i.e., September 30, 2019-September 29, 2021) — a period that included the initial COVID-19 response. CILs provided critically important services throughout the pandemic, and their services to the disability community were at an all-time high during this period. CILs delivered 1,155,560 independent living services in PY 2020 and 1,202,766 independent living services in PY 2021.

COVID-19 forced many CILs to adapt and use new technologies. Many individuals with disabilities were unable to leave their homes, so CILs had to pivot and rethink how they served individuals. Many turned to virtual options to provide independent living skills training, peer support groups, and other critical services.

The stories enclosed highlight how CILs worked tirelessly during these program years to ensure people with disabilities stayed connected, safe, and healthy. CILs also worked with others in the disability community to address significant concerns they were facing during this time, including the shortage of personal care attendants and social isolation, as well as barriers to transportation, education, employment, and housing. Throughout the pandemic, CILs continued to help people with disabilities move out of nursing homes, hospitals, and other institutions back into the community.

¹ Public Law 114-95, Every Student Succeeds Act, enacted on 12/10/2015, made conforming amendments. Public Law 113-128, Workforce Innovation and Opportunity Act, enacted on 7/22/2014, reauthorized the Rehabilitation Act of 1973, which is codified at 29 U.S.C. 701 et seq.

In addition to federal funding during these program years, CILs saw an increase in the number of volunteers and the amount of donations. Together, these contributions allowed CILs to serve many more in need of their services. In PY 2021, CILs reported resource development activities that generated more than \$687.8 million — an amount that was almost seven times more than the federal appropriation for this program that year. Not only did they leverage outside resources, but the CILs built strategic partnerships that allowed them to address complex problems effectively, further maximizing their impact. This report will share information about these partnerships and practices, which also afforded them the opportunity to be fully accessible and inclusive of an unserved and underserved population and a diverse disability community.

Centers for Independent Living (CILs): An Overview

What is a CIL?

A consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency for individuals with significant disabilities, regardless of age or income. CILs are designed and operated within a local community by individuals with disabilities and provide an array of independent living services, including, at a minimum, independent living core services. 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 provision of services of the center. CILs use the term “consumer” to indicate that the individual receiving services has control over the process and is the one making the final decisions.

CILs anchor everything they do in the independent living philosophy (IL philosophy). The IL philosophy is based on consumer control, peer support, self-determination, equal access, and individual and systems 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. The overarching belief is that barriers to full inclusion are based on the environment, not the disability. To help individuals with disabilities overcome these barriers and promote independent living, all CILs are required by the Rehab Act to provide core services. These services include independent living skills training, individual and systems advocacy, information and referrals, assistance with moving from institutions and nursing homes, transitioning from high school into post-school life, and peer support. Many CILs also provide various additional services to advance independent living, depending on the needs of their local community.

In PY 2020 and PY 2021, \$90,805,000 in Rehab Act funding was administered through more than 350 awards to CILs across the nation. CILs used these funds to provide critical services to support individuals with disabilities during the pandemic. They loaned equipment such as wheelchairs, transfer benches, and other assistive devices. They also provided laptops, hotspots, masks, heaters, fans, food, and sanitation packets to individuals and their families who needed them. In response to the COVID-19 pandemic, CILs entered into new partnerships with businesses, service providers, and other disability organizations to coordinate vaccination events and distribute needed food and supplies. CILs worked tirelessly to ensure people with disabilities stayed connected, safe, and healthy – and came together as a network to address key systemic concerns their communities and states faced.

Filling the Gaps: The Provision of Independent Living (IL) Services

Following the IL philosophy, CILs recognize that people with disabilities are experts on their own needs and what services they require. To that end, a CIL's consumers set their own goals that address barriers to independence, such as inaccessible housing or transportation, and then services are identified and facilitated by the CIL, including activities undertaken by a consumer to reach a goal. Consumers might identify one goal, such as gaining access to technology, that is easily achieved in a few months or multiple goals that build on achievements and include services and activities over the course of several years. (For definitions of goals, see *Appendix A*, and for definitions of CIL services, see *Appendix B*)

In PY 2020, CILs assisted 234,872 consumers with their goals — the following year, the number grew to 236,881. Despite the loss of control that many felt due to the pandemic, Table 1 shows that many were still seeking independence over their lives. Moreover, CILs have increasingly helped consumers achieve their goals over the last three years. In PY 2020, 183,418 goals were met — the following year, this number increased to 200,552.

Table 1. Most Consumer Goals Met

	PY19	PY20	PY21
Self-Care/Personal Care/Health & Safety/Nutrition	32,288	35,192	44,832
Personal Resource Management/Budgeting	23,187	26,376	29,571
Community-Based Living/Modifying or Acquiring Housing/Changing Living Situation	21,825	24,454	23,843
Self-Advocacy/Self-Empowerment	22,705	21,369	23,400
Information Access/Technology	13,057	17,453	17,331
Total	172,486	183,418	200,552

Personal care and personal health and safety was the most achieved consumer goal category. During the pandemic, CIL consumers were learning how to stay healthy and how to manage at home as much as possible. Given the economic challenges during this time, the number of consumers with goals focused on budgeting also grew. CILs helped consumers meet this goal by teaching individuals about COVID-19 resources, how to stretch their money, and how to secure food.

During this period, CILs had to pivot and rethink how they served individuals, with many turning to virtual and telephonic options. As a result, information access/technology was the goal category with the greatest percentage increase from prior years.



Many CILs taught consumers how to access and use computers and virtual technology to combat social isolation.

To help consumers meet their goals and ensure they continue to live in their communities, CILs provide a variety of IL services. These services were needed more than ever throughout the pandemic. CILs delivered a total of 1,155,560 IL services in PY 2020 and an all-time high of 1,202,766 IL services in PY 2021 (see Table 2).

Table 2. CILs' Most Frequently Delivered IL Services

	PY19	PY20	PY21
Information and Referral	610,020	575,699	573,977
IL Skills Training and Life Skills Training	73,262	72,623	77,373
Personal Assistance	49,444	62,193	65,661
Advocacy/Legal	58,926	52,440	56,730
Housing, Home Modifications, and Shelter	50,197	49,011	53,080
Peer Counseling	41,353	42,355	50,899
Transportation	60,855	51,143	49,223
Assistive Technology	36,241	31,270	37,715
Total	1,191,042	1,155,560	1,202,766

Information and referral is consistently the most provided service, as it is offered to anyone, with or without disabilities, who needs assistance locating disability resources and supports. The second most requested service was independent living and life skills training, which includes teaching personal care, coping skills, financial management, social skills, and household management. Personal assistance was the third most frequent service, and advocacy/legal services was the fourth most frequently provided CIL service. The following sections share examples of how CILs provided personal care attendant and advocacy services from an individual to a systemic level.

Addressing the Personal Care Attendant Shortage

Many people with disabilities were isolated at home during the pandemic. At the same time, there was an increasing shortage of direct care workers nationwide. As a result, the CIL service type that increased at the greatest rate was personal assistance (PA) services, with a 33% increase from PY 2019 to PY 2021. CILs engage in diverse activities under this service, depending on the individual's needs. Activities included helping locate personal care attendants, training and coordinating personal care attendants, and advocating for more assistance with personal care, as the following example shows.

- » [Lake County Center for Independent Living \(LCCIL\), Mundelein, Illinois](#): In the early days of the COVID-19 pandemic, LCCIL staff called consumers to make sure they were not experiencing any pandemic-related problems with their PAs. On one of these calls, staff discovered that a consumer was left without assistance when both of their PAs became unavailable. Staff worked with the consumer to secure an emergency provider to cover the vacancies. To assure her safety in light of the PA shortage, staff also helped the consumer obtain a life alert device and home modifications to prevent falls. In addition, staff worked closely with the consumer to improve her PA management skills and help with PA retention. This extra support from LCCIL has ensured this consumer remained in her home and felt supported during the pandemic.

Connecting Peers and Reducing Isolation

Throughout the pandemic, social isolation was one of the greatest challenges the disability community confronted, sparking their need to find new ways to connect with others.



Many CILs offered virtual peer groups to ensure individuals felt supported and connected in their communities. They engaged people on topics such as art, cooking, social support and advocacy, and education on issues of interest.

With attendance continuing to be high and new relationships built among the disability community, many CILs are continuing these virtual peer groups.

The availability of virtual peer groups led many CILs to assist consumers in accessing assistive technology to facilitate their participation in these groups, as illustrated by the following example.

- » [Access to Independence, Inc. \(ATI\), San Diego, CA](#): The assistive technology services coordinator at ATI received a phone call from an individual who was visually impaired and wanted to attend the CIL's virtual workshops. The consumer had internet but no device that allowed her to participate virtually. The AT services coordinator assisted her in acquiring a laptop along with an adapter to display on a larger screen. They worked together to determine the best technology to meet her needs, and then the coordinator provided support for accessing the online platform. Thanks to the assistance provided by the CIL, the individual became an active participant in several programs, helping her remain connected to others during the pandemic.

Meeting Transportation Needs

Although there was a significant decline in consumer requests for transportation assistance from CILs during the pandemic, there was still a need for these services. CILs supported individuals and affirmed their rights to accessible and available transportation options. The following are a few ways they did so.

- » [Bainbridge Advocacy Individual Network, Inc. \(BAIN\), Bainbridge, GA](#): With limited local transportation options available, BAIN assisted consumers by locating and coordinating options to help them get to their medical appointments, including out-of-town specialty medical appointments. This assistance enabled many individuals with very low incomes to get the proper medical care to maintain their health.
- » [Center for Disability Rights, Rochester, New York](#): The disability community was facing limited transportation options in Rochester with the potential reduction of the fixed route and paratransit services in the area. To address these issues, Center staff regularly met with the local transportation authority to minimize fixed route and paratransit cuts.
- » [Self-Reliance, Tampa, Florida](#): Recognizing that transportation was a barrier for many to get the COVID-19 vaccine, the CIL organized with the Florida Health Department in Hillsborough County to host a vaccine event, which included transportation support. Door-to-door transportation was arranged for eligible consumers, and bus passes were provided to riders of the public transit system.

