



The Right Talent, Right Now

In October, New York joins the nation in celebrating National Disability Employment Awareness Month (NDEAM) to recognize the unique talents, creativity and skills that people with disabilities bring to the workforce.

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Is it Eddie? Or is it Freddy?



The Mark Twain quote “Find a job you love, and you’ll never work a day in your life,” comes to mind when talking with Edward (Eddie) O’Hearn. While Eddie’s job is one that many might not be drawn to and others would find downright intimidating, for Eddie it’s evident his job is a labor of love.

Eddie plays the popular Freddy Krueger character at the Double M Ranch’s Haunted Hayride in Ballston Spa, NY. “I just love to scare people,” Eddie said. “You never know when I’ll pop out behind someone and scare them.”

Eddie has been part of the Double M Halloween extravaganza for six years or more, playing the gloved-hand serial killer and other similar ghouls including the Grim Reaper. Whether he is hiding in the cemetery, lurking behind trees in the haunted woods or preparing to surround the hay wagon with Michael Myers, Ghost Face, the nuns and other frightening friends, Eddie finds the element of surprise thrilling.

“We absolutely love Eddie here at Double M Haunted Hayride,” said Jennifer Martin, business co-owner. “He is very reliable and has never missed a night of work. And he is one of our most enthusiastic actors.”

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Double M Haunted Hayrides employs 75 people during the months of September and October with positions ranging from phone operators, to actors, to parking attendants. They have been creating fear for over 25 years in Upstate New York.

As a Double M employee, Eddie participates in employee trainings, as well as regular and dress rehearsals before the start of their season. As a seasoned employee, he no longer has to audition for his role. The highlight of his phantom career was when a young boy he frightened actually asked Eddie for his autograph!

When Eddie is not Freddy, you can find him working at the local Speedway where he cleans and stocks shelves. Eddie has been a part of the Speedway team for more than five years. He receives job coaching from Wildwood where staff assist him in attending trainings, remind him about how to interact with co-workers and customers, and encourage him to take the initiative in completing his work or asking for additional duties. At home, Eddie enjoys researching all things horror via his computer, listening to heavy metal music from bands such as Metallica and attending concerts like the recent Slip Knot show.

OPWDD applauds employers like Double M Haunted Hayride and Speedway who realize that employees with disabilities are loyal, hard-working, dedicated assets to their businesses.

“Double M hires people of all abilities, and we are proud to do so,” said Martin.

Employers can demonstrate their support of hiring people with disabilities by taking the [EmployAbility Pledge](#). (See related article on page 6)



OPWDD Commissioner Kastner Salutes Direct Support Professionals

OPWDD Commissioner Ted Kastner joined with staff across New York State to recognize direct support professional honorees in each region during Direct Support Professional Recognition Week. Commissioner Kastner traveled to the six local celebrations statewide that honored the 24 nominees to personally thank them for their dedication and commitment to the field.

A former direct support professional at a nonprofit agency in Massachusetts, Commissioner Kastner paid tribute to the tens of thousands of DSPs working for OPWDD and our nonprofit provider partners.

“I know how hard direct support professionals work every day to ensure that people with developmental disabilities have the supports they need to live, work and enjoy life as independently as possible,” he said. “Direct support professionals are the backbone of our service delivery system, and their dedication and commitment to the people they support is truly inspiring.”

During National Direct Support Professional Recognition Week, OPWDD acknowledged and thanked the more than 13,000 OPWDD DSPs and tens of thousands of DSPs employed by provider agencies statewide for the work they do all year round.

To meet OPWDD’s Direct Support Professionals of the Year, visit our website at https://opwdd.ny.gov/opwdd_careers_training/careers_in_direct_support/dsps-2019-main.

An Update on the Task Force on Special Dentistry

Getting timely and effective preventive and restorative dental care has long been a challenge for people with developmental disabilities, not just here in New York State but across the globe. This challenge is what first prompted the creation of OPWDD's Task Force on Special Dentistry in 2002 and continues to drive its work today.

Dr. Carl Tegtmeier has been Co-Chair of the Task Force on Special Dentistry for the last eight years and says that treating people with developmental disabilities is very much like treating any other patient "Dentists must always get to know their patient and make whatever accommodations the patient requires in order to accomplish dental care." In practice, however, it may require involved behavior management a community dentist cannot offer. It is not uncommon for a person with a disability to have their dental needs assessed by a dentist only to be told afterwards that the actual "treatment" that needs to be done must be performed elsewhere. This can be frustrating for a patient and their family, not to mention inconvenient. And while it's true that sedation dentistry or the use of general anesthesia may be the only option for some patients, many who are now referred to this more invasive and costly option could be treated by their general family dentist if only the dentist had a comfort level and had the right training in patient desensitization techniques.

Getting to Better Dental Care Through Care Management

Dr. Tegtmeier says that the latest Commission on Dental Accreditation approved standards requiring all U.S. dental schools to

train students in the assessment and management of patients with developmental disabilities, along with other special needs populations, will help. So too will care management. With the advent of Care Coordination Organizations (CCOs), care managers are more in tune with their patients' total health and can take steps to intervene if they see an area, like dental home care (brushing and flossing), that is being neglected. Sometimes improving dental care can be as simple as giving an individual additional hygiene training or giving their family member or staff at their group home extra training in delivering the home care in cases where assistance is required.

Building a Network of Dentists Skilled in Special Needs Dentistry

The Task Force is now exploring ways to create more of a safety net for patients who rely on Medicaid for their dental care. Expanding the number of dentists that people with special needs can rely on for their oral health care is critical.

Ideas being discussed to increase the number of dentists include structuring a reimbursement system that is more attractive to dentists who are treating patients with more complex needs and setting up a model for dental care using the *FIDA-IDD model. This model of care has allowed patients who are part of that project to draw upon an extensive network of qualified providers. (Right now, dental care performed in an Article 28 Clinic is reimbursed at a much higher rate than in-office care.)



Enhancing Education of Direct Care Professionals

The Task Force on Special Dentistry is also focusing on enhancing educational opportunities for the direct care workforce. With funding from the Developmental Disabilities Planning Council (DDPC), the Task Force is developing online trainings for DSPs on best practices for oral health.

What if Someone Needs to Find A Special Needs Dentist Now?

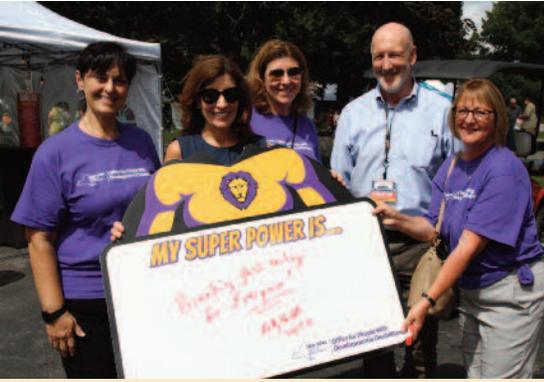
Those looking to find a dentist now can start with the OPWDD website which lists locations by county: https://opwdd.ny.gov/opwdd_services_supports/oral_health/dentistry_locations

They can also talk to their care manager about other dental care options. Additional information about managing oral health is also available on the OPWDD website.

Achieving better oral health care for people with disabilities is a challenge that needs to be confronted from many different angles. The good news is that positive change is on the horizon.

**FIDA-IDD stands for Fully Integrated Duals Advantage for Individuals with Intellectual and Developmental Disabilities and is a partnership between the NYS Department of Health (DOH), the Office for People With Developmental Disabilities (OPWDD), the federal Centers for Medicare and Medicaid Services (CMS), and Partners Health Plan (PHP) a not-for-profit health benefit plan.)*

People with Down Syndrome Are an Ever-Increasing Influence on Our Society



What's Your Super Power?

Each of us has unique strengths, skills and abilities that make us who we are. Are you able to conquer negativity with your sense of humor? Does confidence radiate from you like electricity? Does your kindness win over even the worst supervillains? Can you leap over the most complex math problems in a single bound? Can your artistic masterpieces render people speechless? Does your powerchair make you faster than the speed of light? Is your smile more blinding than a lightning bolt?

For 13 days at the end of August, OPWDD's volunteers invited people who were at the New York State Fair to stop at the OPWDD booth and share their superpower.

Fairgoers wrote their superpower on a superhero photo stand-in, snapped a photo with their phone and were invited to share their photos on the [OPWDD Facebook page](#).

New York State Lieutenant Governor Kathy Hochul joined in the fun by telling OPWDD Commissioner Ted Kastner and Communications Office staff members her superpower is to break glass ceilings. But we already knew that!

It's not too late to share your superpower! Make sure you post it with the hashtag #BeSuper @NYSOPWDD.



October is Down Syndrome Awareness Month, an annual opportunity to raise awareness and advocate for issues impacting the lives of people who have Down syndrome.

In recent decades, opportunities for people with developmental disabilities in the United State have improved dramatically, including people with Down syndrome. People with Down syndrome are proving every day that they can, and do, contribute to society, from starting businesses to acting in mainstream movies.

In 2016, New York residents John Cronin and his father, Mark, launched "John's Crazy Socks," a business that designs and sells socks with crazy and funny designs to people over the internet. At the end of its first month, John's Crazy Socks had shipped 452 orders and earned more than \$13,000 in revenue and continues to thrive today. His customers have included former U.S. President George H. W. Bush.

Kayla McKeon, also a New York native, became the first registered lobbyist in Washington, D.C. with Down syndrome. She is also a motivational speaker, a Special Olympics awardee, and has begun

working towards her associate degree at Onondaga Community College in Central New York. In 2018, after several attempts, her persistence paid off and she received her driver's license.

Most recently, Zack Gottsagen scored the leading role in "The Peanut Butter Falcon," the story of a young man who escapes from the nursing home where he is living to pursue his dream of becoming a professional wrestler.

The New York Fashion Week show in recent years has featured models with various developmental disabilities, including Madeline Stuart, an Australian model with Down syndrome, who afterward received worldwide attention.

All of us benefit when people with Down syndrome have the freedom and support they need to pursue their dreams. We applaud these amazing people with Down syndrome, and the others who are achieving success in their own ways. Their accomplishments demonstrate to the world that people with Down syndrome can absolutely achieve great things and contribute to our communities in ways that many never thought possible.

Poetry as a Form of Expression

Joelene Milano, 36, admits that she sometimes struggles with depression, but she turns to writing poetry to express her feelings, and when she shares her work, she feels less alone.

Perhaps the greatest way of sharing written works of art is through their publication, and Joelene was recently rewarded for her efforts when *Shadow of Darkness* was selected for publication in *Unique*, an art and literary magazine produced annually by ARISE, a non-profit Independent Living Center that provides disability services for people of all ages and abilities in Syracuse and Central New York.

Unique, now in its 19th year, shares the artistic visions and voices of people with disabilities. In addition to the published magazine, the entries are featured in a traveling art and literary exhibit. Joelene attended the opening of the art and literary exhibit at the Everson Museum in Syracuse and was interviewed by WSYR-TV.

More than 100 pieces of art were entered for this year's magazine. Entries are judged by an editorial board made up of volunteers, many of whom have experience in the arts. The three main elements that judges look for are original and unique pieces that are expressive and that attract and hold interest.

"I began writing poetry since I was 11 years old," said Joelene. "My mother inspired me before she died to start writing." Joelene was born in Alaska and lived there as a child. She moved to New York when her mother passed away because her father lives in Syracuse. She says she prefers to write about deep, dark and depressing subjects because they help her express her feelings.

Joelene is looking for additional opportunities to publish other poems that she has written. She also writes daily in a journal using a similar, free-flowing style of expression. When she is not writing, Joelene enjoys playing basketball and taking walks.



"Shadow of the Darkness"

By Joelene Milano

The shadow of the darkness of my future has past.
My life is drowning in sorrow
In pain
Is filled with guilt.
My life has past me by as I go back
In time when nobody was around.
In the shadow of the darkness I'm screaming
In the distance
Echoing in the distance.
As my life passes me by I feel the pain of my heart
In my throat
Trying to run away from it all.
In the shadow of the darkness
The sorrow of my pain is gone.

Everybody Get Together

In its inaugural year, Get Together Day brought out hundreds of New Yorkers to seven select state parks on September 7 ready for an inclusive day of fun for people with and without developmental disabilities.

The New York State Offices for People With Developmental Disabilities and Parks, Recreation and Historic Preservation partnered with Special Olympics New York to bring together fun, healthy activities to encourage participation regardless of level of ability, while promoting the accessible opportunities available at parks across the state.

The parks featured around the state included Sunken Meadow State Park in Long Island, Denny Farrell Riverbank State Park in New York City, Franklin D. Roosevelt State Park the Hudson Valley, John Boyd Thacher State Park in the Capital District, Green Lakes State Park in Central New York, Letchworth State Park in the Genesee Region and Buffalo Harbor State Park.

Plans are underway to continue the event next year.



The Right Talent, Right Now

In October, New York joins the nation in celebrating National Disability Employment Awareness Month (NDEAM) to recognize the unique talents, creativity and skills that people with disabilities bring to the workforce.

Throughout the month, OPWDD has paid tribute to the 58 pioneering businesses that took the [EmployAbility Pledge](#) when it was launched last year and encouraged other businesses to follow in their footsteps. And to help grow New York's workforce of people with disabilities, OPWDD, in partnership with the New York State Employment First Commission, launched a statewide social media challenge on Facebook and Twitter to encourage New York businesses and organizations, however large or small, to take the pledge. Over the past month, 23 additional businesses have signed the pledge. Businesses that take the EmployAbility Pledge receive a window decal and a badge for their website designating their business as one that supports inclusion, as well as recognition on the OPWDD website. Businesses that haven't already signed can visit <https://opwdd.ny.gov/employability/pledge> to take the pledge today!

Employees with disabilities are proven to be dependable, flexible and reliable. They are enthusiastic, have a positive effect on employee morale and remain on the job longer than employees who do not have disabilities, resulting in lower turnover and training costs for businesses.

OPWDD embraces inclusive hiring practices, and invites you to meet several employees whose contributions to the agency make an impact on the lives of the people we support.



Mike Orzel

Michael Orzel traveled a long road before ultimately joining OPWDD. Mike was born with limited use of his body and arms due to cerebral palsy, but went on to graduate from Canisius College. After an early start in radio with WBUF-FM, he pursued other opportunities only to be told, "this organization does not hire the handicapped" and that he "couldn't talk right."

He finally found his calling as a Policy Operation Specialist 1 with OPWDD's Central Office in Albany where he works to help people with developmental disabilities exercise their right to vote. "Now that New York State has early voting it is much easier for people with developmental and physical disabilities to vote," said Mike. "They will have greater options about when they can vote, and staff could be more available to assist them."

As an employer, OPWDD gives Mike the supports he needs to be successful. In addition to typical environmental modifications such as automatic doors and larger doorways, the agency provided an adaptive toilet seat to accommodate his needs.

The most significant assistance came in 2017 when Mike was able to get a Tobii Eye Tracker4C, eye-controlled assistive technology – or "eye gaze" as it is commonly known. Inferred lights from a unit attached to the base of his monitor is reflected off his retinas to the specific keys on the video

keyboard. When the eye gaze receives the reflection from the retinas, it determines the key that he is looking at and types it in. Mike selects items by holding his eyes for a certain amount of time on a key on the video keyboard. This gives Mike the ability to operate a laptop or computer much easier. Prior to this technology, Mike typed with his nose in order to complete many of his work tasks on a computer, causing him much discomfort and neck strain. The system worked so well for him at work that he purchased a second one for use at home. Mike said it's important for people with developmental disabilities to always strive to reach their goals.

"My advice to others is to never give up on your dreams and look for people that will help you without an attitude," he says. "Always try your best and eventually something will come along."



Darren Jackson

Darren Jackson grew up in Springville, south of Buffalo. While he was there, he underwent many operations on his hips and legs due to cerebral palsy and did not start walking on his own until he was 10 years old. As a child, he had wanted to be a veterinarian and get his GED diploma, but was told it would be too difficult for him. Despite being told this, he stuck to his dream and achieved his GED.

Darren went on to work in self-advocacy as a field assistant in Western New York. He used the AmeriCorps project to take a college course and earned a certificate in Human Services. In 2004, he applied

for a job with OPWDD under the 55-B program. The 55-B program authorizes the New York State Civil Service Commission to designate up to 1,200 positions normally filled through competitive examination to be filled through the appointment of qualified persons with disabilities.

As special assistant to the Regional Office Director in Western NY, Darren plans and conducts training sessions at OPWDD and works with provider agencies to help others to be productive and contributing members of committees and boards of directors. A member of the Independent Action Coalition's housing committee, Darren also works to assist people with developmental disabilities in obtaining environmental modifications so they can be more independent.

To help him with his work at OPWDD, Darren uses a computer keyboard with bigger keys and carries a recorder to record meetings so he can remember and refer back to discussions.

His advice to those with developmental disabilities is to always try. "If you feel you can do something, try it," Darren says. "You never know if you can or can't do something until you try."



Arlene Cotto

After working in a factory for 10 years, Arlene Cotto was ready to try something new. Her case manager suggested office work and told her about the Employment Training Program. Her participation in the OPWDD program resulted in a 19+ year career.

Arlene, who lives in Bay Shore, works as an Office Assistant with OPWDD's Long Island office. Director Margaret Stadnicky says Arlene is a conscientious employee. She works at the front desk, greets and signs visitors in, and directs visitors to the appropriate staff. Arlene is bilingual, so this is especially helpful when interacting with visitors who speak Spanish. Arlene is responsible for answering the phone, forwarding calls and taking messages. She also collates and distributes the mail to the various units in the Regional Office.

"Arlene is well known and liked by all staff in the regional office," said Stadnicky. "She is always pleasant, smiling and a pleasure to work with. She is a conscientious employee."

With almost 20 years on the job, Arlene is quite independent and receives only a little support with things like recording and managing her time and attendance. Her advice to others: "Finding a job is a long process. Be patient and your job will come through."



Tim Elliot

Most people would not describe having been paralyzed from the shoulders down as the start of a change for the better – but they're not Tim Elliot.

After growing up in Brooklyn, and graduating from Eli Whitney Vocational High School, Tim joined the U.S. Navy in 1990 at the age of 20. He trained to be an aviation electronic technician, but a bout of spinal meningitis left him paralyzed in April 1991. After being completely paralyzed for three months, Tim moved back to New York City, where he started to gain some movement

back.

He joined an adult day center where he met a mentor who took him under her wing and introduced him to the Self-Advocacy Association. Tim was then hired in 2001 as an AmeriCorps member for two years.

"While working for Self-Advocacy during the AmeriCorps years, I would see other people with disabilities starting their own businesses, owning homes and I started realizing that my life wasn't over just because I was disabled and was in a wheelchair," he says.

In 2008, OPWDD opened a downstate housing office with funding from the United States Department of Housing and Urban Development (HUD), and asked Tim to oversee it. When selecting staff to assist him, he hired four individuals with developmental disabilities.

Tim's advice for others seeking jobs is to find something you like and pursue it.

"The most important thing is to get at least one person in your circle who believes in you and gives you the support you need to develop and follow your dreams and goals," he says.

New Email Address for OPWDD

OPWDD is in the process of consolidating some of our shared email accounts. The Commissioner's email commissioners.correspondence.unit@opwdd.ny.gov has become info@opwdd.ny.gov. In addition, the info.line@opwdd.ny.gov email address which was used by the Advocacy Unit will no longer be available.

Please refer future inquiries that would have previously been sent to either of these two emails to info@opwdd.ny.gov.



Special Olympics New York Kicks off 50th Anniversary

Special Olympics New York recently kicked off a year-long celebration of its 50th anniversary. President & CEO Stacey Hengsterman outlined a vision for the future of the country's largest Special Olympics chapter, saying the organization aims to reach more of the 585,000 New Yorkers who have an intellectual disability by increasing awareness and expanding access to its core sports programs, Unified opportunities, particularly in schools, and initiatives that support athlete health.

Approximately 11 percent of eligible New Yorkers currently participate in Special Olympics New York programming, which has been proven to enhance an athlete's quality of life through improved mental health and physical fitness as well as social acceptance and inclusion.

"As we celebrate 50 years of sports and inclusion and look to the future, Special Olympics New York will continue to ensure an opportunity for every aspiring athlete, regardless of age or ability," said Hengsterman. "We will raise awareness so that people know who our athletes are and what they are capable of. We will advocate for the equitable, quality healthcare that people with intellectual disabilities deserve. And with our athletes leading the way, we will continue our work to make New York the most unified and inclusive state in the country."

The organization also launched a 50-day fundraising campaign aimed at beginning to generate the funds needed to support the next generation of athletes and families. Supporters are asked to give \$10 and get \$10 from a friend. The Next Generation Campaign can be viewed and shared at: www.specialolympics-ny.org/SONY50.

Article provided by Special Olympics NY

FOCUS

Ashley Hupfl, OPWDD Public Education Specialist, writes about living with epilepsy.

on Epilepsy

November is Epilepsy Awareness Month

There are 65 million people worldwide that are diagnosed with epilepsy, with 3.4 million living in the United States. Of that number, one-third of the people living with epilepsy will live with uncontrollable seizures because no available treatment works for them.

Epilepsy is a chronic disorder in which a person suffers from recurrent, unprovoked seizures. Seizures are a sudden surge of electrical activity in the brain that usually affects how a person appears or acts for a short time. When the average person imagines a seizure, they tend to picture the typical Hollywood version, in which someone flops around on the ground and shakes uncontrollably.

In reality, many different symptoms happen during a seizure. While some people suffer from motor symptoms, such as jerking movements, muscles becoming weak or limp, muscles becoming tense or rigid, brief muscle twitching, or epileptic spasms (body flexes and extends repeatedly), others experience non-motor symptoms, usually called absence seizures. These can involve staring spells or brief twitches. Some people can retain awareness throughout their seizures while others lose awareness.

Anyone can develop epilepsy at any age, though it is more common in children and older adults. While some seizures can be entirely unprovoked, people with epilepsy learn to find their seizure triggers, such as lack of sleep, stress, diet and more. Living with epilepsy is a daily task for many that doesn't go away. I can attest to this, for I was diagnosed with epilepsy a year ago at the age of 27, after experiencing seizures and unresponsiveness that came with them.

Although there is no cure for epilepsy, there are things people can do to minimize the effects of the condition. With medication or sometimes surgery, the frequency of seizures can diminish or even go away. As with other conditions, education, diligence in following up with physicians and adherence with doctor's recommendations are essential. And providing information to others who can support you when needed is important, as well. Epilepsy presents challenges, but ones that can be overcome.