

As 2020 marks the 30th anniversary of the Americans with Disabilities it is fitting to examine the ways in which the ADA can be further strengthened to protect the rights of those with disabilities. In July 2019 the Mid-Atlantic ADA Center held a webinar hosted by disability rights attorney John Wodatch and Marian Vessels. Wodatch is a disability rights attorney who was instrumental in the enforcement of the ADA during his time at the Department of Justice. He was also the main author of Section 504 of the Rehabilitation Act of 1973. Marian Vessels was the director of the Mid-Atlantic ADA Center from 1996 until her retirement in 2016.

Despite the protections of the ADA, people with disabilities still face challenges. One of those obstacles is unemployment or underemployment. According to Department of Labor statistics, the rate of unemployment among people with disabilities is 8 % compared to the 3.7 % of able bodied people. Disability advocates Mr. Wodatch and Ms. Vessels attribute this disparity to several factors.

One of the reasons that has been cited is the fact that the ADA's employment protections only applies to businesses with at least 15 employees. Much of the job growth comes from small businesses that are not covered by the ADA. Mr. Wodatch suggests that this can be improved by changes to the law. Such changes would require the support of the federal government. This can be difficult with changing administrations and their shifting priorities.

The misunderstanding of disability also plays into the problem of unemployment. This can especially be an issue for people with invisible disabilities such as mental illness. This is due to the stigma associated with mental illness. Employers may feel as though people with mental health challenges may be a liability to their business. It is important that people with mental health difficulties have access to the care they need to be





contributing members of society.

Wodatch and Vessels argue that hope for change is with the generation that grew up after the ADA became law. Those that grew up under its protection they do not know any different. They know how best to improve it. I believe because of this the ADA is great hands with future generations.



Save the Dates

SUFFOLK INDEPENDENT LIVING ORGANIZATION

HUMAN RIGHTS & ACCESSIBILITY SEMINAR

- New York State's Human Rights Law has provisions that protect persons with disabilities.
- Learn about the recent amendments made to NYS Human Rights Law.
- Come learn your rights under the NYS Human Rights Law.
- Learn about the complaint process at the New York State Division of Human Rights and how it enforces this important law.
- Q&A to follow.

Presented by John Herrion, Director of
Disability Rights, NYS Division of Human Rights

Monday March 9, 2020 at 10:30 AM - 12:00 PM at the Barrier Busters Meeting in the
SILO Community Room

3253 Route 112, Building 10, Medford, NY 11763 Sponsored by SILO www.siloinc.org

If you have any question please call Justin Ainsworth at SILO 631-880-7929 Ext. 113



South Fork Commuter Connection

During May's transportation meeting there was a presentation from Thomas F. Neely, the Transportation and Traffic Safety Director for the town of Southampton. Mr. Neely spoke about the South Fork Commuter Connection (SFCC). SFCC is a coordinated train and bus service for the south fork of Long Island. It only operates during the week. It also does not operate during the five major holidays and Fridays during the summer.

Workforce employees board eastbound LIRR at Speonk, Westhampton or Hampton Bays. The passengers will then disembark at Southampton, Bridgehampton, East Hampton, Amagansett and Montauk stations. Shuttle buses meet the trains to take people to employment hubs in the area. The process is reversed in the evening. This initiative aims to provide intermodal service between busses and trains. The purpose of this intermodal transportation program is to allow passengers to access two forms of transportation for the price of one. For the price of a LIRR ticket, employees in the service area get on the bus for free.

The SFCC program has been considered for some time. A program similar to SFCC was considered under Governor Mario Cuomo's administration in 1994. Beginning in 2000, the five towns that make up the East End collaborated on the Sustainable East End Strategies (SEEDS) program. The effort lasted until 2005. There was short term implementation occurred for nine months in 2007 and 2008. There was a feasibility study done in 2009. It found that there was no other program in the country that coordinated two different forms of transportation.

Mr. Neely also discussed how they found the employees that would most benefit from the service. They identified office workers, hospital staff and teachers as their target audience.

Accessibility is also a basic tenet of this program. Those that use SCAT can present their bus ticket to the driver. This allows them to take advantage of the same deal as other passengers. Passengers that require wheelchair accessible transportation can request an accessible bus with 24 hours' notice. It was also announced that people with disabilities and senior citizens will be able to use the shuttle bus service for free. Those over 65 need to present their state ID's at point of purchase. People with disabilities just have to show their SCAT or MTA cards.

This program was implemented through a joint effort between Southampton and East Hampton. Additional input was given by the MTA and LIRR. This service was also advocated for by Sen. Kenneth P. LaValle and As-

semblyman Fred W. Theile, Jr. Southampton and East Hampton contributed to an advertising fund to let the public know about the service. They are continually looking for feedback from commuters and the employment hubs they work for.

