Center for Independent Living of Central PA

Your LIVING WELL

With A Disability Provider & Advocacy Organization

2017 ANNUAL REPORT
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Our Vision

The Center for Independent Living of Central Pennsylvania envisions a society where persons with disabilities are empowered to fully exercise their rights and fully participate in all walks of life that will enable them to Live Well.
The CILCP served 864 CONSUMERS in 2017

CILCP SUMMARY OF SERVICES
We provide innovative programs and services that empower persons with diverse disabilities to live well, while advocating on numerous levels to ensure all people with disabilities are provided the opportunity to live well.

- Living Well Transport Services
- Home Modifications & Access Services
- Consultation & Training
- DeafBlind Living Well Services
- Living Well with a Disability
- Nursing Home Transition
- Specialized Services
- Independent Monitoring for Quality
More and more, there are conversations being held about **needs** versus **wants**, as it relates to participants receiving long-term supports and services. It has prompted me to try to make better sense about the use of these terms.

I would like to submit the following that makes better use of the words. I “want” to live well and these are the supports and services I “need” in order to better live well.

I **need** reliable attendant care services that fit my lifestyle of working, socializing with family & friends and attending and fully participating in my church.

I **need** a home or living situation where I can freely enter and still retain my security and independence.

I **need** home modifications that fit my functional limitations and are designed with my input and my best interests in mind.

I **need** a reliable form of accessible, affordable transportation that is available when I need it, not only transportation that is scheduled in advance.

I **need** durable medical equipment that works for the particular disability that allows me to function freely and navigate my home and community.

I **need** my attendants, my service coordinators, my doctors, my MCOs and their professional staff to genuinely listen to my concerns and understand my **needs**.

I **need** quality healthcare from quality healthcare providers.

I **need** the peace of mind that comes from knowing my **needs** are being met, by people, who are genuinely concerned about meeting, my genuine **needs**.

I **need** to be respected, I **need** to be included, I **need** to be heard and most of all, I **need** my dignity, regardless of my situation, my condition or my place of residency!

I **need** all of these things because I **want** to live well!

Here at the CILCP, we know the difference between needs and wants!
I am privileged to serve as President of the Board of the Center for Independent Living of Central PA for another term. The Center for Independent Living continues to be committed to serving people with disabilities. We listen to the challenges within the community and strive to help people affect change in order to pursue individual goals. Some of our advocacy projects are focused on transportation, accessible housing and home modifications, access to voting polls, educating legislators and policy makers, and assistance in transitioning to the community from a facility.

The past year was also filled with activities preparing for the Managed Care Model referred to as Community HealthChoices. This change will have an impact on people with disabilities who are receiving waivers as well as those on Medicare and Medical Assistance. The Center for Independent Living’s website offers more details about the transition.

The MV-1 Accessible Van has successfully expanded our Living Well Transport Services by providing accessible and affordable taxi service for late evening hours and weekends.

The DeafBlind Living Well Services continues to train and coordinate Support Service Providers to assist persons with deafblindness to lead an empowered, independent life.

CILCP has developed new marketing and promotional tools including video testimonials. This will greatly expand our outreach efforts, educating the community on what the Center has to offer. All this can be found on our Living Well with a Disability Website and Facebook page.

The Board recommitted itself to the mission and vision of the CILCP at our July Board retreat. We have stronger communication with the CEO. Committees were restructured to be more effective in assisting the board to meet challenges and opportunities as they present themselves.

The CEO and the staff are visionaries and dedicated workers who are well qualified to steer the organization forward. The Board of Directors are passionate, progressive individuals ready to assist bringing CILCP’s mission to fruition.

Vini Portzline
CILCP Board President
The Center for Independent of Central PA’s (CILCP) Board of Directors held a one-day retreat for board members and CILCP management staff on Friday, July 28, 2018, at the Homewood Suites in Harrisburg, PA.

The retreat was facilitated by Ms. Janet Unger, an independent organizational consultant who mainly works with non-profit organizations and membership associations. Janet’s consulting philosophy integrates principles of governance, strategic planning and organizational development.

The day-long retreat focused on the following items:

- Identifying board and organizational challenges
- Roles and responsibilities of the CILCP Board
- CILCP Board Structure and Practices
- CILCP Board Goals

A follow-up summary board meeting was held the following month with Ms. Unger.
In 2017 the Center for Independent of Central PA launched Living Well Transport Services (LWTS), an accessible and affordable on-demand service. CILCP believes that access to affordable accessible transportation is a basic human right. Mobility allows a person to connect with her/his community and other essential life destinations.

