



Creating Opportunities for Happy Lives

MEET PAUL!

STAFF PROMOTIONS

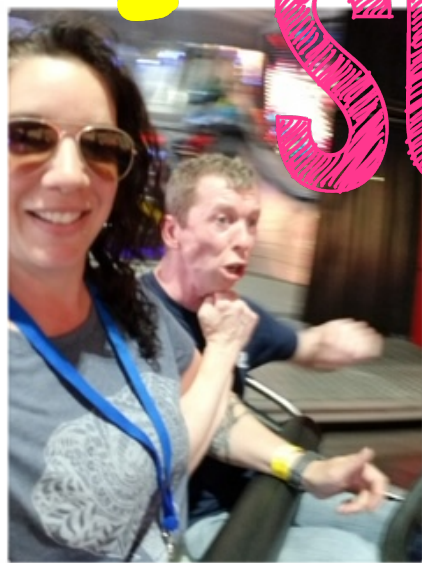
DSP OF THE QUARTER

THE EEDA READER

NEWS FROM EAST END DISABILITY ASSOCIATES, INC.



SUMMER



A MESSAGE FROM THE CHIEF EXECUTIVE OFFICER

Direct support Professionals (DSP) contribute to a person's life in a multitude of ways with the goal of promoting the health, safety, growth, and well-being of those they support. Whether they're helping someone with personal hygiene, assisting in meal preparation, or guidance in making a healthy decision, DSPs are vital in making every day a success for the people in EEDA's programs.

EEDA and our sister agencies in New York State, have been experiencing high Direct Support Professional (DSP) vacancy and turnover rates. Although we have been advocating for higher DSP wages, the government has not responded positively this year. Despite this lack of funds, EEDA made a commitment to raise the starting salary for all new DSPs and adjust the salary for current DSPs beginning July 01, 2019.

I hope this decision will help our organization decrease both vacancy and turnover rates. But more importantly, we want our DSPs to know we appreciate them and are using our resources to support them so they can continue assisting the people we support. We are also committed to analyzing the salaries of all staff positions in the next few months to ensure we are competitive. EEDA recognizes that the most valuable resource we have is our workforce.

September is DSP recognition month, please join me and in thanking them. They are the foundation of EEDA!

Sincerely,



Newsletter Contributors

Jeremy Grand - Kimberly Schebler - Camden Ackerman - John Hatton - Samantha Fenoy
Christopher Zerella - Ilse Hart - Colleen Shanahan - Ronnie Myers - Cheryl Shea - Danielle DeAngelis
Christine Proietti - Patti Maiorana - Simone Martin

EEDA LOVES OUR DSPs!



The Creative Arts Program staff chose to highlight Kate Danega's hard work and creativity. Kate has worked at EEDA as a Direct Support Professional (and previously as a Senior Direct Support Professional at Calverton Day Program) for the past twenty years! Kate's fellow staff note her willingness to help anyone with anything, her creativity, patience, and the compassionate care she provides for the people she supports and her coworkers. Kate is quick to initiate fun and exciting activities with the people she supports, brightening the world around her. Kate will soon transfer to EEDA's newest IRA in Jamesport. When you see Kate, thank her for the great job she's done over the years. Thank you Kate for always going above and beyond!



WHO WILL YOU NOMINATE NEXT???

I went to the gala this year with my mom and it was a lot of fun. My staff Kate got an award at the gala this year and I was so happy to give her the award. I danced all night with Kate and her family. I had a lot of fun at the gala with everyone. I like the video at the gala that we made. I feel so happy I gave Kate her award and I'm looking forward to next year's gala.

Colleen

Creative Arts Program



MEET ONE OF THE GUYS!



Meet Paul, longtime resident of EEDA, currently living at our Corwin Street house.

Paul was born in Brooklyn in 1947 to Joe and Ester Giacalone. Along with his sister JoMarie, he spent his early years in East Meadow where he graduated high school with the class of 1966. Paul remembers spending a lot of that time with his high school sweetheart Joyce Beaty.

Paul's father worked for New York City as a bus mechanic, and brought Paul and his family to the Bay Ridge neighborhood in Brooklyn after high school to be closer to his family and work. During this time, Paul worked at a local Burger King and his mom Ester held a job at Modell's as a cashier.

After Paul's dad retired, he brought his family out to Riverhead, where Paul began to attend EEDA's first day program in 1999. Paul moved into our Eight Bells house in 2002, and became friends with Ronnie Myers—Ronnie started his career at EEDA as a direct support professional, working overnights at Eight Bells—he would come to play a big part in Paul's life. There were seven other individuals living at Eight Bells with Paul. He began attending day program at EEDA's Riverhead site at this time and continued spending weekends and holidays with his family at their home.

In 2015, Paul moved to the new Corwin Street house, where he was reunited with his old friend Ronnie Myers, who was now the coordinator at the Corwin house. Paul was introduced to three new housemates and a more laidback lifestyle. When Paul moved to Corwin Street, he also started attending Calverton Day Program. He continued visiting his mom on weekends, where he kept his collection of toy cars and vintage trains. Paul and his mom were frequently seen out in the East End community—they often ate at Applebee's, where Paul enjoys getting a Cowboy Burger.

Paul's life at Corwin has taken on a slower pace these days, as he enjoys interacting with his housemates and staff. Paul loves watching old black and white movies like Godzilla, King Kong, and Mighty Joe Young, and almost anything on TCM, especially movies with a pretty girl or two. Paul stills gets up early, but now he attends a Day Program in Middle Island, leaving at 7:15 a.m. most days, and returning around 4:30 p.m. after a full day of activities. Paul loves his new day program and looks forward to a nice hot lunch there every day.

Paul still manages to visit his mom twice a week, where they share lunch and stories of the old days. Paul takes advantage of all EEDA's events, some of his favorites being the annual agency picnic, Radio City Music Hall trip, and Winter Clove, where Paul can sit and relax on the hotel deck and watch the world go by.

Although life has taken on a slower pace for Paul, Ronnie has been with him every step of the way for several years as both caregiver and friend. There have been some bumps in the road, but Paul, his mom, his housemates, and his staff have successfully navigated their way through those bumps together.

TULIP FESTIVAL



Spring was in full swing! Members of the Creative Arts Program enjoying a tour of the Tulip Festival at Waterdrinker Farms.

GREENPORT



Calverton Day Program participants spending a gorgeous summer day in Greenport with the Amistad ship.

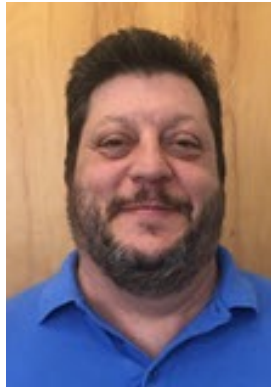
EEDA PROMOTIONS



Cynthia Miles,
Director of Human
Resources



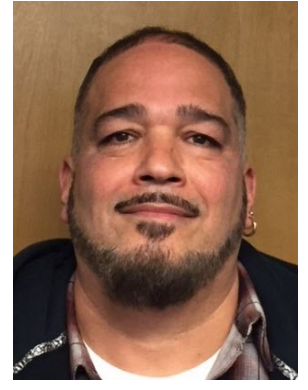
Diane Lagoumis,
Director of Self-
Direction



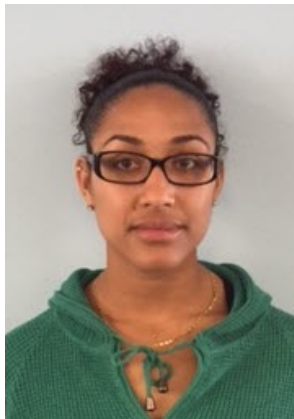
Dan Bogan,
Manager of IT



Caitlin Gordon,
Director of Crisis,
Respite, and
Clinical Services



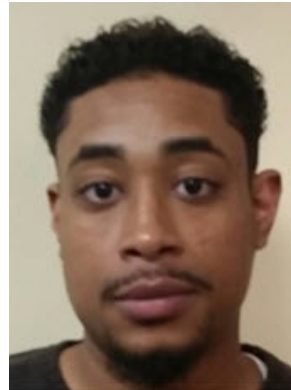
Luis Cruz, Manager
of Crisis, Respite,
and Crisis Team



Nicole Charles,
Coordinator of
Special Events and
Children's Services



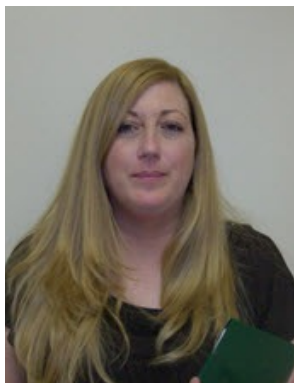
Simone Martin,
Coordinator of
Adult Socialization



Wesley Walker,
Coordinator at
Riverhead Day Hab



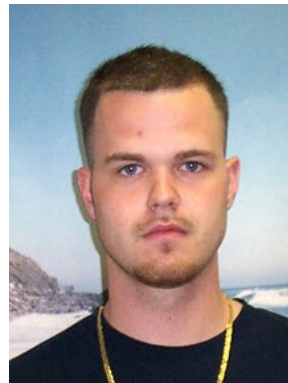
Ashley Alexander,
Senior DSP at
Russell St.



Kelly Summers,
Senior DSP of
Creative Arts



Maryann Iacono,
Senior DSP at
Respite



Michael Jackson,
Senior DSP at Corwin
St.



Monica Hughes,
Senior DSP at
Russell St.

Congratulations to everyone who has moved up in the ranks this year!

EEDA PRIDE



After nearly four years of saving up enough of his own money to do it, Brian, who lives at the Eight Bells IRA, has built himself a “Man Cave”. The newly built shed sits in the backyard of his house and is 8x12’. Brian said he ‘worked hard’ to get to this point and is so proud of his accomplishment. Kudos to Brian and the staff at Eight Bells who helped him achieve his dream!



Save the Date !!
Surfers Healing
September 13th, 2019
Ditch Plains Beach, Montauk NY
9AM - 2PM
A One Day Surf Camp for Children with Autism



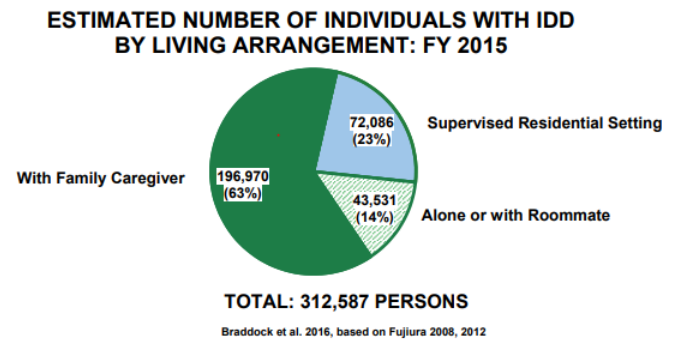


ISS OBSTACLES



Housing for New Yorkers with intellectual and developmental disabilities (I/DD) has been a complicated issue for a long time. The cost of building and operating an Intermediate Care Facility (ICF) or an Individualized Residential Alternative (IRA) has made it more difficult for agencies to create supports. Without those systems where are people expected to live?

As shown in the chart to the right, only 23% of the over 300,000 people in New York with I/DD live in a supervised residential setting. With less opportunities for residential placement, it seems there should be a growth in independent community living, but this isn't the case. Between the 23% of people living in a supervised residential setting, and the 14% living independently, we are left with a staggering 63% living with family caregivers. Where will they live when their loved ones are no longer capable of supporting them?



Those living on their own or with roommates have two options for support through OPWDD: Self-Directed Services and the Individualized Support Services (ISS) Grant. This grant provides a housing subsidy to individuals living alone or with roommates in their community. EEDA has been providing this grant for nearly twenty years. The housing portion of Self-Directed Services is modeled off the ISS grant and they both work similarly and share most requirements.

Most people who utilize our ISS grant come from living with a caregiver who could no longer provide the same level of support. Often there are two kinds of people that enroll: those that want to live independently in their community, and those that *have* to live in the community. I would much rather take thirty people who want to enroll than one person who *has* to enroll. The person who *needs* to enroll has typically lost their primary support person. This individual is already going through a tough time. They're often sad, scared, and now have to deal with the anxiety of moving and living without their support person for the first time. The financial strains associated with moving into a new apartment are a challenge, even for someone who has had time to prepare for them. With affordable Long Island apartments in short supply, the simple act of finding a suitable apartment within the ISS grant's allotted \$1339/month proves to be a real challenge. The housing related funds each individual receives don't cover realtor fees, a security deposit that exceeds one month's rent, utilities, moving fees, insurance costs, or stocking the apartment with food. How is a person who relies heavily on Medicaid and Social Security supposed to cover these expenses?

With 63% of people with I/DD in New York State currently living with a family caregiver, it's important for people to discuss future living options and plan ahead. Speak to your support team, and figure out if independent living is the best choice. If community living seems like the right path, speak to a financial advisor, particularly one familiar with Social Security, Medicaid, and trusts. In addition, get to know the OPWDD services that best suit your needs. Self-Direction offers a lot more financial support than just housing, but it also requires you to have the strong foundation of a support broker and a fiscal intermediary to get the budget moving. The ISS grant isn't funded by Medicaid so people who aren't enrolled in the HCBS waiver or Medicaid are still eligible to apply. If living independently in the community isn't an option, then you'll need to seek services outside of the ISS grant.

Everyone needs to use their voice to advocate. The housing subsidy payment standards have not increased since they were introduced in 2012. OPWDD needs to know that these rates don't work on Long Island. Plan for the future and advocate.

L.I. DUCKS



On July 2nd, EEDA went to the Bethpage Ballpark where they enjoyed a summer evening filled with a BBQ buffet, a Ducks game (even though they lost), and a fireworks show finale. Everyone had fun!



GUILD HALL



Creative Arts Program participants experienced a tour of Guild Hall of East Hampton (both the current museum exhibits and the theater). They were invited to participate as artists in a collaborative exhibition slated to open in August!

DSPs DESERVE BETTER

A recent article in the New York Times, “*Residents Covered While Workers at a Group Home Smacked and Pushed Them,*” depicts direct support professionals as a workforce filled with abusive people and people who stand by quietly while they watch abuse happen. As direct support professionals, we found this article horrifying, but also severely biased, and insulting. Abuse happens in our field, it’s true, but in the non-profit sector, where we work, our every action is held accountable through our agency and the New York State Justice Center. Unlike facilities operated by the state, highlighted in the article, staff are suspended until they’re cleared of an accusation, and fired if an accusation of abuse is substantiated. Staff are not shifted to another program or site, as they are in state run facilities, they’re terminated. If the offense is severe enough, then staff are placed on a list that prevents them from being hired at another agency. We are trained that if we don’t stop and report abuse we’re just as guilty as the person perpetrating the abuse.

Direct support professionals who work in the non-profit sector aren’t paid much more than minimum wage and are required to complete an intensive training and certification program to administer of medications, drive agency vehicles, perform CPR, First Aid, and provide behavioral supports to people with intellectual and developmental disabilities. Direct support professionals are integral to the lives of people with intellectual and developmental disabilities, walking the fine line between caretaker, mentor, and friend. We serve as drivers, transporting people to appointments, community and recreation activities, and running errands. We serve as teachers, showing the people we support how to manage money, do their laundry, cook food, and countless other tasks that most people take for granted. We serve as counselors, assisting the people we support build and maintain relationships as we help them work through their social anxieties. We serve as medication administrators, ensuring people receive the correct dose of medication at the correct time, sometimes passing medications to as many as ten people who each receive several medications. We provide behavioral supports, intervening during aggressive behaviors that despite our best efforts, sometimes involve us being punched, kicked, spit on, scratched, and our hair pulled as we try to keep people safe while remaining calm and collected.

We provide all of these services and endure these challenges that most people don’t have to face at work for little more than minimum wage. New York State didn’t add a cost of living adjustment to its budget for 2020, which means we won’t see an increase in our wages as New York’s prices continue to rise. We work overtime when it’s available, second, and sometimes even third jobs just to provide for our families. Every single one of us could leave this industry and find an easier job with better pay. This is a fact. This job isn’t our only option, it’s the job we choose.

So, why do we stay? We are direct support professionals because we care deeply for the people we serve. It’s not an easy job, but it’s an important job. Without us, institutions like Willowbrook would return out of necessity, and that can never be an acceptable option. At the end of the day, we know we’ve made someone’s day better, and that’s worth so much. When we walk into work people yell out our names in excitement and we feel like celebrities for just a moment because we’re so loved and appreciated by the people we support. It feels good to know you’re making a difference. Working in this field gives us a second family. This isn’t just a job for us.

We will continue to advocate for better pay until the state realizes how important our work is and that the skills we provide and the challenges we face deserve to be rewarded with a livable wage. We shouldn’t have to work two jobs just so we can support people with intellectual and developmental disabilities. We will keep doing our job because the people we serve depend on us, but we’re tired of being demonized. We refuse to be lumped together with abusive state workers who aren’t held to the same standards of excellence that we are. Next time you see us out in the community, full of compassion, patience, and empathy for the people we support, try to see us as we really are, people helping people.

BOY SCOUTS



On March 9th, 2019 EEDA attended a corned beef and cabbage dinner hosted by Boy Scout Troop 29 at East Moriches Fire House. Upon arriving we were greeted with big smiles and helpful hands. The boy scouts had reserved a table just for us and we were seated immediately. When coming to collect the tickets for dinner, the boys were polite and respectful. While waiting, there were other members of the troop socializing with the people that we support. As the night went on, more EEDA groups came in and were greeted in the same manner. The boys were as prompt as they could be with retrieving our meals and returning to the table. They were accommodating to the individuals that received corned beef but changed their mind and preferred hot dogs. We also had two individuals come to socialize, but brought their own dinner due to diet restrictions, when the boys noticed that, they offered to take their meals into the back and warmed them in the microwave. Everyone had a great time socializing, eating, and seeing all of the memorabilia around the fire house, we can't wait until their next event! Thank you Boy Scout Troop 29 for a great evening.

SAVE THE DATE!

EEDA's Annual John V. Beltrani Golf Classic

Monday, September 16th, 2019

Westhampton Country Club



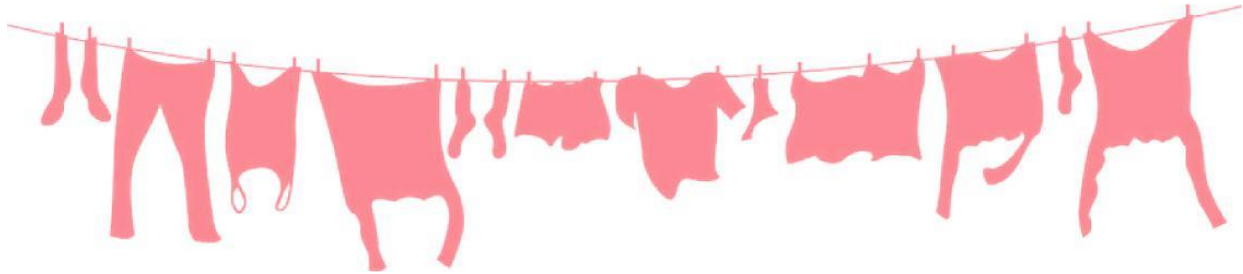
To Register or Become a Sponsor:

<http://weblink.donorperfect.com/GolfEvent>

For more information email Camden Ackerman:

CamdenA@eed-a.org

EEDA CLOTHESLINE



CLEANING OUT YOUR CLOSET?

DON'T THROW YOUR OLD CLOTHES AWAY!

DONATE TO THE EEDA CLOTHESLINE!

**WE ACCEPT CLEAN CLOTHING, BELTS, SCARVES, GLOVES, HATS, COATS, BEDDING,
TOWELS, SHOES AND PURSES, AND FABRIC IN ANY CONDITION.**

DROP OFF AT THE FOLLOWING EEDA LOCATIONS:

MAIN OFFICE: 107 ROANOKE AVE. IN RIVERHEAD

RIVERHEAD DAY HAB: 784 HARRISON AVE. IN RIVERHEAD

CALVERTON DAY HAB: 446 EDWARDS AVE. IN CALVERTON

HENRY PFEIFER CENTER: 4062 GRUMMAN BLVD. IN CALVERTON

MORE LOCATIONS COMING SOON!

Email us for more information: info@eed-a.org



EEDA Creative Arts Program Presents

The Shakespeare Project

A performance workshop exploring elements of comedy and tragedy in the plays of William Shakespeare.

VAIL-LEAVITT MUSIC HALL
18 PECONIC AVENUE, RIVERHEAD
AUGUST 22ND & 23RD, 2019 @ 12:00 PM
DOORS OPEN 11:30AM **FREE ADMISSION**

Optional donation may be made to the Vail-Leavitt Music Hall Preservation Fund

SUMMER FUN



Trip to Adventureland, gardening at the River and Roots Community Garden in Riverhead, Plasterkraze, and the Greek Orthodox Church of the Hamptons Greek Festival.

2019 NYS LEGISLATIVE SESSION WRAP-UP

The 2019 New York State Legislative Session ended in the early hours of June 21st. While there were 935 bills passed by both houses this session, outlined below are those of interest to providers, staff, families, and individuals with disabilities. Most still require action by the governor before they would take effect, as noted in the description.

For more information, to join our legislative initiatives, or to join our advocacy campaigns, contact Camden Ackerman at CamdenA@eed-a.org

PASSED BOTH HOUSES SUPPORT

- **OLAS 4410** – S. 5629 (Mayer)/A. 7694 (Benedetto) – This legislation which authorizes boards of cooperative educational services (BOCES) to enter into contracts with 4410 preschool special education providers to use their online recruitment tool.
- **ABLE Act Expansion** – S. 6238 (Carlucci)/A. 7473 (Gunther) - This Office of the State Comptroller bill increases the maximum account balance for the New York ABLE program in accordance with the NY state college choice tuition savings program.
- **Repeal of Vaccine Exemption for Religious Beliefs** – S.2994-A/A.2371-A (Dinowitz) - Repeals subdivision 9 of section 2164 of the public health law relating to exemption from the vaccination of school children due to religious beliefs. Signed by the Governor on 6-3-19. **Chapter 35 of the Laws of 2019.**
- **Small Business Tax Credit** – S. 5545 (Addabbo)/A.7475 (Cusick) – Establishes a small business tax credit for hiring individuals with disabilities.
- **Complex Rehabilitation Technology (CRT)** – S.5741(Skoufis)/A.7492 (Phil Steck) - Codifies the existing process to qualify for CRT, ensures that appropriately diagnosed patients have access to CRT and that Suppliers meet stringent requirements to protect quality and access to services and repairs. Requires Medicaid billing codes be updated to conform with Medicare.
- **Changes OMRDD to OPWDD** – S.4276 (Skoufis)/A. 6174 (Gunther) – Amends numerous sections of law to change OMRDD to OPWDD.
- **Non-medical switching bill** – S. 2849-A (Breslin)/A. 2969-A (Peoples Stokes) – Prohibits health plans from making prescription drug formulary changes during a contract year except to add generics and a few other exceptions.
- **Rare Disease Advisory Council** - S. 4497 (Rivera)/A. 5762 (Paulin) - Establishes a Rare Disease Advisory Council consisting of 21 appointed members. The role of the Council would be to advise and consult on policy matters related to rare diseases. The Council would meet at least three times annually.
- **Printed Material for College Students with Disabilities** – S.5393 (Lanza)/A. 7251 (Cusick) -Extends the program that provides instructional materials for college students with disabilities for three more years.
- **OPWDD Front Door Process Awareness** – S. 5347 (Carlucci)/A. 6344A (Gunther) - Requires the Commissioner of the Office for People with Developmental Disabilities to publish, on their website, information regarding the process for obtaining eligibility for services and access to services, including but not limited to, residential, respite, employment, habilitation, and self-directed services. This bill was passed in May but has not yet been delivered to the Governor.



East End Disability Associates (EEDA) is a 501(c)(3) nonprofit organization that provides supports and services for people with intellectual and developmental disabilities.

EEDA's Mission Statement: "Your Challenge... Our Commitment. Dedicated to creating practical solutions and providing innovative supports to people with intellectual and developmental disabilities on the East End of Long Island."

www.eed-a.org



Creating Opportunities for Happy Lives.

**EEDA
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Staff**

Chief Executive Officer

Lisa Meyer Fertal

Chief Program Officer

Joy O'Shaughnessy

Chief Administrative Officer

Gus Lagoumis

Controller

Dara Gary

Director of Program Operations

John Hatton

Director of Self-Directed Services

Diane Lagoumis

**Director of Clinical, Crisis &
Respite Services**

Caitlin Gordon

Director of Human Resources

Cynthia Miles

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