Fostering Education and Employment

Employment goals play a key role in the independence of people with disabilities. Adults with disabilities in the United States continue to have high rates of unemployment and underemployment, which were exacerbated during the pandemic. Consequently, adults with disabilities are more likely than their peers without disabilities to live in poverty, experience serious underlying health conditions, and suffer from mental health issues.



CILs deliver training and support and engage in education and employment advocacy to help working-age individuals realize their career goals and aspirations.

Some CILs contract with, or are grantees of, state vocational rehabilitation (VR) programs, or they receive VR referrals to provide many different types of services to promote employment outcomes among consumers with disabilities. Some of the services CILs provide are:

- » Pre-employment transition services (pre-ETS)
- » Work incentive planning and benefits counseling
- » Advocacy and self-empowerment skill development
- » Career exploration
- » Community education
- » Assistance with postsecondary education
- » Vocational training
- » Resume writing and interviewing
- » Job skills development
- » Continuing and adult education
- » Independent living skills training
- » Community participation

In PY 2020 and 2021, CILs provided approximately 55,000 vocational services each year, which included youth transition services. They also assisted veterans.

- » [Tri-Lakes CIL, Saranac Lake, New York](#): This CIL worked with a veteran to advance his education by helping him apply for Social Security Disability Insurance (SSDI), obtain his prior academic records, return to college, and advocate for accommodations. The CIL also provided him with a loaner laptop so that he could continue his college coursework during the pandemic. As a result, the individual has earned a spot on the college's President's List for high academic achievement every semester. He also provides peer support to other veterans within the college.

Services to support the transition to post-secondary life are required services of CILs. The transition from high school to college, vocational training, or work is challenging for every young person and presents exceptional challenges for individuals with disabilities. Youth with disabilities often struggle to find early and meaningful paid work opportunities and experience significant changes to their support systems. As a result, youth with disabilities are less likely to have jobs that pay competitive wages in integrated settings than youth who do not have disabilities.

In response, many CILs are increasingly engaged with youth and young adults, preparing them for life beyond high school. CILs provided a record high of 30,501 youth/transition services in PY 2021. Early in the pandemic, when many schools moved to virtual learning, education for students with disabilities became increasingly difficult, with little to no in-person support available to assist with the new virtual learning environment. As they did before the pandemic, many CILs stepped up to successfully advocate for accommodations and supports for students with IEPs (Individualized Education Programs) and 504s.



CILs frequently educate students and parents/guardians on the IEP and 504 processes and their rights and help them with advocacy with the schools.

In addition, many CILs provide independent living skills to help youth be successful when they leave secondary education. The following examples share the type of rights- and skills-based training and education provided on an individual and group level to strengthen students' confidence and self-determination.

- » [Regional Access & Mobilization Project \(RAMP\), Rockford, Illinois](#): The youth education advocate was contacted by a parent stating that her son was attending an elementary school where he was tied to a chair by his teacher. The school didn't have the knowledge or experience to appropriately respond to his behaviors and support him. The parent felt he should have one-to-one support but didn't know how to get this added to his IEP, and her son was not advancing with his educational goals. The youth advocate developed a plan with the parent and son and then attended the IEP meeting with them, assisting in sharing concerns and advocating for a change in education settings. The student was then placed in a different school where he was safe and able to learn.
- » [Center for Independence of the Disabled in New York \(CIDNY\), New York, New York](#): CIDNY's youth transition staff taught self-advocacy skills to 298 youth as part of a workplace readiness curriculum. In addition to workplace readiness and independent living skills training, the curriculum was designed to increase self-confidence, self-advocacy, and leadership skills in students transitioning to adulthood so they can become as independent as possible.

The post-secondary transition services CILs provide ensure young adults successfully transition into adult life. CILs work with youth to identify goals and take action to advance these plans. For example, youth may have a goal to live independently, away from their family, but struggle to manage necessary attendant care. An independent living transition plan may address that challenge, as well as help the youth access and secure accessible, affordable housing, navigate public transportation, and plan a budget for expenses. The following example highlights ways CILs help support young adults with their career goals.

- » [Center for Independent Living Gulf Coast, Fort Myers, Florida](#): A young man with an intellectual disability participated in Project SEARCH at the CIL in his last year of high school. Project Search is a national program that helps students with disabilities learn skills for future employment. He received training and hands-on experience in several kinds of jobs, including administrative support, managing donations for the CIL, and performing a variety of tasks at the local children's hospital. With this prior experience, he gained a full-time position at a local dealership, power-washing what he loved: cars. The CIL helped the young man and his family navigate the system so that his full-time job did not cause him to lose other necessary benefits. He gained confidence at the dealership and was motivated to get his driver's license and purchase a car. He now drives himself to work — something he always wanted to do.

Highlight: Walton Options for Independent Living, Augusta, Georgia

A young man who self-described as having bipolar disorder was incarcerated after a domestic dispute involving his mother. The CIL staff arranged for his release through the Bail Project, a national nonprofit organization that pays bail for people in need, reuniting families and restoring the presumption of innocence. The CIL team then helped arrange temporary, accessible, affordable housing, coordinated transportation for behavioral health services, helped enroll him in Medicaid, and encouraged the young man to apply for jobs. The CIL helped him become a certified peer support volunteer. He continued actively volunteering with the CIL, working two part-time jobs, and successfully completed two of the four GED test sessions. For the first time in his life, as he describes it, he's living a routine that includes independently providing for his needs and progressing toward a career goal.

Leveraging Resources and Partnerships to Advance Community Living

Federal law requires CILs to obtain additional funding beyond that provided through the Rehab Act in order to expand the reach of their services and ensure long-term sustainability. CILs continue to be successful in meeting this requirement.



In PY 2021, CIL resource development activities generated more than \$687.8 million, almost seven times more than the federal appropriation for this program.

Federal funds contributed 31% to CILs' net operating resources in PY 2021 (see Table 3).

Table 3. CIL Revenue Sources, PY 2016 - PY 2021

Funding Type	PY16	PY20	PY21	Percent change 2016-2021
Part B	\$13,196,664	\$18,615,000	\$20,599,850	36%
Part C	\$80,195,894	\$86,523,495	\$87,796,552	9%
Chapter 2	\$3,436,348	\$5,202,661	\$4,933,516	30%
Other Federal	\$80,299,819	\$92,059,886	\$103,407,555	22%
State Funds	\$373,321,670	\$507,042,236	\$517,329,570	28%
Local Government Funds	\$25,351,954	\$28,630,301	\$31,973,675	21%
Foundation/Grants	\$60,947,460	\$114,931,625	\$126,532,149	52%
Donations	\$4,700,197	\$9,346,086	\$5,838,270	19%
Membership Fees	\$121,046	\$49,740	\$81,243	-49%
Investment Income	\$9,487,596	\$16,233,717	\$19,840,291	52%
Fee for Service	\$310,859,076	\$377,273,317	\$370,720,786	16%
Other Resources	\$22,531,376	\$16,313,931	\$21,040,117	-7%
Pass-Through Funding	\$451,050,569	\$589,381,721	\$622,271,572	28%
Net Operating Resources	\$533,398,531	\$682,800,243	\$687,822,073	22%

CILs use a variety of strategies to leverage resources; some receive additional funding from their states as part of annual budgets, and others are vendors for IL services. As vendors, CILs contract with states to provide services such as self-advocacy and leadership training, assistance with nursing home transition and coordination, benefits counseling, and youth transition services, among many others.

CILs leveraged their partnerships and increased their resources to address pandemic-related issues experienced by the disability community. Many CILs had more volunteers step up during the pandemic, and they received additional donations, allowing them to serve many more in need of IL services. In the two program years, CILs also received increases in pass-through funding. Pass-through funding is funding received on consumers' behalf, which is subsequently passed on to consumers, such as representative payee funds, Medicaid dollars, and the provision of personal assistance services. CILs also received increases in investment income, foundation grants, and local government and state funds.

Moving from Nursing Homes and Hospital Settings

COVID-19 highlighted for the public what the disability community already knew: placement in nursing homes and other congregate, institutional settings can cause higher rates of severe illness and death than living in community settings. By statute, every CIL is required to help prevent placement in institutional settings and to help people with disabilities move out of institutional settings.

Moving people out of institutions (i.e., institutional transition work) is time-intensive and complex. Shortages of affordable housing and direct care workers, administrative delays, inadequate funding, and a lack of coordination with state agencies, managed care organizations, and other partners can cause formidable barriers to successful moves. In addition, outdated attitudes and biases about disability keep some institutional residents from ever being presented with the choice to move.

CIL staff address all these challenges, making difficult transitions from institutions possible. They work to elevate the individual's voice, assure the person has informed choice, and that their choice is honored throughout the transition. CILs meet with the person to determine their needs and budget and then assist with locating and applying for housing, personal care attendants, and other benefits. CIL staff help coordinate the actual move — locating resources to provide furniture when needed and helping the person access home modifications, technology, equipment, and other necessary items. Staff also connect the person who has moved to the community to their peers at the CIL, and they teach independent living skills, such as cooking, budgeting, and employment support. They continually follow up with the person to ensure they are safe and have what they need in their new home.

Despite tremendous barriers to gaining access to nursing homes during COVID-19, CILs continued to make progress in helping people move into the community.



In the two program years, CILs helped 7,456 people with disabilities move from institutions back into the community.

Partnerships and creativity were critical to their success. The following examples show how CILs worked collaboratively with partners in the aging and disability networks, including area agencies on aging, state protection and advocacy programs, and aging and disability resource centers.

- » [Foundation of Resources for Equality and Employment for the Disabled \(FREED\), Grass Valley, California](#): This CIL braided multiple funding streams, pulling from strong partnerships with state and local organizations to help an estimated 60 people a year from institutions and 100 from hospitals relocate in the community. The CILs helped individuals access housing vouchers, the assistive technology reuse program for equipment, area agency on aging and county funding for home modifications, a local donation store for furniture, and state grants for household items.
- » [LIFE Inc., Lubbock, Texas](#): LIFE partnered with other CILs and managed care organizations to help an annual average of 200 individuals from hospitals or nursing homes move back into the community, with very few returning. They credit their success to strong partnerships with state agencies, housing programs, and the CIL network.
- » [The Independence Center \(IC\), Colorado Springs, Colorado](#): The IC and the University of Colorado Health Memorial Hospital collaborated to facilitate successful transitions to home for patients with a complex or difficult discharge through its Hospital to Home (H2H) program. Through H2H, the IC receives funding from the Memorial Hospital Foundation to provide service assessment and coordination of a network of local community-based organizations that provide support services to patients discharging from the hospital so they can successfully thrive at home.

Highlight: A CIL's Help with Returning Home

A consumer and his wife were in the middle of a move from New York to Pennsylvania, but he had a stroke and was hospitalized in New York before the move was complete. His wife called different Pennsylvania agencies for help, but because he wasn't yet residing in Pennsylvania, she couldn't find any help. She was ultimately connected to Community Health Choices and the [Roads to Freedom Center for Independent Living](#) in Williamsport, Pennsylvania. With the help of the CIL, the consumer chose a managed care organization (MCO) and was assigned a service coordinator, but the MCO was unsure how to provide services to him in another state. Due to the CIL's advocacy, the MCO agreed to make an exception to help get him back to his family. The day of his move was an emotional one. After over a year of isolation in a facility during a pandemic, he was finally home! Although he is still learning to use his voice again, he was able to push himself up to a sitting position and whisper to the NHT coordinator, "I want to hug and thank you, too. Thank you for getting me home!" After being home for just 30 days, he no longer needed a feeding tube and could eat his wife's home-cooked meals. His demeanor has changed for the better.

Moving from Correctional Settings

In PY 2020 and 2021, CILs increasingly received requests for support for people with disabilities who were re-entering the community from jail or prison due to expedited releases related to the COVID-19 pandemic. CILs connected these individuals to work programs, housing, and peer support.

- » [Center for Independent Living for Western Wisconsin, Menomonie, Wisconsin](#): The "Jail to Community Reentry" program with the Dunn County Criminal Justice Collaborating Council was a three-year grant to the CIL aimed at reducing recidivism by using a peer mentoring approach. This program was staffed by the CIL's peer mentor, who had lived experience in both mental health and the criminal justice system. Before their release from jail, individuals met with CIL staff for assistance with a goal, a plan, resources, and mentoring to make their transition successful. Forty-five individuals were helped through this program in PY 2021.
- » [Westchester Independent Living Center, Inc., White Plains, New York](#): A young man with learning disabilities had just completed a prison term. He wanted a part-time job but was having difficulty obtaining a copy of the GED he earned while incarcerated. The CIL staff contacted the state education department and assisted the individual with submitting the correct forms to obtain a copy of his GED. They also assisted in his job search, which led to a part-time job.

Preventing Institutionalization Through Housing and Emergency Services Provision

Motivated by their work transitioning individuals from nursing homes and institutions into the community, CILs also engage in the housing and emergency services spaces to expand and sustain community living options. They do so by advocating for increasing the number of affordable housing vouchers available to the disability community and partnering with other organizations and agencies to provide home modifications, like ramps and roll-in showers, so the individual has a safe and accessible living environment.

In PY 2020 and 2021, CILs helped a total of 102,091 individuals through the following services:

- » Housing application assistance
- » Shelter
- » Home modification programs
- » Affordable and accessible unit information
- » Housing education and advocacy for the enforcement of fair housing laws and protections
- » Eviction prevention programs

This assistance allows people with disabilities to remain in the community, as the following stories highlight.

- » [Rolling Start, San Bernardino, California](#): The CIL provided a variety of services and assistance to a woman in her 70s who had been living in a van with her son with intellectual disabilities who was in his 40s. They were first referred to the CIL after calling California’s 2-1-1 for assistance with an emergency housing voucher program application. The CIL helped them complete and submit the application to the housing authority. During this period, the woman contracted pneumonia and was admitted to the hospital while her son stayed in the van in the parking lot. The CIL then helped with her discharge and connected them with Adult Protective Services (APS), which had vouchers for motel stays up to 3 months. The CIL advocated with the mother and son to ensure they could stay together instead of putting the son in a more restrictive setting. The APS voucher allowed them to stay together while waiting for the housing voucher. With the CIL’s coaching, the son found his voice and advocated that he be able to take care of his mom, and the state reinstated him as a personal care attendant.
- » [Dayle McIntosh Center, Anaheim, California](#): CIL staff worked for several months to prevent the institutionalization of a consumer in the advanced stages of dementia. The consumer had no income, a very limited support network, and was weeks away from being evicted and institutionalized because she and her daughter could no longer afford their apartment. Staff assisted the consumer in submitting benefit applications for SSDI and in-home supportive services — both of which were approved. The consumer and her daughter, who has enrolled as a care provider, now have sufficient household income to pay rent.

People with disabilities face numerous barriers to accessing relief during emergencies, threatening their ability to remain in the community.



Many CILs work with their state and local governments to ensure that planning efforts are inclusive of individuals with different access and functional needs so no one is left behind.

In addition, as the following examples show, CILs assist individuals with disabilities and households in planning for and encountering emergencies.

- » [Marin Center for Independent Living, San Rafael, California](#): This CIL launched the initiative “Powered & Prepared” with support from the California Foundation for Independent Living, Pacific Gas and Electric Company, and MCE Community Choice Energy. The initiative aimed to increase disaster preparedness for Marin’s population with access and functional needs by distributing 50+ high-voltage batteries and providing food, shelter, and financial resources during public safety power shutoffs. The CIL subcontracted with eight community-based organizations trusted among underserved populations to engage in outreach efforts and link community members to available resources. In addition, Marin CIL provided in-service training on disability inclusion in English and Spanish for partner staff, including staff from the Partnership HealthPlan of California,

County Health and Human Services Department, Marin Community Clinics, and other community partners. As a result of these activities and partnerships, over 100 people with access and functional needs submitted applications for the “Powered & Prepared” program.

- » [Services for Independent Living, Columbia, Missouri](#): This CIL was awarded a grant through the Christopher Reeve Foundation to help individuals with emergency preparation. Participants learned how to develop their evacuation plan and create a “to-go bag” of essentials, including cell phone chargers, battery backups, and phone numbers for family, friends, and medical providers. One hundred ninety-five individuals and six caregivers participated in this training.

Serving a Diverse Community

CILs have always provided services to people of all ages and disability types, but there have been several significant changes in these service trends over the last two years.

- » **CILs are beginning to serve more older adults.** For the first time, in PY 2021, adults 60 and over were the largest age group served by CILs, making up 42% of the population, with adults 24-59 at a close second, representing 41% of individuals served. Due to the COVID-19 pandemic, many older adults received CIL services to address social isolation and to avoid nursing home placement.
- » **CILs have been successful at serving a racially diverse consumer base.** Just as the 2020 Census has shown that our nation has become increasingly diverse, so, too, has the diversity of CIL consumers served, with 42% in PY 2020 and 2021 reporting their race/ethnicity as something other than white. The most frequently reported race by consumers, other than white, was Black or African American at 21%.
- » **CILs are serving more diverse disabilities.** The [CDC](#) reports that 1 in 4 adults in the United States have a disability, with the most common being a mobility disability, followed by a cognitive disability. These trends are reflected in the consumers CILs serve. No disability category makes up more than half of the CIL’s consumer base. The most reported disability, according to the disability categories listed in the CIL Program Performance Report, is physical at 42%, and multiple disabilities is the second most-served category at 24%. Cognitive disabilities made up 15% in PY 2021, and 12% of consumers served had mental/emotional disabilities.

The following examples show how CILs are serving diverse communities.

- » [Access Living, Chicago, Illinois](#): This CIL created the Disability and Immigration Taskforce of Illinois to empower and support immigrants, refugees, and asylees with disabilities and their families. The CIL helps consumers access culturally and linguistically appropriate services and educate, train, and share resources that are inclusive of all communities.
- » [Independence First, Milwaukee, Wisconsin](#): This CIL fostered connections with diverse communities in a variety of ways. For instance, the CIL advertised on radio stations with a primarily African American audience and placed advertisements through the Hispanic Chamber of Commerce to ensure more people heard about the CIL’s services.
- » [Westchester Independent Living Center \(WILC\), Yonkers, New York](#): WILC uses an outreach office at VIVE Pathways to Success — a dynamic intergenerational public school in the heart of downtown Yonkers. From this office that is trusted by the local community, staff connect and provide information and supports on disabilities to a largely immigrant population facing cultural, language, and economic barriers.

Serving the Unserved and Underserved

Section 21 of the Rehab Act requires that 1% of CIL program funding be set aside for outreach to traditionally underserved populations. ACL funded the Native American Independent Living Demonstration (NAILD) Project in response to this requirement. Started in PY 2017, this demonstration project funded five CILs to:

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

In PY 2021, the demonstration projects led to these CILs being embedded in tribal communities. Following are a few recent highlights from the grantees.

