

ACCESS news

Vol. 35, No. 3 - Winter 2016

“Peers are a Dime
a Dozen” - ???
page 2

Disability Rights
Advocacy
page 5

OAHIO
“The Good Path”
page 8

Holiday Appeal
page 9

Upcoming Events
page 10

Western New York
Independent Living, Inc.
3108 Main St.
Buffalo, NY 14214
(716) 836-0822 (Voice/TDD)
(716) 835-3967 (Fax)

An Open Letter to the Leaders of the Western New York Community

Doug Usiak, Executive Director

Dear Community Leader:

For over 35 years, we in the disability community have worked **with you** to ensure the full integration and involvement of people with disabilities (PWD) in society. In this time, we have been successful in moving many PWD from institutions to community living, (*saving over \$0.5 Billion, alone*), and improving their access to local resources and institutions, and increasing the spending power of our citizens with disabilities. We even have a completely accessible public transit system, allowing people with disabilities to go to work, to play, and to shop! Yet we continue to struggle for the advancements we still need to make in housing and employment for all of us.

Recently, we have seen a surprising willingness for our society to move backwards by sacrificing a sizable part of our community. I speak of the likely expansion to Upstate New York of the so-called “Ride Sharing Services,” (i.e., Uber and Lyft). As it stands, presently, this would be a throwback to our segregated past, in which many PWD would be routinely excluded from the opportunities that are intended to improve conditions for all of us.

Let us be clear; we in the disability community are NOT OPPOSED to the Ride-Sharing service model, we only ask that serious consideration be given about ways to make the service accessible, as is required by law. We disagree

with the self-assessment of those companies that they have no responsibility to provide access, but we have repeatedly tried to discuss the matter, with no response from any companies using this model.

Instead, the complaints of visitors about its absence have been so heavily promoted that the concerns of equal access are being ignored by the policymakers, the press, and our entire regional leadership, in the name of self-interest.

Negotiations on a statewide level have led to comments that PWDs should be considered “Collateral Damage” in the fight to bring Ride-Sharing upstate. This forces us to ask questions of our community we never thought we needed to ask again: Why should Veterans returning from combat, needing wheelchairs or mobility devices, be considered collateral damage? Why should seniors with walkers? Why should blind people with service animals?

The truth is that NO group on our community should be seen as “just collateral damage” when considering the expansion of opportunity for the entire citizenry. The most painful aspect of this debate for us in the disability community is that we know it would be utterly unacceptable for any other minority group to be told this. Our very independence is at risk: if our exclusion can be considered acceptable collateral damage in transportation, what prevents that logic from being applied when we talk about our housing, or our health care?

This proud disabled veteran asks us all to stop and look at whom we are willing to cut loose, and for what purpose?

“Peers are a Dime a Dozen” - ???

By Maura Kelley, CPRP, MHPC Director

In November, I had lunch with a professional colleague who also heads a peer-run, lead-driven agency. He told me he had attended a meeting with many executives of traditional behavioral health agencies and hospitals, where one attendee said, “Peers are a dime a dozen”.

Well, of course, that really bothered me! I’ve had a paying position as a Peer for over 21 years, here at Western New York Independent Living, most of it with Mental Health PEER Connection (MHPC). In fact, I’ve been the only Director of MHPC since it came into existence in the early 2000’s. If only it really was so simple: just hire anyone with a mental health diagnosis, then you have an MHPC Peer. I think not! Perhaps *some* agencies think that hiring any “client”, or someone who identifies themselves as a “Peer” with no other qualifications, is acceptable, and, thus, is one who is “a dime a dozen”... but this, in no way,

shape or form, is what makes an MHPC peer!

I could fill this whole article rattling off the qualifications we require when hiring Peers. But, summing up the most crucial, being a MHPC Peer takes guts, courage, integrity, pride, tenacity, open-mindedness, acceptance, negotiation skills, ethics, personal values, individuality, and risk-taking. These are the qualities needed to push the behavioral health system and the community to respect and accept the rights, freedom, dignity, and choices of those with behavioral health issues. Despite what “some others” think, want, or perceive is best for an individual, MHPC Peers stand on their own — as should every US citizen — affirming and defending every right we have, today, as an American!