CILCP purchased an MV-1 Commercial ADA van to meet the need of lack of transportation after 5 p.m. and on weekends, on an as-needed, first come, first served basis. The target market was easily recognizable with the people that the CILCP serves (which is approximately 677 active consumers) who reported the lack of affordable, accessible transportation.

The CILCP program was licensed by the Public Utilities Commission (PUC) in September of 2017 to operate within both Dauphin and Cumberland Counties. In the fall of 2017 one van diver was hired and trained and a pilot program was launched.

In 2017 an important market segment included private pay customers for the purpose of doctor appointments, errands, groceries, social gatherings and Sunday services. Future markets will include participants who will be connected to the three statewide Managed Care Organizations, Office of Developmental Programs, Office of Vocational Rehabilitation and Office of Long Term Living.

By providing participants with transportation to community events, dinner with friends, or a last-minute decision to see a movie, they are more likely to experience the positive emotional and mental benefits gained through human interaction.

The Pacheco’s took a dream weekend trip to Baltimore (Living Well’s first transport).

The new Living Well Transport Services van.
In 2017, the CILCP created a new position, Director of Program Development & Expansion to meet an unmet need as we move forward as an organization. On May 1, 2017, Sharon Behun joined our staff. As director, Sharon is responsible for developing new initiatives supporting the strategic direction of the organization.

Looking back, Sharon has:

- Fostered a relationship with the 3 managed care companies along with finalizing three contracts; the CILCP is a provider with each company
- Collaborated with our Living Well with a Disability Program to develop materials for our young adult transition program, Youth Matters
- Planned & coordinated our first blood drive with the Central PA Blood Bank
- Coordinated the Day of Caring event at the office with the United Way of the Capital Region
- Developed the infrastructure for Living Well Transport Services
- Created and updated materials to promote DeafBlind Living Well Services

As the CILCP heads into 2018, Sharon will continue to set the CILCP in a position to meet our goals.
2017 proved to be another busy year for the Home Modifications & Access Services department. CILCP provided 138 home modification services to local area agencies on aging, Dauphin Co MH/ID, nursing home transition providers, Under 60 service coordination agencies and the Stabler foundation.

The Director, Lynn Stewart-Krieger, sits on the board of Directors for the Dauphin County Affordable Housing Associates. This group has worked with developers to receive funding for 3 new housing developments in Dauphin County. Two of these projects opened in 2017.

In addition to providing ongoing ADA technical assistance, Lynn Stewart-Krieger and Janetta Green were subcontracted to work on an ADA survey project in Maryland.

In 2017, the CILCP provided 138 home modification services
CILCP provides written ADA surveys or walk-throughs of facilities and programs for compliance with the ADA 2010 Standards for Accessible Design.

In 2017, colleges, universities, churches and human service agencies benefited from the knowledge of our ADA experts at CILCP. Nearly 200 hours of ADA consultations and assessments were provided.

Nearly **200 HOURS** of ADA consultations and assessments were provided.

CILCP also offers a variety of trainings as part of the Mid-Atlantic ADA Center and the National ADA Leadership Network.

The CILCP hosted National ADA Trainer Mark Derry from April 4-6, 2017, for an Accessibility Survey Academy Project (ASAP). This program, endorsed by the National Council on Independent Living (NCIL), was only for CIL staff or people sponsored by the local CIL to teach staff how to provide accessibility surveys and to add credibility to their ADA program.

The three-day training was held at the Giant Community Room in Camp Hill. Sixteen of the seventeen PA CIL’s participated and six of the participants were from CILCP.
In 2017 DeafBlind Living Well Services (DBLWS) continued to provide independence for Pennsylvanians who are deafblind.

A total of 55 Support Service Providers worked directly with consumers who were DeafBlind to assist with activities such as food and clothes shopping, purchasing personal care items, banking, doctor and other medical appointments, community meetings, social interactions, visiting local fairs, festivals, amusement parks, sport games, and exercising. DBLWS staff trained a total of 20 additional consumers on how the program works, how to request services, how to work with their SSPs, how to manage their hours, resources, other state services, and advocacy.

In 2017, DBLWS recorded and published a series of captioned videos that highlight what Deafblindness is, what technology deafblind people use, what a Support Service Providers’ tasks are, what a SSP cannot do, about service dogs, and 2 videos dedicated to a SSP and deafblind consumer in action at the grocery store.

In the later part of 2017, DBLWS began to consider the idea of legislation that would become permanent funding for the program by meeting and educating several General Assembly representatives from the Harrisburg area. DBLWS also met with and collaborated with Secretary Miller from the Department of Human Services (DHS) to continue looking at how SSP services could fit into the soon-to-be Managed Care System.

DBLWS looks forward to providing services for the next year and the increased awareness the program has provided people who are deafblind, the public, and other groups of persons with disabilities!
The Living Well With A Disability (LWWD) Program assisted a total of 135 consumers to acquire affordable, accessible housing, identifying social activities and personal assistant services.

**Nursing Home Transitioning (NHT)**

The CILCP NHT Specialist, Kaori Kelly, was very busy in 2017 working with 59 consumers assisting in locating housing options, connecting people with Home and Community Based supports, purchasing household items/furnishings and coordinating access to needed durable medical equipment and prescriptions. Through her determination, passion and tenacity she was successful in transitioning 26 consumers back into the community from nursing facilities located across 17 counties.

She had been working with a consumer since August 2016 who has Multiple Sclerosis, several heart conditions and a brain injury. He was left for dead in a local nursing facility but made a “miraculous” recovery. He had no informal supports (family or friends) but he begin working with his pastor and the Kaori. After his recovery the nursing facility began working very hard to get him out of the facility as he no longer needed their level of service. Kaori provided nursing home transition services and worked with his pastor. The pastor organized the move, acquiring food from the food pantry and any other essential items he required. He continues to live safely in the community approximately one year later.
Peer to Peer

The Living Well With A Disability Program offered many wonderful events for consumers to have fun and interact with their peers such as the Spring Fling games and Adaptive Gardening; Take Me Out to the Ball Game’ Harrisburg Senators baseball game (Minor League) as well as a picnic and swimming at Little Buffalo State Park.

Advocacy

Staff continue to work towards advancing the “Nothing About Us Without Us” campaign attempting to educate the staff of the City of Harrisburg about lack of access.

- Staff worked with the ADA Coordinator to provide her with resources and networking opportunities at the ADA Update Conference in Baltimore.

- Harrisburg City staff updated their web page.

- Harrisburg City staff continue the work of developing an advisory committee of people with disabilities who live in the city as well as a city ADA plan.

At the state level, Living Well staff, local and state advocates successfully advanced the time delay of the time line for the roll out of Managed Care in our Home and Community Based services. We were successful in having state staff designate consumers to be involved in the determination of preparedness of HCBS providers “Readiness Reviews” to contact with Managed Care Providers.

Staff provided outreach and training at cross-disability events and served on different committees at state and local levels that is cross-disability. Examples: PA Department of Human Services, Managed Care Long Term Services & Supports Committee, local transportation (CAT) advisory, ADAPT, Brain Injury Association, Housing Authority meetings, Local Housing Option Team meetings and the Local Section 811 Advisory Committee.
Specialized Services provide training, advocacy, community integration and other tangible supports to eligible nursing home residents in the Commonwealth of Pennsylvania. These services enable individuals to maximize their abilities to live with as much independence and self-determination as possible.

CILCP is contracted with the PA Department of Human Services and Office of Long-Term Living to provide Specialized Services for 2017.

Seven Service Coordinators provided services to 404 program participants statewide.

The Exceptional Durable Medical Equipment (DMG) Grant Program interviews referred individuals to determine durable medical equipment needs. An Exceptional DME grant authorizes additional funds to nursing facilities enrolled in the Medical Assistance program to cover the costs of the required equipment which is specifically adapted to the individual’s needs. Six Peer Counselors interviewed 2,400 program participants in 2015/2017. Monthly follow-up is conducted to ensure the application process is proceeding and the acquired equipment meets the individual’s needs.
INDEPENDENT MONITORING FOR QUALITY

The Independent Monitoring for Quality Program is an independent program contracted with 3 administrative entities or 6 counties (Cumberland/Perry, Dauphin, Huntingdon, Mifflin and Juniata) to conduct Quality of Life surveys to individuals with intellectual disabilities. The program was established through the State Office of Developmental Programs. This past year ODP highlighted the IM4Q Program in their newsletter with the article, “IM4Q Survey Helps ODP to Improve Individual’s Everyday Lives.”

IM4Q surveyed a total of 290 INDIVIDUALS in 2017

Survey participants: 153 for Dauphin, 79 for Cumberland/Perry and 58 for Huntingdon, Mifflin and Juniata counties.

The IM4Q program uses Independent Contractors to aid in scheduling and completing surveys and this past year used 13 independent contractors.

One individual who expressed wanting opportunities to “make more friends” began attending meetings of a local self-advocacy group, Speaking for Ourselves, which aided in this request and increasing his self-advocacy skills.

