

# ACCESSnews

Vol. 35, No. 2 - Summer 2017

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### What's it all about...Mr. President? (An open letter to President Donald Trump)

Douglas J. Usiak, Executive Director

A lot of noise and haranguing has been coming, (and, I suspect, will continue for some years), from our Nation's capital about capping — if not eliminating — the federal funds going to health care, and otherwise minimizing the spending of dollars on programs in the public sector that empower people with disabilities. We all saw that the original budget proposal issued by the White House was shocking in its numerous recommended cuts, and it has been largely followed by the House of Representatives in its proposal. If such a budget is allowed to pass through both houses of Congress and take effect, it will begin to put the brakes on, if not compel a full U-turn, on our progress in achieving our rights as people with disabilities, as well as our efforts to contribute to society.

### You like smart people, right?

So, Mr. President, stop and think for just a minute about this question... "Who is the smartest person in the world?"

Most people say it's Stephen Hawking, the English theoretical physicist and cosmologist, who is a person with a significant disability, amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's Disease). The holder of multiple academic degrees and recipient of many honors, including the Presidential Medal of Freedom in 2002, he employs a wheelchair for mobility, and uses augmentative communication technologies to speak to us and convey his knowledge and wisdom.

You might ask, "And how was this all accomplished?"

Logically enough, it was advancements in technologies that give people with mobility disabilities the ability to travel, and communication technologies that provide people who can't talk with the ability to speak.

How can we measure the immense contributions this one man has made, the unique knowledge he is still bringing to the world? Can we even begin to place a dollar figure on what he has done, and whom his insights have stimulated to advance the progress of science? Can we really capture his contributions to the advancement of human existence? I suspect not, but with some personal care, assistive technology, and a will to contribute, the "smartest man in the world" continues to provide us insight, knowledge, and wisdom — even though he can't walk, talk, or feed himself!

Now please reflect on this single individual and all he has done since his disability entered his life...and now consider how many other people with disabilities are out there who just need some technology to unleash their contributions to our society.

### The bigger picture

How many other scientists are there who need some accommodations for their disabilities? Not to mention artists, bankers, businesspeople, and just ordinary men and women with disabilities who want nothing more than the ability to get a job, buy a house and raise a family.

To take this thought further, what is the economic impact of the totality of all Americans who have disabilities? It doesn't matter whether they are on Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), public assistance, are working or have inherited millions. We all need to live somewhere, eat, and purchase our consumables, as we travel our pathways through life. This leads to billions, if not trillions, of dollars every year, as we, the people with disabilities, and our families contribute to our Gross National Product. So, why wouldn't we want to ensure that people with disabilities have the tools we need to work?

### It all starts with education, then working...and voting!

Our country realized, generations ago, that it was best that all citizens have a basic education. And why was that?

I won't even attempt to answer that question, since the list of benefits to society is endless, and most consider it one of those "truths that is self-evident". So, why would we want to curtail education for people with disabilities?

Do we really want to confine students with disabilities in the basements of schools to learn, as they did in **my** elementary school?

Do we really want, once more, to imprison people with disabilities in public-supported warehouses to live and die, instead of helping them, literally, to get off their backs and into jobs?

And, Mr. President, think of all the votes a candidate could get, if we made sure that people with disabilities could vote without obstructions, barriers, and negative comments about opening the process to them!

### Take MY life, please!

Yes, Mr. President, I have heard patronizing comments about my desire to vote by myself, using the accessible voting machine, even though I am a Veteran who lost his sight in military service, and who wishes to vote privately for my presidents, senators, congressmen, state legislators, county elected leaders, and my town's legislators. I wish my vote to be as private as you keep your income.

Mr. President, I speak as a person with a disability who acquired his impairment later in life: it was the programs and services I received that helped me to get where I am today.

It was the support of my peers, that is, other people with disabilities, that encouraged me to achieve what I wanted; even though many others in the rehabilitation/education system assumed I couldn't do it, "so, why try?".

It was the laws of this land that said, as a person with a disability, I had *the right to try*: to make it or fail trying, like any other person.

It was the technologies that I was able to use to compete in the workforce and get me here.

### And, where am I?

I am an old man with a wonderful wife, and three wonderful daughters, (who are all working and contributing in the sciences, arts, and business); I'm a grandfather of two grandchildren, a home owner and a taxpayer. Oh, and, by the way, I run a private human service agency that employs hundreds and serves thousands, but that's just another aspect of my life, and not the most important.

I love this country, that enabled a 21-year-old kid, whose accident took his sight forever, to advance himself. I love this country that gave me the opportunity to return to society, to compete, win or lose, and contribute my skills, knowledge and efforts to my community.

#### So, Mr. President, what IS it all about?

It's about Education of all people;

It's about Empowering all people to take charge of their lives and not be held back because of a disability;

It's about Equality for all, so we all can be part of America and not be met with hostility, hate, and mockery.

Isn't THAT a deal you could get behind?

### We are the community... We belong

Maura Kelley, CPRP, CPS-P Director, Mental Health Peer Connection (MHPC)

Literally for decades, MHPC has embraced WNYIL's mission to be a catalyst for change and accessibility **in** the community. Now, I'd even go so far as to say that not only are we **in** the community, but we **are** the community! In my position as the Director, it has been my privilege to represent MHPC throughout New York State, and sometimes the Country, interacting with, and listening to, people in government, in businesses, from insurance companies, and participants in community meetings. I frequently make the point that MHPC is *all about* community, in that we *represent* the community...we *look like* our community...we have improved the access to — and of — our community.

In many meetings and conferences, I hear the State Department of Health, managed care organizations, the State Office of Mental Health, and traditional mental health providers express their frustration that they are not able to *reach* us. (That is, the marginalized "high users of service", "high-need individuals", and so on.) Interestingly, in their confusion, they frequently turn to MHPC seeking some "magic answer". I have to wonder, how can they **not** know? How can they fail to understand that they need to speak to us and *really listen*?

It seems that the gap between the "haves" and the 'have nots" is so wide that those who are tasked with serving our needs do not know how to talk to us, reach out and engage us, or understand us. But I know that this is America, where we take our liberties and freedom very seriously, and people, **all people**...well, *most* people, have choices. We at MHPC choose to be a part of the society that we serve, as far as living, playing, *and buying* in our community. In our minds, we are no different from the people we serve, because *we are* 

them, and they are us. We participate in the same churches, community centers, daycares, clinics, neighborhoods, Tae Kwan Do classes, gyms, soup kitchens, grocery stores, apartment complexes, musical events, foods, etc. We also have the same types of diversity: diversity in race, gender, disability, marital and family status, sexual orientation, and much, much more.

After many decades of being isolated by stigma, it feels nice to be "on the inside", to be included, and a part of, a larger entity. Admittedly, we still have a long way to go to achieve full acceptance, but we *are* getting there. In fact, we have tangible proof that we are embraced by the community. This past April, MHPC invited the public to two separate events occurring within 24 hours. The first event was the premier local viewing of a documentary movie, "Healing Voices"; the second was a fundraiser for the MHPC housing fund, (money used to assist people labeled with mental illness in improving their living situations), a Policymaker Breakfast.

The "Healing Voices" night was an effort of the MHPC Council to bring the community together to see five years in the lives of real people who hear voices, and have a conversation on the issue. We held the event at a commercial venue, the Amherst Theatre by Dipson in the University District in Buffalo...and boy, did the community show up! We had standing room only, as the theatre filled with families, church leaders, University students and professors, neighbors in the University District, State employees, and other people whom I could not place. We all watched the movie and then we talked...about recovery, choice, openmindedness, and stigma. It was a simple conversation, within the community, about people "labeled with mental illness". Without making judgments, we shared with one another, and questioned each other. I think many gained something many of us didn't have at one time or another in our lives: **Hope**. This was never expressly mentioned, but I truly believe that the event caused people to leave the theatre thinking one thing: *I belong!* 