- » [Disability Services and Legal Center \(DSLCL\), Santa Rosa, California](#): The CIL established a tribal advisory board comprised of five tribal chairs, three tribal educators, and two tribal health providers, representing the interests of 25 reservations and rancherias within the CIL's catchment area. Through these relationships, CIL staff were invited to participate in many tribal gatherings, including health fairs, Big Times, and powwows. Through these relationships and the networking of their project coordinator, DSLCL was invited to participate in the surrounding tribal communities as never before, resulting in ongoing relationships and a higher referral rate for IL services.
- » [Superior Alliance for Independent Living \(SAIL\), Marquette, Michigan](#): This CIL provided information and referrals to 155 individuals from tribal communities and assisted in creating 118 independent living plans for tribal members with disabilities from October 2019 through September 2021. It provided summer workshops for students as well as the general tribal community and hosted two "Well-Balanced" classes for tribal elders in the Keweenaw Bay Indian Community. The CIL also hosted regular office hours for Bay Mills, Sault, and the Hannahville tribal communities.

In addition to the NAILD project, Section 21 set-aside funds support the Disability and Rehabilitation Research Project (DRRP): Independent Living Transition Services for Youth and Young Adults with Significant Disabilities from Minority Backgrounds. The DRRP is conducting research to generate evidence-based practices for services provided by CILs to facilitate the transition to post-secondary life of youth with significant disabilities from racial and ethnic minority backgrounds who were eligible for IEPs and who have completed their secondary education or otherwise left school. This research project is in the process of:

1. Identifying promising practices for facilitating the transition of youth and young adults with significant disabilities from minority backgrounds.
2. Developing at least two transition interventions for youth and young adults with significant disabilities from minority backgrounds.
3. Assessing the feasibility and efficacy of transition interventions for youth and young adults with significant disabilities from minority backgrounds.

A final report on outcomes achieved by the DRRP will be developed by ACL in 2024 after the project's conclusion.

On-Site Reviews



ACL monitors all programs for programmatic and fiscal compliance and overall performance based on the standards and assurances found under Section 725 of the Rehab Act.

Section 725 requires that all CIL programs and activities are planned, conducted, administered, and evaluated in a manner consistent with the purpose established in the Rehab Act. It affirms that grantees assist CIL consumers effectively and efficiently. Each grantee undergoes programmatic and fiscal reviews annually to verify adherence to Section 725. Federal staff conduct desk audits by evaluating program performance and fiscal reports submitted by all grantees to assess compliance. To improve CIL programs, ACL offers technical assistance on issues that emerge after reviewing annual submitted performance reports. Grantees at risk for programmatic or fiscal issues receive heightened monitoring, which may be conducted remotely or on-site.

Purpose of Title VII, Chapter I of the Rehab Act

Promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems 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.

In December 2019, ACL completed three on-site reviews of CILs located in Michigan. The CILs were Disability Network West Michigan, the Disability Network, and Bluewater CIL. Bluewater CIL could not follow the submitted corrective action plan and establish internal controls to address the prior embezzlement, which resulted in its closure. The other two CILs have come into compliance. The results of these reports and more information about the Office of Independent Living Program's monitoring process based on the Compliance and Outcome Monitoring Protocol (COMP) can be found under the "compliance and outcome monitoring" tab on [ACL's CIL webpage](#).

Three additional on-site reviews were scheduled for PY 2021 but were postponed due to the COVID-19 pandemic travel restrictions and staffing shortages.

Conclusion

In PY 2020 and 2021, CILs reported a record number of services delivered in communities nationwide. The data ACL gathered through CILs' annual Programmatic Performance Reports (PPRs) demonstrate that people with disabilities across the nation continue to benefit from the services and activities provided by CILs. At no time was this more evident than during the COVID-19 pandemic. The examples provided in this report represent a snapshot of the direct impact CILs have on the lives of people with disabilities. The data in this report show that CILs that received Part C funding during that time have complied with the standards and assurances in Section 725 of the Rehab Act.

Appendix A

Program Performance Report: Goal Definitions

- A. **Self-Advocacy/Self-Empowerment** – Goals involving improvement in a consumer’s ability to represent himself/herself with public and/or private entities, the ability to make key decisions involving himself/herself, or the ability to organize and manage his/her activities to achieve desired objectives.
- B. **Communication** – Goals involving either improvement in a consumer’s ability to understand communication by others (receptive skills) and/or improvement in a consumer’s ability to share communication with others (expressive skills).
- C. **Mobility/Transportation** – Goals to improve a consumer’s access to her/his life space, environment, and community. This may occur by improving the consumer’s ability to move, travel, transport himself/herself, or use public transportation.
- D. **Community-Based Living** – Goals that provide for a change in living situations with increased autonomy for the consumer. This may involve a consumer’s goals related to obtaining/modifying an apartment or house. Community-based living arrangements may include apartments, privately owned housing, self-directed assisted living, or self-directed living with family/friends.
- E. **Educational** – Academic or training goals expected to improve the consumer’s knowledge or ability to perform certain skills that would expand his/her independence, productivity, or income-generating potential.
- F. **Vocational** – Goals related to obtaining, maintaining, or advancing in employment.
- G. **Self-Care** – Goals to improve/maintain a consumer’s autonomy concerning activities of daily living, such as personal grooming and hygiene, meal preparation and nutrition, shopping, eating, and other aspects of personal health and safety.
- H. **Information Access/Technology** – Goals related to a consumer obtaining and/or using information necessary for the consumer’s independence and community integration. These may include the use of a computer or other assistive technology, devices, or equipment, as well as developing information technology skills, such as using computer screen-reading software.
- I. **Personal Resource Management** – Goals related to a consumer learning to establish and maintain a personal/family budget, managing a checkbook, and/or obtaining knowledge of available direct and indirect resources related to income, housing, food, medical, and/or other benefits.
- J. **Relocation from a Nursing Home or Institution** – Goals related to relocation from nursing homes or other institutions to community-based living arrangements. This significant life area specifically pertains to consumers who live in a nursing home or institution, unlike the Community-Based Living life area above, which includes any consumer regardless of his/her living situation prior to receiving IL services.
- K. **Community/Social Participation** – Goals related to full participation in the mainstream of American society, including the ability to participate in community events, such as community fairs and government functions, attend worship services, and access recreational activities and facilities.
- L. **Other** – IL goals not included in the above categories.