One gentlemen stated during his survey that “he wants a job.” He also indicated that getting a job would make his life better and make him happy. He has been working with a counselor from the Office of Vocational Rehabilitation who is assisting him to find employment.

Another individual who wished to work more and buy a laptop computer became an independent contractor with the IM4Q Program as a team partner and was able to achieve these requests.

A sign of quality noted during a survey: a woman who lives on her own expressed that with support services she is able to actively participate in her community throughout the week.
2017 BOARD OF DIRECTORS

Vini Portzline, President
Craig Bachik, Vice President
Ann Keiper-Smith, Treasurer
Angela Wiley, Secretary

Diana Deeley
William Gannon
David Gates
David Reager

MANAGEMENT STAFF

Theo Braddy
Chief Executive Officer

Janetta Green
Chief Operating Officer

Marilyn Zarreii
Chief Financial Officer

Pictured left to right: Marilyn Zarreii, Theo Braddy and Janetta Green.

2017 CILCP STAFF

Seth Ambrose
Living Well Specialist

Linda Arguedas
Director of Administration

Pam Auer
Director of Living Well

Sharon Behun
Director of Program Development & Expansion

Gabby Boyd-Chisholm
Community Resource Specialist

Margo Brown-Pinder
Service Coordinator, Specialized Services

Patricia Burke-Dawson
Accounting Supervisor

Jim Cavanaugh
Accounting Clerk

Robert Clapp
Assistant Director of Specialized Services

Marsha Drenth
DeafBlind Living Well Program Manager

Carrie Fowler
Living Well Specialist, Community Advocate

Erin Gaul-Weierbach
Living Well Specialist
CILCP staff celebrate at the 2017 holiday party.

Brenda Harding-Albert  
Community Resource Specialist

Kaori Kelly  
Nursing Home Transition Specialist

Madeleine McMahan  
Service Coordinator, Specialized Services

Ahmed Mohasseb  
Senior Accountant

John O’Rourke  
Service Coordinator, Specialized Services

Nora Proctor  
Living Well Transport Services, Van Driver

Yolanda Quinones  
Service Coordinator, Specialized Services

Kathy Reisch  
IM4Q Coordinator

Shaun Robison  
Service Coordinator, Specialized Services

Lynn Stewart-Krieger  
Director of Home Modifications & Access

Ann Talbot  
Director of Specialized Services

Ben Williams  
Administrative Assistant

Ellen Winters  
Administrative Assistant

Cindy Young  
Subsidiary Accounting Liaison
The 14th Annual Highmark Walk for a Healthy Community was held at Harrisburg Community College on Saturday, May 20, 2017. Highmark underwrote the event so that 100% of charitable contributions benefited each of the more than 40 nonprofits supported by it.

Staff and supporters of the CILCP raised over $12,000.00 in support of the new Living Well Transportation Service.
Throughout 2017 the CILCP Board and staff diligently worked on PANO’s Standards for Excellence reaccreditation application. The Standards for Excellence program includes an ethics and accountability code consisting of 6 Guiding Principles, 27 focus areas and 67 benchmarks. The code provides a framework and step-by-step guidelines to achieve a well-managed and responsibly governed organization.

This will be CILCP’s 2nd reaccreditation.

**Standards for Excellence**

The Standards for Excellence program includes an ethics and accountability code consisting of 6 Guiding Principles, 27 focus areas and 67 benchmarks. The code provides a framework and step-by-managed and responsibly governed organization.

The 6 Guiding Principles are:

1. Mission, Strategy and Evaluation
2. Leadership: Board, Staff and Volunteers
3. Legal Compliance and Ethics
4. Finance and Operations
5. Resource Development
6. Public Awareness, Engagement, and Advocacy

**Pennsylvania’s Standards for Excellence Program**

The Pennsylvania Association of Nonprofit Organizations (PANO)’s community of 58 accredited and recognized nonprofits can be found in 21 counties throughout Pennsylvania!

There are 63,345 nonprofits in Pennsylvania
They employ 727,200 individuals — 15% of the state’s workforce
Generate close to $132 billion in annual revenues
Hold assets of $306.3 billion dollars
Pennsylvania foundations give over $2.4 billion annually
Pennsylvanians are generous and give almost $6.5 billion to charity every year

*(from Independent Sector 2016 State Profile)*
The CILCP’s annual financial statements are audited annually by a Certified Public Accountant. The full board approves the audited financial statements annually. CILCP’s most recent completed audit can be found on our website at:
