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I. EDITORIAL

A Message from Laura J. Kennedy, President



Laura J. Kennedy, *President, AHRC NYC Board of Directors*

“It has been a long difficult winter this year, and not only in regards to the weather. In a year with a \$7 billion dollar budget surplus, the State’s proposed financial plan and Governor Cuomo’s “Opportunity Agenda” provided little opportunity for people with intellectual and developmental disabilities (I/DD). Although news today seems to indicate that our advocacy efforts are not going unnoticed.

The State’s preliminary financial plan for the coming year did not address the currently pressing needs of our community--residential development and the dire financial situation of preschools and school age programs for children with special needs. Today 13,000 people in New York State have asked OPWDD for help with 6,000 of them living at home with elderly and/or ailing parents and in need of immediate residential placement. We have a statewide crisis!

Our preschools, essential services for 3-5 year olds with developmental disabilities, as well as our school-age programs for students who cannot be served by school districts because of the severity of their disabilities, have not received increases in years and will be forced to cut services or in some cases close. Preschool and special education services have been the foundation for future success for people with disabilities as we have seen over the years. This foundation cannot be diminished.

The agreement reached by the Governor and the Legislature on March 30th includes language that shows some recognition of these critical issues. Strong family advocacy needs to continue! We must continue to implore our leaders to reject hollow words and advocate for people with disabilities that want to work, live with dignity and enjoy the opportunities and rights that are available to everyone. Our self-advocates who visited with their legislators in Albany back in February and are written about in this issue of the Chronicle are an inspiration. We all must seek to renew our partnership with the State in the spirit of cooperation and to create a “win-win” for all.

- Laura J. Kennedy, *President, [AHRC New York City](#); President, [NYSARC, Inc.](#)*

A Message from Executive Director, Gary Lind



Gary Lind, *Executive Director, AHRC NYC*

I am so pleased that we have added this e-Chronicle to the tools that we use to communicate with AHRC NYC’s membership and supporters. This issue reflects the vibrancy, energy, and commitment to quality that embodies this great organization.

Please take a look at the article about our new mission statement. While on its face this is a simple statement of things that may otherwise seem obvious, it actually reflects countless hours of discussion and thought by our many constituents. It truly reflects the critical elements that will help to assure our continued success.

- We are “family governed” with a rich history of selfless service on our Board of Directors as exemplified by the Chronicle article marking the passing of Al Agovino.

- AHRC NYC works tirelessly to “find ways...to build full lives” as exemplified by the articles in this issue of the Chronicle that explain our technology initiatives and our new One-to-One Program.

- As an organization we stay attuned to what each person defines as their vision of a full life. What a great example we have of this in the story about self-advocates meeting with their legislators about the issues that are of most important to them. This exemplifies the importance AHRC NYC places on its self-advocacy leaders.

- And finally, great things happen when our work is “supported by dedicated families, staff and community partners.” You can read about great examples of this kind of partnership in the article about the employment education event held at Brooklyn Borough Hall and the article that notes the great fund raising success at the Foundation’s 35th Annual Thurman Munson Dinner. You can see just how critical our community partners are to our ability to achieve our mission.

I hope that each issue of the Chronicle will give you continued insight into ways in which we at AHRC NYC try to be true to our mission and values.

- Gary Lind, *Executive Director, [AHRC New York City](#)*

II. FEATURE



Self-Advocates Meet with Legislators to Discuss Important Issues

It started with a simple question: “What do you want to do?”. The answer given by a number of people during CQL interviews led to a path of advocacy that will lead the way for others. Self-advocates supported by AHRC New York City were given the opportunity to discuss issues of importance to them directly with legislators, legislative leaders and the Governor’s staff in Albany this February.

Kristen Thatcher and **Paul Scherzinger**, both of whom attend or graduated from [AHRC NYC’s Melissa Riggio Higher Education Program](#) at the [College of Staten Island](#), were joined by **Jessica Giorgio**, *Higher Education Support Professional*, **Carmine Cammarata**, *Community Support Professional*, and **Al Kaplan**, AHRC NYC’s *Senior Policy Advisor*. At several sessions organized by **Carole Gothelf**, *Director of Individualized Supports* and **Matthew Weiler**, *Program Director* at the College of Staten Island and [Kingsborough Community College](#), prior to their trip to Albany, they met to prepare for this exciting opportunity to speak for themselves about their lives and what they as citizens wanted from their legislators. Al Kaplan spent several hours over several sessions advising the group on the logistics of budget legislation, the way government operates, as well as assisting them in understanding how to state their case and the specific issues that are at play legislatively at the current time.

“Legislators pick and choose what issues they focus on, and so do we,” Al explained. “You have things that are a concern to you, and you want the people who represent you to know what they are.”

Al gave Kristen & Paul an assignment,



asking them to answer three questions:

“Who am I/what’s my story?”

“Why am I here/what are my concerns and issues?”

and

“What do I want you (our representative) to do?”

Kristen, who is 26 wanted to focus her conversation with legislators on employment issues. “I want to talk with them about jobs for people with disabilities,” she said. “I don’t think there are enough jobs and we’re limited in the kind of jobs we can get.”

Paul decided to talk about an issue that was personally affecting him. “My issue is that Medicaid stopped covering my physical therapy after 26 weeks,” he said. “My mom can’t afford to pay for it without insurance.”

Al encouraged Kristen and Paul to speak more freely, especially when they were speaking about themselves. “When you’re meeting with the legislators, make sure you make eye contact with them,” he advised. “All people respond better when they feel that you are talking directly to them.” Al also suggested areas where Kristen and Paul may want to focus their arguments based on the most recent budget proposals available.

The day finally arrived and Kristen, Paul, Jessica, and Carmine were very excited and nervous. They did exceedingly well in speaking for themselves. They said they were most impressed with reception they received from *State Senator, Andrew Lanza* (R), who represents most of Staten Island. “He talked a lot about our issues and listened to what we had to say,” Paul said. Sen. Lanza also said that he would specifically follow-up regarding Paul’s insurance situation.

(continued on next page...)

"He was relaxed," Kristen said. "It was just human-to-human talking, we were equals."

"I was surprised that legislators did not know about a lot of our issues," Jessica



said. "Al told us though that there are so many issues facing the budget that legislators often don't know anything other than what they are working on."

Kristen, Paul and Jessica said they had

a great experience in Albany speaking for themselves about themselves. Kristen has been up to the state's capital before but only for conferences and had never met with legislators before, while this was Paul's and Jessica's first visit to Albany. They expressed interest not only in going there again, but also in lobbying for issues that are important to them in New York City.

"I'd love to talk about making subway station more accessible," Paul said.

Kristen has been frustrated with Access-a-Ride and said "They're not reliable and I don't feel like they treat people with disabilities with respect."

"Kristen, Paul and Jessica did a great job!" Al exclaimed. "They spoke with confidence and clearly about the issues they wanted to talk about. I think they really got their message across to the legislators, and the legislators listened."

They had fun too, spending two snowy nights in a hotel, dining out as a group and garnering the confidence to do this again and again and to help their peers to do the same thing.



On to the next meeting with the MTA and the Access-a-Ride folks!

III. PROGRAMS, SERVICES, AND SUPPORTS

AHRC New York City Has Updated Its Mission Statement

AHRC New York City, an organization which for over 65 years has served people with intellectual and developmental disabilities and their families, has updated its mission statement to reflect the changes in our society and the services we offer. The new mission statement is:

A family governed organization committed to finding ways for people with intellectual and other developmental disabilities to build full lives as defined by each person and supported by dedicated families, staff and community partners.

"This new mission statement is a great expression of our traditions over the last 65 years and what we're looking for in the future," **Michael Decker**, Chief Operating

Officer, said.

"Since we began our journey with the Council on Quality and Leadership," **Carole Gothelf**, Director of Individualized Supports added, "It became apparent to us that we needed a new mission statement to be reflective of everybody's voice."

Three sessions in three boroughs using the World Cafe model of group discussion were utilized, with approximately 30 people per session taking part. "This was done to be reflective of what everybody thinks - Board members, people receiving supports, and staff," **Jennifer Teich**, Project Coordinator of Individualized Supports, said. The language was reviewed and discussed at the Board of Directors retreat and formally adopted at the December board meeting.

AHRC New York City Mission

A family governed organization committed to finding ways for people with intellectual and other developmental disabilities to build full lives as defined by each person and supported by dedicated families, staff and community partners.

Values

- Each member of the organization is committed to promoting a culture that embraces:
- P**assion: Committing wholeheartedly to the mission of the agency.
 - R**espect: Responding to all members of the AHRC community with courtesy, kindness and open and honest communication.
 - I**ntegrity: Making decisions based on fairness, honesty, morality and ethical principles.
 - D**iversity: Respecting and appreciating the differences found among individuals with intellectual and developmental disabilities, their families and our colleagues.
 - E**xcellence: Providing an environment in which distinction and merit are affirmed, celebrated and enhanced.

"Our field is in a time of change, and we face many challenges during these times," Mr. Decker said. "It is critical to reflect during periods of change, and it provides us a chance to properly identify who we are now and what we want to be going forward."

Tech Project Seeks to Foster Independence and Life Skills

“Have you ever heard the sentence ‘The quick brown fox jumps over the lazy dog’?”

Charles Umaña asks this question to Autumn Hester, a student enrolled in [AHRC New York City’s Melissa Riggio Higher Education Program](#) at [Kingsborough Community College](#), in an effort to demonstrate a typing exercise. The sentence, Charles explains, uses every letter of the alphabet. “When you have some free time and you want to practice your typing, remember that phrase,” he encourages Autumn. Together, they try out the exercise.

Charles is helping teach Autumn this and numerous other functions on her iPad, which she received as a participant in the **Individualized Technologies Strategies-Balanced Incentive Project**, (ITS-BIP). “This is a grant-based research project where the primary goal is to correlate technology with independence,” Charles said. “Technology is an important factor in everyday life. We use it on a regular basis, but not all the people we serve have access to it or know how to use it.”

Thirty-two people from across three departments in AHRC New York City, ([Adult Day Services](#), [Employment and Business Services](#), and [Residential Services](#)) are taking part in the project. Charles, along with **Tenzin Pao Dhashi** and **Glenna Sasiadek**, (all of whom are *Individualized Technology Strategy Specialists*), works with a specific group of people and assists each one of them for an hour per week, providing individualized technological support



based on their needs. The ITS-BIP is supervised by **Philip Proctor**. People needing varying levels of support and many types of assistive technology are involved in the project. For example, Charles said he is working with a person whose main device is the [HAPIfork](#), a utensil designed to assist people with difficulty eating in practicing safe mealtime habits. Among the goals for people in the project are health, academic success, employment, stress management, and community and social skills.

Autumn’s hopes for her involvement in the project include improving her organizational skills and learning how to use technology to improve her everyday life both in school and outside the classroom. “I want to know how to use the iPad so I don’t have to use so many pages to do schoolwork,” she explained. She is interested in a number of subjects, such as history, marine biology, and

especially education, as she wants to become a preschool teacher. She also wants to use the iPad for reading and research, and when asked what feature she is most looking forward to using, she excitedly said “I can take pictures, of course!”

Charles said technology has been a huge factor in his success at AHRC NYC, and that he is excited to share his knowledge of it with the people he supports. “My goal over time is to get [the people I support] to use tech on their own and to have staff be comfortable with it,” he said. Although the project is still in its early stages, having started in mid-January (and lasting until September), he was able to share a heartwarming story. “One person I’m working with expressed a desire to relearn the piano,” Charles said. He showed him a piano-based app on the iPad. “He began to play ‘Mary Had a Little Lamb,’ and I could see the emotion in his face.”



One-for-One Volunteer Program Begins Its Journey

A new [volunteer program](#) has gotten underway at AHRC New York City! Our **One-for-One program** pairs volunteers from both within the agency and in the community with a person with developmental disabilities. It is run by the [Residential Services](#) department and funded by the [AHRC New York City Foundation](#).

On Wednesday, January 21, volunteers met up with people living at the **Rupert Towers IRA** on the Upper East Side at Uno's Pizzeria on East 86th Street.

"The program was a suggestion from Sharyn VanReepinghen [AHRC New York City's First Vice President]," Craig Becker, Associate Director of Residential Services, said. "It is something we wanted to do for a long time, getting adults we serve matched up with people in the community."

Craig put together a proposal for the [Board of Directors](#) and for the AHRC New York City Foundation that took cues from [Big Brothers/Big Sisters](#), a well-known organization pairing volunteers with at-risk youth. In May of 2014, the Foundation approved a grant for the program, which was used to bring on **Stefanie Nelson**, the One-for-One Volunteer Coordinator. While One-for-One was initially intended to focus on people living in AHRC New York City residences who were fairly independent already, *(and potentially looking to move into the community)*, "we have broadened the idea to include people who aren't as independent but would still like to build long-term relationships," Craig said.

At Uno's, five pairs were matched up for the first time. **Joseph Morocco**, who works in real estate and is part of the Foundation's Young Leadership Committee, was matched with **Peter VanReepinghen** (Sharyn's son). *"I found out about [One-for-One] through a mutual friend involved, and I always like to make new friends,"* Joseph said.



Peter works at the Disney store and said he enjoys video games and sports. *"My favorite character is Mickey!"* he exclaimed, and Joseph wholeheartedly agreed. **Shanna Salmon**, HR Coordinator, volunteered for One-to-One for a very simple reason. *"I just wanted to meet someone new and get involved in the community,"* she said. *"This program seemed like a great match."* Shanna said that while she briefly worked with people with developmental disabilities at a summer camp while in high school, she had not had much more experience with the population.

Shanna was paired with **Diana Oquendo**, a Rupert Towers resident who *"wanted someone to talk to and everything."* Diana works at Metropolitan Hospital and enjoys cooking Spanish food, and much like Shanna, going shopping. They also both like films, and agreed to meet later in February to have dinner and see *The Wedding Ringer*.

Stefanie has used many outlets to find volunteers, including sites such as [VolunteerMatch](#) and programs like the aforementioned Young Leadership

Committee. There are currently 14 participants in One-for-One (*seven pairs*), with five more volunteers waiting for orientation.

"Currently Rupert Towers and Fineson IRA in Manhattan are part of it, and I am now interviewing people in Queens and Staten Island," Stefanie said. *"It has reached out quicker than we thought it would. People from out of the blue have been calling."*

Craig and Stefanie's vision for One-for-One is to have 25 volunteers by the end of the year. Next year they would like to expand to people who don't live in AHRC New York City residences. They also expressed a desire for AHRC staff to join One-for-One. *"Me and many of my colleagues have had long-term relationships with people we serve, but we are still viewed as employees of the agency,"* Craig said. *"We would love people who aren't necessarily working directly with people we serve to get involved."*

If you are interested in becoming a volunteer for the One-for-One program, email: Stefanie.Nelson@ahrcnyc.org.

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

Melissa Riggio Higher Education Program at Hostos Completes Inaugural Semester



Looking back on your first semester of college, were you nervous, scared, or excited? Six students reflected on their first semester experience as a new student at [Hostos Community College](#) in the Bronx as part of [AHRC New York City's Melissa Riggio Higher Education Program](#). At the start of the semester, **Javaris Haynes, Jessica Gonzalez, Krysten Lopez, Geraldine Roche, David Olenick, and Kieamisha Fowler** were asked to write down their fears and place them in a time capsule to review when they graduate in 2017. Upon completion of their first semester they had many exciting experiences to share.

Javaris is proud to have a Hostos I.D. card because he feels included in the campus life. *"I can use my I.D. to borrow books or movies from the library and also to work out in the gym,"* Javaris says. *"This semester I took freshman seminar and I learned a lot about personal relationships."* Javaris is putting together a job portfolio to help him when applying for a career.

David is studying criminal justice. *"I joined the criminal justice club where we watched the Central Park Five film. They brought in one of the men who was wrongfully accused to speak with us,"* David says. *"We got to interview him and I learned what it was like for him to be falsely accused, but he expressed how he got over it."*

Each student had an end-of-semester project to complete; Jessica's project included things she is interested in such as writing, reading, and studying. *"I wrote about Martin Luther King Jr., homelessness, and a project about domestic violence,"* Jessica says. *"I learned that in domestic violence [cases] those who were abused were often driven to shelters."*



Javaris with Mike Ortega, Higher Education Support Professional

The campus offers a variety of activities and clubs that students participated in. Krysten took a Zumba class and is interested in painting and drawing. *"Next semester I would like to find an art club or a place to display the art I have created,"* she says. Krysten's end of semester project was learning about people with Alzheimer's disease.

Geraldine auditioned for a dance club and took part in a capoeira class. *"For some reason I didn't really like capoeira, but next semester I am excited to take a Spanish class since I can speak it but cannot read Spanish,"* she says.

This semester was just the start of many exciting things to come in the future. Kieameisha's goal is to work in a day care.

"I volunteered for the campus community shows as an usher. My next step is to volunteer and work at the day care on campus," she says. *"I love working with children because I have a son myself."*

The students have some advice for those who are set to begin their first semesters later this month. *"To learn how to adjust to the campus and you might be nervous since you don't know what to expect,"* David says.

Kieamisha adds, *"Don't push yourself too hard, and adjust by taking it day by day."*

Next semester each student will take one or two classes to get them closer to graduation in 2017. They will collectively work on a newsletter that will be read on campus.

AHRC Middle / High School and Pace University Collaborate on Class Presentations

Did you know that the best-reviewed video game of all time is *Super Mario Galaxy*? Or that an estimated seven million people ride the New York City subway system per day? Or that wrestling legend Shawn Michaels' given name is Michael Hickenbottom?

All these fun facts and more were presented by [AHRC Middle High School](#) students and Pace University students as part of their collaborative class entitled *Community Empowerment through Information Systems*.

The course is taught by **James Lawler**, DPS, Professor of Information Technology at Pace's [Seidenberg School of Computer Science and Information](#)

Systems.

Students from each school, faculty, AHRC NYC staff, and parents gathered at [AHRC NYC Headquarters](#) to witness the presentations, which were a mixture of PowerPoint presentations, videos, and spoken portions.

Each Pace student was paired with a student from MHS and throughout the semester, accompanied each other in a number of community endeavors, such as visiting the Avengers exhibit in Times Square and the Brooklyn Bridge.

For the presentations, the groups picked a topic of interest to both parties and researched the information together.



Among the topics covered were US Presidents, Bridges of New York, Applying for College, and France.

The students also gave insight into their personal backgrounds as well as what they would like to do in the future. The result was an informative, humorous, and introspective series of talks.



Remembering Al Agovino

The AHRC New York City Board of Directors, staff, membership and people supported and their families mourn the passing of AHRC New York City's former Board Member, and extend sympathy to his beloved and bereaved family. The father of a daughter with an intellectual and developmental disability (I/DD), Al and his late wife Vera worked tirelessly to improve the lives of people with I/DD and their families - work that continued even after the tragic loss of their beloved daughter. Al was a person of great integrity and common sense who helped many others get through the difficult trials in their lives. His commitment to advocacy for people with I/DD was exemplary.

Al served on the AHRC New York City Board of Directors for twenty-six years. He resigned in 2002 because of ill health, but remained an active member of the organization. Al served as AHRC New York City's President, chaired many

committees over the years and was on the NYSARC Board of Governors. He was appointed to the New York State Board of Visitors of Metro NY in 1978 by the Governor and served in that role for two decades including serving as President in 1995 and 1996. Al served in an advisory capacity on many state councils and commissions including the New York State Commission on Quality of Care for the Mentally Disabled, and the NYS Autism Advisory Council. He was well known and well respected throughout the I/DD community in New York State.

We offer our sincere condolences to his children and grandchildren. Al will be remembered by his AHRC New York City family and will be greatly missed.

Laura J. Kennedy, *President*
Gary Lind, *Executive Director*



Save The Date: Saturday, May 16, 2015 - Please join us for **AHRC New York City's 66th Annual Dinner** at the Grand Hyatt New York!
WE WILL BE HONORING: *Congresswoman Carolyn Maloney, District 12; Joel Manley, DDS, Staten Island University Hospital; Jamal Kobeissi, M.D., Access Community Health Center; Willie Mae Goodman, Parent Advocate & Marie Dickson, Community Board Leader (Posthumously)*

It Works: AHRC NYC's Employment and Business Services Holds Employment Education Event at Brooklyn Borough Hall



including the [Staten Island Ferry](#) and the U.S. Bankruptcy Court,) [SHREDability](#), and [Specialisterne USA](#).

Sal explained how SHREDability, an AHRC NYC-operated business in the Bronx, provides secure document destruction for a wide variety of businesses in the region, while employing people with disabilities. He also explained that the company has a strong interest in opening a SHREDability location in Brooklyn, and as gift to Borough Hall, he announced that SHREDability would provide shredding services free for one year.

AHRC New York City's [Employment and Business Services](#), (EBS,) hosted an event at [Brooklyn Borough Hall](#) on Thursday, January 22, 2015. Taking place in the beautiful courtroom area of the building, the event was an opportunity for EBS leadership and staff to explain the mission of EBS and how they can help prospective partners achieve their goals. Also featured were current partners of AHRC NYC, who provided testimonials about the successes they have had with employees who are supported through our services.

"We create awareness in the community and educate employers on the benefits of hiring people with developmental disabilities," **Shauna Lozada**, *Director of Marketing*, said. Shauna outlined a number of ways AHRC New York City can help businesses, including tax credits. *"Our guys can do any job that any of us can do, just with reasonable accommodation,"* she added.

The event began with a welcome to Borough Hall from **Lori Lewis**, Head of External Affairs and Marketing, who thanked AHRC New York City for their continued partnership and provided a brief history of the building. She then gave the floor to **Steve Towler**, *Associate Executive Director*, who explained how he helped to create Employment and Business Services in 1986 and how he still sees the first person whom he found a job for. He also responded to a question on the importance of integration in the workforce. *"Integration is one of the real keys to long term success, and we work to make that possible whenever we can,"*

Steve said. *"The majority of people we support are fully integrated into their workplace..."*

Steve also expounded on AHRC New York City's work with [Specialisterne USA](#), a company founded in Denmark that helps find jobs for people with disabilities who typically require low levels of support, and who can work in the all-important technology sector. *"These workers have great attention to detail, high tolerance for repetitive work, the kinds of things in the modern economy we need a lot of,"* **Konstantin Zborovskiy**, *Program Director*, said.

"From a business perspective we're meeting you're needs," Sal said. *"From a social perspective we're putting people with disabilities, at-risk youth, and community members to work. From a sustainability perspective, SHREDability helped save over 26,000 trees last year. Many individuals go above and beyond once given the opportunity [to work],"* Sal added. *"And we are looking for opportunities to grow in Brooklyn. It's a great place to do business and it's wonderful to see it growing."*

In a testimonial to the great partnership EBS has had with so many employers, **Greg Costa**, *Associate Director for Food and Beverage* at Brooklyn's [Barclays](#)



Salvatore Moran, *Associate Director*, EBS, highlighted many of the programs that AHRC NYC makes available to serve the needs of businesses that hire people with disabilities, including [Hudson River Services](#), *(which provides janitorial services to a myriad of locations,*

[Center](#), summed up the arena's experience with AHRC New York City's supported employees. *"Here's two words for you:"* he said. *"It works. - And if it works for us in our ever-changing environment, there's no situation where it doesn't work."*

Munson Dinner is a Huge Success for the AHRC New York City Foundation

The 35th Annual **Thurman Munson Awards Dinner** was held on Tuesday, February 3rd, at the Grand Hyatt New York, benefiting the [AHRC New York City Foundation](#). The honorees this year included New York Yankees pitcher [Dellin Betances](#); New York Giants punter [Steve Weatherford](#); and Olympic gold-medal-winning ice dancers [Meryl Davis](#) and [Charlie White](#). **Joel S. Isaacson**, *President* of Joel Isaacson and Co., received the Business & Philanthropic Leadership Award. New York Mets star reliever [John Franco](#) accepted the Munson Award on behalf of Mets hero [Mookie Wilson](#), while former Yankee third baseman [Charlie Hayes](#) accepted the Legend Award for [Bernie Williams](#).

For the 35th consecutive year, **Diana Munson** attended the event and gave thoughtful and heartwarming remarks. *"I feel truly honored to receive this award from an organization that has been dear to my family for three generations,"*



Honorees of the 35th Annual Thurman Munson Awards

Mr. Isaacson said. *"From a young age, AHRC taught me about the importance of community, a value that has penetrated every aspect of my life and one that I hope to inspire in clients, colleagues and family. I look forward to continue supporting its remarkable work to bring dignity and purpose to the lives of those it touches."*

The Munson Awards are presented to professional & Olympic athletes in recognition of their athletic accomplishments & contributions to the community.

The awards honor the memory of [Thurman Munson](#), a Yankee legend who captained the team to two World Series championships in 1977 and 1978. This year's event raised approximately \$700,000 for the AHRC New York City Foundation, and since the event's founding it has raised over \$13 million.



News About the Individuals with Disabilities Education Act (IDEA)

Analysis done in the **Journal of Autism and Developmental Disorders** finds that a number of issues, including income, behavior, and school placement can impact whether a family chooses to pursue mediation or due process to receive services outlined by the Individuals with Disabilities Education Act (IDEA). Parents with low-income are less likely to pursue any remedies due to the high costs of litigation, while families whose children have more social anxiety issues as opposed to severe behavioral issues were more likely to seek litigation.

In related news, a bipartisan House effort has emerged to fully fund IDEA. Full funding at the congressional level is considered to be 40 percent of the cost, but Congress has never reached that threshold and currently funds 16 percent. Under the language of the proposed bill Congress will gradually increase its funding of IDEA over 10 years to finally reach the 40 percent level.

Autism Tracking Device Legislation Gains Steam

Spurred by the tragic and unnecessary death of Avonte Oquendo, Sen. **Chuck Schumer** (D-NY) has reintroduced Avonte's Law, "which would establish and fund a federal program to provide electronic tracking devices to families of kids with developmental disorders who request them." Avonte, a young man with autism, wandered out of his school in Queens unsupervised and despite a massive search effort was found dead several months later. The government would provide \$10 million to fund the devices under the current language of the proposal.

Self-Advocate Invited Guest at State of the Union

Sara Wolff, a woman with Down syndrome, was an invited guest of Sen. **Bob Casey** (D-PA) at this year's State of the Union address. Sara was a strong advocate for the ABLE Act, which established savings accounts for people with disabilities similar those found in 529 college saving plans. Sen. Casey was in frequent contact with Sara during the process of passing this legislation, and to thank her for her support and guidance he asked her to sit in the house gallery to watch President Obama deliver his speech.

New York Continues to Improve Medicare & Medicaid Models

For years, New York State has been on the forefront of improving the way Medicare & Medicaid is delivered to its citizens. Now, the state has been commended for its model of value-based health care, which reimburses payments to providers based on how well the patient is doing, not on the number of visits or procedures performed. Sylvia Burwell, the Secretary for Health and Human Services, announced that her agency hopes to have 85 percent of Medicare payments tied to health outcomes by 2016, and the state's Medicaid director Jason Helgeson says they would like to do the same for that program. To view a video about this subject, [CLICK HERE](#).

OPWDD Forms Transformation Panel to Address Numerous Issues

OPWDD held its first meeting of the Transformation Panel on February 26, 2015. The panel consisted of a distinguished group of experts in the field of serving people with developmental disabilities, including Steve Kroll, Executive Director of NYSARC, Inc; self-advocates; families; and legislators. In a January document explaining the mission and goals of the panel, Kerry A. Delaney, Acting Commissioner of OPWDD, said, “*We are clearly at a critical juncture of transformation in our field. The central question we are all asking is this: how do we build our system to better support people with intellectual and developmental disabilities now and into the future and make our system sustainable for years to come?*” The panel will focus on a number of specific issues such as managed care, OPWDD funding, and employment for people with disabilities. The panel will meet every two weeks until June 2015.

Medicaid and Medicare: The Fifty-Year Anniversary of Landmark Healthcare Legislation

Fifty years ago, **President Lyndon B. Johnson** signed legislation that would revolutionize the way Americans receive healthcare. **Medicare** and **Medicaid**, Titles XVIII and XIX of the Social Security Act, respectively, extended healthcare coverage to tens of millions of citizens. **As we approach the fiftieth anniversary of these landmark programs, it is important to take a look back and see how the legislation was formed, developments to Medicare and Medicaid in the last five decades, and the programs’ future.**

HISTORY

There could be no Medicare or Medicaid without the act that they were spun off from, the Social Security Act. Passed in 1935 under **Franklin D. Roosevelt’s** New Deal program, “this epochal piece of legislation contained old-age insurance, unemployment compensation, and maternal and child health, but not health insurance,” according to the [Centers for Medicare & Medicaid Services](#) (CMS). Roosevelt wanted to implement a national health insurance program, but in the wake of the Great Depression (and soon World War II) found it too risky. Roosevelt’s successor, **Harry Truman**, was the first president to propose a national health insurance program but Congress did not approve. CMS states, however, “In 1950, [Truman] signed the Social Security Amendments, which provided federal funds to states for vendor payments for medical care of poor aged called Old-Age Assistance; it became the foundation for the Medicaid program.”

In 1960 Senator [Robert Kerr](#) (D-OK) and Representative **Wilbur Mills** (D-AR) collaborated on legislation that provided medical coverage to the elderly whom were not poor enough to qualify for Old-Age Assistance but too poor to afford their medical bills. **John F. Kennedy** made it a mission of his to get

Medicare passed but died before this could happen; Lyndon B. Johnson took up his predecessor’s mantle, and on July 30, 1965, signed Title XVIII and Title XIX of the SSA, establishing Medicare and Medicaid. Harry Truman received the first Medicare card. Medicare provided almost all Americans over the age of 65 with healthcare services; Medicaid provided the same but to people also receiving welfare services, mostly low-income children and families, the elderly, and people with disabilities. Additionally, Medicare is a federal program where the rules for eligibility and implementation are uniform across the country; Medicaid is funded by the federal government but administered by the states.

In the early 1970s, two major changes to Medicaid directly affected people with disabilities. In 1971, states could begin to implement intermediate care facilities (ICF) for the elderly and people with intellectual and developmental disabilities whose healthcare needs were fewer than for people in a nursing home. The next year, Supplemental Security Income (SSI) was established, providing monetary assistance to the same members of the population; in New York, people receiving SSI are automatically eligible for Medicaid benefits as well.

The 1980s brought some changes to these two programs which “include expanding Medicaid waivers to allow states more flexibility in providing home and community-based services to beneficiaries who otherwise would have been institutionalized...” according to CMS. In 1982 the Katie Beckett option was added to Medicaid, allowing for children under 18 who live at home but otherwise would receive institutional care to have income requirements waived to receive SSI and Medicaid. In 1996, under **Bill Clinton**, the Personal Responsibility and Work Opportunity Act ended the direct connection between Medicaid

and monetary welfare assistance. The U.S. Supreme Court also made a ruling about Medicaid during that decade, in [Olmstead v. L.C.](#) (1999) stating the Americans with Disabilities Act allows for states to fund community-based services where institutional care is not appropriate. **George W. Bush** presided over a big addition Medicare called Part D, which subsidized the cost of most prescription drugs for seniors. Most recently, in 2010, The Patient Protection and Affordable Care Act was passed in Congress and signed by President **Barack Obama**; it greatly expanded Medicaid to include all individuals and families up to 133% of the federal poverty level, although many states have chosen not to expand Medicaid to their citizens as is their right under the current language of the law and in the aftermath of a Supreme court decision on the constitutionality of the law ([National Federation of Independent Business v. Sebelius, 2012](#)).

THE FUTURE

Medicare and Medicaid face many daunting challenges in the years ahead. As the baby boomer population continues to age more and more people will become eligible for Medicare (which as it stands today is still available at 65 years old). An idea frequently proposed is to increase the eligibility age to 67, but the [Congressional Budget Office](#) has indicated this may only save the government a negligible amount with few other benefits. Medicaid’s future appears to be linked to the Affordable Care Act and whether or not states who have yet to expand Medicaid will do so. For both programs, it will be up to elected officials at both the state and federal levels to come up with economically sound solutions that do not compromise coverage for those who are eligible for or receiving services funded by Medicaid and Medicare.

VI. ACCESSING INFORMATION AND SERVICES

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'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/>

THE BACK PAGE

A Day on the Job with Richard Ward

Working in the cold, surrounded by mounds of dirty snow and wet asphalt, isn't for everybody, but it doesn't bother **Richard Ward**. With a smile yet intense focus, Richard goes to his job three times a week at [Fairway](#) in Douglaston, where he helps reorganize shopping carts and baskets for the customers. Wearing the classic green Fairway smock and a beanie, Richard moves quickly through the parking lot with purpose—maybe the cold does bother him a little.

"The people here are very nice, the customers too," Richard says. *"I have a lot of friends here. My boss is very nice to me."*

Richard has been working at this Fairway for almost four years. He receives services at [Far Rockaway Adult Day Center](#), and commutes to



the supermarket either through Access-A-Ride or, like today, via a program vehicle accompanied by his support staff. **Cassandra Sanchez**, *Community Support Professional*, says that she is part of a rotating group of Far Rockaway staff who come with Richard.

"I really only need to remind Richard of

the time so he can eat lunch and when to go home," says Cassandra. *"Otherwise he'll just keep working! He's very independent here. He knows exactly what he has to do and doesn't want somebody following him around the store."*

The Difference it Makes

Richard's colleagues at Fairway see and appreciate the work he does every day he is there. *"Richard is an awesome worker,"* Chad, a cashier, says. *"I know he has a disability but he does the best he can and he's great to work with."*

When asked why he chose to work at Fairway, Richard has a simple answer. *"It's a job! I like to save my money in my bank account."* He is always looking forward to his next day of work, even if it's cold.