AbleNews



THE NEWSPAPER FOR, BY, AND ABOUT PEOPLE WITH DISABILITIES

Celebrating the Life and Legacy of Brooke Ellison

By Emily Ladau and Allison Howe



Photo: Christine Carrion-Alfano

Brooke Ellison of Stony Brook, NY, an accomplished disability advocate and the first person with quadriplegia to graduate from Harvard, passed away on February 4, 2024 at the age of 45. She leaves an immense, world-changing legacy behind.

Reflecting on Ellison's impact, Dr. Chris Rosa, President & CEO of The Viscardi Center shared: "Brooke's passing is felt deeply by the disability community around the world, but especially here on Long Island. Her personal story of striving for independent living — achieving academic and professional excellence and sharing incisive social commentary about access, opportunity, and the intrinsic dignity of the disability experience—resonates deeply for people with disabilities and their families here on the Island. We are all so proud to claim Brooke as our own."

At age 11, Ellison became paralyzed after being hit by a car while walking to school on her first day of junior high. She survived and thrived, and after graduating high school, was admitted to Harvard University where she graduated with honors and received a B.S. in cognitive neuroscience. She later earned a master's degree in public policy from Harvard, followed by a doctorate in sociology from Stony Brook University (SBU) in 2012.

Ellison was an associate profes-

sor in SBU's School of Health Professions and a research assistant professor in SBU's Renaissance School of Medicine. She also served as director of Education and Ethics of the SBU Stem Cell Facility and cofounded the SBU VENTure Think Tank that works to develop policy and technological solutions for people on ventilators.

Ellison's parents, Edward and Jean, who graciously took the time to speak with *Able News*, lovingly said that keeping up with their daughter was a "remarkable ride."

"She worked from the moment she woke up until she went to sleep at night," shared her father. "I believe she wanted to squeeze in as much as she could in the world she lived in and affect as many people as quickly as possible because she never knew when she might leave this world."

Indeed, Ellison's efforts reached far and wide. Outside of her duties at SBU, Ellison served on New York State's Spinal Cord Injury Research Board, the New York Civil Liberties Union Board, and the Empire State Stem Cell Board. She was also politically active, and ran for the New York State Senate in 2006.

Ellison was the Vice President of Technology and Innovation at United Spinal, where she led their Tech Access Initiative. Kai Wong, Senior Manager of Digital Accessibility at Teladoc Health, served on United Spinal's Tech Access Corporate Advisory Board, working alongside Ellison. "Brooke saw technology as a mechanism through which people with disabilities can achieve independence," Wong shared. "She ignited a sense of purpose for many of us working in healthcare and technology. Brooke's legacy will continue to illuminate our path towards a more inclusive world."

A few of Ellison's many well-deserved honors include being named a World Economic Forum Young Global Leader, a Truman

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National Security Project Political Partner and a commissioner on the Suffolk County Human Rights Commission. Further, she was inducted into the Suffolk County Women's Hall of Fame, received the Inspiration Award at the 2008 World Stem Cell Summit, and was named a New York State Woman of Distinction.

In 2002, Ellison wrote her first book, "Miracles Happen: One Mother, One Daughter, One Journey," with her mother. Christopher Reeve later adapted the book into a poignant movie, "The Brooke

New York Disability News

Is the New York City Subway Truly Embracing an Inclusive Era?

By Kieran O'Brien Kern



Things that make life in New York possible: a trustworthy news source, a reliable bagel place, and public transportation. People may not agree fully on news or bagels, but of the over eight million New York City residents, millions have in common the regular use of public transportation. However, for the nearly one million disabled New York City dwellers, going to work, appointments, school, or out with friends isn't as easy as hopping on or off a bus or train.

NYC subway construction was approved in 1894. It opened 10 years later, on October 27, 1904, connecting boroughs while structurally excluding disabled people.

Today, there are 472 subway stations in New York, but less than one-third are accessible. Making the subway system accessible has been an ongoing process since the 1980s. Following the passage of the Americans with Disabilities Act (ADA) in 1990, the Metropolitan Transit Authority's (MTA's) 30-year plan to make 100 key stations accessible was approved. Three decades later, it's still a work in progress.

Bronx native Natàlia Méndez, who sustained a spinal cord injury 17 years ago, has long lived the

"is it/isn't it" accessible anxiety of navigating subway stations. Last year, Méndez, the founder of an organization called Women on Wheels, had a two-and-a-halfhour commute on the train from her home in the North Bronx to her job in Brooklyn. Her closest Subway stop was inaccessible. "I'd roll a mile praying that the elevator was working," she said.

Méndez's next hurdle was to get to the accessible portion of the platform to access the train. "Every morning, that anxiety-inducing roll through the crowd of people on their way to work...I

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Ellison Story." More recently, in 2021, she published a second book, "Look Both Ways." In her writing, Ellison encapsulated her experiences as a person with a disability, aiming to encourage people to rethink their perceptions. Building on the common disability rallying cry of "nothing about us, without us," Ellison's mother shared that her call to action was "nothing without uspeople with disabilities should be included in all aspects of life."

Ellison's efforts to educate truly moved the needle on conversations about disability. "Her scholarship on disability identity and the lived experience of disability is transformative," said Dr. Rosa. "She will always remain with us through the sheer power of her paradigm-shifting ideas. Personally, I feel so blessed to be able to

call her my mentor and friend."

Along with her parents, Ellison is survived by her brother Reed, her sister Kysten, and five nephews.

A celebration of Ellison's life is being planned for March 24 and will be livestreamed. For those who would like to make a donation in Ellison's honor, her family recently established the Brooke Ellison Legacy Scholarship Fund at SBU: bit.ly/42H5DrV

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Managing Editor Kim Brussell

> Editor Emily Ladau

Contributors

Sharifa Abu-Hamda Christopher Alvarez A.G. Fitzgerald Allison Howe Marcus Johnson Kieran O'Brien Kern Danielle McKoy Jean Minkel Warren Shaw James Weisman Sharon McLennon-Wier, Ph.D. Rebecca Williford

> Publisher (emerita) Angela Miele Melledy

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Celebrating the Beauty of Disability

By Christopher Alvarez

Do you ever underestimate your beauty because you don't look like the poster models in stores and advertising?

A Long Island-based nonprofit organization is fighting that stereotypical ideology and encouraging people with limb differences to embrace who they are. Jill Smith, an occupational therapist and founder of the Show Your Shine Adaptive Runway event said the show "is not about the glitz or the outside of us. It's about celebrating the journeys that you all have had and what's in your heart and everything in your life that has led you to that point, that makes you shine."

And that's exactly what the soldout crowd of over 500 guests did: celebrated with love and kindness, giving the models a boost of confidence as they strutted their stuff down the runway.

"I want people to stare for the right reasons," Smith said. "These

individuals are stared at daily due to their differences, but at this event, all eyes will be on them, celebrating their courage and resilience."

Last month, the fourth annual runway event featured 20 children and adults with limb loss and limb differences.

After a rotationplasty amputation of her left leg in 2022, six-yearold Belle, from Centerport, Long Island became a cancer survivor who "wasn't going to be knocked down without a fight," said her mom, Sara Svoboda. After testing her limits and building up her strength, she learned how to walk with her new prosthetic limb, which she received just one week before the show. Belle "roared," ending her runway moment showing off her shiny prosthetic limb with a leg lift.

Six-year-old Amalia, who goes by Molly, traveled five hours from Virginia with her parents and sister to join the party this year. Born with a heart condition called hypoplastic left heart syndrome, Molly's limb tissue began to die when put on a form of life support known as extracorporeal membrane oxygenation (ECMO), resulting in hand amputations at seven months old and leg amputations below the knee just a year ago.

"Watching a part of your child's body die...was horrible," her mom, Rachel Conway, said. Because Molly has been waiting for a heart transplant, the family did not attend the runway event last year, but this year, her dad, Dan Conway said, "the heck with it. We're gonna try to do it while she can."

Matias Ferreira, 30, described the whole experience as "transformational." He danced salsa down the runway with his daughter, showing people "what the possibilities are with prosthetics," Ferreira lost both legs in Afghan-



The writer on the runway. Photo by Bob Arkow.

istan when he stepped on an improvised explosive device (IED) during a combat tour. Now with a purple heart, he feels honored "to do the Lord's work...to help people and bring good energy when some [in the limb difference community] may be struggling."

Smith is proud to announce that the runway event raised over \$60,000 for her brother, Robert Shulman's, nonprofit organization, The Limb Kind Foundation, which provides services both domestically and internationally to the limb difference community, including Zambia this year.

Is the New York City Subway Truly Embracing an Inclusive Era? Continued from page 2

never knew how it was going to go." Once she was on the train, it would be a showdown between her and the inevitable passengers who would inhabit the mere two accessible spots in the train car. After disembarking and getting above ground, Méndez would then have a 15-minute roll to get to work, passing two more inaccessible stops on the way.

In 2022, the MTA made a landmark agreement to make at least 95% of the remaining inaccessible subway stations accessible by 2055. The MTA reached out to New York University's Rudin Center for Transportation for fresh perspectives on delivering on this promise, covered in a January 2024 report, "Accelerating Progress: Making Transit Accessible for All New Yorkers."

Rudin Center Director Sarah M. Kaufman shared with *Able News* the accessibility aspects her team considered. The initial focus was on ADA compliance. The research team analyzed the rate at which the stations were upgraded per year. Between 2015 and 2020, the MTA averaged almost three station upgrades annually. Since 2020, this average has more than doubled, with eight stations completed in 2023. Production needs to increase to almost 10 stations made accessible annually to meet their goal for 2055.

"We also looked at the number of stations per borough and per line to measure geographic distribution of accessible stations," Kaufman explained. Manhattan has the highest ridership, and prioritizing Brooklyn and Queens is essential as their subway traffic is on the increase.

Inclusivity doesn't come cheap. "Accessibility upgrades cost tens of millions of dollars per station, not just for the elevators, but for building the supporting infrastructure, passageways, utilities needs, and rerouting services to stations under construction," Kaufman shares. "It is clear that MTA needs an influx of funding to meet accessibility goals, and the clear path forward on that is congestion pricing."

According to the MTA, The Central Business District Tolling Program (congestion pricing) will reduce traffic in Manhattan's most congested areas and fund improvements to the transit systems. The proposed daytime toll for passenger and small commercial vehicles is \$15 and the evening toll is \$3.75. The toll would only be paid once daily, and there would be certain mandated exemptions, including for qualifying vehicles transporting disabled people.

MTA Chief Accessibility Officer Quemuel Arroyo claims that what detractors perceive as a nuisance would open a world of transportation opportunities for our disabled community. "So much of our success has come from our historic capital plan which is now in jeopardy by the rise of attacks against congestion pricing," he elaborates. If the congestion pricing attacks succeed, enhancing transit accessibility could indeed derail.

So what does the inclusive

future look like for New York City transportation? Kaufman sees a near immediate win in congestion pricing by clearing the bus lanes. Cars in the bus lane delay traffic and commuters. Citywide automated bus lane enforcement could help to keep cars out of bus lanes opening up the flow of bus traffic. "If we can move traffic along," Kaufman says, "we can benefit everyone, especially riders with disabilities."

Arroyo believes that fearing change has brought the transit system to where it is. "We can and should always strive to learn more about our customers' needs and evolve as an organization to deliver for our riders...Technologies are quickly changing and with those changes come a suite of opportunities." That means engaging emerging voices and collaborating with end users to better deliver for disabled riders.

Widespread inclusive public transportation not only benefits disabled patrons, it benefits all New Yorkers.

National Disability New Inclusive Starbucks Stores in Progress **Inclusive Starbucks**

Last month, Starbucks announced a new development in making the store experience more accessible: the Inclusive Spaces Framework. The framework lays out a set of physical and lenged ourselves to imagine digital accessibility guidelines developed in partnership with Starbucks employees, customers, and accessibility experts.

The first location built using the Inclusive Spaces Framework opened February 16 at Union Market in Washington, D.C. Moving forward, all new and renovated Starbucks stores in the United States will leverage the framework. In addition, the

framework will also be open sourced and further developed to help expand accessibility across the retail industry.

"At Starbucks, we have chalwhat's possible when we take a closer look at the many ways our partners and customers interact with us and experience our stores every day," said Katie Young, senior vice president of store operations, in a press release. "Building and scaling an Inclusive Store Framework is central to our mission of connection and will lead to greater access for all."



Photo courtesy of Starbucks.



Southern Land Company (Owner), in cooperation with the Village of Garden City (the "Village"), presents an affordable rental opportunity in the Village of Garden City known as "FLORENT." Florent is a new beautifully designed rental complex located at 555 Stewart Avenue in Garden City containing 150 one, two and three-bedroom apartment homes, 15 of which will be made available to households with incomes at or below 80%, 50% and 30% of the area median income as determined by HUD. Please see Income Chart below.

Lottery Intake Forms will only be accepted by the Long Island Housing Partnership, Inc. (LIHP) beginning 9:00 am May 1, 2024 and ending 5:00 pm on May 30, 2024.

Lottery Intake Forms will be available, beginning May 1, 2024 through LIHP's website at https://www.lihp.org/rentals.html. Lottery Intake Forms will only be completed and submitted online at www.lihp.org/rentals.html.

A lottery will be held to determine the order in which applicants will be reviewed for eligibility. Submission of the Lottery Intake Form for does not guarantee a unit. Applicants must meet Owner tenant screening requirements and income requirements must be complied with. Please consult the Program Guidelines for detailed information available at www.lihp.org/rentals.html.

Income Limits:

Household Size	1	2	3	4	5	6	7	8
80% AMI	\$86,200	\$98,500	\$110,800	\$123,100	\$132,950	\$142,800	\$152,650	\$162,500
50% AMI	\$53,900	\$61,600	\$69,300	\$76,950	\$83,150	\$89,300	\$95,450	\$101,600
30% AMI	\$32,350	\$36,950	\$41,550	\$46,150	\$49,850	53,550	\$57,250	\$60,950
nit Type Units Available AMI								*Rent
bedroom	2			1 @ 30% AMI				\$688
				1 @50% AMI				\$1,304
2 bedroom	12			4 @ 30% AMI				\$866
				4 @ 50% AMI				\$1,636

All Fair Housing laws will be followed. If assistance, including language assistance, is needed or if you have questions, please contact LIHP at 631-435-4710 or email at info@lihp.org.

4 @ 80% AMI

1 @ 80% AMI

\$2,790

\$3,226

Easterseals Launches Disability Film Challenge

The 2024 Easterseals Disability Film Challenge (EDFC) is a filmmaking contest that provides a pathway for new voices in the entertainment industry. Registration to participate in the 11th annual EDFC is ongoing until April 1, with the competition to be held April 2 - April 7.

During the Film Challenge, registered filmmakers are given a span of five days over the designated timeframe to write and produce short films that promote disability inclusion. Films must be between one to five minutes in length based on this year's genre, "buddy comedy." Submissions are judged in six award categories: Best Film, Best Director, Best Actor. Best Writer. Best Editor and Best Awareness Campaign.

"I love participating in the Easterseals Disability Film Challenge," said New York-based

filmmaker and EDFC award-winner Anna Pakman, "because it provides disabled talent a massive platform to tell the types of stories we wish were more often represented in what's coming out of Hollywood."

The EDFC recognizes the talent and hard work that goes into producing a short film and will hold an awards ceremony on May 9 at Sony Pictures Studios in California. This year-in addition to the traditional awards of cash, goods, subscriptions, mentorships, and screening opportunities-the EDFC will be awarding 10 \$15,000 seed fund/ film finishing grants, made possible by a grant provided by the Adobe Foundation as part of the Adobe Film & TV Fund.

Learn more about how you can get involved: disabilityfilmchallenge.com

New Bill Would Support Disabled Entrepreneurs

By Christopher Alvarez



Senator Jeanne Shaheen (D-NH), Chair of the U.S. Senate Committee on Small Business and Entrepreneurship, and Senator Mike Braun, Ranking Member of the U.S. Senate Special Commit-

tee on Aging, introduced the Supporting Disabled Entrepreneurs Act, a new bipartisan bill aimed at expanding access to resources for entrepreneurs with disabilities to successfully start and run small businesses. According to a report by the National Disability Institute, approximately 1.8 million individuals with disabilities are business owners. Entrepreneurship offers an alternative path to traditional employment for disabled people, but those who choose self-employment have historically been underserved by both agencies that serve individuals with disabilities and agencies that serve entrepreneurs.

The bill instructs the Small Business Administration (SBA) to appoint a Coordinator for Disabled Small Business Concerns and to collect data, on a voluntary basis, on the disability status of small business owners participating in SBA programs. Although endorsed by the National Disability Institute, America's Small Business Development Center Network and many other disability groups, a government source gives the \bar{bill} a 32%chance of passing the Senate Committee on Small Business and Entrepreneurship and an 11% chance of being enacted.

"Entrepreneurs with disabilities start small businesses, create jobs and ensure our local economies thrive. Through this bipartisan legislation, we will help them access the necessary resources to start and expand their small businesses," said

Chair Shaheen. "Innovators who are disabled deserve equal access to SBA programs that can support their dreams of owning and operating a successful business. I'm proud to introduce this important legislation that reaffirms our support and opens the door to opportunity."

Eric Ryan, owner of the small business TRIPPr, a wheelchair accessible transportation company in Long Island, said this bill is "incredible."

"Who do we know who is a better innovator than someone with a disability," he asked. "We are forced to adapt, problem solve, innovate, and overcome out of necessity and survival. I think cultivating those things and helping people create businesses that will help their communities is a good thing not only for the disabled community, but the country."

Starting February 27, 2024 Accepting Applications

Senior & Disability Housing

74 One-Bedrooms
 13 Studios
 12 Mobility-Impaired Studios

55 GOODWIN PLACE BROOKLYN, NY 11221

Visit the property to get an application or print an application using the link below. Deliver or mail your completed application to the property by March 18, 2024. Must be at least 62 years of age or living with a disability to apply.

https://riseboro.org/housing/waiting-list-applications/

If you require a reasonable accommodation, call (718) 366-3800.

Starting March 6, 2024 Accepting Applications

Senior & Assisted Living Housing

44 One-Bedrooms
4 Assisted Living Studios
24 Assisted Living One-bedrooms

BROOKLYN, NY 11207

Visit the property to get an application or print an application using the link below. Deliver or mail your completed application to the property by March 26, 2024. Must be at least 62 years of age to apply.

https://riseboro.org/housing/waiting-list-applications/

If you require a reasonable accommodation, call (718) 366-3800.

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Vincent Marchiselli, NYC Disability Rights Pioneer

By Warren Shaw



Left: December 23, 1968: Mayor Lindsay signing into law an amendment to City's Human Rights Law. From left to right: Julius Shaw, Vincent Marchiselli, unidentified, Mario Merola, Joel Tyler, Mayor Lindsay, Dr. Howard Rusk, City Council Majority Leader David Ross. **Right:** Vincent Marchiselli on the left, with Governor Mario Cuomo on the right, circa 1988. Photos courtesy of Warren Shaw.

Vincent Marchiselli was one of the founders of disability activism in New York City. He was responsible for the very first legal protections for the civil rights of people with disabilities. Significantly disabled by polio, a user of crutches and a wheelchair, Vincent built a decades-long career as a political advisor, activist, and elected official, all the while maintaining the family business—a funeral home. His unlikely journey and pioneering path deserve wider recognition.

Vincent was born in 1928 in the Bronx, and contracted polio in 1931. After a lengthy hospital stay followed by a series of corrective surgeries, the young Vincent was ready for an education. Public school was only available for kids who could get on and off the schoolbus by themselves, a feat that Vincent, then exclusively a wheelchair user, couldn't manage. But through his father slipping five bucks a month to the bus driver, a second wheelchair kept at the school, and another five bucks a month to the school's elevator operator, Vincent was able to get a regular education.

At age 15, Vincent completed high school. He then enrolled at Iona College, where he was elected Vice President of the student council and became an athlete—the steersman for the boat racing team.

Meanwhile, Vincent's father had gotten involved in Bronx politics. The Bronx was politically unique. It had both a potent heritage of activism and a durable party machine. Influenced by his father's experience, Vincent jumped in, picking the lane of a moderate reformer not tied to the organization.

In short order, Vincent became campaign manager for a former Assemblyman who was angling to regain his seat. He did well enough to get hired in the same capacity for three or four other Assembly races. By 1959 he was President of the North Bronx Democratic Club.

Soon he was Board chair of the Bronx County Civic Association, and was engaged to a social worker from Manhattan, Eunice Pavia. Armed with a master's degree from NYU, Vincent was taking liberal public positions on issues like gun control, property tax breaks for the elderly, and air pollution control.

Mobilization for Maturity was one of the organizations that emerged from all this activity. Founded by Vincent in 1964 as a self-help group for disabled and elderly Bronxites, it had some 150 members.

Vincent had not been generally involved in disability activism. The turning point was Mayor John Lindsay's towaway plan of January 1967—an effort to clear traffic congestion in midtown by prohibiting most parking and towing away parked cars, including cars owned by people with disabilities (even though they had no other means of travel at the time). Vincent denounced the plan as a "cockamamie idea." He was so incensed that he agreed to become the named plaintiff in a lawsuit challenging the policy.

Marchiselli v. Lindsay went nowhere. The judge refused to sign the papers (an Order to Show Cause against the Mayor), and that was that.

But disability rights remained on his radar. Through a colleague, Councilmember Mario Merola, Vincent succeeded in introducing an amendment to the City's Human Rights Law to add disability to the classes of people protected against discrimination in employment, housing, education, and recreation. After a lengthy fight (which included opposition from the Human Rights Commission itself), Mayor Lindsay signed the amendment into law on December 23, 1968.

This was legal protection without precedent in human history so far as I am aware, and a great triumph for Vincent and the Bronx Democratic leadership that had backed the bill. Among other things, the amendment was notable for its definition of a person with a disability as someone who relied upon a device, appliance, or seeing-eye dog in the performance of "daily responsibilities as a self-sufficient, productive, and complete human being." This remarkable phrase, Vincent later told me, was suggested by his wife.

In 1973, having assisted in many elections, Vincent decided to try the game himself, and in 1974 he took office as a member of the New York State Assembly. He had run on mainstream issues like subway crime, air pollution, and public ethics.

Disability rights remained in his wheelhouse. Vincent was one of the prime movers behind a 1981 event in which members of the Assembly donned blindfolds and used wheelchairs for several days in order to acquire, even briefly, insight into disability. And he was one of a select group of Democratic convention delegates with disabilities who supported Ted Kennedy's bid for President in 1980.

Through it all, Vincent remained a moderate. But as the public agenda evolved, some of his once solidly majoritarian positions came to seem conservative. As a practicing Catholic, for example, he was opposed to what was then known as gay rights. He was also an opponent of abortion rights but—with a consistency rare in public officials—he was also opposed to capital punishment, believing government should not deal in lives.

I got the chance to interview Vincent in 2011. We spent a few hours together at an IHOP in the Bronx. At more than eighty years old, he was friendly, quietly authoritative, an elderly gentleman of Italian stock, and a compelling storyteller. We had a lovely brunch, and parted promising a repeat, but as so often happens, that repeat meeting never took place.

Vincent died in 2013, so I didn't get to know him well. But he was among the founders of the New York City Disability Rights Movement, one of the first visibly disabled elected officials, and a principled politician. He deserves a place in our collective memory.

For more of Warren Shaw's work in disability history, please go to **DisabilityHistoryNYC.com**

Community Events

Sensory-Friendly Fun at Long Island Children's Museum

The Long Island Children's Museum hosts monthly Friendly Hours designed for families with children with disabilities. Friendly Hours include alterations to Museum lighting and sound. Pre-registration for this event is required as attendance is limited. Free tickets are available on the first day of each month. Mark your calendar so you can register for April's Friendly Hours, as well as a free sensory-friendly performance of "Don't Let the Pigeon Drive the Bus" by Mo Willems and Mr. Warburton, happening April 26 from 6:00-8:00pm. Learn more: licm.org/programs/communityprograms/licm4all

Accessing Reproductive Justice

Join disability advocate Robin

Wilson-Beattie virtually on March 7 at 5:00pm for the Distinguished Carrie Buck Fellowship keynote event hosted by the Lurie Institute for Disability Policy at Brandeis University. Hear how Robin's journey utilizing an intersectional disability advocacy approach supports disability and reproductive justice worldwide. Register: <u>heller.brandeis.edu/</u> <u>lurie/education/carrie-buck-fel-</u> <u>lowship/2024-fellow.html</u>

Annual Longmore Lecture in Disability Studies

Register for "Wake Up America!: Black Disabled Women on the Future of Democracy," happening March 12 at 4:00pm ET, featuring Dr. Keisha N. Blain, Andraéa Lavant and Vilissa Thompson, moderated by Keah Brown. Register now at <u>tinyurl.</u> com/longmorelecture24

Disability Policy Seminar

Taking place April 8-10 in Washington, D.C., the Disability Policy Seminar is an annual federal legislative conference co-sponsored by eight leading disability advocacy organizations. Attendees will learn about the issues from experts across the disability community, network with others who are passionate about advancing the priorities of the disability community, and put their new skills to practice with in-person visits with representatives. Online registration ends Friday, March 29. You can register onsite from April 7-9. Learn more: disabilitypolicyseminar.org **2024 Annual Disability Statis-**

2024 Annual Disability Statistics Conference

On March 28—in a one-day hybrid conference in Washington, DC and via Zoom—The Annual Disability Statistics Collection will be released. This collection fills critical gaps in national, state, and historic data related to people with disabilities by synthesizing complex data from numerous U.S. federal agencies into accessible formats. The event will also include two sessions addressing the latest in disability statistics, including survey methods and how disability is defined in national surveys. Register: <u>researchondisability.org/annual-event</u> **Stroke Summit**

Connect with fellow stroke survivors at the New York City Stroke Summit, taking place from 8:30am-5:00pm on April 19 at BKLN Art Haus in Brooklyn. This free event will include roundtable discussions, presentations, and demonstrations. Learn more and register: knsct.com/register-here

Connect, Learn, and Advocate

Microsoft Disability Scholarship

The Microsoft Disability Scholarship seeks to empower students with disabilities to achieve more through access to education leading to a career in technology. Up to 10 awards of \$5,000 will be granted. Applications will be accepted until March 13. Learn more: <u>microsoft.</u> <u>com/en-us/diversity/programs/microsoftdisabilityscholarship.aspx</u> **Play Wheelchair Softball**

The Nassau Aviators wheelchair softball team will take the diamond for their 22nd season at Eisenhower Park on Mondays from May-September, beginning on May 6. Get some fresh air and sunshine this summer while playing America's favorite pastime! Interested in joining the team? **Contact Drew at 917-709-5394.**

Autism Can Do Scholarship

Are you a high school student who will be graduating this year, or a current college student who will be enrolled for the Fall 2024 semester? John's Crazy Socks is accepting applications for the Autism Can Do Scholarship. Applicants are asked to share a brief personal statement and what they will do with the scholarship. They are also asked to submit a design for a pair of socks. Applications will be accepted until March 15. Learn more: johnscrazysocks. com/pages/autism-can-do-scholarship-2024

National Federation of the Blind Scholarship

The National Federation of the Blind's annual scholarship program applications are now open. There are thirty \$8,000 merit-based scholarships currently available. All scholarships are awarded on the basis of academic excellence, community service, and leadership. Applications will be accepted until March 31. Learn more: scholarships.nfb.org

Global Heumann Fellowship

The World Institute on Disability's 12-month Global Heumann Fellowship seeks disabled, visionary leaders with a demonstrated history in advocacy, communications, and influential collaboration. The program will honor and grow Judy Heumann's legacy by supporting disability leaders and advocates around the world to work on projects that promote disability rights and disability justice in their regional communities, as a bridge to an equitable, inclusive, and just world. Applications will be accepted until March 31. Learn more: wid.org/global-heumann-fellowship United Spinal Updates

United Spinal Updates Disability Etiquette Guide

First published in 1990, United Spinal's Disability Etiquette Guide has been recently updated for the digital age. The guide offers insights to make interacting with members of the disability community more comfortable, leading to increased understanding and improved accessibility for all. Download the revamped guide: <u>unitedspinal.</u> <u>org/top-10-disability-etiquette</u> **Guidebook on Accessible Social Media**

An updated version of Accessible Social, a comprehensive guidebook by Alexa Heinrich that takes you through the basics of accessible best practices

for social media, was recently released. The guidebook can be purchased through Amazon as a physical book or an eBook. You can also download a free PDF that mirrors the layout of the printed book or as a plain text edition that is more screen reader-friendly. Learn more: <u>accessible-social.</u> <u>com/guidebooks</u>

Small Business Inclusion Toolkit

The Employer Assistance & Resource Network on Disability Inclusion (EARN), in collaboration with the U.S. Department of Labor's Employee Benefits Security Administration; the Job Accommodation Network; the U.S. Black Chambers, Inc.; the Colorado Division of Vocational Rehabilitation; and Iowa Vocational Rehabilitation Services, released a new Small Business Toolkit to help small businesses build a disability-inclusive, diverse workforce. Using the toolkit, small business owners can learn how to recruit, hire, retain, and advance people with disabilities. Access the toolkit: askearn.org/ page/small-business-toolkit

Sports Report

Full Wheels Ahead to Collegiate Championship: CUNY Outmuscles Mizzou

By A.G. Fitzgerald

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 $Photo\ featuring\ player\ Chris\ Saint-Remy.\ Courtesy\ of\ WeCapture\ Media.$

The CUNY Men's Wheelchair Basketball program continues to hit new milestones in its second year. Most recently, they celebrated a win on the hallowed hardwood floors of the University of Illinois Urbana-Champaign campus—historically significant as the university is arguably the cradle of adaptive sports and collegiate wheelchair basketball in the United States.

On February 10, Team CUNY took the court opposing the Mizzou Tigers of the University of Missouri. An accomplished and competitive program with over two decades of experience, Mizzou beat CUNY in their last matchup. The game started out with each team trying to exploit vulnerabilities. The Tigers had a speed edge while the New Yorkers had size. Missouri attempted fast breaks while CUNY set the pace to get the ball in the paint. After exchanging baskets and leads, the first half concluded with CUNY ahead by 24-23.

Fouls would factor in. Ten minutes into the second half, the top scorer for The Tigers picked up his fourth foul. Team CUNY capitalized on this as Malkeet Singh-Gill finished his layups. Rodger Shelton distributed the rock and Abdoul Aziz Sow played big on the boards all game. Chris Saint-Remy had some success posting up and with four minutes left, CUNY had built a ten-point lead.

But the Tigers refused to be tamed and roared back, 45-43. With a minute on the clock, Isaiah "Instant Message" Moore buried a 3-point bomb, giving CUNY the lead, 48-43. Mizzou scored again, but CUNY was able to hold on and secure a 48-45 victory. Saint-Remy led the team in scoring with 16 points.

Coach Ryan Martin was proud of the way his squad played. "I loved our team defense and the way we were able to push through some tough moments," he said. "There was no caving in. These guys continued to fight and work...everyone stuck to their role and stayed focused."

Collegiate adaptive sports programs are scarce, with only 11 in the country, so having one here in New York opens up a pathway not just to the basket, but to a better life. CUNY provides the opportunity for Individuals with disabilities to experience and achieve alongside their peers as student athletes. If this program had been in place when I became paralyzed at 26 years old, I would have said, "where do I sign up?"

Team CUNY will be at Southwest Minnesota State University on March 13th to compete in the National Wheelchair Basketball Association Intercollegiate Men's Wheelchair Basketball National Championships.



Through Mobility, Our Community Thrives

By: Jean Minkel, Senior Vice President, Rehabilitation and Mobility Services, Independence Care System



Mobility is paramount for health and independence, especially for persons with a mobility disability. Without good health, none of us can fully participate in the life we choose. And freedom of movement is a key element of independence. Being able to go where you want, when you want, is often a journey which starts with getting the right mobility device that meets your needs.

Getting the right mobility device, however, is only half the battle. The other half? Keeping that device in good working order! The repair battle is increasingly harder. As all wheelchair riders know, a broken wheelchair can be devastating. If the chair is not operable, you have lost your freedom of movement. For some,

Mobility is paramount for the result is being stuck at home alth and independence, espeally for persons with a mobility have one chair, that loss of mobilsability. Without good health, ity can last days or even months.

> Getting your chair fixed is taking longer and longer, for a wide variety of reasons. There is a shortage of trained technicians. There are still supply-chain issues. Then, there's the paperwork needed if you are going to use your insurance to pay for the repair.

> ICS believes in your freedom of movement, and the importance of keeping you rolling, even when your chair breaks down. We can help you support a back-up chair (if you have one that still meets your needs). Or, our wide variety of loaner chairs, while perhaps not an exact match, could be

another option while working on a long-term solution.

Moving from point A to B should be a given in your day-to-day activities. We know, however, that for many wheelchair users, it isn't. There is the subtle, but persistent, concern: my wheelchair may break down at any time.

Your mobility matters. Let us help you reduce at least one stress in your life. If you or someone you know needs reliable, timely service with experts who can make sure your chair stays in top condition, ICS offers On A Roll Private Pay Wheelchair Repairs throughout the New York metro area as an option. Give us a call at 646-653-6411 or send an email to <u>oarrepairs@</u> icsny.org to get started on getting the support you need.



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OPINIONS

United Spinal Now

The Rigidity and Flexibility of "Reasonable Accommodation"

By James Weisman, General Counsel, United Spinal Association

While the American with Disabilities Act (ADA) is almost 34 years old, the definition of "reasonable accommodation" continues to evolve. Two recent cases—one an employment discrimination case, the other disability discrimination by a healthcare provider—illustrate this evolution.

First, a quick refresher. Who is protected by the ADA? Those whose physical or mental impairments substantially limit a major life activity, those who have a record of such impairments, and those regarded as having such impairments.

What must employers and the institutions that make up public life in America do to accommodate people with disabilities? They must make reasonable accommodation to the known disabilities of a qualified applicant, employee, customer or participant, provided it does not cause an "undue hardship."

Let's consider the employment discrimination case, which happened in Massachusetts. A teacher scheduled a hip replacement during the first week of school, and said she'd be out four weeks. Complication after complication occurred, and the school paid substitute teachers, as it extended the teacher's leave repeatedly while she recuperated at a critical care facility and then in residential rehabilitation.

In January, the school terminated the teacher's employment, as she could not return to work and requested extended leave for an indefinite period. The school did inquire of her doctor whether there was an accommodation that would make her able to perform the essential functions of her job, but eventually determined that no accommodation was possible, as attendance—that is, her physical presence—was essential. The teacher sued, and the court was influenced by the burden placed on the school system, and the lack of continuity for students. The court found that she had not demonstrated that she was a qualified individual who could perform the essential functions of the job, since regular attendance was essential.

Now consider this second case. MedStar Health, the largest medical provider in Washington, D.C. and Maryland has agreed to a federal settlement regarding allegations of disability discrimination during the COVID-19 pandemic. MedStar Health's policy, which was grounded in safety precautions, prohibited patients from being accompanied when they visited their facilities. The U.S. Department of Justice felt that MedStar misapplied/overapplied the prohibition on being accompanied to some people with disabilities-that the policy ultimately denied patients with disabilities equal access to care. For instance, patients with cognitive impairments, those needing sign language interpreters, or people who have personal care attendants were qualified individuals under the ADA, and should have been accommodated by being allowed to have someone accompany them. Granted, MedStar's motive was safety of patients and employees, but policy changes are required when reasonable. ADA case law has established



that probability of harm would be a legitimate reason to deny accommodation, but not just the possibility of harm.

Assume all of the opposing forces in both examples were acting in good faith. The teacher really was rehabbing and wanted to work. The school system was spending a lot because of her absence but the students' educations were suffering because of a string of substitutes. MedStar just wanted to protect patients and staff, and of course, its patients with disabilities just wanted access to treatment.

Even so, these cases highlight both the rigidity and flexibility of "reasonable accommodation." Ultimately, a failure to accommodate, reasonably, violates the ADA.

CIDNY Says

Empower Disabled Women to Be Safe

by Sharon McLennon Wier, Ph.D., MSEd., CRC, LMHC, Executive Director for the Center for Independence of the Disabled, New York (CIDNY)

The month of March is Women's History Month, a time for us to think about the rights of women living in the United States. We reflect on the contributions of women that shaped the academic, cultural, environmental, scientific, technological, financial, and legislative landscapes. Women have helped to build and reform this country and we have a strong voice at the table. We should honor women because of all they do to make a difference.

However, the rights of women continue to be challenged—and

we must consider the impact on disabled women, specifically. Women with disabilities face higher rates of sexual assault and sexual abuse. According to an investigation conducted by Joseph Shapiro for NPR in 2018, a review of unpublished Depart-

ment of Justice data regarding sex crimes found that people with intellectual disabilities are victims of sexual assault at rates over seven times higher than their non-disabled counterparts. Women specifically with intellec-*Continued on page 11*

OPINIONS

Shifting Systems

Creating Systemic Change with Disability Rights Advocates (DRA)

By Rebecca Williford, DRA President & CEO

approached me about producing a regular column. First, because I'm a wheelchair-user who frequently travels to New York for my work as a disability rights lawyer and non-profit leader. I believe strongly in this newspaper for, by, and about people with disabilities that has served the community for more than three decades. Second, because Disability Rights Advocates (DRA), the national non-profit organization that I lead as President & CEO has also been around, serving the disability community for 30 years, and boy, do we have a lot of news to share!

When I was a law student exploring career opportunities, I searched for an organization that was using the legal system to create systemic change for people with disabilities. At that time, DRA was led by co-founders Larry Paradis and Sid Wolinsky. By all counts, these two were leading the way in bringing big. bold cases that were changing the fabric of American society to improve access to education. transportation, healthcare. employment, and more. I packed

I was thrilled when Able News my bags and moved from North Living Center, Disabled in Action Carolina to Berkeley, California where the disability rights movement all began. Larry, who was also an attorney with a disability, became my mentor and now, nearly two decades later, I have the privilege of leading DRA's national work to advance the rights, inclusion, and equity of people with disabilities through high-impact litigation, education, and advocacy. Our work is improving the lives of people with all types of disabilities, including the aging population and people with chronic illnesses who may not even identify as disabled but who are nonetheless protected by disability rights laws.

DRA's specialty is identifying and dismantling systemic barriers in partnership with a broad network of local and national client organizations—many of whom you are very familiar with if you're a regular reader of Able News. For example, we worked with Center for Independence of the Disabled. New York, Brooklyn Center for Independence of the Disabled. Bronx Independent Livina Services, Harlem Independent

of Metropolitan New York, New York Statewide Senior Action Council, and many passionate, brave individual clients to bring about a settlement with the MTA that will make the New York City subway accessible for more than half a million people with disabilities who cannot use stairs to access the system. Years of hard work and litigation resulted in the MTA committing to making 95% of its inaccessible stations accessible.

This kind of tangible, monumental, systemic change takes time, resources, and community. And that's where you all come in! In this column, I will share with you what issues DRA is working on and how you can support our work. I'll tell you when we're looking for folks to share their personal experiences or show up to a local courthouse to support a critical case. We will celebrate together DRA's recent victories, because our victories are the disability community's victories, and they span the gamut. Because of these wins, many people with disabilities



can now access basic healthcare through accessible exam tables and effective communication at medical appointments. Members of our community can now cast their votes independently at accessible polling places that were inaccessible for far too long. Others can watch movies and television shows with audio description. The list of successes goes on, but so does the list of systemic barriers we still need to dismantle together!

I look forward to the journey ahead with you all and welcome ideas about what you'd like to read here! You can reach out to me at info@dralegal.org and find me on Instagram (@rebecca. williford.dra) and LinkedIn. If vou want to read more about DRA's recent work, you can visit our website's press page: dralegal.org/category/press/

Empower Disabled Women to Be Safe Continued from page 10

tual disabilities were found to be nearly 12 times more likely to be sexually assaulted than people without disabilities.

These statistics are deplorable. As a disability advocacy organization, CIDNY is shining a spotlight on the need for comprehensive action to protect women with all types of disabilities from sexual assault and abuse. Here are some actions we encourage

to ensure women with disabilities 3. Educate medical providers, are listened to and safe:

- 1. Teach women with disabilities about sex and sexuality; appropriate and inappropriate touching by people they know, caregivers, and strangers; and reproductive healthcare.
- 2. Empower women with disabilities to share their feelings and concerns, no matter how they communicate.
- teachers, the media, law enforcement, parents, guardians, and caregivers about the higher rate of sexual violence that women with disabilities experience.
- 4. Develop comprehensive tools to properly assess women with diverse disabilities to determine if sexual abuse has occurred.
- 5. Develop support groups to work with women with disabilities who have been victims of sexual violence.

As we celebrate and honor the impact that women have made on our society this month it is important to prioritize safety for all women, including those with disabilities. For a safe space to request resources, please contact info@cidny.org or 212-674-2300.

Opinions expressed are solely those of the writer(s) and do not necessarily reflect the opinions of Able News at The Viscardi Center and/or The Viscardi Center. Submissions should be on topics affecting the disability community, maximum 600 words, and must include the writer's name and phone number for verification. Able News reserves the right to edit for grammar, length, and factual accuracy. Able News cannot respond to all submissions and publication of submissions is not guaranteed. To submit an op-ed for consideration, please email a full draft to ablenews@viscardicenter.org.

Access Aging

More Funding Necessary for New York's Aging Population

By Kathryn Carroll, Esq., Disability and Program Coordinator, Association on Aging in New York

Governor Hochul recently services to those older adults. submitted her proposed budget for the coming year (2024-2025). To say that the budget is insufficient for aging services would be a gross understatement. Every year, the message from the Executive Branch is that it "will be a tough budget year" to lower expectations about increases to important programs. Services that ensure disabled adults of all ages can live at home and in the community are important and necessary programs. However, it seems that the Governor has forgotten about the 4.6 million older adults and the 4.1 million caregivers who provide essential

There are approximately 20 million people currently living in NYS. That number continues to New York State (NYS).

Nearly half (around 9 million) are either over age 60 or a caregiver of someone over 60 or disabled.

The entire New York State Office for Aging (NYSOFA) budget is approximately \$200 million.

The entire NYS overall budget for the coming year will be \$229 billion, which means that the entire NYSOFA budget is less than one-tenth of 1 percent of the overall state budget for the year. There are currently over

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18,000 older adults currently on waitlists for aging services in grow every day that there is not sufficient funding allocated to provide services such as homedelivered meals, comprehensive case management, personal care, transportation, and many other services that enable older adults to stay in their home.

Fullv funding NYSOFA's services makes sense for many reasons. Economically, these community-based services are the right choice because they can be provided for pennies on the dollar versus costly out-ofhome care in skilled nursing or assisted living facilities. While some people do need that level of service, many people can age in their own homes (if sufficiently funded) with far less expensive, community-based services provided by NYSOFA's Area Agencies on Aging (which are in every county in NYS). For example, expenses for individuals using NYSOFA's community-based services average less than \$10,000 per year. Meanwhile, the state pays about \$140,000 per year in Medicaid costs if an individual is placed in a facility.

older Also, adults overwhelmingly would rather stay in their home than be placed in a facility. As you age, wouldn't you want to stay in your home, if possible? This seems like an obvious answer but does not reflect the insufficient funding for aging services in the Governor's proposed budget.

Furthermore, the Governor proposed a number of cuts to Medicaid-funded services, especially in the area of homecare, and consumerdirected homecare in particular. If people cannot access these

servicesviaMedicaidortheaging services network, where will they get them? Our state already relies heavily on the labor of unpaid family caregivers. What's more, the Governor has already invested half a million dollars into the Master Plan for Aging and proposed to invest another half a million. Planning for the future is always a helpful activity, but to cut and underinvest in services we know we need now is a step backward before we even take a step forward with a completed Master Plan for Aging.

200 Over organizations throughout NYS are calling on the Governor to reassess her priorities and double the state's budget for aging services. This increase can help meet the demand for services from the 65-and-older population, which has increased by 21% between 2011 and 2021. This would allow older New Yorkers to age at home, which is preferred and the right thing to do.

If you or a loved one are aged 60 or older, or you're a caregiver, and you're in need of services, please don't hesitate to contact your local area agency on aging whose information you can find on the NYSOFA website.

The mission of the Association on Aging in New York is to support and enhance the capacity of New York's local Area Agencies on Aging and to work in collaboration with the aging network to promote independence, preserve dignity, and advocate on the behalf of aging New Yorkers and their families. AgingNY wants to be a strong partner in creating a New York free of ageism and ableism.

Learn about us at agingny. org, and follow us at @AgingNY on X, and Aging New York on Facebook and Instagram.

OPINIONS

Civics League Conversation

Does the Home Care Savings and Reinvestment Act Support the Needs of People with Disabilities?

Sharifa Abu-Hamda and Marcus Johnson

Last month, a group of stakeholders from across New York released a fiscal analysis of the Home Care Savings and Reinvestment Act, a bill proposing to eliminate Managed Long Term Care (MLTC) plans and move the payment of home care services for the seniors and people with disabilities to a fee-for-service model. The week prior, advocates of the legislation touted a \$3 billion savings if the bill were to be enacted. Neither side has explained how this legislation will be better for consumers of home care services. Presumably, the savings will be reinvested in home care and we will benefit from those reinvested dollars. This plan sounds like trickle-down economics to us, and we all know how well that works for the people on the bottom.

As consumers of home care services, we have no fancy lawyers or lobbyists; all we have is decades of experience living in the community with physical disabilities. We rely on home care workers and believe they should be compensated fairly for their critical roles. Based on our experience with both Managed Long Term Care (MLTC) and fee-for-service, we know both systems have challenges. The legislation proposed vilifies MLTCs for cutting services and reaping enormous profits. Still, the New York State Department of Health can require MLTCs to provide appropriate services and limit their profits. They don't.

The union is focused on home care workers, the plans contest the savings, and the providers are focused on their rates. We are concerned about how we will get the needed services and how many hoops we must jump through to secure them. Our community already faces huge health disparities and early deaths due to the unnecessarily complex healthcare system. As one of our colleagues often says, "Being disabled can be a full-time job."

We have seen consistent efforts by the New York State Department of Health to cut services to people with disabilities. Independence Care System (ICS), founded in 2000, was created to fill a gap in managed long-term care for people with physical disabilities and was considered the go-to MLTC plan for New Yorkers with disabilities. The State Department of Health closed ICS, the only MLTC plan designed to meet our needs, on March 31, 2019, and the majority of members transitioned to the VNS Health MLTC.

ICS transitioned to a Health Home program on April 1, 2019, and is now the first and only organization operating a Health Home program in New York State with specialized expertise and care-coordination services supporting people with physical disabilities-many of whom are affiliated with VNS Health. The Department of Health thought they could save money by forcing us to a larger MLTC plan. The savings were not realized. The alternative to home care services is costlier nursing home institutionalization or death.

We live by the motto that our lives are not complex, the system is. The proposed legislation does not address how people like us will get other services currently authorized by our MLTC, like access to our wheelchairs (complex rehab technology) and medical supplies like catheters needed to remain independent. Getting these via the fee-for-service model was extremely difficult. With MLTC care coordination, getting



Left to right: Sharifa Abu-Hamda and Marcus Johnson

a new wheelchair takes many months. We can only imagine how much longer it will take without the advocacy of a care manager.

Other services in the MLTC benefit package, like social adult day care (SADC), designed to address depression and loneliness so prevalent in our community, are not funded anywhere else. The Surgeon General recently recognized loneliness as a health crisis. Our population is more likely to live alone and have difficulty accessing transportation and finding accessible facilities, leading to higher-than-average levels of loneliness. What will happen to SADC if the legislation passes? No one knows. The answer to ''What comes after MLTC?" is, at best, vague, and there is no guarantee that consumers and consumer advocates will have a role in designing a new system.

One proposed solution is to replace the MLTC care coordination with Health Homes. While these organizations are good at providing Care Coordination services, the most recent New York State budget proposed a \$125 million cut to the program the third year of significant cuts. We worry that these programs will not be adequately funded to do a good job.

The landmark Olmstead decision by the Supreme Court solidified our right to live in the community. Still, progress will only come from ensuring that those impacted have a seat at the decision-making table. This isn't merely about token representation or checking boxes; it's about fundamentally shifting power dynamics to center on the voices with the most to lose. By embracing consumer expertise and ensuring their active involvement in decision-making processes, we can create a more responsive and inclusive system that promotes genuine empowerment and autonomy for individuals with disabilities. After all, it's our lives and our futures that are at stake.

Sharifa Abu-Hamda and Marcus Johnson are co-leaders of the Civics League for Disability Rights, an independent, volunteer-led group of New Yorkers with disabilities who advocate for themselves, their community and for change in the healthcare system for people with physical disabilities. To learn more about the Civics League, email civicsleague@gmail.com.

Stevie Hopkins, Founder of 3E Love

By Allison Howe

Stevie Hopkins, 40, of Batavia, Illinois, a well-known disability advocate and public speaker, passed away on January 24, 2024. Hopkins was born with Spinal Muscular Atrophy type 2 and had been a lifelong wheelchair user. As a youth, he attended the Muscular Dystrophy Association summer camp for many years. He earned bachelor's degrees in both business administration and finance from the University of Illinois.

In 2007, along with his sister Annie, he launched 3E Love, a disability pride lifestyle brand. The name of the organization stands for "Embrace, Educate, Empower." "I have loved 3ELove for close to 15 years," said disability advocate Cara Liebowitz. "It was and is a true movement, a way to literally wear disability awareness and pride on your sleeve. And it wouldn't have happened without Stevie. I had the privilege of meeting him a few times and he was always thrilled to meet fans and so humble."

Hopkins traveled throughout the country to promote 3ELove's mission of acceptance. The 3E Love brand has reached over 50,000 customers in more than 35 countries. "He was very special," said Reveca Torres, friend of Hopkins and founder of the disability organization BACKBONES. "We were both at the beginning of our entrepreneurial journey. We traveled to Abilities Expos throughout the country, which is where he grew his company."

On January 20, 2009, Hopkins' sister passed away. To honor her memory, he declared the day to be the International Day of Acceptance. Each year, on this day, people are encouraged to host a disability-themed event or a guest speaker, create a campaign, provide staff training, encourage volunteering, and embrace loving and accepting all people. Hopkins also founded Vote With Heart, an advocacy group for people with disabilities to enforce equal rights for voters of all abilities. The initiative also worked to encourage members of Congress to publish an official platform explaining their stance of disability issues.

In addition, Hopkins created many businesses in his lifetime, including a company called Second City Prints, which created merchandise for the music industry. He also owned a small record label and was a concert promoter.

In a 2018 interview with "The Live On Movement," Hopkins said, "Having disability pride for me boils down to being proud of myself and confident, while at the same time being fully aware and accepting of my disability. Combining those two things can be very empowering. This idea is the basis of my company's mission, which is to provide the tools



for others to embrace diversity, educate society and empower each other to love life."

Abilities.com has announced that every Sunday of 2024 Abilities Expos will be "Stevie Hopkins Day." Friends and fans are asked to wear their 3E Love apparel and accessories on those Sundays.

Stevie is survived by his parents Steve and Leslie Hopkins, grandmother Rosie Hopkins, aunts, uncles and cousins.

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The Power of Disability Representation in Film

By Danielle McKoy, Head of Fundraising and Development, ReelAbilities

A little over a year ago, I lost my father rather unexpectedly. He had

battled with diabetes and leukemia for years but always seemed to beat the odds, to the surprise of his doctors and family. He had pulled through so many times and for so long that I kind of thought he was invincible—until he wasn't. His last bout with leukemia coincided with his recovery from a fourth amputation surgery that ultimately left him needing to use a wheelchair for the first time in his life.

While my father had experienced the ups and downs of chemotherapy and amputation surgery before, his experience of becoming a wheelchair user was extremely difficult for him. As he realized how inaccessible some of his favorite restaurants and sightseeing spots were, he became depressed. Traveling to and from doctor appointments and treatment sessions became a source of embarrassment for him as his fellow travelers became increasingly annoyed by the extra time it took him to board the bus or train. He felt insecure and alone,

with no one to really talk to about what he was going through.

As hard as I tried, I couldn't find a community for people experiencing illness-related disability that my father could join in the same way that I had found cancer survivor and diabetes support groups for him before. By the time I had managed to locate a small support group for New Yorkers experiencing temporary disability, he had been admitted to a hospice with only a few days to live.

In the wake of my father's passing, I suddenly found myself on a rollercoaster of loss and transition that left me numb to everything that didn't involve me finding a way to make peace with his absence. I thought tirelessly about what he experienced in the last stage of his life and how I could use that passion for advocacy he had always admired in me to engender some type of change in his honor.

And then, less than a month after the one-year anniversary of his passing, I was introduced to ReelAbilities! I finally felt like the aimless path of grief I had found myself traversing had led to a destination of purpose.

ReelAbilities is a groundbreaking disability advocacy nonprofit that leverages the unique power of film to celebrate people with disabilities around the world. And the films that ReelAbilities features are not one-dimensional, outdated sob stories about individuals to be pitied. They are powerful films starring people with disabilities in nuanced, complex roles. They're not predictable sidekicks; they're leading superheroes. They're not naïve victims; they're shrewd, witty villains. And they're not the cliché "best friend" in a romantic comedy; they're the main objects of unyielding passion, tragic love, or unrequited desire.

The films featured in the ReelAbilities film festival dissolve stereotypes about people with disabilities. And they enable people within and outside the disability community to truly understand our shared humanity.

But one might say that the most important thing ReelAbilities has done in the past 16 years—from hosting the world's largest film festival dedicated to stories by and about people with disabilities, to facilitating film-based disability awareness and accessibility corporate training workshops—has been building accepting spaces for the disability community to come together in authentic, meaningful ways.

It is this kind of community and its empowering sense of acceptance that I wish I could have given my father before he passed.

So, this year, at ReelAbilities' 16th flagship NYC film festival, taking place April 3-10, I will watch every film and participate in every post-screening discussion with my father's memory in mind.

I invite every member of the *Able News* community to join me for a captivating cinematic experience, either in person or virtually, in celebration of all within the disability community who ReelAbilities works so hard to celebrate, empower, and uplift.

Learn more and purchase tickets: <u>reelabilities.org/newyork</u>

