

The ECDA Citizen

SPRING 2017

NEWS FROM EAST END DISABILITY ASSOCIATES, INC.

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PARENT POWER!

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SELF-ADVOCACY

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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









Members of Forward Motion jamming at Grace Episcopal Church in Riverhead.

EEDA'S OWN SCHOOL OF ROCK 'FORWARD MOTION' A HUGE HIT!

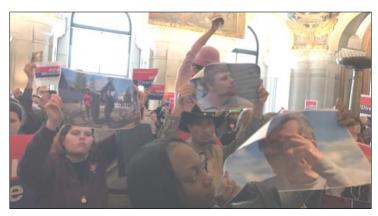
By Chris Colantuono, Direct Support Professional

Hi, I'm Chris Colantuono from Forward Motion at EEDA. We are a performance based group specializing in musical endeavors for people with special needs. Services offered are individual lessons, group performances and writing workshops tiered to each of the musician's aptitudes and goals. We meet at Grace Episcopal at 3:00 PM, four days a week and the groups right now consist of ten individuals along with Marisol in the audience when there are ladies present. We have individuals learning drums, bass, keyboard and guitars at the present time. I teach each of the students rudimentary exercises that lead to jamming and playing music together, finding a balance between the frustrations of learning an instrument and the sublime experience of "the jam." I've have had some fantastic collaborations with the guys already. To hear a snippet of "My Life My Song," words by James McCormack, music by James McCormack and Chris Colantuono, log onto www.eed-a.org/forwardmotion.

After presenting my idea to management and getting the green light, I have received invaluable help and support from Marisol Vargas, Kimberly Schebler, and Natasha Reese. Special thanks to Anthony Ayers for drum tuning. Very special thanks to Joy O'Shaughnessy for logistics and organization and Lisa Meyer-Fertal for her praise and support.

A MESSAGE FROM THE CHIEF EXECUTIVE OFFICER:

EEDA was founded in the early 90s by parents of children with intellectual and developmental disabilities advocating for support on Eastern Long Island. opportunities Advocacy has always been at the core of EEDA's foundation and provides motivation to foster and advance inclusion and acceptance of people with intellectual and developmental disabilities. EEDA encourages others to join our advocacy efforts knowing together our message is stronger and believing everyone has the opportunity to bring value to one another and the community.



EEDA's self-advocates at a #beFair2DirectCare rally in Albany.

Today, advocacy remains vital as New York State transforms our delivery system to provide sustainable services focused primarily on individual needs. EEDA and our sister agencies have experienced financial reductions while simultaneously experiencing an increase in regulatory requirements. These financial cuts are a great reminder that if we do not continue to advocate for individuals with intellectual and development disabilities our support system will potentially be very different.



Official #bFair2DirectCare logo.

Two advocacy efforts EEDA has focused on is the #beFair2DirectCare (Be Fair to Direct Care) and SOS (Save Our Services) campaigns. I hope you are familiar with both. Briefly, #beFair2DirectCare advocacy petitioned state legislators to fund the minimum wage requirement for direct care workers. This seems simple I know, but many governmental mandates are required but not funded. A tremendous effort went into this work and included a unified approach in sending emails, making calls and visits to state legislators and the governor's office, asking for full funding of the minimum wage requirements. These funds were added to the New York State budget and I believe this happened due to the overwhelming number of people who focused on the same message. The SOS Campaign focused on petitioning

federal legislators and asking them not to reduce the Medicaid budget. The advocacy action taken was similar; sending emails, making calls and visits. Has this message been heard? The Medicaid reduction has not taken place to date but we need to continue with the message of how important Medicaid is to you or your family member so this is not considered again.

When EEDA sends you an email or asks you to call a legislator it is with good intentions and always part of well organized campaigns that focus on the greater good for all individuals living with intellectual and developmental disabilities. This year, EEDA is creating robust and active advocacy groups and has prioritized this as an agency goal. We will be working with staff, parents, family members and individuals with intellectual and developmental disabilities, vendors and community partners to engage as many people as possible to help our advocacy efforts. I hope you will join us. Advocacy is not a one-time action, it is a life-style engagement. Speaking up for the things you believe in matters; speaking up for those who can't, matters more.

Lisa Meyer Fertal
Lisa Meyer Fertal



EEDA THANKS NEW YORK COMMUNITY BANK FOR GENEROUSLY DONATING THE PRINTING OF THIS ISSUE

LEADERSHIP EVOLVES AS EEDA GROWS







Gus Lagoumis is promoted to Chief Administrative Officer (CAO) & Joy O'Shaughnessy is promoted to Chief Program Officer (CPO). Both positions are critical to executive management and work collaboratively with Chief Executive Officer to articulate and implement EEDA's strategic vision, provide agency leadership and grow the company.

Gus Lagoumis joined EEDA in 2000 assisting EEDA's growth by establishing traditional services and developing a strong management team. As CAO, Gus will have the opportunity to focus on the operations side of the business where he will manage the dayto-day activities.

Joy has been with EEDA since 2001 creating sustainable agency growth through Family Support Services, Crisis & Respite Programs, Self-Direction and other innovative programs. As CPO, Joy will oversee EEDA's portfolio of programs and related services.

EEDA welcomes Fran Fitzgerald to the EEDA Administrative Team in the role of Associate Director of Program Operations. Joining us in early Spring, Fran, a seasoned professional in the field of service provision, brings a depth of experience and knowledge coupled with enthusiasm and passion for the people we support that is sure to be a winning combination for EEDA. Fran began his career as a DSP in college and grew through the ranks to senior management level positions. We are lucky to have him join our team. Welcome, Fran!

"DAY BY DAY": EEDA'S BUSY DAY SERVICES

By Lisa Kennedy, Sr. Manager of Day Habilitation

EEDA's day service programs have been very busy this year. Our Calverton and Riverhead sites have continued their volunteer efforts at Southampton Hospital where we assist in cleaning the cafeteria. At Bid-a-Wee Animal Shelter, we enjoy assisting in cleaning cages, playing with the animals, and giving them fresh water. At Island Harvest and Meals on Wheels our groups pick up food and deliver it to people in need. We also help to clean and organize the EEDA Thrift Shop.

Both our Riverhead and Calverton sites have worked in three different community gardens located in Southold, Flanders and Riverhead through the spring and summer months. Our Individuals planted, cared for and grew a variety of vegetables and flowers. Once the vegetables were harvested we brought them back to our kitchens and prepared them in healthy delicious meals and snacks. The EEDA Falcons basketball team fought hard this year. With team members from Calverton, Riverhead, and our



Jennifer on an outing to the aquarium.

Creative Arts Program we took home the first place trophy winning against a tough team in the finals. We are looking forward to defending our title in 2017! We have had a lot of fun making floral arrangements at Moriches Florist, attending plays at our sister agency, going to the movies, bowling, shopping, and dining in our community. We also love to sing karaoke in the afternoons.

In 2015, our Creative Arts Program put on a full production of Joseph and the Amazing Technicolor Dream Coat. This year, our group worked extremely hard to bring you The Wizard of Oz. The show was performed at the Gateway Playhouse in Bellport on April 21st at 7:00 PM and April 23rd at 2:00 PM. Last year we had an improvisation show at the Vail-Leavitt Music Hall as well as a karaoke sing-a-long during the holiday season. The Creative Arts Program works on dance, music appreciation, singing, karate and yoga. They start their day with a social circle showing their friendship and support to one another. All of EEDA's Day Service Programs are looking forward to another year of exciting activity!

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EEDA SAYS BEST WISHES TO JIM MARTINSEN IN HIS RETIREMENT

By Lisa Meyer-Fertal, Chief Executive Officer

It is really hard to imagine EEDA without Jim Martinsen. As a founding member and pillar of the organization, Jim was responsible for creating multiple departments and developing many policies and procedures that EEDA still uses today.

Jim's title is Chief Financial Officer, but his responsibilities reached much further than traditional CFO duties. He created and supervised the Finance department, Human Resources, Information Technology, Maintenance, Purchasing, Transportation, and has managed multiple development projects among a myriad of other things over the years.

One of the amazing things about Jim is that he was not formally trained as a CFO, nor did he work in this field prior to 1995; his education and background is in engineering! He got involved because he is an amazing father who dedicated himself to making sure his intellectually and developmentally disabled son, Mike, could live the best life possible. His vision and commitment to building EEDA created



Jim Martinsen

opportunities for Mike, and a whole lot of other people. Jim likes to say of himself, "I'm a Jack of all trades and a master of none." This is somewhat true. Jim can do a lot of things well but he certainly does "master" in many areas including relationships, where this mastery matters most. Jim is one of the kindest people I have ever met. He is compassionate and generous, always willing to help and modest when acknowledged. Everyone loves Jim. He has the ability to be able to deliver the most unpopular news and have the recipient think it's a good idea. He's supervised a lot of people over the past twenty plus years and in speaking to many in recent times the common theme is how much they learned from Jim, how fair he is, and how kind.

It has been a privilege for me to work side by side with him. I have learned so much from him and will miss him, especially his stories and sense of humor. He has been a source of great strength, intelligence, and irreplaceable dedication. The contributions he has made to EEDA and the social impact to the East End communities will yield farreaching and sustainable results, benefitting individuals with intellectual and developmental disabilities and their families yesterday, today and tomorrow.

EEDA WARMLY WELCOMES DARA GARY



Dara Gary

Dara L. Gary joined the EEDA team in October 2016 bringing thirty years of experience in non-profit finance management and administration. In her role as Controller, Dara will oversee the accounting and finance division while participating on the executive team with strategic initiatives to help positon the agency for continued growth in a changing industry.

Prior to joining EEDA, Dara Gary held key executive positions at Family Residences and Essential Enterprises (FREE), a sister Long Island agency. As Chief Financial Officer for twenty five years and most recently Vice President of Strategic Partnerships for four years, she played a pivotal role in the expansion of the FREE network, helping to grow the organization's annual budget and operations through internal expansion and external collaborative network development.

Dara is a C.P.A. and has a BBA in Accounting from Dowling College. She has served on several statewide committees and was the Long Island Region fiscal representative for both the New York State Association of Community and Residential Agencies (NYSACRA) and Interagency Council of Developmental Disabilities (IAC) for four years. She is a finance committee member for the IAC Board of Directors and volunteer committee member for the Pronto of Long Island Board of Directors. In 2016 she received the Long Island Smart CEO Brava Executive award.

PARENT POWER! EEDA PARENT ADVOCACY

By Diane Arpaia, EEDA Fundraising Committee Member



The Arpaia Family at the annual EEDA Gala.

I have been involved in EEDA's fundraising activities for the past couple of years, and it is rewarding to be able to help our children by helping EEDA. In our discussions, we have realized that there are probably many other families that would like to learn more about services, get involved, and meet parents in similar circumstances. In light of the constant fight for funding, our knowledge is especially important.

As parents and guardians of children with intellectual and developmental disabilities, we often have to learn on the fly how to best help them. This is difficult to accomplish in a vacuum. If we network with others in the same position, and those who provide services and know what's going on legally, we can optimize the experience of our children and the services they receive.

EEDA will soon be introducing a Parent Advocacy Group. EEDA staff will let us know what's going on in local, state, and federal government and what we can do to advocate for our children. We can also learn about different ways to get involved with EEDA, and perhaps organize new events to benefit us all.

Please be on the lookout for an announcement of the first meeting date. In the meantime, if you have questions, please contact Matthew Kuriloff, Manager of Development, Advocacy & Public Relations at Matthew K@eed-a.org.

INTRODUCING THE EEDA BLING-LEADERS!

By Katherine Haas, Self Direction Coordinator



Katherine assists Jerronda in creating a pendant.

Fun was in full-swing at EEDA on Thursday, February 16th at 5:00 PM as a group of gals of all ages came together with one thing on the mind: jewelry! Well, maybe three things: jewelry, snacks and fun—all of which were enjoyed. This was no viewing, but a hands-on jewelry making party. Several participants arrived ready to dig into a DIY necklace project. Present at the first party were: Millie, Diane, Jerronda, Mary, Lillian and Mia.

Participants used two sets of plyers, assorted-sized freshwater pearls, head pins, a toggle clasp, and rolo chain to create a classy bling necklace. Tracy and Debbie helped Katherine offer hands-on assistance to the party-goers. Natasha made sure we had delicious food and drink. We played some background music as everyone enjoyed getting their creative juices flowing, along with having some good laughs. Sometimes making little mess-ups when you're creating jewelry is the best and most fun way to learn! If you see any of these ladies around sporting their fabulous creations, just know they didn't purchase these jewels, but made them from scratch! By the way, male attendees are invited as well,

whether making for yourself or that special someone—we would love to have you join us!

Future classes are scheduled on the last Tuesday of the month from 5:00-7:00 PM. For \$5 a class, refreshments are provided in addition to all the materials necessary to make the "jewelry du jour." Space is limited, so please RSVP at least a week prior to each class to inquire availability with Katherine: KatherineH@eed-a.org; or 631-369-7345 ext. 244.



One of the finished Bling-Leader pieces.

THIRTY-ONE YEARS... AND COUNTING

By Felicia Foster, Community Habilitation Coordinator & Laurel Weresnick, Training Manager



James and Tina on their wedding day.

There are many success stories here at EEDA. Tina and James McCormick are our longest married couple, devoted parents, and are now proud grandparents. This is their story of love and growth. We hope you enjoy it as much as we do.

James and Tina first knew each other in school. They went to the same early education school and then BOCES. They were not friends, but knew of each other. Tina said she noticed James, but was busy with other things. James says he noticed Tina, and had always wanted to talk to her, but didn't have the nerve. James worked weekends at Shirley Feed back then. One day a couple of years after she graduated BOCES (James was still attending), Tina was going grocery shopping for her mom and was walking past Shirley Feed. Although she noticed James working she did not stop until after she finished her grocery shopping. She slowed down while passing Shirley Feed and James started talking to her. They both agree that James started the conversation. If you know James then you know he's the strong silent type. He is not one to necessarily start a conversation, so this was big. They dated for about three years before they decided to get married. On August 29, 1985, James and Tina were married by the Justice of the Peace at Town Hall in Patchogue. Tina said they didn't have enough money for a formal wedding in a church. Tina's mom had passed away, and they moved into her home. They both agree that one of their biggest challenges was dealing with family members who

thought they knew what was best for them. They didn't have enough money to move into an apartment and James was just twenty one. James was the only one working at this time so it was hard supporting a wife and paying the bills.

Challenges over the years included the usual such as, who felt they did more chores than the other, who spent too much money, and for James, getting some "me" time. There was a short time where they even split up to take a break from each other but realized they would rather be together than apart.

On February 20, 1990 at 2:33 weighing in at 6lbs 14oz, James and Tina became the proud parents of Michael James McCormick. They both agree they were a little nervous having a baby and Tina says she was sure she was going to have a girl so they hadn't even picked out a boy's name. James was not in the room during delivery because Tina had a C-section, but he was excited when they announced he had a healthy baby boy. He said it was like holding a football.

James and Tina got involved with EEDA almost from the beginning, about 1997. Joan Lucarelli, who was the second service coordinator to work with Tina and James, said that Tina was always a loving, caring, overprotective momma bear to her son



James with Michael Jr.



Tina with Michael Jr.

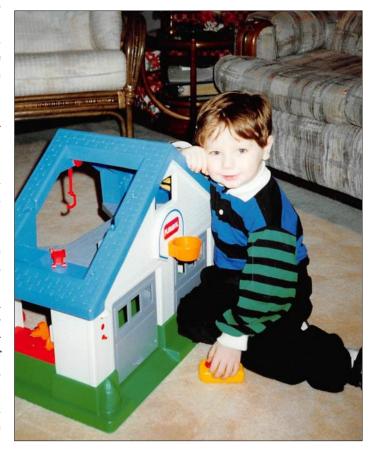
Michael. Michael always came first and she truly loved him and did her best. Joan said she hasn't seen Tina in a while, but she just saw James, and he was beaming when she asked about his precious grandson.

James and Tina finally moved into Riverhead in early 2000. Raising a son came with all the challenges most parents faced. One the hardest things was how to help Michael with homework that they did not necessarily understand themselves. Tina wanted one of her outcomes to be helping her son do his homework since he was beginning to fall behind. Although EEDA could not provide services to Michael they were able to be creative and found a community habilitation worker who happened to be going to school to become a teacher. Sharon would work with Tina during homework time and show both of them what

needed to be done. Tina could help answer questions and felt satisfaction in assisting Michael. His improved grades made both James and Tina happier, and Michael enjoyed school a little bit more. When asked, James said that some of his best memories are playing soccer and baseball with Michael. When Michael hit his Junior year of high school, like many kids, he started hanging out with a crowd his parents didn't approve of. Michael did graduate, but it was a struggle for all. After graduation, the three finally agreed that Michael needed some help and he moved into Hope House. Tina remembers bringing water bottles for all the kids when they visited. This was a tough time for the McCormicks, but with the help of Father Frank who encouraged Michael to attend classes at Suffolk Community College, Michael set himself on a new path.

He eventually moved down to Florida where he met his future wife. They moved back up here and on June 26, 2016. Tina and James enjoyed watching Michael get married in a wedding that Tina describes as one of the most beautiful she has ever seen. James kept smiling while Tina discussed the wedding. Michael is a trucker and his wife is studying to become a nurse. James said he is really proud of Michael. What makes James even more excited is that on September 26, 2016, Michael became father to his own son. James is proud of the fact that they chose to name him Michael James McCormick Jr. Although busy with work (both Tina and James work) they enjoy babysitting for Michael Jr. Tina loves when her son "asks for help" with the baby. Today, James and Tina continue to work. James takes guitar lessons and would like to see Tina get involved with something so she has her own "me time." Many of us enjoyed when James wrote his own song and sang it at one of our talent shows. When asked, James said he has not played for his grandson but would really enjoy doing that. He might write a song for him. We asked James and Tina if they had any advice for people with developmental disabilities who were thinking of getting married. Tina said they should work things out so they don't stay mad at each other, and to split the chores. They both said to have patience with one another and suggested to take a walk if you are mad so that you can come back and talk calmly. Advice we can all follow.

Tina and James have made a beautiful family, and became a part of ours in the process.



Michael Jr. as a toddler.

RELIAS: A WEB-BASED LEARNING SYSTEM

By JoAnn Ainbinder, Quality Assurance Coordinator

EEDA's MSCs took the top spot on the Relias leaderboard for the second half of 2016. Relias Learning Management System is EEDA's web-based learning management system (LMS) that allows the staff to see when their trainings are due, register for trainings, and track what trainings they have completed.

Relias gives the staff access to a whole online e-learning library of courses on a variety of topics at any time. Most of the learning modules are interactive, interesting and apply to the day to day issues the staff come across. This online application is now being used for orientation of all new staff members, and for staff development and growth. They even have a whole section of wellness trainings for the staff such as stress, time and weight management, as well as heart disease and diabetes prevention. Relias has become a valuable tool in training staff and maintaining their records.

The Relias leaderboard is part of a new gaming feature which incorporates friendly competition while making it easy to track results for each individual, team or department. The staff's compliance rate and final average grade for each module are averaged to give them their score. The staff have an individual score based on their own trainings and then as a department competing against other departments in the agency. The score influences the team rank on the leaderboard. The staff earn rewards for every training they complete. With the rewards the staff can build a custom crest to show off their progress. The gaming element increases staff engagement which results in improved knowledge retention, performance and client outcomes. We are very proud of our MSCs with a high score of 95% for the second half of 2016. The administration and managers round out the top three. The MSC department will receive a special prize for coming out on top. Congratulations to everyone and the scores reset on January 1st so here's your chance to rise to the top.

SELF DIRECTED SERVICES

By Diane Lagoumis, Sr. Manager of Self Directed Services



Debbie and Ricky

Self-Directed Services is a service in which individuals with intellectual disabilities design their own plan of services with help from their circle of support, including their family and advocates, Medicaid Service Coordinator, Support Broker, and Fiscal Intermediary. The philosophy of Self-Directed Services is to provide support to individuals so they have the opportunity to learn skills by accessing services and activities in the community. EEDA acts as the Fiscal Intermediary (FI) arm of the service, meaning we manage the finances of providing services including paying the workers and consultants hired by the individual, paying for classes and memberships in the community and reimbursing costs associated with accessing these services, among a myriad of other services an individual wishes to access.

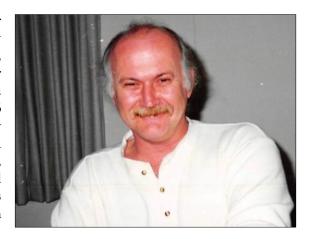
But what does this all mean for the folks who are participating in the service? Music and dance are wonderful activities that our folks are accessing in the community. Dance lessons are being taken at local dance studios in fully integrated settings. Swim lessons, art classes, gym memberships, fitness classes, horseback riding and recreation, leisure and social events are all being accessed in the community; WITH the community. Self-direction also supports volunteering, gaining employment, and enables people to live in their own apartments in the community. By spending their money in the community, not only are they living independent, productive and fulfilling lives, but they are also supporting our own local businesses. We have over 200 individuals who are accessing Self-Directed Services through EEDA. They are spending their dollars in the community and living their lives by design; realizing their hopes and dreams.

There are many ways to learn more about Self-Directed Services, and you can start by accessing the EEDA Self-Direction page at www.eed-a.org/selfdirection—For information about Self-Directed Services through EEDA, please contact Diane Lagoumis, FI Sr. Manager at (631)369-7345 ext. 109.

EEDA IS-LIKE-A FAMILY: REMEBERING JAMES WALSH

By Joy O'Shaughnessy, Chief Program Officer

EEDA is a family. Outsiders could easily presume we are careless or frivolous in the way we throw this term around. EEDA is certainly not a typical nuclear family or household, we are not brothers, sisters or cousins, we do not share common faith or beliefs, biology or hale from the same lineage. This may all be true, yet, EEDA is a family – you cannot convince me otherwise. On October 31, 2016 the EEDA family lost one of our own, Mr. James V. Walsh. I know James considered himself a lucky man to have a family like EEDA who provided him with an outpouring of support, concern, assistance, humor and love during the course of his illness and beyond. As good families do we came together to support James while he was sick and supported each other through our grief when we lost him This is what families do.



James was born in Northern Ireland and immigrated via Canada with his family to the United States as a young boy eventually settling on Long island. James earned his degree at Stony Brook University and enjoyed a rich life supporting and helping others. A highlight for James were the years he spent in the Peace Corps as a teacher in the Democratic Republic of the Congo (formerly Zaire). Over the years we never tired of his stories about Africa; like the uncle returned from a great adventure, he spoke of huts, snakes, the silverback gorillas, the beautiful landscape, the music and the wonderful people. He was very proud of this experience.



James with his best buddy Courtney.

The majority of his adult life was spent supporting people with intellectual disabilities who he treated like his family.....some of these people he loved dearly like children or brothers and sisters and others like distant cousins. James loved "good people" and did not define folks by their disabilities, wealth, status, or race but rather who they were inside. James was an important member of the EEDA family who could share wisdom like your grandfather, had the humor of your siblings, would feed you like your grandmother, correct or teach you like your father, make you proud he was your son and embarrassed like he was your brother. James was the mischievous nephew who loved a good joke, spoiled your appetite with candy, and could drive you crazy at times but always circled back around to apologize with a sweet treat when he was wrong. He was as real and genuine as it gets.

James came to EEDA in 2000 and was extremely proud of his efforts in developing this agency into a large extended family. Prior to his years at EEDA he enjoyed a career at our sister agencies FREE and DDI. There are some family members you grow apart from and only get to see at weddings and funerals. This was true as colleagues from James' many years working at EEDA, FREE and DDI all came from near and far to pay their respects and honor James at his wake and funeral. Together we recalled his love of music, baseball, women, history, boxing, Africa, "good people," and all the laughs. There are still so many great James stories to tell to the next generation.





Joy, Gus, and James on the annual Winter Clove trip.

RESIDENTIAL SERVICE'S 4 DAY WORK WEEK

By John Hatton, Sr. Manager of Residential Services



Alissa and Shaunice at the Spring Dance.

EEDA has five Residential IRA's that provide a home for thirty seven individuals. Our dedicated residential and maintenance staff maintain these homes in pristine condition. The needs of our residents are met twenty four hours a day 365 days a year. Perhaps the biggest challenge that the folks in the Residential division are attempting to overcome is staffing. We have, in the past, been unable to find enough qualified staff to fill all the open shifts. We have been required to use current staff in overtime hours which is concerning with regards to the well-being of our staff, and a financial burden to the agency.

However, this October, the residential division introduced a new four day schedule that is designed to eliminate the overtime hours. The new schedule allows for fulltime seasoned staff to be scheduled on the weekend where our staffing needs are more acute, and gives staff a guarantee of two consecutive days off, and only requires staff to work one weekend day.

The results of this new scheduling have been dramatic. The staffing crisis at the residences has been alleviated, the staff enjoy their "three day weekend" and the overtime costs have been reduced. Going forward, EEDA is only hiring new residential staff on the four day work week and we eventually plan to have "extra" staff on certain overlap days enabling us to cross train our staff and make them even more valuable to the agency.

WARM WELCOME AND CONGRATULATIONS

By Joy O'Shaughnessy, Chief Program Officer



WELCOME WALENTAS HOUSE: EEDA's community partners at L'Arche Long Island (LLI) had a lot to celebrate as 2016 came to a close with the opening of the Walentas House right here in downtown Riverhead. The residents are both people with and without developmental disabilities who live and share their lives together in the beautifully renovated seven bedroom home. The Community Center is adjacent to the home and serves as a space for social gatherings, prayer, and celebration.

LLI is a community where people with and without intellectual disabilities live together as peers. As part of the worldwide L'Arche movement, they are committed to creating inclusive communities of faith and friendship, and to transforming society through relationships that cross social boundaries.

LLI and EEDA began working together several years ago to plan the establishment of Long Island's first L'Arche community, which will include the one home, a community center, and several neighboring apartments. EEDA provides administrative support for LLI and acts as the Fiscal Intermediary for the core community members who self-direct their supports and services.

Congratulations to L'Arche Long island on achieving this major goal in your development!

40 YEARS: PRETTY AMAZING STUFF: Joy O'Shaughnessy was honored to serve as the Chairperson of this years NYSACRA Statewide Conference Committee along with EEDA's own Matthew Kuriloff. This year's conference theme, "40 Years: Pretty Amazing Stuff" represents the organization looking forward while celebrating how far we have come in supporting people with intellectual and developmental disabilities in living rich lives of distinction. The annual conference is a special gathering of NYSACRA members and friends all united through a powerful, shared vision of community and opportunity. EEDA will be well represented at this great learning and networking event. Congratulations to NYSACRA on reaching this significant milestone in your history.

HAPPEEDAYS

NEWS FROM EEDA PROGRAMS WRITTEN BY PROGRAM PARTICIPANTS AND STAFF

EEDA SELF-ADVOCACY UPDATE

By Alissa S., Secretary of Self-Advocacy of the East End

SANYS U CLASSES: I started taking SANYS U classes in January. My graduation is at the end of this month. For those who don't know, SANYS stands for Self-Advocacy Association of New York State. We learned about how SANYS was founded and the history of the Disability Rights movement. To be honest, I did not agree with everything that was said in the class. I tend to lean on the more conservative side of things, but that's another story. Although I have no intention of being a state-wide leader, I did learn how important it is to speak up for your rights as a human being. I am starting to ask for help more when I need it now, even though I am still a little afraid. Janice Kennedy, our advisor, is helping my group work on a project for graduation. Although I have no plans to repeat the class or go any further with it, I admit, I will be proud of myself when I graduate.

MEETING WITH OUR LEGISLATORS: On February 14th, 2017, I went upstate with my peers Cale B., Christine B., and Glenn P. to speak up for the #BFair2DirectCare act, along with our staff Janice Kennedy and Matthew Kuriloff. We all feel that Gov. Andrew Cuomo is not being fair by raising the minimum wage for people who work at McDonald's, but not for DSPs. I work with many wonderful DSPs at my house and program, and I think they deserve to be paid more due to the hard work they do. I mean, face it! We're more important than a burger! We spoke to our local councilmen, and they all seemed very receptive. Hopefully, we will be able to get better pay for our DSPs soon. #bFair2DirectCare!



Self-Advocacy crew in the halls of the Legislature in Albany.

EEDA's self-Advocacy Group, Self-Advocacy of the East End, meets the last Thursday of the month at the EEDA Main Office in the Large Conference Room from 4:30pm-6pm. Refreshments are always served! For more information, contact selfadvocacy@eed-a.org.

IN A HEARING WORLD

By Mary V., Self-Advocate



Mary

Back in the days when I was in school I lived at home with my family. My mother had a friend whose name was Joan. She came from Germany. She had a son named Steven. All the time, Steven would like to make fun of me. Steven went to the same school where I studied and we took the same mini-bus to school.

One day, I overheard Steven say to his mom, "hey, look at that retard going on the minibus!" I felt so sad inside me as I went to the school that day. I saw tears rolling down my mom's face because she heard it too. But, my mom kept her composure and told me, "have a nice day, honey!" All I could say to mom was a sincere, "thank you, Mom!"

Joan's kids were very cruel. They did not understand someone with a disability. Steven has a sister called Diane, nick-named Dee Dee. Dee Dee would make fun of me too. Dee Dee's mom Joan used to make good mac and cheese (I could still taste it in my mouth).

From what I remember, our neighbors had their own problems. But aside from the name calling of her children, their mother was good to me. Come to think of it, it was not that bad. I have seen worse in other people.





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Friday, August 18th, 2017 Indian Island Park, Riverhead

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Friday, September 15th, 2017 Ditch Plains Beach, Montauk

For more information on these and our other exciting events, check out our events page at www.eed-a.org/events