

SELF ADVOCATES NEWSLETTER

DON'T TALK ABOUT IT, BE ABOUT IT

VIRTUAL CENTRAL PARK CHALLENGE

BY KENNETH YOUNGBLOOD

This year, I had a Virtual Central Park Challenge from YAI on Zoom at home. I gave my mom my XL T-shirt with Virtual Central Park Challenge as my T-shirt is not big enough for me. I signed at the register in Central Park Challenge from YAI this year. I took pictures at the Central Park Challenge last year. I learned to take the pictures at the Central Park Challenge from YAI. Jessica Stinchcomb gave me my email address for the Central Park Challenge. There was a socially distanced 3K walk and 5K run this year because of coronavirus.

They had music, dancing, and a DJ for the 2020 Virtual Central Park Challenge.

They had music, dancing and a DJ for the Virtual Central Park Challenge. I ran and walked at Central Park Challenge last year. I wore my Central Park Challenge T-shirt from 2 years ago. I learned to say hello and how you are doing from Virtual Central Park Challenge on Zoom. There were people in wheelchairs with canes and walker at Central Park Challenge from YAI. Everyone was having a great time. We are not going to the Central Park this year because we are staying home. We will be going back to Central Park Challenge next year. Next year, I will register for the Central Park Challenge next year. I will have a lot more fun.

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Amy Sigona and Car'melo Grau Puig at YAI HQ, running the livestream setup.

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BLACK LIVES MATTER PROTESTS AND DISABILITIES

MICHAEL HOWARD

All minorities are affected by the recent police brutality protests, including people with disabilities. The system has been broken for decades. It has really affected all types of minorities – it's not about race, it's about oligarchy vs. democracy. We the people are trying to save democracy.



BLM protest in New York City on June 9, 2020

Even though I live in a safe part of my neighborhood in Far Rockaway, Queens, there are nearby parts that are not as safe. In those areas, I haven't felt comfortable asking a police officer for help after the George Floyd incident, but I hope it changes in the future. I must be extra careful around these officers and must be cautious. This is also a real threat for people of color with disabilities, who may not have access to other support systems. As of now, I recommend that people with disabilities reach out to their allies that they know and trust if they are in trouble. The black lives matter protests are still going strong, and they will continue until white supremacists no longer have a platform and there is racial equality.

WOW! HOW EVERYTHING CHANGED FOR THE BETTER

BY CAR'MELO GRAU-PUIG

Before COVID-19 came around the corner, my life had changed for the better meaning that on Sept. 27th, 2019 it was my final year at Gramercy and I went from being a housekeeper to becoming a caregiver for my sibling with a disability and it has been one amazing ride. I can still take responsibilities at the same time by devoting my time in taking care of what needs to be done, continuing to do my co-facilitating for the ILSP group, focusing on YAI projects, but being the YAI SA President and help lead the Self-Advocacy group for two terms.



Car'melo Grau-Puig at YAI Headquarters

Later, I've received a five-year award from the YAI Community and Family Services for the contributions I've done. I didn't expect to receive it, but hey it was well worth it. I still devote my time in doing public speaking at any places like schools, colleges, the UN headquarters and of course YAI. I'm enjoying every moment that's been put in front of me and I will continue to take part with the agency.

Next, something happened this past March of this year that will forever change our lives. There was a lockdown on March 16th of this year and all the YAI programs were affected, and I didn't know what to do to make the best of it. I had to sacrifice myself by giving up social events, going to see friends and family members as well as protecting myself from getting Coronavirus. For couple of months everybody was required to put on a face mask or face cover when everybody was going out, practice social distancing meaning 6-feet apart and also let us be mindful anybody that not affected could get tested. If it's negative or positive everybody needs to protect themselves by taking proper vitamins so that we could stay healthy and safe at the same time. Nowadays while the COVID-19 crisis continues to be affected; to keep myself busy I now temporarily use ZOOM: a virtual video chat. It's a way to communicate with loved ones as well as the staff and self advocates and that's why we don't lose track of everything but so far it could challenging but going forward all I could do is continue to be positive at the same time and set an example.

Finally, on June 6th, something happened that was a surprise: I got asked to co-host the 1st-ever Virtual Central Park Challenge with ABC news icon Bill Ritter and YAI staff Kathy Schiavi standing side by side. It was such an amazing experience and mind all of you I never get stage fright but it was well worth it and definitely I paid my dues. The staff, self advocates, friends, and family members applauded me for all the accomplishments I've done and I will forever cherish these moments and I'm sure next year for 2021 CPC we will re-prevail, continue to stand up and remember: Y'all don't talk about it, ya'll be about it. That's all I got it say about my experiences.

INTERVIEW WITH NAOMI ORTIZ

BY ISMAEL NUNEZ

Can you tell us a little about yourself? My name is Naomi Ortiz and I am a disabled Mestizo living in the US Mexico borderlands.

What got you into writing? I always wrote poetry, but with my disability, I can't type very much with my hands. When I was in school, dictation software (computer programs that write down what you say when you talk into a microphone) didn't work well enough for me to take writing classes. I really came into writing much later. I was working in activism and kept seeing people get exhausted and leave organizing work. I was curious about how people who did activism for a long time kept motivated, interested, and didn't burn out. I thought about this a lot for a couple of years before I decided to put my time into writing a book.

The publishers and the editors - did they react when they saw a latina with a disability writing? I was really worried about this when I went to go look for a publisher. Especially because publishers often have really high expectations for what authors can do to promote and share their book. There's no way I could travel to do a book tour or things like that. I am slower getting tasks done because of my disability. At a disability conference, I met some Queer disabled folks who were starting a press and they were really interested in my book. They respected the way I came at things in my book, things like using Spanish and English and using dichos (Spanish sayings) in my work. I got lucky.

There is a movement to "Erase the R Word." What is your opinion on that word? I think that the R Word is a derogatory word. It has no place in our society.



Naomi Ortiz

Any advice you'd to give to a fellow person with disability like myself? One thing I did that I think can be helpful for disabled folks, people with all kinds of disabilities, who want to be writers is to find someone to trade your writing with. This means meeting up and sharing your writing was somebody who is also sharing their writing with you. Doing that really helped me get my book done and helped me know that somebody else understood what I was writing or let me know where they got confused. I think that is something that most of us with disabilities share is having to go at a different pace than other people. Sometimes that can feel frustrating, but I've learned to trust that that's just part of my process and to not only accept it, but advocate for it.

MACY'S 4TH OF JULY FIREWORKS

BY KENNETH YOUNGBLOOD

We always watched the Macy's 4th of July Fireworks Spectacular on NBC. My favorite colors of fireworks are purple, orange, blue, red, white, green, pink, and golden yellow. I asked my mother and sister; can we go to the 4th of July please? My mother and sister said yes. I asked my mother; can I do the firecrackers and fireworks in 4th of July please? My mother said no, it's too dangerous for me. I wrote and read about the United States of America in High School. I learned to sing the Star Spangler Banner, Lift Every Voice, This Land is Your Land, and America, the Beautiful in Public School. I learned to sing Lean on Me and God Bless America in High School. I took pictures of the Fireworks with my camera on 4th of July. The 4th of July Fireworks is canceled, because of the coronavirus this year. We will go to 4th of July until next year. We always have a great time.



Fireworks over Manhattan

DATING FOR PEOPLE WITH AUTISM

BY JANICE MCPHILLIPS

I saw a video online about young girls and guys with autism, who are dating each other. They have similar interests with each other. Dating with people who have disabilities is hard because they get put down. But you know who they are on the inside. In the video, each of them meets each other for the first time. They got to talk to each other, they had fun together, and started dating.



EFFECTS OF COVID-19

BY JANICE MCPHILLIPS



MTA employee cleaning an NYC subway car

Through the Coronavirus we should be safe and social distance from each other. In the state agencies the staff told individuals not to visit other people in their apartments at this time. All individuals, including people with disabilities, must wear masks. Staff must go for training for Covid-19 mandated by state law. The staff comes into the individual's apartment and gives them information about how to protect themselves. If the staff refuse to wear masks, they have to leave.

On mass transit, everyone must wear a mask until further notice. The staff must go with the individuals to their doctor appointments also. If you do not have a mask when you go to the doctor's appointment, they will give you one.

DANGEROUS HEAT

BY KENNETH YOUNGBLOOD

This past summer, we had the hottest day in July. If it's hot outside, please call 311 to find the nearest cooling center in your area. I turned all the lights off and turned on the air conditioner and stay cool inside like my mom said. I told my mother, "Can I drink plenty of water please?" My mom said yes, it's hot outside. I checked the weather forecast is hot outside on Eyewitness News. We wore my lightweight, light colored shirt, sunscreen, sandals, hat and sunglasses. Because it's dangerous heat. I told my mother, "Can I wear my A-Shirt and lightweight pants please?" My mom said yes! Last year, It's a dangerous hot temperature in the summertime. I'm staying cool in my house.



A hot summer day in NYC

INTERVIEW WITH JOSE RIVERA

BY ISMAEL NUNEZ

Editor's note: Willowbrook State Development Center in New York is infamously known for its inhumane treatment of people with disabilities who resided there. This scandal was exposed when a young reporter, Geraldo Rivera, released a series of horrifying images that depicted more than 5000 children and adults living in ghastly conditions.

YAI Self Advocate Ismael Nunez follows up with Jose Rivera, a disability and civil rights activist who had close ties with Willowbrook. Rivera, along with Willie Mae Goodman, a family member of one of people residing at Willowbrook, went on to lead a civil rights campaign for people with disabilities which involved a fight with the State of New York for the rights of people with disabilities.

How did you end up getting involved in Willowbrook?

My involvement or experience with Willowbrook State School began with the placement of my brother Luis Rivera in 1961. Luis was one of 200 individuals selected by the Department of Mental Hygiene from those in Willowbrook and transferred to another State facility on the lower east side of Manhattan called Gouverneur State School.

It's interesting the only time when they talk about Latinos in Willowbrook: You only see/hear Geraldo Rivera, not the Latinos who were there or the Latinos who fought to change Willowbrook. I agree, however we were all confronting the same challenges in getting the services needed. It should be noted that the language barrier and cultural differences made it more difficult for Latino families. Therefore I found myself needing to step up and get involved.

How did you meet up with Willie Mae Goodman? At Gouverneur, I met Willie Mae Goodman and together we began the fight with the State of New York for the rights of our individuals. Goody and I had the same goals and we worked well together. I admired her passion and drive; and in me she found the energy and dreams of the kind of life my brother and her daughter were entitled to live.



Jose Rivera

There is now a movement: "To Erase the R Word" what is your opinion on that word. In my opinion the R word is offensive and should never be used. I understand that the American Psychological Association no longer recognizes this as an official classification of cognitive capacity. I agree and support the movement to erase the R word when referring to people.

Finally, what would you tell a person like me who has a learning disability? What I would say to you Ismael and individuals with any type of disability is the following: Follow your dreams, pursue your goals what ever they might be. We are all God's children with the same rights to life, liberty and the pursuit of happiness.

VIRTUAL TOURS

BY JANICE MCPHILLIPS



Taipei's National Palace Museum, which offers virtual tours due to Covid-19.

People with disabilities can explore some virtual zoom places. Due to COVID-19, the Museum of Modern Art has zoom tours of different galleries in the museum. There are also zoo virtual tours around the world. Lego Land in Florida has virtual tours as well. Walt Disney has virtual tours for the rides. The US national parks have virtual tours, and one can go on a virtual cruise. Baseball museum has virtual tours. There's also the boxing hall of fame.

MICHAEL JACKSON

BY KENNETH YOUNGBLOOD

Michael Jackson was born on August 29th, 1959 in Gary, Indiana. He died on June 25th, 2009 in Holmby Hills, Los Angeles, California. Many people learned to do the moonwalk from Michael Jackson. We always watched Michael Jackson on BET and VH1 on cable network. I learned to sing I'll be There, we are the World, Bad, Black or White, and Man in the Mirror from Michael Jackson. I liked to read about Michael Jackson. I learned to do Dancing Machine and Shake Your Body from Jackson 5 and The Jackson. Some of my favorite Michael Jackson song is called Rock with You, Billie Jean, Off the Wall, Beat It, Thriller, Don't Stop to Get Enough, Bad, The Way You Make Me Feel, Dirty Diana, Smooth Criminal, Man in the Mirror, Leave Me Alone, Black or White, Remember the Time, Dangerous, You're not Alone, Earth Song, Scream, Cry, We are the World, Got to be There, Rockin' Robin, I Wanna Be Where You Are, and Butterfly. My favorite Jackson 5 theme song is called ABC, I'll be There, Never Can Say Goodbye, Dancing Machine, Sugar Daddy, I Want You Back, The Love You Save and Daddy's Home. The soundtrack movie is called "Ben" from Michael Jackson in 1972. I went to Target to get the Jackson 5 CD's. We will be celebrating Michael Jackson's birthday way into the future.



Michael Jackson

Pieces by Guest Writers

CORONAVIRUS

BY KATHY TURNER AND SUSIE GOLDBERG

The coronavirus is keeping us inside since we do not want to get sick. It is hard to stay inside, but you got to do it, so you do not get sick. We need to keep the right distance to keep safe and wear masks if you go out. We need to wash hand with soap or use sanitizer. We are not going to the Day Hab, no Dunkin Donuts, no trips, can't see my parents, no Moonstone, can't go to the Poconos, no camp, and we cannot go to therapy. With all this we feel sad and disappointed. We are all working on being flexible. We stay home every day and the Day Hab comes to us. The Day Hab works with us. They do my goals, money, take walks all the way to Northern Blvd, go to the park and play uno, Bingo, jeopardy, and Wii Dance. We cannot see our family, so we are flexible. We both speak to our aunt, uncle, and our cousins. We even had a Zoom party for my dad. My parents send food for the whole house. We got a cake for the dad's birthday. We still have therapy since Abby is on Zoom. We have the best staff at Glenwood. The staff keep us safe. The staff help us out by getting things we need, they cook food for us to eat, they go shopping to get things/food at BJ's and they do a good job. They help us out to make Glenwood fun. We bake, play basketball in the backyard, go for a walk, play games, and they try to make us happy. We are lucky to have the Glenwood staff they are the best. Even though the Coronavirus is here being flexible makes us happy and not get sick. We are lucky to have Glenwood.



Kathy Turner



Susie Goldberg

Pieces by Guest Writers (continued)

AUTISM AWARENESS AND SOLUTIONS

BY ASHLEY MURRAY AND LORENZO MYERS

Recently I heard that the "#AutismChallenge" on TikTok was insulting, belittling, degrading, and demoralizing all people with disabilities by making fun, taunting, and discouraging them mentally, emotionally, and psychologically. Parents, children, and kids were mocking people with disabilities by creating harmful dances. Autism advocates are working to ban this app for the betterment of today's economy and society. This is why we need more advocates to further support and inspire, teach and help those who are in need of it. We can benefit and grow as a multi-functioning movement that overcomes, prevails and conquers all obstacles. How can people with intellectual disabilities seek the proper resources and support that they are in need of?

Autism is a psychological impairment that, while most people think delays and postpones their ability to function in normal circumstances, people with these disabilities often turn out to be very outspoken, unique, more intelligent, and are equal to neurotypical people. Rather than degrade, demoralize, and belittle them, people should get up, wake up, and educate themselves with the proper resources and support to further increase their own intelligence about Autism. People assume the stereotype that neurodiverse people are genetically inferior to most, but in reality all people should be treated as equals. Sometimes, people need further assistance, but they should have their personal assistant or advocate teach them how to stand up for themselves and be a part of a movement for equality, where all the people who are mistreated can become advocates and support systems. This can show the true embodiment of the word "equal."



TikTok receives backlash from the disability community for its "#AutismChallenge"