The South Fork Commuter Connection is the first service in the country to provide intermodal transportation to commuters during the week. It is a testament to what can happen when different entities work together for the betterment of commuters.

If you would like more information about this program go to www.sfccLIRR.com or www.southamptonny.gov/sfcc.



Food Farmacy at HALI

Did you know that what you put at the end of your fork is more powerful medicine than anything you will find in a pill bottle? **Food is the most powerful medicine available to heal chronic disease**, which will account for over 50 million deaths by 2020.

All you need to do is “eat” your medicine and think of your **grocery store as your pharmacy**.



Join our FREE 12 week Food Farmacy program and learn:

Money Management (eating healthy for less, Meal Planning)

Support groups (emotions tied to eating/improving quality of life)

Cooking (with limited resources; ie: hot plate, microwave)

Daily exercise (Walking club, Yoga, Zumba)

Free Registered Dietitian support

Weekly food and activity Journaling

Weight Loss

Manage chronic disease such as:

SILO's Annual ADA Celebration

On July 26, 2019 hundreds of people gathered at SILO's offices to celebrate the 29th anniversary of the Americans with Disabilities Act. This year's festivities honored the memory of President George H.W Bush. President Bush signed the ADA into law in 1990. He worked with both Democrats and fellow Republicans to get this important civil rights legislation passed.

The event featured family friendly activities and remarks from Joseph Delgado the CEO of SILO and local representatives. I spoke with Joseph DeStefano, the Assemblyman represents the third district of Long Island. He represents Holtsville to Mastic Beach. The freshman Assemblyman is eager to work with SILO to protect the rights of people with disabilities. "I couldn't be happier to be part of the 29th anniversary of the Americans with Disabilities Act. Disabilities know no boundaries and we want to make sure at the state level that we continue to have the funding resources, partnering together with town, county and federal governments to make sure that the services you are due and expected to have we will make sure we can do that for you. This effects everybody. We want to make sure that you can live in your own homes and enjoy the same privileges and rights that Americans without disabilities have. You have my commitment that I will work tirelessly for your benefits and the things that your benefits and the things that you need are done. We will work hard together. I look forward to partnering with this organization."

I also had the opportunity to speak with Brookhaven Town Supervisor Edward P. Romaine about the importance of celebrating the ADA. "I want to congratulate SILO on the 29th anniversary of the Americans with Disabilities Act. They do a wonderful job advocating for the disabled community. I welcome the opportunity to work with our disabled community and believe that we can do a better job and do more here in Suffolk County to empower all of our residents including the disabled."

Suffolk County Comptroller John M. Kennedy, Jr. was also in attendance. He shared his thoughts about the significance of the ADA. "One of the

great things in the history of the United States was the passage of the Americans with Disabilities Act on July 26, 1990. What it said is that even people with special needs or disabilities should be part of the American fabric of life. They should have equal opportunity to access services. I'm very happy to celebrate this day and work to ensure that everyone with special needs or disabilities enjoys a full life."

I also had an opportunity to speak with Dominick Thorne. Mr. Thorne is running for Suffolk County legislature. He is running for the 7th district. He was thrilled to attend the ADA celebration because he believes in SILO's mission of supporting and advocating for the independence of people with disabilities. "We always need to do more to make sure that we make everything as adaptable as possible for every resident in the community. It's truly an honor to be here and I sincerely appreciate the opportunity to be with you."

SILO's CEO Joseph Delgado also spoke about the importance of reaching across the aisle to get the ADA passed. "There comes a time when we have to put politics aside and concentrate on what's really important in this country. What's really important is total accessibility for everybody at all times. One thing that is not negotiable is accessibility for everyone in our society."

SILO's celebration of the 29th anniversary of the ADA was a fitting tribute to President George H.W. Bush. It focused on the fact that accessibility for all should not be a political issue. The ADA celebration is a great re-

minder of where we have
been and how far we still
need to go.

Kings Park: Stories From an American Mental Institution.

Documentary filmmaker Lucy Winer showed the staff at SILO some scenes from her documentary Kings Park: Stories from an American Mental Institution. The documentary was born out of Ms. Winer's need to revisit her experiences at Kings Park as a patient therein the 1960's. Prior to beginning work on the documentary Ms. Winer had walled off her experiences at Kings Park. This meant turning her back on her formative years. When she visited the grounds of Kings Park she found that the mental hospital had been closed. She began to wonder what had become of the thousands of people who were patients there.

The first scene that was shared showed Ward 210. This was the female violent ward in the Admissions Building that Lucy Winer was placed in when she was 17. Ms. Winer felt it was important to visit Ward 210 because she knew part of herself was still there. She made the documentary in part to recover that piece of herself.

The scene in Ward 210 showed the area where patients were expected to give up their belongings in exchange for state issued clothing. In the documentary, Ms. Winer describes this experience as punitive even though that most likely was not the hospital's intention. Like the other patients she was also forced to wash and dry herself with one washcloth at a sink in front of the other patients. Later, Ms. Winer was able to get two washcloths because her mother advocated for her with one of the attendants. During the day patients stayed in one room where they slept on the floor or windowsills because they were severely depressed or overly medicated. The ward she was on did not offer any activities for the patients to participate in. Early on in her stay at Kings Park she was warned by a fellow patient not to cry. If she cried she risked being hurt by the guards.

Before showing the audience this clip Ms. Winer asked us to imagine ourselves in her position. As a person with a physical disability the

thought of having to stay in an institution like Kings Park was frightening.

The next scene that was shown featured former nurses at Kings Park. They shared their experiences working with the patients. There were times when the nurses were afraid to do their jobs. They made it through by working together and showing compassion to the people in their care. Several of the nurses interviewed expressed that they knew how afraid the patients must be and they did all they could help. The nurses knew that the roles could easily have been reversed.

Some people in the audience felt that the nurses were making excuses for the behavior they saw from staff because they became accustomed to the culture of their workplace. They also needed to go along with the administration in order to keep their jobs. Additionally, it was pointed out that training for nurses has changed since the people featured in the documentary worked at

Kings Park.

We were also shown the perspective of Elizabeth, a former patient at Kings Park. Elizabeth was traumatized by her experiences there. She had this to say about her time at the institution, "When I left this hospital, they didn't have hope for me. They said I was coming back again." Elizabeth also described Kings Park as being empty and full of horror. After she left she was depressed and cut herself off from other people. She was able to find peace and recover from her trauma when she started working with Roni at Club House. Through their work together Elizabeth was able to find a community of people that cared about her. She was also able to give back.

Kings Park: Stories from an American Mental Institution sheds light on an important part of American history and its treatment of mental health. With this documentary Lucy Winer hopes to educate the next generation of healthcare workers and advocates so that the mistakes of Kings Park will not be repeated.

Feature Person: Laurie Delgado

I had the opportunity to interview Laurie Delgado. Mrs. Delgado is the director of special programs and projects at SILO. She was integral in the planning and execution of SILO's celebration of the 29th anniversary of the Americans with Disabilities Act.

Laurie began her association with SILO as a volunteer. She assisted with the crafts classes and the holiday dances that were put on for the clients of SILO and their families. She then came on as the director of special programs and projects. The things she enjoys most about working here is the opportunity to help others. "I love the interaction with clients. I love helping people."

She jokingly added, "I think I have a pretty good boss."

I was curious what a typical day looked like. Since she reports to the human resources department her assignment can vary. At the time of our interview the most recent project she had worked on was the ADA celebration. She also helped locate a new location for SILO's offices. The planning for the ADA celebration alone takes a year from the date it ends. The event always takes place around the anniversary of the ADA. The planning discussions are concerned with securing a date, reaching out to local businesses for goods and services to be raffled off to the attendees. Laurie is also responsible for reaching out to local elected officials in order to invite them to the event.

A theme also needs to be decided on before a flyer can be created and distributed. This year's theme focused on the legacy of George H.W. Bush because he signed the Ameri-

cans with Disabilities Act into law in 1990.

Once a theme is decided on and a flyer is created, the event can be advertised on social media, radio and television. Vendors and food need to be lined up. This year the staff cooked the food for everyone. Vendors also bought tables for the event.

After the ADA celebration is complete Laurie sends out thank you letters to everyone who donated something to SILO.. This year's event had 300 attendees. It grew from last year and Laurie considers it a success.

Since she works so closely with the disabled community I was curious what the ADA means to her. "The ADA means choice. Everyone should have a choice where they want to work, play and live."

When not at work Laurie enjoys traveling with her family and cheering on the New York Mets and the Denver Broncos. Something people may not know about her is that she likes to fish and can be competitive.

I enjoyed getting to know Laurie Delgado better. It is clear that she loves the work she does. In particular, she enjoys organizing the annual ADA celebration for the participants at SILO and the community at large.

Fourth Annual Self-advocacy Conference

On October 17, 2019, SILO held its fourth annual self-advocacy conference. It was run by Barrier Busters committee chair Justin Ainsworth. The conference featured several workshops and speakers. As always, the goal of the conference was to teach the attendees how to better advocate for themselves.

The keynote speaker for this year's conference was Michael Stoltz. After an exemplary career in the field of social work Mr. Stoltz became the CEO of the Association for Mental Health and Wellness (MAHW). MAHW accomplishes this by providing peer support and groups. He spoke at the conference about the increase he has seen in anxiety and depression he has seen among the community he serves. He came to the conference to discuss strategies people can use to better advocate for their mental health needs. He strives to remove the stigma oftentimes associated with mental illness. MAHW accomplishes these goals by providing training for first responders and others in mental health first-aid. The organization also provides peer support and other services for those living with mental illness.

After his presentation I had the opportunity to ask Mr. Stoltz his opinion about the conference and how he thinks the conversation around mental health conditions has changed during his time working in the field. He had this to say about the conference, "I think this is a wonderful gathering of courageous people. When you put together people who have

this level of courage only good things can happen. To help make sure that people that are feeling some distress get the assistance that they need.

Mr. Stoltz also said that the treatment of those with mental health disorders. The focus has changed from hospitalizing people with mental health disorders to teaching people how to best address these issues in the community. A second major shift that Mr. Stoltz mentioned was the increased use of peer support. Peer support is an important tool when addressing mental health difficulties because it gives the person living with a disorder a role model. They have someone they can relate to because they have both faced similar challenges.

Motivational speaker and Licensed Social Worker Steven Licardi also spoke at the conference. His remarks focused on how his being on the Autism Spectrum himself allows him to empathize with his clients. In his work he seeks to validate the different worldviews of his clients and strives to help build a world in which all ways of interacting with the world are accepted and valued. These are his thoughts about attending the self-advocacy conference for the second time, "It was an honor to participate as a motivational speaker for the second time at the SILO Self-Advocacy Conference. As an individual who was diagnosed on the Autism Spectrum -- a label that some might call an invisible disability -- my own story has been one of learning to redefine the nagging suspicion that "there is something wrong with me". The SILO Self-Advocacy Conference provides a space for each of us to explore how to redefine this narrative, how to take ownership of our strengths, and how to affirm our innate human right to thrive unapologetically. The world is too limited in its perceptions of what should and should not be; of what is and is not possible. Each of us who have been labelled as disabled or "other" by systems of power exist in a world that is too often seen as incompatible with the one able-bodied folks have collectively, and perhaps unconsciously, consented to upholding. Many of us do not have access to the convenience of conformity. The SILO Self-Advocacy Conference thus provides each of us, disabled or otherwise, with the language to demand

that the world be transformed to embrace our worlds, our realities, and to ensure our stories are heard, affirmed, and validated. It is a gift for me and my poetry to be a part of that legacy."

The conference also featured a self-advocacy panel. Sophia Ardi, Brian Solomons, Marilyn Tucci and Dawn Cokeler discussed how they became effective self-advocates and provided feedback to questions submitted from the audience. Sophia Ardi also created an action plan for participants so they can learn how to better advocate for themselves when they encounter a problem or issue.

The conference also featured workshops about accessible transportation, the Consumer Directed Personal Assistants program, the Start the Conversation support group, housing discrimination and work incentives for people on Social Security.

The closing keynote speaker was John Nocera. John spoke about his experiences while living in a nursing home. He had to stay in nursing homes for quite some time after surgery to remove a tumor from his spine left him paralyzed from the waist down. John faced this change in circumstance with the same positive attitude that had served him throughout his life.

After breaking his ankle while visiting a friend, he was forced to move to Avalon

Gardens in Smithtown. John's experiences at Avalon Gardens were vastly different than his previous experiences at Smithtown Nursing and Rehabilitation. During his first stay at a nursing home the staff was kind and respectful. In his experience the patients were treated like prisoners and were not allowed to sit outside the facility until they passed a series of burdensome tests that were impossible for many residents to complete. Despite these hardships, John's continued advocacy for himself and the other residents resulted in the firing of several members of the staff.

Mr. Nocera concluded his keynote speech by thanking Lori Corrar and the team at SILO for helping him transition out of Avalon Gardens. He encouraged them to continue their work because, "There are people that could be out, that should be out."

The fourth annual self-advocacy featured many informative workshops and speakers. When I spoke to Justin Ainsworth shortly after the conference he said that the feedback he had received from the attendees had been positive. He looks forward to expanding the conference even further in the future.

Board of Directors

President

Mary Ann Sciacca

Vice President

Patrick Mitchell

Secretary

Geraldine DePersio

Members

Bernard Ferracane

Donald Gomez

Roger Smith

Krista Giannak

Dawn Cookler

Chief Executive Officer

Joseph M. Delgado