The next morning, different folks than the night before came to the fundraiser breakfast for our "Housing Fund". People just came pouring into the Templeton Landing Banquet Hall, on the Buffalo Marina, to participate and give to our cause. Among those attending were mental health agency providers, employees of peer-run agencies throughout the State, people who have benefited in the past from the fund, half-way house residents, people living in government-subsidized and Mental Health housing. We had a keynote speaker from the Buffalo Common Council who talked about his neighborhoods, and, to my knowledge, didn't mention mental illness or Mental Health, once. This fundraiser was meant to help our brothers and sisters, that is, *ourselves*, to move up in — not out of — the community. We raised a modest amount of money, enough to assist a few more people this coming year. Once more, people with Mental Health Issues pulled off an event that gave "Hope"...and I truly believe people walked away feeling that they "belonged".

Looking back over the history of our movement in Western New York, I cannot imagine this particular combination of inclusive events ever happening before. Some of our catchphrases

that will probably become the norm: "No, we will not go away!" "Yes, we are the community!" "Yes, We Belong!"

To find out more about upcoming Community Events that MHPC will be hosting, please check out our website at: http://www.wnyil.org/mhpc.html.

### The Importance of Advocacy

By WNYIL Staff Advocates

"Advocate as if your life depended on it...For indeed it does" – Justin Dart, Jr. ("The Father of the Americans with Disabilities Act")

As this issue of the <u>Access News</u> approaches, we face some of the most serious challenges ever to critical services upon which people with disabilities depend, in order to continue as fully functioning members in our community. The Health Care debate includes reductions to Medicaid. Budgetary projections for federal spending reduce most, if not all, programs for people with disabilities and seniors in favor of other spending.

On the state level, while things have come a long way, we still face great challenges. Medicaid redesign is in full swing, and with the change to Managed Care, we need to learn to deal with new players in a very old and important system.

Hardest of all, unlike when independent living started in the 1970s, we now have something to *lose*, whether it be services we depend on, or the laws that guarantee our freedom.

With these things in mind, we must remember that *advocacy* is the most important tool we have to make it through these trying times. We must apply the same logic as we apply to security: "if you see something, *say* something!...And get your friends to say it too!"

There is no more important time to write, call, or visit your elected officials about things that you need and you're not getting, or, of which you need more. If you make a request, and receive a "No" in response, file an appeal, write a policymaker, or complain to the media. Being our own best self-advocates is the very freedom we fight to have — so shouldn't it make sense that sometimes we need to fight to keep it?

One caution we might extend, however: we must avoid making this about political parties. Our crisis isn't about Democrats or Republicans. The message must be about our civil rights as *people* living within our communities. Our needs are more than budget line totals — and that message crosses political parties. Allies to save the services we need may be right on the other side of the political aisle, and it is critical to our success that we don't ignore or forget

them. After all, the late Justin Dart, Jr. was one of the most committed, enthusiastic and effective advocates the disability rights movement has ever seen – and a Republican!

If you've never done any of the things we've suggested before, don't worry. That's what the staff of the WNYIL Family of Agencies is for. We can help you learn what you need in order to effectively communicate what it is that you want. In addition, our social media pages will keep you up-to-date regarding the things you might want to keep an eye on.

Justin's quote was true when this movement began, and it resonates even more today. Lead on, readers!



### **UPCOMING EVENTS**



A Taste of Independence
Wednesday, September 13, 2017
Batavia Country Club
7909 Batavia-Byron Rd., Batavia, NY 14020
5:30 p.m. - 8:00 p.m.
\$15.00 per ticket





Saturday, September 16, 2017 Gratwick Park, North Tonawanda 11:00 a.m. - 3:00 p.m.

For more information contact
Marykate Waringa at 716-836-0822, ext. 146 or <a href="mailto:mwaringa@wnyil.org">mwaringa@wnyil.org</a>

WNYIL is conducting a Consumer Needs Survey of individuals who have received services from the Agency. The Board of Directors would like to know what your needs are in regards to programs and services WNYIL offers. The survey will be open until September 30, 2017. Thank you! <a href="https://www.surveymonkey.com/r/WNYILNeedsSurvey2017">https://www.surveymonkey.com/r/WNYILNeedsSurvey2017</a>

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### OAHIO "THE GOOD PATH"

Volume 1 / Issue 1 JUNE 2017

#### **RECENT NEWS**

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Easter Ham Giveaway!!!



From left; Corinne Abrams, Cynthia 'Sam' Printup-Harms, Lois Jircitano and Tina Kettle

### ADMINISTRATION FOR COMMUNITY LIVING GRANT FUNDING OAHIIO's DEMONSTRATION PROJECT

OAHIIO is a proud recipient of the Native American Independent Living Demonstration (NAILD) Project. There were only three of these grants awarded in the entire country and Western New York Independent Living's OAHIIO is pleased to be one of them! This grant is intended to develop relationships and bonds within existing Centers for Independent Living to increase service to individuals with disabilities in Indian Country. We seek to gain understanding of the service needs of Native Americans living with disabilities who are residing on and off reservations in Western New York. We realize that our native populations differ greatly from urban to rural, as well as throughout each of the different Nations' territories that exist throughout New York State and the surrounding area. We embrace the diversity among Native Americans and wish to help improve the quality of life of those living with disabilities.

As part of the demonstration project, we seek to improve cultural competence regarding the needs of specific tribal organizations. Meaning that we are willing to work with Nation Leaders to incorporate the Independent Living

philosophy into our efforts, in a way that promotes diversity, cultural understanding and sensitivity and helps to establish lessons and best practices for other Independent Living Centers to utilize for service delivery. If you know someone who could benefit from OAHIIO's program, please feel free to refer them to us. — *Corinne Abrams* 

#### OAHIIO SPRINGING INTO ACTION IN THE COMMUNITY!

The OAHIIO team is focusing its efforts on approaches to help heal our Iroquois communities. One of the recurring issues we have found is the long-term effects of trauma in families. Trauma is the root of many of the drug and alcohol issues we have on the reservation, as well as domestic violence. Dr. Lois Jircitano has been advocating to get more Iroquois people trained in Trauma Informed Care. This means that the individuals who are already working with our people will be prepared to help those suffering from Post-Traumatic Stress Disorder (PTSD), resulting from their trauma. Instead of possibly turning to alcohol or drugs, they will have the opportunity to talk to someone who is trained to guide them through the healing process in a healthy way. We will have members from the Seneca Nation of Indians Cattaraugus/Allegany, Tuscarora and Onondaga who will participate in the Training.

Together, we are working with the University at Buffalo to begin this training in October. Recently we received the good news that UB has decided to train our participants at no cost to any of the nations! We at OAHIIO are grateful for the opportunity to become trauma-informed care providers. — *Corinne Abrams* 

### WOMEN'S PLACE FOR SPIRITUAL WELLNESS

The Mission of the Women's Place for Spiritual Wellness, or, in Tuscarora Language, Kakunewe?kye He?:we Ekaku?tikehrakwasnek, is to assist and empower Native American women and their children to build healthy, productive and stable lives, free from domestic violence and/or sexual abuse. And also, we wish to maintain individual and Native community support through aftercare initiatives designed to sustain healthy life choices of the women and children assisted under the services of this program.

The need for mental health services in our families is clear: we are still currently striving to provide enough funding to buy a house and provide families with a place to stay; we will continue until we reach our goal of providing this safe haven for families and individuals to use. We are looking to get the Women's Place for Spiritual Wellness up and running within the next year! Currently we are looking for any donations to help get our initiative for the Women's Shelter up and running. If you would like to donate, please contact Lois Jircitano (716) 836-0822 ext. 220. — Corinne Abrams

For more info please visit http://www.womensplacespiritualwellness.org/

### FULL CIRCLE: EXPERIENCING INDEPENDENCE

When I first came to Western New York Independent Living, Inc. (WNYIL) seeking services for my son John, who is on the Autism Spectrum, I was unsure of what was available for him. I didn't know exactly what the agency did or how it worked, but I knew that my son could only benefit from a type of service geared toward his developmental disability.

After calling in to the OAHIIO branch office of WNYIL, which largely serves Native Americans with disabilities, I was referred to an Independent Living



Specialist (ILS) who assisted me with the needs of my son. The ILS came out to my home to discuss concerns and goals that I had for John.

Everything seemed a bit overwhelming with the entire process of arranging services for John, from what seemed to be endless paperwork to be signed, to countless meetings and phone calls. However, with the help of my son's Independent Living Specialist, we developed an Independent Living Plan and started to achieve some of the goals on our list.

Through outreach and referral, my son was linked to the appropriate agency to help meet his needs and goals. My son is now an active consumer with the New York State Office for People with Developmental Disabilities, (OPWDD).

The OPWDD is just one of the agencies to which a person can be referred through the Western New York Independent Living Family of Agencies. Respite, transportation, and advocacy are some of the services that John will receive through this agency. The OPWDD will also assist him with transitioning into adulthood and living as independently as possible on his own while keeping him in a safe environment.

WNYIL has also assisted John with educational advocacy. John does not take well to transitioning from one class to the next or from one school to another school. During those phases of transition, I was in close contact with an educational advocate from WNYIL. The educational advocate accompanied me to all of our Special Education meetings for John. After a lengthy transitioning period and proper placement, John is now doing a fantastic job in school. He has made the honor roll for two marking periods in a row and does exceptionally well in Art class, (art is one of his specialties).

Oftentimes, when living with Autism Spectrum Disorder and/or a loved one on the Autism Spectrum, life can frequently seem hopeless and overwhelming. After a while, it had appeared that we were finally making progress towards goals and living a relatively stable and comfortable lifestyle. Things were going good.

In December 2016, I was offered an Administrative Assistant's position with the OAHIIO branch of WNYIL. After the application process and interviews, I started the training for my new job. Everything went along smoothly and the transition was gradual, which worked out great for me. Since I started working for OAHIIO, I have had the opportunity to volunteer at our annual "Night for Independence" Gala this year. All of the proceeds went to benefit our transportation department, 'Independence Express'.



Independence Express is low-cost van transportation for our consumers. Consumers who are OPWDD-eligible like John, can receive transportation through Independence free Express. I have also had the privilege of being able to accompany my son John on a van ride to Niagara Climbing Center in North Tonawanda as one of his van rides this month. John has always wanted to try indoor wall climbing, (simulated rock climbing) and has now had the opportunity to try it out, thanks to Independence Express! — Loretta Lizzio

"Kids have to be exposed to different things in order to develop. A child's not going to find out he likes to play a musical instrument if you never exposed him to it..." -Temple Grandin

### EASTER HAM GIVEAWAY!!!!

This spring, Tina Kettle took the initiative to donate a holiday ham for Easter dinners to all of the consumers at OAHIIO. Together with the help of some volunteers, we distributed 63 hams to families in the WNY area. We would like to thank the management of Wine on Third for allowing us to store hams in their refrigerator. And thank the Seneca Niagara Gaming Corp for donating the funds we used in order to buy the hams! Nya:weh!!

This event was a great success. Everyone who received was very grateful for the caring staff at OAHIIO, who are always looking for ways to help in the community. Thanks to all who helped to make this event possible! — *Corinne Abrams* 



(MEUIT) Lois Jircitoan, Lorette Lizzio, Tino Delle and staff delinering Easter Hous in April.

Contact Us

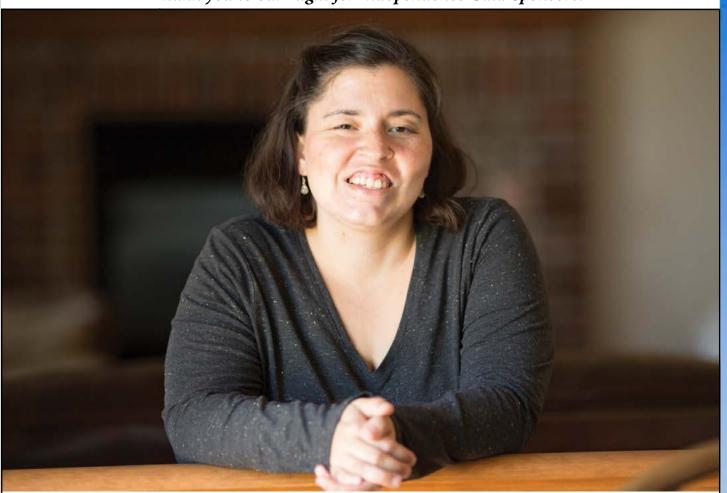
OAHHO "The Good path"

473 Third Street

Niagara Falls, New York 14301

(716) 836-0822 oahiio@wnyil.org

Thank you to our Night for Independence Gala Sponsors!





Proud to support Western New York Independent Living, Inc. and its mission to enhance the quality of life for all individuals with disabilities.

People Inc. is Western New York's leading non-profit human services agency. We help people with developmental disabilities, special needs and seniors live more healthy, independent and productive lives.

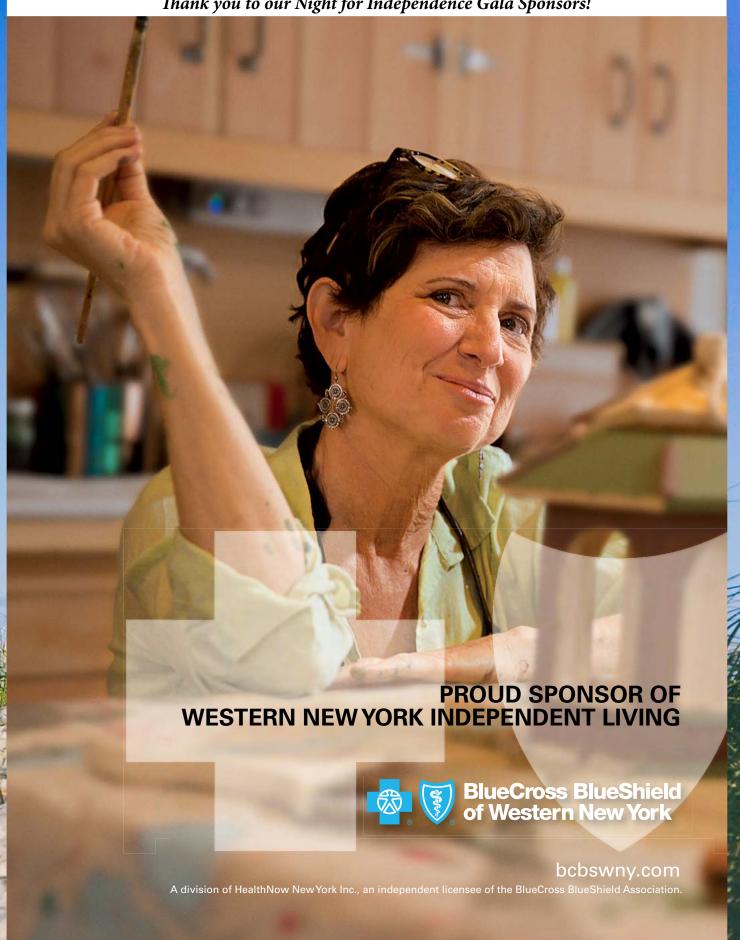


















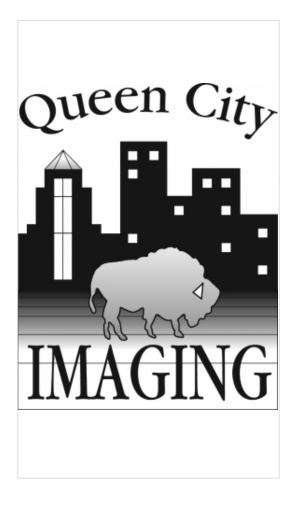


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### A Night for Independence



To benefit Independence Express Transportation

# May 2018

High end live and basket items

Music and Entertainment

Sit-down dinner and a night of fun!



# **July 2018**

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:















