

# ACCESS news

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## Why Choose a Peer at WNYIL?

*Douglas J. Usiak, Executive Director*

For at least five decades, Independent Living advocates have asserted that peer services are the ideal avenue to enable people with disabilities to improve their lives, and a driving force to create opportunities for these citizens to become full and equal partners in the growth of our communities.

Having lost my sight in military service, I was thrust into the disability rights movement 43 years ago, getting my first introduction to Peer Support from the consumer advocate National Federation of the Blind's local affiliate in Chicago, while learning daily living skills in the Blind Rehabilitation Program at the Edward Hines, Jr. Veterans' Affairs Hospital.

It played a vital role once again, when I returned to Buffalo and started college on the GI Bill. After just the first semester, the school became nervous about a blind student using equipment in class, and initiated a series of measures intended to push me out of my chosen program, Industrial Arts Education. If I hadn't had the support of the Veterans Administration, the National Federation of the Blind, the Blinded Veterans Association, and a little-known law, Title V of the Rehabilitation Act of 1973 (Public Law 93-112), the College might have succeeded.

Back then, disability rights advocacy was pretty much in its infancy. I needed peer support from Veterans Affairs and the network of Blind advocates to gain the resources to enable me to stay in college, primarily, technical support to learn techniques I needed to function in class, and legal support



to assert my “right to try” as an American with a disability. The good news: not only did I try, I succeeded and received my education and diploma, along with a public apology by the College for their failure to support my educational choices!

Nowadays, looking at the changing landscape of disability programs, I see that Peer Services are being embraced by consumers, supported by government entities, and, in many places, are on the menu of choices available to people with disabilities who are: seeking to return to the community, pursuing higher education, exploring work opportunities, and developing their own healthcare options. From Vocational Rehabilitation to Care Coordination, from Mental Health Services to overcoming the obstacles that prevent full inclusion into society, every day, we Peers are working to improve the social factors that impact on the work, health, and safety of all people with disabilities.

Why is it so important that Peer Services be part of the rehabilitation landscape? Because they work!

Let's say that you are a person with a disability, you are seeking to discover in what direction you wish to go, and you want advice to help you decide. Traditionally, you would turn to a professional Counselor who does NOT have a disability, and he/she would attempt to connect you with programs, emphasize certain options, and cure what ails you. Under the long-standing “Medical Model” of rehab, they either “fix” you, or, regretfully, pack you off to an institution.

Well, I'm not sure how your interactions with able-bodied counselors have been, but, for the most part, mine have not been too encouraging. For example, when I was feeling that I had a bit too much stress at work, my counselor said, “Why don't you quit?”

When I wanted to take a technical class at school, following “normal practices”, the Counselor dismissed it: “I am unable to find any blind people who took that course, so maybe you shouldn't try that.”

And recently, when I cut my little finger on a table saw while making a tactile wooden checkerboard for my grandson, several of the nurses and aides at the Emergency Room had to come and see the blind guy who injured himself with a power tool. The treating physician's sage advice to me was: “No more working on the table saw!”

Depending on your life experiences, you might ask what's wrong with these statements?

I guess nothing was wrong -- *IF you don't wish to live a meaningful life!* Stress on the job? My, what a novel thing! So, as a person with a disability, the best way to deal with increasing stress ***is to quit?***

What happened to cooling off by getting exercise, listening to soothing music, or enjoying a round of golf, (in my case, with a ball that beeps loudly)?

So why not challenge myself by taking a college course, which no blind person is recorded as having attempted before?

If all humankind had shared this “it’s never been done” mentality, we never would have gone to the Moon, explored the North Pole, and discovered most of our scientific advances.

And finally, the edict not to use the table saw in the future? I’ve been using a table saw and other workshop tools for over 40 years, and this was the first time, ever, that I cut my little finger. It didn’t require stitches, my finger is still where it should be, and, you know what? The tactile checkerboard was finished, and my grandson and I are using it!

So, you may ask, “How would the advice from a Center for Independent Living peer be any different”?

The “consumer’s desires come first” principle of a Center for Independent Living (CIL) is only the first of the differences.

The Peers employed, and their attitudes, are vastly different from what you would find at a traditional agency. People with various disabilities work at CILs -- in many cases, they have *more than one disability*, and yet are working on **change!** Community Change, Individual Change, and, most importantly, working with consumers to help them discover HOW TO LIVE WITH THEIR DISABILITIES, AND BE PRODUCTIVE, VALUED, AND HEALTHY! When you look around a CIL you see people who are definitely **not** trying to hide from the stresses and pressures of life.

You’ll find people problem-solving to find the best ways that a deaf person can communicate on the job.

They are examining how the blind person can navigate around in the City.

They can explain the options the wheelchair user has when traveling.

They find ways of reducing the stigma of mental illness, so the employer can see past the prejudicial concept of the formal diagnosis, to find the true value of the employee.

Every minute of the day, the CIL’s focus is to get people involved in their own lives, and to take control of the decision making that impacts them; to actively educate the community and empower the individual to be an equal partner.



If you want to learn how to be seen, accepted, and established as a contributing member of our society, without constantly having to prove it, the CIL is the place to be.

No one here cares if you have a disability, it's just a descriptive attribute, like your hair color, or the color of your eyes. It's no more limiting to your quality of life than being tall or short, young or old, male or female.

It is simply what you have, and you can learn how best you can live with it.

And that is precisely where we start: by asking "what do you really want?"

We can help you explore how you can get there ... learn what resources are available to achieve your goals ... find who can assist you in reaching those objectives ... and discover what you need to do to make it happen.

Of course, there are many more questions, which only YOU can answer.

You will determine your own future. You alone will be responsible for what you gain and accomplish. We are ideally your partners, and, at least, your consultants.

You will employ self-direction; if necessary, you will be taught how to advocate in your own best self-interest.

And you will have the satisfaction of knowing that YOU did it; it was not given to you, nor done for you.

Some terms you may have heard and wondered: what's the difference between "Peer-Run" versus "Peer-Led" services?

From this one person's perspective, Peer-Led is the traditional way of saying that the agency has people who have a disability that will LEAD you to your end goal. However, at the CIL, our Peer-Run program puts you in the driver's seat, and it is YOU who RUNS the show.

So, it boils down to: what do you really want?

The service for today, or the long-term control of your life?



*Keep an eye out for Western New York Independent Living's Annual Appeal Letter. Anyone who makes at least a \$5 donation to the Annual Appeal will receive a \$5 gift card thanks to our friends at Delta Sonic good towards oil changes, car washes, and/or detail services!*

# It's a simple fact.

People with disabilities get **sick and die** because they can't get access to health care.

## Have you been denied access to medical care because you have a disability?

People with disabilities receive fewer preventive services and have higher rates of many medical conditions such as high blood pressure, stroke and diabetes.



Healthcare facilities are required by federal, state and local laws to be accessible to anyone with a physical disability. This includes doctors' offices, labs, medical screening and testing facilities, dentists, hospitals and clinics.

If you have been prevented from getting healthcare services because of your disability or feel you have been discriminated against by a healthcare facility because of your disability, the ICS Health Access Program wants to hear from you.

**Please call our hotline, leave your name, number, and the best times to reach you, and a Health Access Program staff member or volunteer will return your call.**



The Health Access hotline  
number is 646.653.6242.

Email the Health Access  
Program at [whp@icsny.org](mailto:whp@icsny.org).





# Independence Care System of New York

*www.icsny.org*

Have you been discriminated against while trying to get healthcare?

It's a simple fact that people with disabilities sometimes get sick and die because they can't get access to healthcare despite the fact that, by law, all healthcare facilities and services are supposed to be fully accessible. This includes hospitals, clinics, labs, screening facilities (such as places that provide MRIs, CT scans, mammography), doctors' offices, and dental, hearing, and vision services.

Independence Care System (ICS) has been working since 2008 to make healthcare more accessible for New Yorkers with disabilities.

Now ICS is taking this advocacy to the next step, gathering information from consumers who have been discriminated against by healthcare providers because of their disability. The information they are gathering will be used to help make healthcare facilities and services more accessible.

If you have had this experience, please call the ICS complaint hotline or send them an email. Leave your name, number and the best times to reach you. An ICS Health Access program staff member or volunteer will call you back.

You do not need to identify yourself publicly to participate or to make a difference. You just need to reach out and tell your story.

Please call the Health Access Hotline at 646.653.6242 or send an email to [whp@icsny.org](mailto:whp@icsny.org).

## Annual Report

Western New York Independent Living would be happy to provide you with an electronic version of our Annual report for FY 15-16. As WNY's largest service and advocacy organization controlled by people with disabilities, we can share with you an overview of our programs and services that touched over 7,000 people with disabilities and their families throughout NYS.

If you would like an electronic version of the report please email our Director of Community Engagement, Daniel Colpoys, at [dcolpoys@wnyl.org](mailto:dcolpoys@wnyl.org).



# Silver Lake Nature Center Opens New ADA Compliant Trail

*Erich Martin*

Silver Lake Nature Center celebrated the opening of a new Americans with Disabilities Act (ADA) compliant trail with a ribbon cutting and celebration Saturday afternoon.

The trail connects the Earthship piece of the center to the main nature center building along Bath Road in Bristol Township. It allows visitors to go from one part of the center to another easily and through trails. The trail also connects the whole of the Silver Lake Nature Center to Silver Lake Park, both of which are part of the county park system.

The trail is the result of a multi-faceted effort. The money for the materials was donated by Parx Casino, the nature center bought all of the supplies and a Boy Scout constructed the trail for his Eagle Scout project.

“We’ve always wanted ADA trails in all parts of the nature center,” explained Jerry Kozlansky, the director of the nature center.

Terrain means some part of the land are not able to have an ADA trail, Kozlansky said.



Credit: Erich Martin/Levittownnow.com



“It really enhances the park and makes the trail much more accessible,” said Hope Sauppe, president of the nonprofit Friends of the Silver Lake Nature Center. “This is one of those occasions where you just have to take time to celebrate your accomplishments.”

Josh Stephens, the Eagle Scout who helped to construct the actual trail, said he spent a lot of time at the nature center as a child and wanted to spread some love there for his Eagle Scout project.

“I wanted to do good for the community and make the trails a little more accessible,” Stephens explained.

Bigger projects, like the new trails, wouldn’t be possible without gifts and donations like the one from Parx Casino that made the trails possible, nature center officials said.

“It gets everyone inspired and gives us the funds and the means to be able to do what we want to do,” explained Patti Ann Cutter, the assistant director of the nature center.



Credit: Erich Martin/Levittownnow.com



# 17 Years in the Making

*Lynnette Torgalski*

Western New York Independent Living (WNYIL) is a place of employment enriched with individuals living and working in the community with disabilities working with others to empower, educate and in accessing equality to work and live in their community of choice.

For over seven years now I have been part of this team that makes up the staff at WNYIL and have served in various capacities prior to becoming the director of the Independent Living Center based in the Buffalo office. What you might not know, I am an individual with disabilities as well as the parent of children with disabilities. I am proud of the disabilities I live with as well as those of my children since they contribute to the person that I have become and who they are growing into being.

My advocacy started almost 17 years ago with the birth of my twins. From that day, I needed to learn about the various medical providers, what their specialties were and their purpose in my children's life. Over the past 17 years there have been no fewer than 28 medical specialists that I can list off the top of my head and interactions with over 100 staff at each of those check points. We had no fewer than 2-6 medical appointments in a week for years, and came to a break only due to the November storm and driving bands where I canceled four appointments.

It is also important to understand that those appointments were anywhere from 5 – 75 miles from home and could last up to 4 hours.

Outside of the medical appointments there were Committee on Preschool Special Education (CPSE), Committee on Special Education (CSE), 504 meetings, monthly Medicaid Service Coordination (MSC) meetings, counseling, psychiatrist, dental appointments that exceed what the "typical parent" deals with. I spent several days a month attending trainings that could last a couple of hours to a couple of days to obtain information regarding my children's disabilities.

There is also the additional burden of paperwork when you are involved with Office of People with Developmental Disabilities (OPWDD), Office of Mental Health (OMH), Social Security Administration (SSA), Medicaid, New York State Education Department (NYSED), Adult Career and Educational Services-Vocational Rehabilitation (ACCES-VR), Department of Health (DOH). Services that we would have never accessed without learning how to access those resources, advocate within them, understanding what is available when you are a part of them.

The reason that I am at WNYIL is to make sure that the information I have gained can be



shared. I do not want another parent giving up, feeling defeated, always feeling challenged by the systems. I want to empower all individuals to recognize their ability to contribute and to live life to the fullest however they define that. I want the ability to gather and share our challenges. Most of all I want the individuals who use the resources that they are there to serve you. If services are not working, don't just stand by, learn to identify it to those who fund the programs. We can educate the systems and to make changes for ourselves, our families and others.

Working at WNYIL has empowered me to realize the strength that we have, our ability to contribute, and my dedication to the community of individuals living with disabilities to live your life of choice. This was not my original path in life, but my children have given me purpose and I embrace the moment.

I wanted to take this opportunity for individuals accessing, working and funding community based organizations to understand the person I have become and why I am the director that I am at WNYIL.



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# UPCOMING EVENTS

**5th Annual Night for Independence Gala**  
Saturday, May 5, 2018

**Disability Pride Parade and Festival**  
Saturday, July 28, 2018

**ILNC's Fishing Derby**  
Sunday, August 5, 2018

**Summit on Aging**  
Tuesday, September 18, 2018

For more information contact  
Marykate Waringa at 716-836-0822, ext. 146 or [mwaringa@wnyil.org](mailto:mwaringa@wnyil.org)

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# A Night for Independence

# Gala

*To benefit Independence Express Transportation*

*Saturday, May 5, 2018*

*High end live and basket items*

*Music and Entertainment*

*Sit-down dinner and a night of fun!*



Inclusion, Awareness, Visibility



# Disability Pride

**FREE!**

## Parade & Festival

**Saturday, July 28, 2018**  
**10:30 a.m. - 3:00 p.m.**

Western New York Organizations invite you to join us to celebrate the Americans with Disabilities Act and Disability Pride with **FREE** food, fun, and games will be provided.

We look forward to having you celebrate with us!

*Thank you to our 2017 sponsors:*



Niagara County Dept.  
of Health Children  
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