MHPC Peers hold the system accountable, and question the practices of some providers who may think they are doing the right thing, but infringe on the rights of confidentiality, parenthood, freedom, and dignity of those with behavioral health issues. MHPC Peers speak up in the media and in community forums, educating the public to better understand behavioral health issues by sharing their own experiences.

MHPC Peers do this because they have realized that they have been oppressed by family, the behavioral health system, the criminal justice system, and/ or the community, solely because of their own behavioral health issues. They react to this oppression by spurring themselves into positive action to advance the quality of life for our brothers and sisters with behavioral health issues. MHPC Peers are not co-opted to act, or think, like those who paternalistically present themselves as “knowing better for” those they serve. MHPC Peers are a team of brothers and sisters who hold each other to high standards of integrity, in order to always protect the rights, freedom, and choices, of those they serve, because they do not forget where they, too, have come from. We keep on reminding each other as an agency. “They are us; we are them.”

Within the first year of employment at MHPC, the MHPC Peers are highly trained on the practice of “Eight Dimensions of Wellness”, developed by our colleague Peggy Swarbrick, that SAMSHA (The U.S. Substance Abuse and Mental Health Services Administration) indicates are the cornerstones of recovery. In the forefront of every MHPC peer’s delivery of services is the Intentional Peer Support process of developing partnerships and dialogues, created by another colleague, Sherry Mead. Mary Ellen Copeland’s evidenced-based WRAPs (Wellness Recovery Action Plans) are taught to MHPC staff, annually, by trainers instructed by the Copeland Center. The employment of a thorough understanding of the neurological, biological, psychological and social effects of trauma, known as “Trauma-Informed Care”, is taught to MHPC staff by national presenters of the Mental Health Empowerment Center in two days of training, annually. The skills of Advocacy are honed, practiced, and exercised throughout MHPC peer employment.

MHPC Peer Programs have also been a part of several groundbreaking research projects

in collaboration with the University of Buffalo's Department of Family Medicine, the New York State Mental Hygiene Research Department, and the Columbia University Mental Hygiene Research Project.

MHPC peer programs and advocacy issues are cited and featured in our articles in many national publications including: "How Empowerment Changed My Life: 'I don't have to live in my car anymore...'" in the U.S. Department of Education's Rehabilitation Services Administration's *American Rehabilitation*, Autumn 2004; "Don't Let Mental Illness Stop You From Working" in the *Buffalo News*, June 20, 2012; "Peer Connection: Empowering people with mental illness to become more self-sufficient." In Horizon Human Services' *Horizon Health Pulse*, Spring 2003; "Why I Choose Sanity" in the *Peace of Mind* section of MilwaukeeRenaissance.com, April 2009. With four colleagues, this writer co-wrote "Assessing the Financial Capability of People with Psychiatric Conditions to Develop a Peer-Supported Economic Empowerment Intervention" in the New York State Office of Mental Health's *January 2015 News*.

We were quoted in the National Council on Disability's January 2000 book "*From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves*"; and in Buffalo News' *NeXt Magazine*, March 12, 2014 in "Places for Depressed Teens to Turn" by Rachel Whalen; and involved in the New York Association for Psychiatric Rehabilitation Services' "'We Can Save' Campaign: A Workbook for People in Recovery Seeking Economic Self-Sufficiency". Other publications cited are by the National Commission on Human Rights, and the American Psychiatric Journal of Medicine.

MHPC's face has been featured presenting peer advocacy issues on national CBS and CNN news. MHPC peer programs have been presented on local, state, and National platforms. MHPC staff sit on State government boards, including Governor Cuomo's Behavioral Health Services Advisory Council, NYS Commission on Quality of Care & Advocacy for Persons with Disabilities, Protection and Advocacy for Individuals with Mental Illness (PAIMI), Governor Cuomo's Inclusive Workforce Alliance, and State and local Board of Directors. MHPC has also received numerous advocacy, exemplary program, and professional of the year awards presented by Government, State, and Local agencies.

The MHPC mission is "Peers Empowering Peers Together". However, it is only thanks to our history, values, beliefs, integrity, the training we've received, our contributions to research, informing the media, educating the Country, and recognitions we've received, that this is true.

"Peers a Dime a Dozen"? No person should be valued so cheap, especially an MHPC peer!

And, oh...this item doesn't even mention our array of phenomenal recovery outcomes that will be presented in my next article! Stay tuned, here...

Disability Rights Advocacy: 2016 was a mixed bag; all hope not lost in 2017

By Todd Vaarwerk
Director of Advocacy and Public Policy

While 2016 brought some good news on the disability advocacy front, some are primarily defensive actions to stave off attempts to undermine our hard-won rights.



National Holding Action

In the current U.S. Congress, there were not one but *three* bi-partisan bills proposed for the House of Representatives that would considerably complicate anyone making Americans with Disabilities Act (ADA) complaints about businesses that discriminate against people with disabilities. One even called for criminal penalties for complainants who did not correctly jump through a number of hoops before taking action. Thanks in large part to the uproar raised by advocates, as of this writing, none of the generally-termed ADA Notification Acts have emerged from the House Judiciary Committee for a floor vote – but they were not withdrawn, either.

Statewide Success

The New York State Department of Health has authorized a new category of Advanced Home Health Aides, which will allow Personal Attendants with additional training to perform some tasks previously reserved for nurses, enabling more people with disabilities to live outside of institutions.

Progress is a mixed bag, locally

At least since the 1970's, folks in Western New York had become resigned to a downward slide in their fortunes, as much manufacturing and industry have been closing down or moving out to other states and overseas. Suddenly, with the arrival of the Buffalo Billion and other “economic engine” investments to underwrite development of twenty-first century technologies, we're hearing about a renaissance in our region. Solar City; the Buffalo Niagara Medical Corridor; the Larkin Square business and outdoor entertainment center; the Buffalo Institute for Genomics; the Canalside multi-purpose event area; sports teams owner Terry Pegula's Harbor Center, they all give us hope that things are on the upswing!

But before we cheer too loudly, we fear that the most diverse minority group, with members from all races, religions, ethnicities, economic classes, ages, genders, and lifestyles, **citizens with disabilities**, may be disregarded. Here are just two examples...



Approved by the City Common Council on December 27th after years of discussion, the Buffalo Green Code was intended to be a Land Use Plan. That is, a complicated zoning ordinance, directing what types of construction and renovation can be done in different areas, such as Brownfields and the Waterfront. But the detailed requirements in its Unified Development Ordinance have become a defacto building code, brushing aside the existing New

York State Building Codes – but lacking the State’s disability access provisions. The federal Americans with Disabilities Act (ADA) allows states and localities to enact protections that are MORE rigorous than its federal Accessibility Guidelines, but **not** ones that have less safeguards or none! As the new Green Code kicks in, our advocates have their work cut out for them!



Did someone say “Uber”?

The ride-sharing company Uber, and, to a lesser degree, its competitor Lyft, have been waging media campaigns that cite complaints by visitors – and bar owners – that Upstate New York lags behind the nation in not offering a ride-sharing service that is scheduled and paid for via a smart phone application. They urge citizens to demand their State legislators remove the legal barriers to their Empire State expansion beyond New York City.

Anyone who has learned of WNYIL’s objections to this expansion may be surprised to hear that the disability community is **NOT OPPOSED** to the coming of the ride-sharing companies, (technically Transportation Networking Companies or TNCs), *as such*. The greater convenience of scheduling and payment through smart phone or computer apps seems appealing and progressive. However, the “fly in the ointment” is their steadfast refusal to promise to find a way to accommodate people with some disabilities, such as those who use wheelchairs

that do not fold.

Following the standards of the Americans with Disabilities Act (ADA), State law demands transportation companies make disability access accommodations for those with mobility disabilities, like wheelchair and scooter users. We find ridiculous Uber's claim of exemption from disability access requirements, saying they are not a "transportation company" under the law, just an "intermediary" that brings riders and drivers together through their smart phones. Since they screen, dispatch, coordinate, regulate, and pay the drivers, TNCs function like taxi companies, and the ADA says they must have a means of accommodating riders with disabilities! When pressed, they point to the UberWAV (Wheelchair Accessible Vehicle) pilot program in select cities, which is just a name for formal partnerships with existing local wheelchair taxi companies to which the riders are referred. Wheelchair taxis are not available in every town in Upstate New York.

While the TNCs have refused to even discuss the issue with disability advocates, some leaders elsewhere in the State have suggested that TNC expansion is so important that sacrificing citizens with disabilities is acceptable "collateral damage". It would be unimaginable to expect any other racial, ethnic, gender, lifestyle, or other sub-set group of the population to quietly agree to be "thrown under the bus".

You were promised a peek into a possible 2017

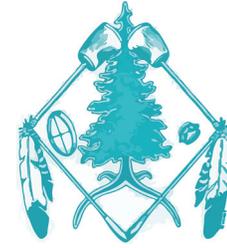
Due to remarks made before and after the campaign questioning the need for social programs, many in our community are gravely concerned about the incoming Donald Trump Administration's attitude toward disability rights. It may be counter-intuitive, but this writer suggests we wait and see what the new year will bring. Prior Republican administrations with which advocates have worked found appealing that the supports empowering people with disabilities to live independently in the community cost the government only \$35,000 to \$40,000 per year, versus \$120,000 for nursing home institutionalization.

To sum up...

Some of my colleagues have been fighting for over forty years to achieve the rights that we are just barely holding on to. We must be vigilant or they could be lost in the name of expedience for some people and supposed "progress" for the community.

OAHIIO “The Good Path”

Cynthia Printup-Harms



OAHIIO Services

Independent Living Specialist

The Native American Independent Living Specialist provides assistance and instruction to Native Americans wishing to learn or relearn daily living skills. These could consist of matters such as managing family activities, household chores, work tasks and education assignments through the use of tools, techniques and assistive technology for greater independence.

Benefits Advisement

A program designed to assist people in obtaining/maintaining government benefits in order to manage their disability. Benefits advisement provides information & referral, advocacy, and peer counseling in obtaining SSI, SSDI, Social Services (Health Insurance, Food Stamps, Cash Assistance) benefits and maintaining them.

Student Educational Supports Specialist

Student Educational Support Specialist services provides consultation and advocacy services to Native American Indian students with disabilities, and their families, throughout WNY. This program was created to assist the Native Indian student in ensuring their rights while navigating the educational system.

Family Reimbursement Program

The New York State Office of People with Developmental Disabilities (OPWDD), offers families of developmentally disabled consumers to utilize services through the OAHIIO Family Reimbursement Program. This program, upon approval, allows goods and/or services, not funded through other sources, to be purchased by the family, provision of a receipt is needed for reimbursements. Preference is given to Native American Indians during the first half of the calendar year.

OAHIIO Mission

The OAHIIO Council, staff, and volunteers are comprised of Native Americans, the majority of which are individuals with disabilities. We operate a consumer focused, person centered, culturally based organization, creating opportunities for choice, independence and community participation by advocating for the elimination of physical, cultural and attitudinal barriers that restrict individual access to entitlements and support services.

473 Third Street, Niagara Falls, New York 14301

Phone: (716) 284-4204 ext. 127 • Fax: (716) 834-5647 • Toll-free: 1-800-348-8399

Dear Friend of Independent Living:

Winter is coming quickly to Western New York, and those who love skiing, tobogganing and sledding are looking forward to a blanket of the white stuff. But the approaching times of snow and cold pose particular challenges to citizens with mobility, visual and other disabilities, who don't have a sport utility vehicle in the driveway to take them where they need to go.

How about public transportation? The Niagara Frontier Transportation Authority's wheelchair-lift-equipped Paratransit vans can be a help, but they only travel within three-quarters of a mile of the fixed-route Metro bus and rail lines. Outside Buffalo and its immediate suburbs, service is scant in Erie County, and very limited in Niagara County. Only a few Regional Transit Service vans travel to a handful of municipalities in Orleans, Genesee and Wyoming Counties.

While some private van services will cover Medicaid hospital and doctor visits, who will take people to go shopping, to church, or for visits to friends and relatives? This is so important to keep families together, especially during the holidays!

In the five counties just mentioned, the Western New York Independent Living Family of Agencies' Independence Express (IE) offers seven-day-per-week curb-to-curb wheelchair and ambulatory van service for customers with disabilities, by appointment, at rates much less than wheelchair taxicabs.

However, what IE takes in doesn't cover the cost of operating this vital service: salaries, fuel, maintenance, licensing fees, and other expenses. To continue empowering people with disabilities to live independently in the community, we need your help!

To make this process easier for you, we have some suggested levels of donations, which you'll find on the enclosed card. Remember, your contribution is tax deductible!

Please be one of the enlightened folks who realize the important role that transportation plays in enabling your neighbors with disabilities to live outside of institutions – especially in Western New York Winters!

Thank you for your thoughtful consideration.



Dennis M. Kessel
President

UPCOMING EVENTS

**New York Association for Independent Living
(NYAIL)'s 2017 Annual Legislative Day**
Monday, February 13, 2017

ILNC's Policymaker's Breakfast Friday, April 7, 2017
8:30 a.m. - 10:30 a.m.
Antonio's Banquets, Niagara Falls, NY

MHPC's Healing Voices Showing
Thursday, April 27, 2017
Time & Venue – TBD

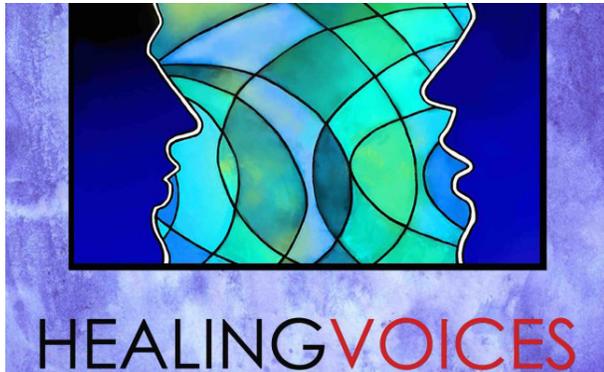
4th Annual Night for Independence Gala
Saturday, May 20, 2017
5:30 p.m. - 10:00 p.m. Salvatore's Italian Gardens

ILGR's Policymaker's Luncheon
May 2017
Time & Venue – TBD

Olmstead Day (ILNC)
Thursday, June 22, 2017
11:00 a.m. - 3:00 p.m. Hyde Park, Niagara Falls, NY

For more information contact Heather at 716-836-0822, ext. 146
or hmattiuzzo@wnyil.org

Mental Health PEER Connection invites you to attend the
“Healing Voices” movie premiere and the Policymaker’s Breakfast



Thursday, April 27, 2017

Amherst Theatre by Dipson
3500 Main St., Buffalo, NY 14226
6:30 p.m. - 9:30 p.m.

*Free of charge, with a suggested donation of
\$5.00 to go to the MHPC Housing Fund*

PEER Connection 9th Annual
**Policymaker's
Breakfast**
Friday, April 28, 2017
Templeton Landing
2 Templeton Terrace
Buffalo, NY 14202
8:30 a.m. - 11:30 a.m.
Tickets \$30
Guest Speaker: Richard Fontana
Lovejoy District Common Council Member



When you shop at AmazonSmile, Amazon donates 0.5% of the purchase price to Western New York Independent Living Inc. Bookmark the link <http://smile.amazon.com/ch/22-2316065> and support us every time you shop.



*This holiday season,
make a difference,
with a meaningful gift from*



**EMBRACE THE
DIFFERENCE®**

AVAILABLE AT

REEDS  JEWELERS

**\$10-\$100 IS DONATED
WITH EVERY PURCHASE**



We are a participating charity

WWW.EMBRACETHEDIFFERENCE.ORG

Thank you to our Night for Independence Gala Sponsors!



**Buffalo Bills
Alumni Foundation Inc.**



3198 Main St.
Buffalo, NY 14214
(716) 836-5337



MIRANDA
REAL ESTATE & MANAGEMENT
716.836.6600

Queen City Imaging, Inc.



EFPRGROUP^{LP}
Certified Public Accountants

280 Kenneth Drive, Suite 100
Rochester, NY 14623
Phone 585.427.8900
Toll-Free 800.546.7556

northtownauto.com



866-650-7408



BlueCross BlueShield of Western New York
257 West Genesee Street
Buffalo, NY 14202-2657



People Inc

Where your world opens up.



EBC is proud to support
**WNY Independent Living
& The Annual Night for
Independence Gala!**

1.877.6EBCINC

www.ebcinc.net



M&T Bank

Understanding what's important®



9580 Main Street
Clarence, NY 14031

716-759-6811

www.mainmobility.com

What Makes a Good Tenant?

- A) Pays the rent on time
- B) Respects the property
- C) Respects the neighbors
- D) ALL of the above



HOME

Housing Opportunities Made Equal

Being a good tenant has **NOTHING** to do with your race, whether you have kids or a disability, or your sexual orientation.

If you feel like you have been discriminated against,

Call HOME - (716) 854-1400

You have rights, we can help!

Sponsored by a grant from the U.S. Department of Housing and Urban Development.

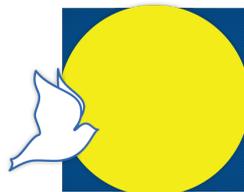


Lions Clubs
International



CARETIME

The Best Home Healthcare Software
Economical Visit Verification
888-400-5048
www.caretime.us



**Southwestern
Independent
Living
Center**

843 North Main Street
Jamestown, NY 14701
(716) 661-3010
www.ilc-jamestown-ny.org



Eaton
All for a day's work

Eaton Office Supply
180 John Glenn Drive • Amherst NY, 14228
Serving Western New York and the Greater Buffalo Region



Independent Living of the Genesee Region (ILGR) is participating in the

**the New York Association for
Independent Living (NYAIL)'s
2017 Legislative Day in Albany**

Monday, February 13, 2017

Please join us.

We need YOU to be there!

Free transportation and meals for our friends and consumers.
The bus will be leaving directly from ILGR's 113 Main Street,
Batavia office at 6:15 a.m., and returning at 9:00 p.m.

We should arrive at the Legislative Office Building in time for the
11:00 a.m. NYAIL Rally and presentations, going to scheduled meetings
with our region's legislators starting at 12:00 noon.

To save your seat, call Donna at (585) 815-8501, extension 411

Your voice is particularly important, this year!

Donald Trump has emphasized:
enforcing *existing* anti-discrimination laws;
eliminating "unneeded" regulations and bureaucracies to reduce waste;
minimizing the federal role in education;
and leaving issues affecting people with disabilities to the forces
of supply and demand.

It's up to us and our fellow advocates to tell our legislators that,
regarding pro-actively establishing equal rights for citizens with disabilities,
the ball is in their court!

A Night for Independence

Gala

To benefit Independence Express Transportation

Saturday, May 20, 2017

Salvatore's Italian Gardens

6461 Transit Rd., Depew, NY 14043

5:00 p.m. - 9:00 p.m.

\$75.00 per ticket • \$125.00 for two (2) • \$600 table of ten (10)

(Basket, premium auction, and live auction separate costs)

Emcee: Angela Christoforos from Channel 4 (WIVB)

High end live and basket items

Music and Entertainment

Sit-down dinner and a night of fun!

For more information

and to RSVP by May 1, 2017

www.NightForIndependence.org

Phone: Heather Mattiuzzo (716) 836-0822 x 146

Email: hmattiuzzo@wnyil.org

Inclusion, Awareness, Visibility



Disability Pride

FREE!

Parade & Festival

SATURDAY, JULY 22, 2017

PARADE: 10:30 - 11:30 a.m.

streets around Coca-Cola Field
(Niagara Square to Coca Cola Field)

FESTIVAL: 11:30 a.m. - 3:00 p.m.

in the VIP Section at Coca-Cola Field

BY SEA: 11:30 a.m. - 3:00 p.m.

at Canal Side

First 250 attendees to the Festival will receive two free tickets to the Bison's Home Game on ADA Day, July 26th 2017!