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Devin's House
Opening

**2017
Highlights**

**DSP
Awards**

THE EEDA READER

NEWS FROM EAST END DISABILITY ASSOCIATES, INC.



EEDA DAY AT CITIFIELD

by Jeremy Grand, Executive Assistant

Danny (with his dad) throwing out the first pitch.



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."

On Friday, August 4th, a group of 175 EEDA family members filled the stands wearing their freebie deGrom jerseys to cheer on the Mets at CitiField, but they weren't just there to cheer on the home team. EEDA had the privilege of being honored on the big screen and on the field as one of our residents, Danny P., made us proud by throwing out the first pitch with his dad...

(Continued on page 3)

A MESSAGE FROM THE CHIEF EXECUTIVE OFFICER

Advocacy is fundamental to the successful work accomplished in the field of human services and has positioned individuals with developmental disabilities into a recognized place in our society. Over the past forty years, New York State has transitioned its thinking and actions from “*committing someone to an institutional setting*” to “*providing community living options,*” and the shift from “*taking care of*” to “*providing support*” to an individual. These are important strides, but we still have so far to go in establishing true integration and appreciation of the value individuals with intellectual and developmental disabilities add to our world.

It’s an election year in New York State, with 150 seats in the Assembly, 63 Seats in the Senate, the Governor, Lieutenant Governor, Attorney General, and State Comptroller, all open for votes. EEDA is an active member and partner with the Coalition of Provider Agencies and New York State Alliance for Inclusion and Innovation. These advocacy organizations help us unify and mobilize our efforts to improve the lives of individuals with intellectual and developmental disabilities and the staff who support them.

Advocacy must be focused on areas that will enable the advancement of support and resources to individuals living with intellectual and developmental disabilities. This year we remain focused on the #bFair2DirectCare campaign that seeks to provide a living wage for Direct Support Professionals (DSPs) working with people who have complex needs, often acting as nurse, driver, behavior specialist, technology concierge, activity coach, cook, cleaner, and advocate. DSPs are not compensated at a level matching the skill-set required to do their job every day. New York State is currently experiencing a DSP workforce crisis with almost 15% vacancy and nearly 27% turnover rate leaving a vulnerable population without dependable care.

Another area of equal importance is obtaining additional resources for residential opportunities. There are over eleven thousand people in New York State in need of support services to address long term care needs. The report to the Governor: “Keep the Promise,” describes the significant need for residential housing and provides solutions to address the issue.

Please join us by asking your legislator to provide the resources to stabilize our workforce and provide additional resources for residential opportunities. Follow this link to EEDA’s website at www.eed-a.org/advocacy and access simple instructions on how to participate in the advocacy process and to read the report “Keep the Promise.”

Advocacy requires action, and no one knows more about action than parents and family members of those requiring support. EEDA’s Family Advocacy Group meets monthly to discuss the important issues that affect their children/loved ones with intellectual and developmental disabilities, focusing on advocacy within the multiple systems. Please join us to learn what’s going on in the industry, at EEDA, and help create a strong advocacy base that will ensure the services we have today will continue to be available tomorrow. Visit EED-A.org/Advocacy for the meeting schedule.

Lisa Major Furtal



Lined up at the dugout: Matthew Kuriloff, Mark R., Jim Martinsen, Danny P. and Mr. P., Christine B., Janice Kennedy, and Thomas W.

continued from page 1

The EEDA group cheered Danny on, lighting up the field brighter than all the lights in the whole stadium.

When EEDA was announced as the day's honorees, a group of EEDA staff and individuals at the dugout came up on the big screen to represent our agency to the thousands of fans at the stadium (see photo on left). Not only was this an incredible experience for those on the field, but for us in the stands. This was one of EEDA's proudest moments (if not THE proudest moment) for the whole year.



The annual Thanksgiving food drive was a huge success this year. On November 9th 2017, we partnered with Stop & Shop, where the EEDA day services individuals gathered in front of the store to collect donations towards the food drive.

We collected six large turkeys and almost two shopping carts of nonperishable items. Later in the month, we were able to put together seven baskets and distribute them within the agency to families in need. Not only was this activity rewarding, but it filled everyone's hearts with a sense of accomplishment. Everyone was so excited to see the pile of food getting higher and higher as the minutes went by.



Public Forums Now Available

As you may know, the Office for People With Developmental Disabilities (OPWDD) is making an important improvement to the way services are coordinated. The Medicaid Service Coordination (MSC) program which is currently used to coordinate services will be replaced by a new and improved program called Health Home Care Management beginning July 1, 2018. Health Home Care Management will continue to provide the service coordination that people currently receive, and will also provide coordination of other services, such as healthcare and mental health supports.

Health Home Care Management Services will be provided by Care Coordination Organizations (CCOs), new entities formed by existing providers of developmental disability services. To provide you with information about the transition, OPWDD and the CCOs are hosting regional public forums across the State.

*These forums are intended to educate the people we support about the transition. In order to accommodate the greatest number of individuals with developmental disabilities and their family members, we ask that you attend no more than one People First Care Coordination public forum. **The same information will be presented at all regional forums, regardless of location and date.***

You are cordially invited to attend the forum most convenient to your location:

April 2nd – 6 p.m. to 8 p.m.
 Independent Group Home Living (IGHL)
 Administration
 221 North Sunrise Service Road
 Manorville, NY 11949

April 11th – 6 p.m. to 8 p.m.
 OPWDD Regional Office
 415A Oser Avenue – Multipurpose Room
 Hauppauge, NY 11741

April 18th – 6 p.m. to 8 p.m.
 Adults and Children with Learning and
 Developmental Disabilities, Inc. (ACLD)
 807 S Oyster Bay Road
 Bethpage, NY 11714

REGISTRATION CONTACT PERSON:

MICHELLE GIULIANO -
michelle.giuliano@opwdd.ny.gov -
631-416-3838

STEPHANIE GINSBERG -
stephanie.ginsberg@opwdd.ny.gov-
631-416-3903

To register for the forum nearest to you, please call or e-mail the regional office staff listed above by three business days before the event.

Each forum will be hosted by OPWDD’s Regional Office Director and will have OPWDD and CCO representatives on hand to answer any questions.

We hope to see you there.

EEDA DREAM COMES TRUE . . . DEVIN'S RESPITE HOUSE OPENS!

By Joy O'Shaughnessy, CPO



Overnight Respite is one of the most valuable services we can provide to families who have their loved ones living at home, giving families a break from the rigorous demands of caregiving in a safe environment their children enjoy visiting. The new Respite House serves as a place where caregivers can leave their loved ones in a safe, supervised environment so they can attend to life's other duties or simply take a needed break.

EEDA has provided Overnight Respite since 2002 in a series of rentals and has long dreamed of having a house that met all of our wish list items. We wanted a house that would support our ability to serve people with ambulation challenges, requiring ramps and bathroom accommodations; we envisioned it to be set back off the road in a semi-private location with a fenced-in yard, a shaded patio and playground equipment; safety features such as delayed egress door locks, central station fire monitoring, security cameras, and walls with extra reinforcement that could withstand heavy traffic and use; recessed lighting in every room so we didn't have to worry about lamps that can easily be knocked over; ample parking for families, staff, and program vehicles; a safe and private area to administer medications; an aesthetically pleasing and fun environment so guests would want to return again and again. Without government funding for the development of a Respite House, especially one with all of these special features, significant financial support was needed. We turned to the EEDA community for help.

The generosity of many helped this dream come true for EEDA and we want to thank everyone for their support:

To everyone who attended our Golf Outing, Gala Dinner Dance, donated to our Annual Appeal, purchased a raffle ticket, or a brick for our Path to Respite; to the wonderful men and women who donated their time year after year at the Golf Outing, Gala Fundraising Committees, and the EEDA staff who volunteer their time to help run events; to Maureen Fanning and the Jack Fanning Foundation Angels for Autism for extremely generous donations not once, but twice, and for your patience with us in developing this unique project over an extended period of time; to the Southampton Bath and Tennis Club Charitable Fund for your generous contribution towards this very special project; to all of our OPWDD partners from the Long Island DDRO and the Department of Quality Improvement; to Timothy Ealy from Toshiba Business Solutions for sponsoring our Respite House office; to Mary Blanthorn and Frank James who spent countless hours designing and decorating the house, donating and installing all of our beautiful window treatments and linens, and securing all interior paint through a generous donation from Sherwin Williams; to the McCarrick Family for being great community partners and understanding our needs and vision in building this beautiful house; to Ed Bonsignore for his thoughtful donation that helped form the foundation of our Respite House fund; to everyone who purchased housewarming gifts through our Target Registry; to those of you who realize it's not too late to donate now and help us defray debt and operation costs to maintain this beautiful house in the days to come; to all the wonderful families we admire and respect who have motivated us to build this house where their loved ones can grow and flourish while they recharge their batteries; to honor the memory and spirit of Devin Fertal who enjoyed many years of Respite services in his young life, and his dad George for leading the way in fundraising, making this dream come true for other families to benefit from in years to come, **Thank You! Thank You! Thank You!**

MEMORY LANE



Clockwise from top:

- **Voter Registration Drive at the The Vail Leavitt Music Hall**
- **Annual Picnic at Indian Island Park**
- **8 Bells Crew during DSP Week**
- **Annual Golf Classic at Bellport Country Club**
- **Laura Jens-Smith Campaign for Town Supervisor**
- **The Ladies of Finance at the Annual Picnic**





Clockwise from top:

- Pumpkin picking with Riverhead Day Hab
- Grace's Place clean-out day
- Goofy Glasses Day at Calverton Day Hab
- Goofy Glasses Day at the After School Program
- Surfers Healing at Ditch Plains Beach

2017





EEDA's Kevin Parker and Kevin Darrell (back row) were among Long Island's best and brightest DSP's presented Leadership Awards at the conference.

Over 100 of Long Island's best and brightest DSP's from across Long Island, including nine from EEDA, attended the Annual NYSACRA DSP Conference in the Sea Star Ballroom at Atlantis in downtown Riverhead. The conference is a day DSP's can step away from their typical daily responsibilities to be recognized for their efforts in supporting people with intellectual disabilities. The conference provides opportunities to be inspired and learn from each other and guest speakers.

EEDA's own Russell Street IRA staff Kevin Parker and Kevin Darrell, were presented Leadership Awards for their commitment to the men they work with. The "Kevins" are a great team on the overnights at Russell Street who demonstrate some of the best qualities of DSP's including being reliable, committed, fierce advocates, and the voice of the men they work with. The "Kevins" have a strong connection to the men they support, comforting and caring for them during each night and starting each morning off on a good note as they help the residents wake and get ready for the day. Their positive and sensitive interactions with the residents really set the tone for the day.



Stephen "Dr. Bird" Birchak delighted attendees with an inspirational message about choice drawn from his personal and professional experiences. "There is one thing that no person can ever take away from you — your choice. No one can ever take away your ability to choose what you want to do in a given set of circumstances. No one can ever take away your potential to make the world a better place." Other speakers included the staff of the Regional Center for

Workforce Transformation and Chris Reinhardt who spoke on overcoming "Imposter Syndrome."

A highlight of the conference is the "Inspiration and Innovation Fair" when DSP's present ideas to one another. EEDA staff shined as they presented on our Walking Wednesdays initiative, Surfers Healing, and the Forward Motion music program. Attendees from other agencies were inspired by our DSP's and their great work. Who wouldn't be?

NEW YORK ALLIANCE FOR INCLUSION & INNOVATION (NYAII)

by Joy A. O'Shaughnessy, CPO



EEDA has long been an active member of the New York Association of Community and Residential Agencies (NYSACRA). I have had the privilege of serving as a Vice President on the Board of Directors for the past five years, and members of our leadership team participate on NYSACRA's various committees and educational conferences.

For the past three years NYSACRA has been working with another statewide association, the New York State Rehabilitation Association (NYSRA) and has recently merged into the newly formed New York Alliance for Inclusion & Innovation to strengthen their voice on advocacy and enhance public policy and technical assistance efforts. With this merger, the New York Alliance for Inclusion and Innovation (New York Alliance) becomes the premiere resource for advocacy, education and training, technical assistance, and leadership for New York's disabled community. The three-year merger process was executed skillfully and thoughtfully, serving as a textbook example of how organizations can become stronger together by remaining true to their missions.

"As both boards agreed that the two corporations had similar purposes and apparent opportunities for synergies existed, it was clear that more opportunities would evolve for New Yorkers with disabilities and the agencies that support them if the two organizations became one. The New York Alliance will take the disabilities community to new heights," said Louis Cavaliere, President of the NYSACRA Board of Directors.

Building upon the two associations' missions and visions, the New York Alliance will have the capabilities and resources of NYSACRA and NYSRA and serve more than 200 not-for-profit agencies which serve the highest interests of people with disabilities in all parts of New York State.

The New York Alliance will focus on uniting and empowering its membership, their ideas, and energy to design a better future for people with disabilities, together.



We are so grateful to Diane Arpaia, EEDA Board member and parent (fourth from left) and the Long Island Board of Realtors for their generous donation to EEDA!



REALLY JUST A FAMILY

by John Hatton and Samantha Fenoy, Residential Services Managers

When does $75 + 5 + 5 + 4 = 1??$

It does when you add up all the parts of EEDA's Residential Program: Seventy-five direct care staff; Five house managers; Five houses; Four clinical staff. That is what it takes to make the EEDA Residential Program work. Twenty-four hours a day, three hundred sixty five days a year, year after year.

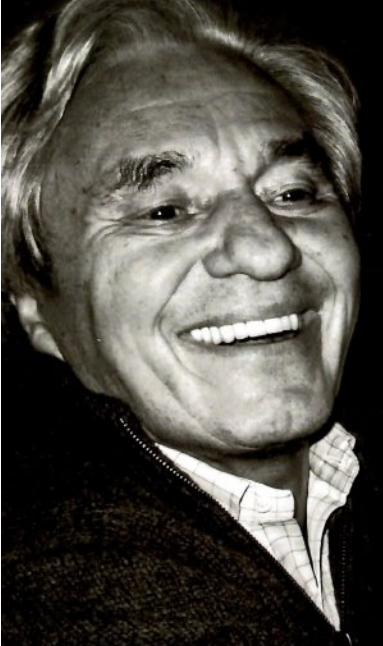
There are so many moving parts, different locations, different people, and different needs that when all put together into one big program equals one big family.

The residential program has evolved in the last couple of years into a single unit, no longer a conglomeration of five IRA's. The managers and staff are collaborating on the goal of working together. Staff move from house to house when the need arises, and managers call on each other for help in many ways. If Chris needs an overnight staff, then Andre may have one. When Ronnie needs an AMAP to pour meds at his house, then Danielle can usually send one over. Need a ride to ministries? Call Nicole, and they can pick you up on the way. Our "guys" live together and socialize together. There's a holiday party at Eight Bells, a Fourth of July party at Corwin, Halloween is celebrated at Southfield, Thanksgiving dinner is at Barnes, and if you feel like a burger in July, Charles is guaranteed to be grilling at Russell Street (just don't forget your swimsuit).

Our talented team of clinicians are always on-site or a phone call away. Appointments are made and kept, people get to be where they need to be when they need to be there. There are always meetings, and parents and families are aware and involved. If a problem or concern arises it is dealt with swiftly. Do we get it right all the time? I like to think so, but we are only human; we learn from our mistakes, and then move on. There are no timeouts, very few do-overs, and no giving up. Staff do come and go, but like Gus has told me many times, "People leave. We wish them luck and the next day we get back to work." Our responsibility is to our guys and we never waver.

Residential and Day Programs are the backbone of the agency. Day Program staff transport our guys, help us fill staffing shortages, and cover our houses during snowstorms. When you step back, the family gets bigger. At EEDA, we know the name of the person working next to us, we know the name of the guys we are with, and we always have the support of anyone who is wearing EEDA blue.

REMEMBERING MICHEL BERTY, L'ARCHE BENEFACTOR AND EEDA BOARD MEMBER



Michel Berty was the driving force in developing a relationship between EEDA and L'Arche Long Island. Michel's positive attitude and no-nonsense approach to life and business fully engaged us all in working toward collaboration and partnership. Michel was on the EEDA Board of Directors from 2016 until 2017. Unfortunately, Michel left us too soon, but not without leaving imprints of friendship on our hearts and minds, and the knowledge that anything is possible. Best memories of Michel will remain with the EEDA family always.

DSP AWARD NOMINEE SHARON CARRIE MANUEL

by Kimberly Schebler, Grant Writer

In December, EEDA nominated Sharon Carrie Manuel for ANCOR's annual DSP award. Sharon has built relationships with the people she supports and their families that are filled with genuine love and compassion that extends far beyond the reaches of what is required of a direct support professional. Sharon has replaced broken lunch boxes, spent her Saturday cleaning out the thrift store, driven people to family parties and advocacy events upstate on short notice, serves as a natural support in the evenings for someone she works with, is critical in the success of our annual Thanksgiving food drive, and is invaluable to the people she supports. We interviewed several people when nominating Sharon for the DSP award. Each person's glowing words of admiration help us see a side of Sharon that everyone doesn't always get to see because you'll never catch Sharon talking about how she's helped someone. One of the people we interviewed was the president of EEDA's self-advocacy group, Christine B., who said, "Sharon's my rock. She's been there through all my ups and downs. Whenever I need a shoulder to cry on, or somebody to make me laugh, she's there. Trust me, if I lost her it'd be like a piece of me is missing. She's the most loving, sweetest, and caring person I know. She would give the shirt off her back if she saw another person was cold."





WE'RE OFF TO SEE THE WIZARD

Picture highlights from the Wizard of Oz. The EEDA Creative Arts Program put on a rousing performance of the Wizard of Oz in April of 2017 at the Gateway Playhouse.



SELF-ADVOCACY UPDATE

by Kimberly Schebler, Grant Writer



EEDA's self-advocacy group, Self-Advocacy of the East End, was delighted to receive Jessica Lucas from Bethpage Federal Credit Union as a guest speaker at their meeting on Thursday, November 30th. Jessica is the Community Development Relationship Manager at Bethpage Federal Credit Union and she came to speak to EEDA's self-advocacy group about budgeting. Jessica handed out several budgeting worksheets to the group and went through some of the expected and unexpected expenses that each person would encounter living on their own. We discussed how to budget our monthly expenses for clothing, technology, housing, food, and

transportation. The group quickly realized how fast expenses add up, and how a latte purchased from Starbucks five days a week will cost you \$1200 a year! Many self-advocates vocalized a desire to live in their own apartment someday and found the information they received relevant to their goals. Jessica kept everyone engaged and interested in budgeting. Jessica Lucas will be back to speak to the group about credit in the near future. In the meantime, Self-Advocacy for the East End meets on the last Thursday of every month. We hope to see you there!

A VIEW FROM THE NEW KID ON THE BLOCK

by Fran Fitzgerald, Associate Director of Program Operations



I'm about to mark my one year anniversary here at EEDA. As with so many things in life, it's been a paradox of time. On the one hand, my first day here seems so long ago; On the other hand, it seems like yesterday!

My background and experience in the field of providing services to people with intellectual and developmental disabilities spans well over thirty years. During that time, I mostly worked with very large agencies – the DDI's and the UCP's and the AHRC's. These are all organizations that provide a wide range of high-quality services. But there's something different about working here at EEDA. While we're large enough to have a true and significant impact on many individuals, we're still small enough that we haven't lost that "family" feeling. And we're still small enough that our core mission hasn't been lost in the bureaucracy.

By no means do I mean to imply that larger organizations have lost sight of their mission and goals. They haven't and we

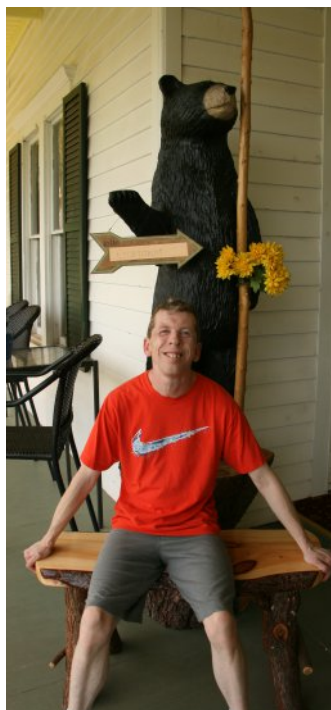
should be thankful that there are so many agencies that provide services, giving individuals and their families far more choices than when I started some thirty-odd years ago. But with many of the EEDA executive and managerial staff having been here since our first participant entered EEDA's first day program and our first resident stepped into their new home, there's a "parental" feel to everything we do.

Our staff has a historical body of knowledge for each individual we serve – when that individual started with us, what programs he or she has attended over the years, their likes and dislikes, and their strengths and challenges. When faced with making modifications in an individual's services, first, of course, we work with the individual and their family with person-centered planning. But it's also as if there are "Aunts" and "Uncles" walking the halls here willing to provide insight and information for each and every individual. Yes, it's family!

Last but not least, EEDA has welcomed me (and Rusty) to that family with open arms. I've been met with a collaborative and collegial spirit that's refreshing. I want to thank everyone for helping make my transition in this new position a smooth one. I look forward to many years with the family!



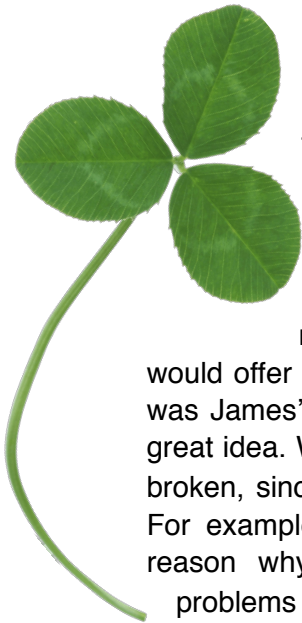
EEDA THANKS NEW YORK COMMUNITY BANK FOR GENEROUSLY DONATING THE PRINTING OF THIS ISSUE





A TRIP TO REMEMBER

by Orlando Urena-Cordero



In 2002, I met the great late James Walsh when I was volunteering for East End Disability Associates. At times, James and I had different points of view. There were times where his views made me irate. However, James always gave me that fortitude to improve in my professional career as well as in my academic skills at Penn Foster Career School and Briarcliffe College. Since my arrival to East End Disability Associates and enrolling in the ISS apartment program, James not only made certain everything was satisfactory with me, but also with the rest of the East End Disability Associates individuals receiving services. James offered to help me pay for my mother Daisy Cordero’s headstone. I must admit I was surprised, but happy that James would offer to help me pay for my mother’s headstone when he had never met her. In addition, it was James’ idea for me to travel the globe, which was and still is a great idea. When Patti informed me of James’ passing, my heart was broken, since I never received a chance to tell him how I really felt. For example, I regret that I neglected to inform James as to the reason why I became so proficient at dealing with behavioral problems as well as crisis situations in my mental health jobs, as well as the reasons I have to do with my leadership skills and I conduct myself in team meetings.

On August 26th, 2017, I went to Ireland to honor James. When I met the tour group in Ireland, I received utmost verbal praise regarding honoring James to the point that I felt James’ spirit when I arrived. There is not a day that passes when I do not think of James. I will always love James and honor him.



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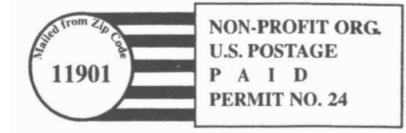
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Your Challenge... Our Commitment



CURRENT RESIDENT OR

**The Annual Gala Celebration, this year
partnered with L'Arche Long Island will be
held on Friday, May 4th, 2018 at
East Wind Caterers!
Email gala@eed-a.org for more information.**