



AHRC
new york city

CHRONICLE

WINTER 2016



CONTENTS:

I. EDITORIAL

A Message from Angelo Aponte, President

A Message from Gary Lind, Executive Director

II. FEATURE

Let Our Elected Officials Hear Your Voices!!!

III. PROGRAM, SERVICES, AND SUPPORTS

AHRC NYC Presents the Technology Toolkit at Prestigious Coleman Institute for Cognitive Disabilities

AHRC NYC Completing First Phase of Work on New Agency Information Platform Funded by OPWDD BIP Transformation Fund Contract

AHRC NYC's Specialisterne Program: People with Autism Getting Hired by Big Companies

Meet Alex Torres: Artist and Entrepreneur

AHRC NYC's Brooklyn Blue Feather Elementary School Had a Visitor from Australia

AHRC NYC and Long Island University's Health Advocacy and Wellness Program

IV. HAPPENINGS

AHRC NYC Department of Employment & Business Services Celebrates National Disability Employment Awareness Month at Barclay's Center

2015 NYSARC Volunteer of the Year Award Presented to AHRC New York City Board Member ,Marilyn Jaffe-Ruiz

Senator Martin Golden's Visit to AHRC NYC's Middle / High School

Save the Date for the 67th Annual Dinner

A Special Night for Special Children: AHRC New York City Foundation's Real Estate Dinner, Is a Resounding Success

V. LEGISLATIVE ISSUES

Update on Legislative and Entitlements

It Matters to Me! NYSARC Statewide Advocacy Campaign Continues Your Legislators Need to Continue to Hear From You

VI. ACCESSING INFORMATION AND SERVICES

Sibling Matters!

Special Globe: A Travel Resource

Sprout

Upcoming Family Education Sessions

AHRC New York City's Referral and Information Center (RIC)

VII. NEWS IN THE FIELD

Unraveling the Genetic Complexities of Autism

THE BACK PAGE

James Thompsen - Living Independently

A Message from Angelo Aponte, President



Angelo Aponte, President, AHRC NYC Board of Directors

“At this moment in history, the disabilities community faces its greatest challenge since the crisis of the mid-1970’s that led to the closing of the Willowbrook State School. Willowbrook was the great seminal event for the disabilities community: it took disabilities out of the shadows and into the bright light of public scrutiny and compassion. I believe New York State’s present fiscal distress can do the same by providing us with an unprecedented platform to advocate, educate, and invigorate our delivery of services to our community. In the coming public debate on how the state will spend its resources, we must become the voice and the face of people with disabilities. While other advocates for public funding may position themselves as agencies with agendas, AHRC is a vibrant community with a conscience. Passionate advocacy and smart administration can transform our challenge into triumph. It requires people with dedication, energy, and eloquence to convince others of the rightness of our cause.”

- Angelo Aponte

Angelo Aponte became AHRC New York City’s President in July of 2015. As a father of a child with a disability and a tireless advocate for families who have children with disabilities, Mr. Aponte has been on the forefront of developing a forceful and compassionate platform on behalf of the disability community. Mr. Aponte has been on the AHRC New York City Board of Directors for almost two decades.

Mr. Aponte’s administrative and political skills have developed over a lifetime in public service, including his tenure as New York City Commissioner of Consumer Affairs from 1984-1990, Commissioner of Housing in Mario Cuomo’s administration from 1990-1993, and administrative and financial vice president in the City University of New York System from 1972-1980 and 2003-2008, Secretary of the New York State Senate from 2008-2010, and many other positions.

Mr. Aponte holds a juris doctor degree from New York Law School, and two graduate degrees. He and his wife, Linda, are the parents of four children and live on Staten Island.

A Message from Executive Director, Gary Lind



Gary Lind, Executive Director, AHRC NYC

The English writer, Samuel Johnson is quoted as saying, *“Great works are performed, not by strength, but by perseverance.”* That spirit of perseverance is evidenced in the stories that you will find throughout this issue of the Chronicle. I was awestruck by the energy and clarity of purpose reflected by those family members who spoke out at the public hearing sponsored by local NY State legislators (Section 2). With little advance notice, on a winter evening, midweek, over 300 family members showed up to express their grave concerns about the government’s commitment to adequately resource services and supports in the face of growing demand. It is my hope that their dedication and perseverance are contagious. Such sustained passion is the best hope we have to redirect government policies that threaten a sustainable future.

I am also moved by the stories you will find here that reflect the life success of two men who we support. Alex Torres has turned his passion for art into business opportunities (Section 3). James Thompson’s move into his own apartment in Staten Island (The Back Page) is a testament to his tenacity. And now James is mentoring others on the path toward more independent living.

The strength of AHRC NYC is reflected in such stories. The path forward is uncertain, but let no one doubt that we will persevere.

II. FEATURE



Let Our Elected Officials Hear Your Voices!!!

Senator Bill Perkins & Assemblyman Robert J. Rodriguez Give Families an Opportunity to Express Their Concerns to Legislators at Public Hearing on January 14th, 2016

On Thursday January 14th, a public hearing was held for families, self-advocates, and all who support people with intellectual and developmental disabilities (I/DD) to express their concerns about funding for programs and services. The field of I/DD in New York State has experienced devastating cuts over the last few years. The large turnout of family members - over 100 people signed up to speak at the hearing with many more present - is a testament to the strong concerns being voiced by families.

[Mrs. Willie Mae Goodman](#), parent, advocate, and Willowbrook litigant, requested that her local State legislators listen to parents of people with developmental disabilities like herself, regarding the current situation. State [Senator Bill Perkins](#) and NYS Assembly member [Robert J. Rodriguez](#) led the hearing that was held at the [Adam Clayton Powell, Jr. Office Building](#) in Harlem. They listened attentively to the scores of family members who came out on a cold winter night to have their voices heard.

Mrs. Goodman opened the discussion with powerful words about how the time had come once again to speak out about the deplorable cuts that have been made in recent times, cuts that are impeding the progress that had been made over the last four decades. "...I'm a Willowbrook parent. I'm one of the parents who helped close Willowbrook in 1970," she began. "We are here to talk about all the children, regardless of where they are, and where they live, and who they are. It's time for us to get together and speak up on the behalf of those who cannot speak for themselves."

Although the meeting was not an AHRC



Willie Mae Goodman, Parent, Advocate and Litigant speaks to attendees of the Public Hearing

New York City event, AHRC New York City members of the Board of Directors, who are all family members, were in attendance and presented testimony. They included [Germaine Laviscount Scott](#), [Meri Krassner](#), [Marilyn Jaffe Ruiz](#), President of NYSARC INC. [Laura J. Kennedy](#) and AHRC member [Elly Rufer](#) who also co-founded the new parent organization, [NYCFair](#). They all made powerful speeches that were impassioned and really hit home.

[Laura Kennedy](#) opened her remarks by saying: "I am proud to be a citizen of this state, proud that New York had the courage and determination 40 years ago to address a failed system of institutional care ...and change to a system of care that has been a model for our country and the world. Families, professionals, and advocates collaborated with government to develop community based services of housing, day programs, supported employment, and family supports in a planned way. We went from a government that was ignorant, arrogant,

and indifferent to one that has supported and provided an array of supports so that people could be included and be valued members of their communities, but that is now all changing."

Unfortunately, the New York State government has made it difficult for family members to understand and follow their agenda. Funding for many services is being cut and people are being denied services under the guise of being given choice. People who have family with I/DD are not clear about how much money is being allotted to the field and where it is actually going according to one family member, [Attorney Stacey Osborne](#), who is on the Board of Directors of the Arc of Westchester and has been trying to get answers from [OPWDD](#).

[Marilyn Jaffe Ruiz](#), the AHRC Board Member and sister of [Joel Jaffe](#), a man with Down Syndrome who passed away three years ago, gave testimony...

(continued on next page...)

... pleading for funding for the development of residential homes for people with I/DD. experiences what it is like for a family member who has kept their son or daughter home for his/her entire life to face the unknown future.



Marilyn Jaffe Ruiz,
Sibling and Member of AHRC NYC's Board of Directors

"Without these safe, secure, loving homes, you are rupturing families leaving them in despair, depriving them of hope, and a sense of security that their loved one will be safely cared for when the family is no longer able to," said Marilyn. "Yes, we generally think of parents as primary caregivers and relatives and they are. And there are also many grandparents, sisters, and brothers (I am one) who also share the love, concern, responsibility, and fear, we are fighting for the reinstatement of services."

AHRC New York City Board Member **Germaine Laviscount Scott** echoed these sentiments reflecting her current situation. *"...I am one of those parents who recognize that unless residential placement is there to be offered, the future for [my son] Gregory becomes very scary to contemplate... I, like you, am willing to do everything that I can with the help of family and friends. But I, like you, will not be here forever. And the driving force that I have for Greg's well-being will be someone else's force. Thank God there are agencies and departments that offer help. And those agencies look to the state of New York for help funding so that they can continue to offer daily programs, work environments, residential placement, and respite arrangements for the parents when they need breaks. If the state's desire is that we keep our loved ones at home, as so many of us have been doing, then the state should be willing to make that easier for us to do*

as well as help us plan a future- a future that makes the lives of our loved ones as meaningful as possible..."

Early intervention, a system of services that helps babies and toddlers with developmental delays or disabilities, has been severely cut for several years to the point where fewer and fewer New York City providers every year can afford to offer this valuable service. AHRC New York City Board member **Meri Krassner** spoke about the importance of early intervention programs and how early intervention greatly helped her son, Daniel. *"...When Daniel was an infant, there was early intervention for babies like him... Early intervention is responsible for his growth in ways that are too numerous to count and for which I will be forever grateful. Now that early intervention programs are closed due to cutbacks, sadly other children born like my son [will not benefit]..."*

She continued, *"My son is now 27 and has come miles from his first days. His prognosis was he couldn't walk, talk or be able to do anything for himself. This is the power of early intervention special education. Now we are at the point of needing a place for him to live when we are no longer around to take care of him. Like many other parents in our situation, the only choice at the moment is to live forever, but try as we might, we can't. The idea of not knowing where he will live and having any assurance there will be help for him is what keeps me up at night. The only defense against my fear is denial, but that only solves momentary distress. There have been serious cuts to OPWDD's budget disguised under rate rationalization and budget neutrality. Budget neutrality is another way of saying that you have the same amount of money no matter how many new people need services or whether expenses have increased. This is in effect, a cut."*

AHRC member **Elly Rufer** spoke about her daughter Katie, *"...OPWDD wants to find creative ways to administer services to Katie. I know that given time and money for development that there is the potential for meaningful, cost-effective change for the better. That's exciting. However, what is incredibly frightening is that [as regards OPWDD] change in EVERY area of concern is coming all it*

once... Programs are being dismantled without other services in place. Change needs to be done in incremental steps to make sense and keep Katie & others safe. Moving people without having somewhere appropriate for them to go



Elly Rufer,
AHRC NYC Member

is far too reminiscent of the time New York State emptied the institutions for the Mentally Ill... This cannot and will not be allowed to happen to our loved ones."

She continued, *"OPWDD was created as a separate agency because at the time New York State recognized that people with Intellectual and Developmental Disabilities ARE different -They don't have a medical issue with the expectation of a cure, my daughter isn't "sick"; she is a person who needs help with many activities that the rest of us can do with ease and take for granted. She will need some sort of help until she dies. The OPWDD service system was built as collaboration between parents, government and agencies. Parents knew what their children needed, government listened and together they created a service system of voluntary agencies that worked well for decades. Parents are still the best resource for understanding what is going on - they know their family members needs in ways Government never will."*

The public hearing legislators seemed very receptive to what everyone had to say. The legislators announced their plan to collect copies of all testimonies, letters to the Governor, and petitions to make a case to reinstate and create services and residences that people with Intellectual and Developmental Disabilities so desperately need.

If you would like to speak to someone about how AHRC New York City can help you or your loved one, please call our **Referral and Information Center at 212-780-4491** or email your inquiries to referrals@ahrcnyc.org



AHRC New York City Presents the Technology Toolkit at the Prestigious Coleman Institute for Cognitive Disabilities

The [Coleman Institute for Cognitive Disabilities](#) at the [University of Colorado](#) was established in 2001 by the Board of Regents at the University of Colorado. Their mission is to catalyze and integrate advances in science, engineering, and technology to promote the quality of life and independent living of people with cognitive disabilities. The Institute is actively engaged in supporting research, development, dissemination, and education in cognitive disabilities.

On October 15, 2015, AHRC New York City's *Director of Individualized Technology Strategies*, **Philip Proctor** and *Chief Operating Officer*, **Michael Decker** were invited to give a presentation called *Embedding Emerging Technologies into the Planning Process and Personal Outcomes* at the prestigious *15th Annual Coleman Institute Conference on Cognitive Disability and Technology*. In their presentation, they explained how the successfully identified technology-based approaches allowed them to create a technology toolkit so these approaches can be shared with staff. The team supports people to achieve their goals, increase their independence, and contribute to their safety by using technology.

Funding received from the Department of Health and partnerships with [General](#)

[Electric Global Research](#), [Columbia University](#), [Teachers College](#), and [Pace University](#) made the Individualized Technologies Strategies-Balanced Incentive Project, (*ITS-BIP*) possible.

In the past 2 years, Phil and his team have created partnerships and developed a technology-based approach to make their project and technology toolkit successful. As of today, there are 118 people using individualized technology to achieve their goals and become more independent. The types of technology used are iPads with several applications, laptops, iPods, cell phones, FitBits, Spire and Muse headbands (*devices used to calm people down*), and a virtual personal assistant called Amazon Echoes, which is in the beginning stages.

Staff from AHRC NYC's [Home Care](#) and [Adult Day Services](#) departments, as well as people receiving services through these programs have reported that assistive technology such as the iPad have helped to create meal schedules, schedule and organize medical appointments, assist with meal preparation skills, discover new recipes, travel to different locations using Google Maps, exercise, and increase social skills.



Not only were skillsets broadened; self-confidence was increased.

The conference was tightly focused on the application of technology in the field of providing services to people with developmental disabilities. However; it was a great turnout filled with attendees of the conference, which included politicians, the industry, service providers, and academics who expressed interest in supporting people with intellectual and developmental disabilities in their use of technology. There was a lot of positive energy and the conference made it possible to bring people together to discuss a project that is being proven to help people with developmental disabilities. It is affecting people's lives and hopefully the AHRC New York City technology toolkit will encourage staff and other agencies in the field to infuse technology into learning.

AHRC New York City Busy Completing the First Phase of Work on New Agency Information Platform, Funded by OPWDD BIP Transformation Fund Contract

In late January 2015, OPWDD awarded AHRC New York City with a generous BIP Transformation Fund grant! The purpose of the contract was to provide resources for the development of a long term services and supports electronic health record, (*LTSS EHR*) with mobile functionality that would provide a technological means to impact the delivery of LTSS both in the current fee-for-service system and in the transition to managed care. Working together with

the other four [NYSARC, Inc.](#) Chapters that comprise the Metro Arc as advisory partners - ([Nassau AHRC](#), [Suffolk AHRC](#), [Rockland Arc](#) and the [Arc of Westchester](#)) [AHRC NYC](#) hopes to find a technology solution that will help us move to the new ways of doing business that are in our future.

AHRC New York City partnered with Deloitte Consulting over the last year to accomplish the task outlined in our

BIP contract. AHRC NYC staff from all departments have been involved in the project and we are very excited about the prospects of selecting an electronic system in the next few weeks that will support our efforts to accomplish our mission.

The BIP Transformation Grant utilizes "Federal funding" per section G, page 20 of 26 of the Master Contract for Grants.

AHRC New York City's Specialisterne Program: People with Autism Getting Hired by Big Companies

AHRC New York City and [Specialisterne](#), a global nonprofit, have formed a partnership in New York City that began officially in January 2014. Since then AHRC NYC and Specialisterne have focused on providing assessment, training, and job placement services to individuals with Autistic Spectrum Disorder in the field of IT and business-related areas.

The program focuses on harnessing the unique skills demonstrated by people with Autism while marketing the special qualities of this labor pool to the business community.

In the two years, the program has assessed and trained 62 people and placed many in jobs. The jobs include computer programmers, employee expense account analysts, editing analysts, billing specialists, as well as many others reported **Michele Shapiro**, who directs the program at AHRC NYC's [Dorothy and Michael Styler Day Center](#).

According to a June 2, 2015 Bloomberg Business article, [Autistic Coders Get Jobs as Microsoft, SAP Woo Software Sleuths](#), there are currently more than 3.5 million people with Autism in the

United States. This has led to companies jumping on the bandwagon to hire more people with Autism.

Some people with Autism have a great ability to concentrate and have a high tolerance for repetitive tasks. Some people with Autism have different ways of thinking and find solutions that others may not find.

Companies are learning ways to work with people with Autism to utilize their strengths effectively.

Meet Alex Torres: Artist, and Entrepreneur



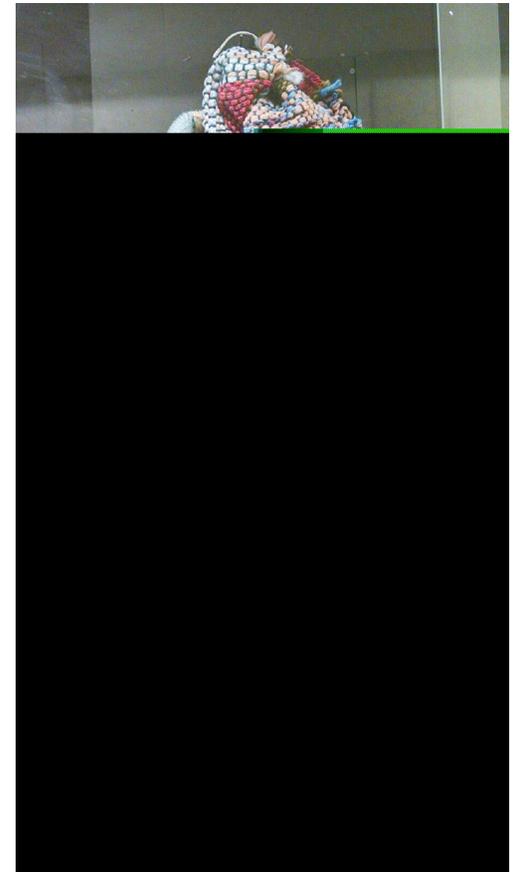
Being an artist requires experimentation and dedication. For some, being an artist isn't just a title; it's an essential part of their self-expression and overall life. Alex Torres, for example, is a painter, designer, and musician. Over the past decade he has devoted himself to cultivating his identity and artwork.

Alex's devotion paid off in January 2015 when the [Brooklyn Arts Council](#) awarded him a Community Arts Fund (CAF) grant in the amount of \$1,000. Alex received the grant to develop his clothing line, Baby Skills. Alex was able to take his designs and bring them to life using the digital platform, [to.be](#). With his t-shirt designs printed and tangible for the first time, Alex had to experiment with and dedicate himself to selling them. Alex has always wanted to sell his artwork; for him, this has always been more satisfying than traditional job roles filled by people with disabilities.

Alex connected with the [Downtown Brooklyn Partnership](#) to sell his t-shirts at the [Albee Square Farmer's Market](#) over the summer. Every Friday in June

and part of July, Alex set up a table, interacted with potential customers, and handled cash and credit for the shirts he sold. While Alex had shown his paintings at a few galleries ([Silent Barn](#), [Front Street Galleries](#), [Arts Unbound](#)), this marked the first time that Alex was directly engaged in the process of selling his work and courting customers. There was a big learning curve; Alex adjusted and readjusted his pitch, how his shirts were displayed, and prices week to week. Alex learned how to use the [Square App](#) to accept credit and debit payments for his shirts. After the Farmers' Market, Alex had two more opportunities to display and sell his work through gallery shows at [Gridspace](#) and [Pratt Institute](#). To date, Alex has sold 15 of the 20+ shirts printed with the grant money and made approximately \$300. Alex is very grateful to have received the CAF grant for it was what made his dream possible.

Alex and his family plan to reinvest the money made from the shirt sales into Alex's future artistic and musical pursuits as well as those of his Brooklyn Day Hab peers in the [Arte Moose Collective](#).



The Sunday December 20th New York Times Magazine contained an article entitled, [Art House](#) by Nathaniel Rich that spoke about an Oakland, California not-for-profit organization that has helped artists who also happen to have developmental disabilities to become prolific and make a profit! Some of AHRC New York City artists, such as Alex Torres, have been busy doing the same thing!

Brooklyn Blue Feather Elementary School Hosts Visitor from Australia

AHRC New York City's [Brooklyn Blue Feather Elementary School](#), (BBF,) hosted its second visitor from Australia this Fall, **Anna Rigoni**. Ms. Rigoni is the *Principal* of one of two campus school programs under the auspices of the [Northern School for Autism](#), (NSA,) in Victoria, Australia.

NSA is a Victorian State Government specialist school that exclusively addresses the educational needs of students with autism. The school was established in 2006 to meet the needs of students with autism in the northern suburbs of Melbourne. The NSA has grown to become a center of excellence in the provision of programs for students with autism.

The Reservoir School campus serves students with autism from ages 5 to 14. The Labor campus services students ages 15 to 18.

NSA is committed to the implementation of best practice in teaching and learning for students with autism. As a result, Ms. Rigoni applied for and was awarded \$10,000 to observe schools and programs of excellence. The grant allowed her to visit schools in other continents that were considered to demonstrate "best practice" as defined by the industry.

Ms. Rigoni's search took her to Singapore, London, North Carolina, and New York to AHRC NYC's Brooklyn Blue Feather Elementary School.



In each locale, Ms. Rigoni visited three different programs. She spent her day at BBF observing and meeting with senior AHRC New York City staff: **Christina Muccioli**, *Director of Education*, **Mary Donahue, Ph.D.**, *Director of Psychological Services and Board Certified Behavior Analyst (BCBA)*, **Zoe Ann Deeds**, *Principal of BBF*, **Sana Shadad**, *BCBA for the Education Department*, and **Jennifer Kerr**, *Supervisor of Clinical Services for the Education Department's [School Age programs](#)*.

Ms. Rigoni hopes to develop a professional collaboration with AHRC NYC in the future. She was excited and pleased to observe that BBF best aligned to her beliefs and to the Northern School for Autism's mission.

It was a very productive and rewarding day; it re-energized all of the staff who met with Ms. Rigoni and reminded us once again how wonderful BBF is.

Now let's see if we can swing a trip to Australia!

AHRC NYC and Long Island University's Health Advocacy and Wellness Program

The Health Advocacy and Wellness Program has been running for two years at [Long Island University \(LIU\)](#). The program has created a valuable partnership between AHRC New York City and LIU. People who attend AHRC NYC's [Brooklyn Day Habilitation Center](#) and [Day Habilitation Without Walls \(DHWOW\)](#) have the opportunity to attend a semester-long course held every Friday to learn about bettering their health. "A healthy active quality of life is important," said LIU *Director of Athletic Training, Health, and Exercise Science, Professor Gene Spatz*.

People supported by AHRC NYC programs are taught by LIU students. The LIU students receive three credits for the

course, but many return to volunteer after the course as they enjoy the program and the people. Prior to the start of the course, staff and students are thoroughly trained to teach healthy behaviors and practices to people supported by AHRC NYC; each person is supported and taught based upon their needs.

In the presentation portion of the course, people supported in AHRC NYC programs learn about nutrition, different exercise methods, and the importance of drinking lots of water. After the in-class learning portion, they break off into small groups and choose to learn different exercise techniques like Zumba, floor hockey, deep breathing exercises, and yoga. In addition to the physical fitness

portion, people supported by AHRC NYC programs are informed about what muscles are used when they do specific exercises.

To wrap up the course, AHRC NYC Health Advocacy and Wellness Program participants received certificates on December 11, 2015 for all of their hard work.

The people supported in AHRC NYC programs enjoy the course and report back to the class on Friday eager to share their healthy lifestyle choices. Health and wellness promotion for people with disabilities is becoming a growing movement and more people are being encouraged to get healthy and informed.

IV. HAPPENINGS



AHRC NYC's Employment & Business Services Celebrates National Disability Employment Awareness Month at Barclay's Center, An Employer of People Supported by AHRC New York City

[National Disability Employment Awareness Month](#) is a time to celebrate the many contributions of America's workers with disabilities. The theme for this year, which marks 70 years since the first observance, is "My Disability is One Part of Who I Am."

The Barclay's Center and their various partners have committed to working with AHRC New York City. Since the opening, they have hired over 55 people in various roles.

Greg Costa, Associate Director for

into entry level concession and food running positions, with the hope that it will serve as a training opportunity to determine where else within the arena they could fit.

Many awards were distributed and several people were recognized for all that they do to assist people with developmental disabilities to be successful employees.

Outstanding Employer Awards were given to employers who support and encourage their employees with developmental disabilities, including [Applebee's](#), [Aramark](#), [Sims Municipal Recycling](#), [Staples](#), and Barclays Center. The Special Honoree award went to **Marie Elena Chindamo**, Chief Human Resources Officer and Executive Vice President of Human Resources for the Brooklyn Nets and Barclays Center.

The *NYSID William B. Joslin Outstanding Performance Award* had been awarded to [James Walker](#), an employee at [Westchester Community College](#) at this year's NYSID Convention. James was recognized again at the Barclay's event among his friends and colleagues.

"James Walker has been a huge asset to American Maintenance since the start of the corporate partnership," said Regional Director at Bronx EBS, **Wayne Thomas**. "He is hard working, diligent, and self-motivated. James puts a smile on the faces of all Westchester Community College staff members, and doesn't miss a day of work."



Sharon VanReepinghen and Anne Gordon, of AHRC New York City's Board of Directors with Gary Lind, Executive Director, AHRC NYC

To mark the month, the [Barclays Center](#) in Brooklyn, New York, hosted a celebration organized by AHRC NYC's department of [Employment & Business Services](#), (EBS), on November 4, 2015.

Employers from around the city were invited, as were people supported by AHRC NYC who are employed through EBS, and other important stakeholders. Held at Barclay's [40/40 Club](#), the event provided an opportunity for attendees to partake in good food and great views of the Center. The event was a slam dunk and all were proud to be in attendance.

Food and Beverage at Barclays Center donated the labor, food, and space for the celebration. Greg has been AHRC NYC's biggest employment advocate, taking personal responsibility for promoting and ensuring people with disabilities have every opportunity to work. He does not focus on their disability, but instead focuses on their abilities. He leads every interview with discussion about the wants and needs of each person, believing the best way to know a person is to have a real conversation with them. With Greg championing the initiative, the Barclay's Center would like to hire as many people

(continued...)

Other people supported by AHRC New York City were also recognized for all the hard work that they do: **Felicia Scott, Jarod Ellis, Richard Hanna, Jonathan Martinez, Teresa Mariano, Stephen Cruz, Kadijah Badiaka, Lexis Henton, and Armando Reyes.**

“When a person goes out to work for the first time it is a life-changing event,” said **Steve Towler**, Associate Executive Director and Director of EBS. “Having a job is one of the big parts of citizenship, and having that opportunity is something that is valued by Americans across the country.”

AHRC New York City’s Employment Business Services staff worked hard to make this event successful. Here’s to next year’s NDEAM event!



Our [Supported Employment Programs](#) offer people with disabilities opportunities to enter the workforce, and to be successful in maintaining their employment. If you would like to speak to someone about how AHRC New York City can help you or your loved one, please call our **Referral and Information Center** at 212-780-4491 or email your inquiries to referrals@ahrcnyc.org

2015 NYSARC Volunteer of the Year Award Presented to AHRC New York City Board Member, Marilyn Jaffe-Ruiz



AHRC NYC’s Executive Director **Gary Lind**, AHRC NYC Board member, **Marilyn Jaffe-Ruiz**, and **Angelo Aponte**, President of AHRC NYC’s Board of Directors

The **NYSARC** Volunteer of the Year Award is presented to a chapter volunteer in recognition of their continued dedication, service, and advocacy on behalf of people who have intellectual and other developmental disabilities.

Congratulations to this year’s award winner, Dr. **Marilyn Jaffe-Ruiz** of AHRC New York City, the City Chapter of the state organization.

Dr. Marilyn Jaffe-Ruiz was the President

of AHRC NYC [Home Care](#) and the President of [ACCESS Community Health Center](#), (formerly AHRC NYC *Healthcare*), until June 2015. She was an active member of the NYSARC Board of Governors from 1997 to 2012, and she served as the Chair of the NYSARC Prevention Committee and as a member of the Adult Services Committee. Additionally, while on the Board of Governors, Marilyn initiated many excellent workshops related to siblings of people with developmental disabilities, as well as educational sessions regarding issues associated with aging.

Furthermore, she has served on the AHRC New York City Board continuously since 1984 and was President of the Board from 1997 to 1999. It was her efforts that created the Chapter’s first Sibling committee, the first Technology Committee, and the first Diversity Committee. Outside of her volunteer activities, Dr. Jaffe-Ruiz is Professor Emeritus of nursing at the [Lienhard School of Nursing at Pace University](#).

Dr. Marilyn Jaffe-Ruiz is committed, not only to the dignity of the people we serve, but also to the volunteers and staff who have devoted their lives and careers to making our world a better place to live. AHRC New York City is very fortunate to have Dr. Jaffe Ruiz on its Board.

Senator Martin Golden Visits AHRC Middle/High School

This fall, [Senator Martin J. Golden](#) visited [AHRC New York City's Middle/High School](#).

Christina Muccioli, *Director of AHRC NYC's Educational Services*, and **Andrew Winfrey**, *Principal of the Middle/High School*, provided the Senator with a tour of the school, where he was able to meet the students and see what they do in class every day.

Senator Golden was very receptive and understood the struggle that schools for children with developmental disabilities are facing after years of no funding increases, in spite of increasing costs. He spoke about ways to get more funding to the schools, how he feels about the need for special education, and his passion



Thomas Sposato, Assistant Principal, Andrew Winfrey, Principal of AHRC Middle/High School, Christina Muccioli, Director of AHRC NYC's Educational Services, with Senator Martin J. Golden

regarding the issues facing people with intellectual and developmental disabilities.

Senator Golden's support will be acknowledged this year at AHRC New York City's Annual Dinner where he will be the recipient of the AHRC Humanitarian of the Year Award!



Saturday May 14, 2016
AHRC New York City's

Celebrating 67 Years

AHRC New York City's Annual Dinner will take place on May 14, 2016 at [the Grand Hyatt Hotel at Grand Central Station](#).

Honorees will be announced in early 2016. If you want to sell raffles or ads and purchase tickets, information will be sent to you in the coming months, or call **Donna Gifford**, *Special Events Coordinator* at **212-780-2713**.

Cocktails will be followed by a dinner and dancing into the night!

A Special Night for Special Children: AHRC New York City Foundation's Real Estate Dinner Is a Resounding Success



Elizabeth Wright Kahane with Michael A. Happel

Approximately \$557,000 was raised at the 33rd [Annual A Special Night for Special Children](#) hosted by the real estate, construction, and design industries of New York City. The event was held at the [Mandarin Oriental New York](#).

Michael A. Happel, *Chief Executive Officer and President of [New York REIT](#)*, was honored with the M. Anthony Fisher Humanitarian Award, recognizing business and philanthropic achievement. New York REIT is a publicly traded company that owns and operates commercial real estate in New York City.

In accepting the award, Mr. Happel spoke about a young man he met at MTA's headquarters where the young man was employed on an AHRC New York City janitorial crew.

"He took incredible pride in his work," Mr. Happel said, adding that the job had made it possible for the young man to move out of his parents' home and get his own apartment.

"You could see the pride in his face. You could hear the pride in his voice," Mr. Happel said. "AHRC has really changed this young man's life, and that's just one of thousands of stories."

He encouraged those present to get

involved with AHRC NYC, saying the organization is "absolutely fantastic."

Service as co-chairs of the event were **David A. Falk**, [Newmark Grubb Knight Frank](#); **Kenneth Fisher**, [Fisher Brothers](#); **Elizabeth Wright Kahane**, [Milestone Partners](#); **Sonny Kalsi**, [Green Oak Real Estate](#); and **Patrick O'Malley** and **Zachary Pomerantz**, [New York NEIT](#), **John T. Pavone** of [Colliers International](#) was the journal chair.



Kenneth Fisher

V. LEGISLATIVE ISSUES

Update on Legislation and Entitlements: Governor Cuomo's Proposed Budget for New York State and People with I/DD

Governor Cuomo delivered his State of the State address on January 13th, which was followed by the release of his proposed budget for the new fiscal year. As regards the areas of the budget that are relevant to the field of I/DD, funding for [OPWDD](#), Early Intervention and Education, he did appear to consider several of the issues that advocates for people with disabilities across the state have been fighting for.

The one area that was not addressed in the budget at all was funding for Direct Support Professionals, special education staff, and other low-wage workers whose rate of pay is set by the State. He did propose a \$15 minimum wage for all, but then did not include this provision in his

OPWDD and Education budget proposal. Advocates need to urge the Governor and the Legislature to propose a minimum wage funding solution for the workers who support individuals with intellectual and developmental disabilities. The proposed **.2% COLA** increase is insulting.

OPWDD received an overall spending increase of 4.3% and includes several initiatives to improve services for aging people with I/DD who still live at home with their families and have been waiting for residential placement, although it is unclear what this funding increase will mean for people on the waiting list. It is felt by analysts in the field that the proposed budget increases in no way make up for the enormous cuts and

end to development of the past several years, and additionally include the ever growing number of individuals who enter the OPWDD system every year as they age out of the education system once they reach 21. The 1% increase for Early Intervention (EI) services will help, but in no way counter the fact that in the past several years many EI programs have closed because they could not provide services with the allocated funding. And the proposed money for 4410 preschools and 853 programs is a help, but does not cover the operating expenses incurred over the last few years and the fact that there have not been any increases in funding for those years.

It Matters to Me! NYSARC Statewide Advocacy Campaign Continues Your Legislators Need to Continue to Hear From You

In order to bring attention to some of the critical issues affecting people with intellectual and developmental disabilities (I/DD), their families, and the providers and staff dedicated to serving them, the chapters of NYSARC throughout the state, including AHRC New York City, have launched an advocacy campaign to share personal, compelling stories, and circumstances of concerned families and providers on the issues that matter most to them.

These are difficult times for the I/DD community and those who are concerned about services for people with developmental disabilities must advocate in order to make sure that:

- There are residential opportunities
- People's wishes are respected regarding where they want to work
- DSP's receive a fair wage
- Preschools receive the funding that is due to them

- Transitional services for young adults exist

In the late Fall, AHRC New York City Member Giacomina (Jackie) Macchia was filmed telling the story of her family and her daughter Cathy who needs a residence. And AHRC New York City's Director of Educational Services, Christina Muccioli, and the parent of a child that attends AHRC New York City's Central Park Early Learning Center, were filmed speaking about the need for preschools serving children with special needs that are in jeopardy because of funding issues. This video, introduced by Laura Kennedy, (*former President of AHRC New York City and current President of NYSARC Inc.*) has been successfully used by NYSARC to inform legislators of the need for services and supports that are not being met by the state because of changes in policy and decreased or inadequate funding.



[Watch the video!](#)

"It Matters to Me" topics from NYSARC Inc.'s website, include:

Residential housing and other opportunities for people with I/DD living at home with aging caregivers: Thousands of families statewide live in constant fear as to who will take care of their sons and daughters when they are unable to do so.

Employment: NYSARC advocates that people with I/DD have the choice to remain in non-competitive settings, consistent with the individuals' wishes and the Olmstead Supreme Court decision.

Wages: Direct Support Professionals (DSPs) are the foundation of New York's system of supports for people with

(continued...)

(...continued)

...I/DD. With newly adopted minimum wage increases for fast food workers, NYSARC contends consideration should also be made for DSPs, including the immediate and significant adjustment in approved rates, fees and state contracts, to ensure the ongoing financial viability of I/DD providers.

Preschools: Preschools that serve

children with I/DD are paid significantly less than it costs to operate these programs. NYSARC Chapters can no longer offer programs that operate at a deficit and thus jeopardize the entire agency.

School to work transitional services for young adults with I/DD: Where are the programs for young adults with autism and other developmental disabilities after they graduate from high school?

To post your testimonials online and for information on sending Letters to the Editor, please visit <http://cgrcengage.com/nysarc/ItMattersToMe>. You will also find talking points on all of the topics outlined in this article. Call your legislators and make contact with anybody in the media that you may know. Services are in danger!



Sibling Matters!

The **Sibling Committee** of the AHRC New York City Board of Directors is planning to launch a new electronic publication exclusively for the sisters and brothers of people with intellectual and developmental disabilities. If you are a sister or a brother or know of a sister or a brother that would benefit from information geared to the needs of siblings, and sharing information with other sisters and brothers, please forward the sibling name and email address (*both required*) and your snail mail address (*not required*) to kate.isenberg@ahrcnyc.org.



Special Globe: A Travel Resource

Are you planning to go on a trip with your loved one who has special needs? SpecialGlobe provides travel resources, lodging, locations, and restaurants that have accommodations for people with disabilities. Visit www.SpecialGlobe.com to plan your next trip!

Sprout: "Making the Invisible Visible"

Sprout is a New York City based organization "*dedicated to helping people with developmental disabilities grow through challenging, creative, and fun experiences that enhance socialization, self-confidence and inclusion.*" They offer travel opportunities, music, arts and film festivals trips, and a program that helps people make and produce their own movies.

For those interested in vacations for people with I/DD, check out a preview of Sprout's 2016 Brochure. In addition to Sprout's vacation program, they will be growing their Sprout Touring Film Festival. For more information about Sprout, visit their website: www.gosprout.org.

AHRC New York City's Family Education Series

Valuable information is available to families, including FREE educational workshops, which are offered twice per month. Our Family Education Series includes workshops and informational sessions on topics of great interest to families of people with developmental disabilities.

Through these workshops, we provide education and information for families in obtaining services for their family member with a developmental disability, and help families to cope with challenges that may arise as they care for their loved one.

Upcoming workshops appear on our website:

<https://www.ahrcnyc.org/services/families/education/>



VII. NEWS IN THE FIELD

Unraveling the Genetic Complexities of Autism

In the spring 2015 edition of the Howard Hughes Medical Institute (HHMI) Bulletin, [Bryn Nelson wrote an article](#) about new research taking a fresh approach that is unraveling the genetic complexities of autism. Pinpointing a cause for the onset of the disorder has proven very frustrating to many researchers. .

University of Washington HHMI researcher, Evan Eichler, has been using a “genotype-first” strategy that is now apparently giving the search for answers

about autism a needed boost. *“Eichler sequences large amounts of DNA from multiple patients and then seeks out shared genetic variants that may point toward common paths to the disorder,”* the article author Bryn Nelson explains. Eichler has organized a large data-sharing consortium of labs and the power in numbers is beginning to pay off! They are identifying groups of independent gene mutations or genetic sub-types that are associated with certain clinical manifestations that may lead to potential

interventions.

Nelson says that Eichner notes *“a genetic diagnosis may help parents understand the basis of autism, connect with other families for support and realize that they’re not to blame for their child’s condition.”*

To read more on this research, visit:

<http://www.hhmi.org/bulletin/spring-2015/autism-genetic-roots>



THE BACK PAGE

James Thompsen- Living Independently

James Thompsen had been living in a private house on Staten Island through the [Senior Citizen Home Sharing program](#) for 12 years when he decided that he was ready to have a home of his own.

In 2012, James visited AHRC NYC’s department of **Individualized Supports** to receive assistance so he could live independently. James decided that he would like to use a housing subsidy through New York State [Office for People with Developmental Disabilities](#).

Once he was approved for the subsidy, James and his support staff began to look for an apartment that would suit his needs. They discussed where he likes to shop, what he likes to do, and if there were people he wanted to be close to. He chose the St. George neighborhood so that he could be close to the [Staten](#)

[Island Ferry terminal](#), as he used to work there and still remained acquainted with his coworkers. He decided upon a studio with a view of the Staten Island Yankees ball park. In May of 2013 he moved in.

Using a Transition Stipend fund from New York State, Individualized Supports assisted James to furnish his apartment and make sure his extensive “oldies” CD collection would have a good spot in his living room. James receives support from his AHRC NYC staff member, **Elizabeth Massalee** who comes weekly to assist him to live independently in his neighborhood.

James likes that he is well-acquainted with many of his neighbors: *“All of my neighbors are excited about the new Staten Island Ferris Wheel and how it is going to change this neighborhood,”*

said James. *“I am really grateful for the support that I get from AHRC [New York City]. It’s nice to know that someone is always there when I need help.”*

James is so happy in his home that he volunteers to be an ambassador for other people who are looking to move into their own apartment using a housing subsidy. He enjoys telling people his story and what to expect from living on your own. His warm personality and witty sense of humor make him a great candidate for this role.

AHRC New York City is appreciative that James is volunteering his time to help other people live independently. He is currently paying it forward by mentoring two young men through their transition to [independent living](#).