Appendix B

Program Performance Report: Service Definitions

- A. **Advocacy/Legal Services** – Assistance and/or representation in obtaining access to benefits, services, and programs to which a consumer may be entitled.
- B. **Assistive Technology** – Any assistive technology device, that is, any item, piece of equipment, or product system that is used to increase, maintain, or improve functional capabilities of individuals with disabilities and any assistive technology service that assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.
- C. **Children's Services** – The provision of specific IL services designed to serve individuals with significant disabilities under the age of 14.
- D. **Communication Services** – Services directed to enable consumers to better communicate, such as interpreter services, training in communication equipment use, Braille instruction, and reading services.
- E. **Counseling and Related Services** – These include information sharing, psychological services of a non-psychiatric, non-therapeutic nature; parent-to-parent services; and related services.
- F. **Family Services** – Services provided to the family members of an individual with a significant disability when necessary to improve the individual's ability to live and function more independently or engage or continue in employment. Such services may include respite care.
- G. **Housing, Home Modifications, and Shelter Services** – These services are related to securing housing or shelter and adaptive housing services (including appropriate accommodations to and modifications of any space used to serve or occupied by individuals with significant disabilities).

Note: A CIL may not provide housing or shelter as an IL service on either a temporary or long-term basis unless the housing or shelter is incidental to the overall operation of the CIL and is provided to any individual for a period not to exceed eight weeks during any six-month period
- H. **IL Skills Training and Life Skill Training Services** – These may include instruction to develop independent living skills in areas such as personal care, coping, financial management, social skills, and household management. This may also include education and training necessary for living in the community and participating in community activities.
- I. **Information and Referral Services** – Services that assist a consumer in locating or using available and appropriate resources.
- J. **Mental Restoration Services** – Psychiatric restoration services, including maintenance on psychotropic medication, psychological services, and treatment management for substance abuse.
- K. **Mobility Training Services** – A variety of services involving assisting consumers to get around their homes and communities.
- L. **Peer Counseling Services** – Counseling, teaching, information sharing, and similar kinds of contact provided to consumers by other people with disabilities.

- M. **Personal Assistance Services** – These include, but are not limited to, assistance with personal bodily functions; communicative, household, mobility, work, emotional, cognitive, personal, and financial affairs; community participation; parenting; leisure; and other related needs.
- N. **Physical Restoration Services** – Restoration services including medical services, health maintenance, eyeglasses, and visual services.
- O. **Preventive Services** – Services intended to prevent additional disabilities or to prevent an increase in the severity of an existing disability.
- P. **Prostheses, Orthotics, and Other Appliances** – Provision of, or assistance in obtaining through other sources, an adaptive device or appliance to substitute for one or more parts of the human body.
- Q. **Recreational Services** – Provision or identification of opportunities for the involvement of consumers in meaningful leisure time activities. These may include such things as participation in community affairs and other recreation activities that may be competitive, active, or quiet.
- R. **Rehabilitation Technology Services** – Provision of, or assistance to obtain through other sources, adaptive modifications, such as wheelchairs and lifts, which address the barriers confronted by individuals with significant disabilities concerning education, rehabilitation, employment, transportation, IL, and/or recreation.
- S. **Therapeutic Treatment** – Services provided by registered occupational, physical, recreational, hearing, language, or speech therapists.
- T. **Transportation Services** – Provision of, or arrangements for, transportation.
- U. **Youth/Transition Services** – Any service that develops skills specifically designed for youth with significant disabilities between the ages of 14 and 24 to promote self-awareness and esteem, develop advocacy and self-empowerment skills, and the exploration of career options, including the transition from school to post-school activities, such as postsecondary education, vocational training, employment, continuing and adult education, adult services, independent living, or community participation.
- V. **Vocational Services** – Any services designed to achieve or maintain employment.
- W. **Other Services** – Any IL services not listed above in A-V.