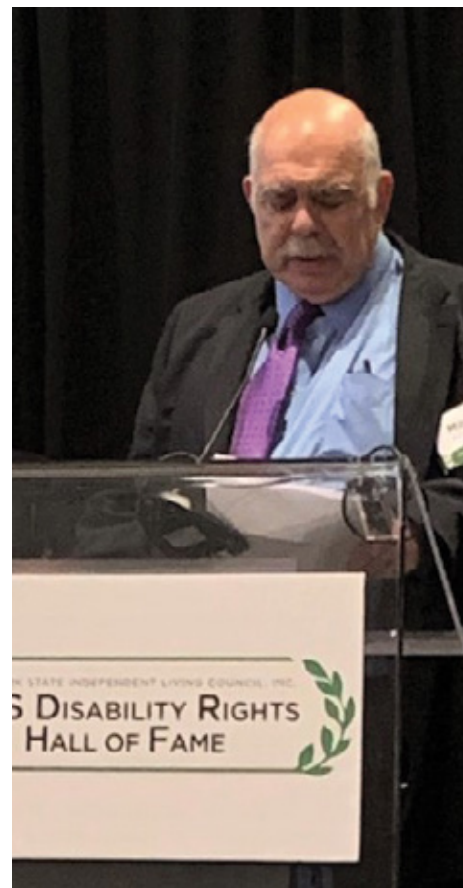
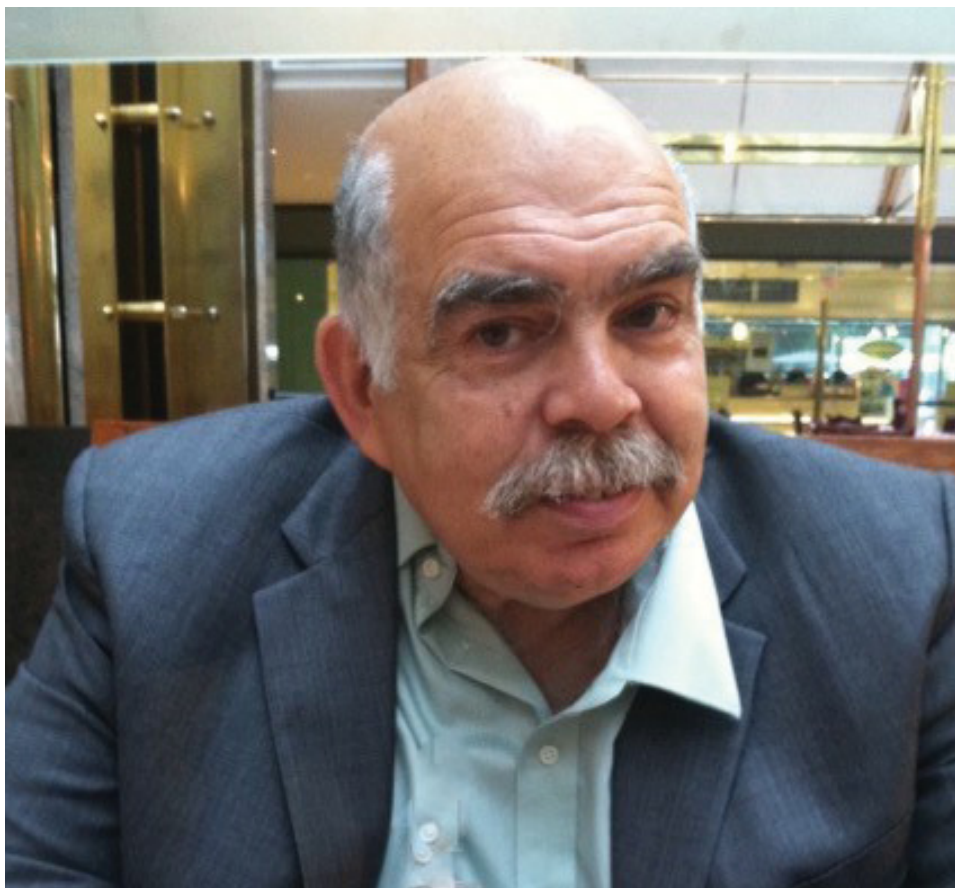


## Marvin Wasserman: Leaving a Legacy in New York City

By Warren Shaw



Left: Marvin Wasserman, 2012. Right: Marvin Wasserman accepting induction to the NYS Disability Rights Hall of Fame on behalf of the late Sandra Schnur. Photos by Rita Seiden

Marvin Wasserman, a pivotal leader of the disability rights movement in New York City, passed away on Sunday, September 22, 2024, in California, where he had lived since 2012. He was 79 years old and had been battling a recent diagnosis of leukemia and multiple myeloma. But his death was sudden and unexpected.

Marvin's accomplishments include co-founding and leading the 504 Democratic Club and the Taxis For All Campaign, and re-invigorating the Brooklyn Center for Independence of the Disabled (BCID).

To convey the mammoth impact of these achievements, let's revisit the state of the City's disability community around 1979, when Marvin's career in disability rights began. It was an era when the absence of curb cuts forced wheelchair users to travel in the street instead of on the sidewalk. Buses, subways,

and taxis were unusable.

There were a number of disability rights groups, like Disabled In Action. There was an established liaison between the community and City government—the Mayor's Office of the Handicapped (my father Julie Shaw was its director at the time). Independent living centers like BCID and the Center for Independence of the Disabled, New York had been established the year before. There was quite a bit of organizational energy in our town. But it didn't cohere very well, and disability activism largely consisted of separate and distinct campaigns that took on one issue at a time.

Marvin came to the City's disability rights movement after many years of experience in mainstream political activism and Democratic party politics. He ran for Democratic District Leader and the New York State Demo-

cratic Committee, and served as President of the Queens County New Democratic Coalition, which worked in opposition to the infamous Borough President Donald Manes. These experiences had given Marvin an appreciation of the importance of developing an ongoing presence and dialogue with elected officials.

Through his Democratic party work, Marvin had become aware of efforts to found issue- and demographically-focused political clubs, such as the Rachel Carson Club, which focused on environmental issues, and a lesbian and gay club. These examples planted the seed for what would become his most central accomplishment—a political club targeted to New Yorkers with disabilities.

The new citywide organization, the 504 Democratic Club (504 Dems), eventually developed a well-defined practice of

### IN THIS ISSUE

*Page 3*

Letter from Editor

*Page 6*

Sports Report

*Page 9*

Events and Advocacy Opportunities

*Page 12-14*

Commentary and Opinions

**Subscribe to Able News!**

Scan the QR code below or visit [AbleNews.com](https://AbleNews.com)



endorsing electoral candidates, educating them on disability issues, and lobbying officeholders, just as Marvin had envisioned. The impact of this organization has been far reaching. As 504 Dems' current President, Michael Schweinsburg, told me, "504 Dems is known and respected throughout city government, in Albany, and in Washington, D.C. and is considered one of the most powerful political clubs in New York State." Among other things, the resulting alliances earned Schweinsburg a spot on the most recent Mayoral transition team, a first for a City disability activist and proof of the enduring power of Marvin's conception.

*Continued on page 2*





Assembly Member Grace Lee, Warren Shaw, Congressman Jerry Nadler, 504 Democratic Club President Mike Schweinsburg, Assemblymember Alex Flores, and 504 Democratic Club members Phil Beder, Lenny Faziola, Rory Mondschein, and Ibrahim Alevante. Shaw is holding a memorial poster of Marvin Wasserman created by Schweinsburg for the 2024 Disability Pride Parade.

## Marvin Wasserman: Leaving a Legacy in New York City

*Continued from page 1*

Getting 504 Dems off the ground took several years, and in the process Marvin came into contact with another movement figure, Sandra Schnur (best remembered as a founder of Concepts of Independence). Sandra and Marvin got married in 1983, and they remained inseparable until Sandra passed away in 1994. For many years afterwards, Marvin hosted annual Passover seders in her honor that were open to the disability community, and served as annual presenter for Concepts of Independence's Sandra Schnur Advocacy Award.

Marvin's success with 504 led to another major project—the Taxis For All Campaign (TFAC). An outgrowth of the long fight for accessible buses and subway stations, the campaign achieved palpable impact: today, a third of the City's cabs are accessible to wheelchair users; e-hail cab service has been established; and companies like Uber and Lyft have agreed to important accessibility accommodations. And the TFAC fight continues: just a few weeks ago, on October 18, 2024, the City's Taxi and Limousine Commission adopted a rule requiring all taxis to be wheelchair accessible by 2028. The rule stemmed from a new court order issued in the very class action lawsuit that was started by the TFAC, with Marvin, back in 2011. I'd like to think that

Marvin is up there somewhere, smiling at this news.

In 2008, Marvin was elected Executive Director of BCID. BCID had been experiencing difficulties. But over the course of Marvin's tenure, BCID recovered and expanded. It took on high-profile projects like BCID v. Bloomberg, a federal class action that brought sweeping accessibility changes to the City's emergency preparedness. Marvin set BCID on a course towards the powerhouse organization it is today.

In these and in innumerable other projects, Marvin raised the level of organization and the visibility of the City's disability community. But I don't think these institutional innovations fully capture what was so unique about Marvin as a leader, or explain the enormous outpouring of affection and sadness that flowed in response to his sudden and unexpected passing—truly a remarkable tribute to a man who had retired and moved across the country fully a dozen years before.

By way of an answer, I'm going to start with myself. I met Marvin in 2010, when he came to one of my history talks. Marvin really changed my life as a chronicler of the City's disability history. Marvin became my sherpa, my guide into disability activism in the present tense. He unhesitat-

ingly shared everything he knew, and contacts for everyone he knew, and over the years since, whenever I needed background or context he was right there.

And it wasn't just me. As Gabriela Amari put it, "We met at a healthcare town hall. After the meeting, Marvin invited me to BCID. I went from being a shut-in to a Housing Education Specialist. Marvin brought me back into the world."

Or take T.K. Small: "Back in 1994, I ran for New York State Senate as a dreaded Republican. At the time, the district stretched from Brooklyn to the Lower East Side of Manhattan, where Marvin lived. Years later I learned that Marvin put his political views to the side and voted for me. In his gravelly voice he said 'You are the only Republican I have ever voted for. Don't tell anyone.'"

Perhaps Mike Schweinsburg put it best: "Marvin was my mentor and was among my very best friends. I was honored to stand as his best man at his wedding to his adored second wife, Rita. He was a true giant in the community and his presence continued to be felt long after he left New York City. There are many heroes in the disability community, but Marvin was a legend, and as it is said, 'heroes get remembered, but legends never die.'"

Rest well, my old friend.

**ABLE NEWS**  
201 I. U. Willets Road  
Albertson, NY 11507  
[ablenews@viscardicenter.org](mailto:ablenews@viscardicenter.org)  
**516-465-1416**  
[ablenews.com](http://ablenews.com)

**Published By**  
The Viscardi Center

**Managing Editor**  
Kim Brussell

**Editor**  
Emily Ladau

**Designer**  
Neil Esposito

**Staff Writer**  
Christopher Alvarez

**Contributors**  
Sharifa Abu-Hamda  
Jake April  
Kathryn Carroll, Esq.  
Craig M. Rustici  
Warren Shaw  
Nina Vincoff, MD  
James Weisman, Esq.  
Rebecca Williford, Esq.

**Publisher Emerita**  
Angela Miele Melledy

**Advertising Sales Representative**  
Wendy Kates

  
The  
**Viscardi Center**

Postmaster: Send address changes to *Able Newspaper* at 201 I.U. Willets Road, Albertson, NY 11507. Periodicals are being paid for at Bethpage, NY post office. *Able Newspaper* is published by The Viscardi Center, 201 I.U. Willets Road, Albertson, NY 11507. *Able* welcomes article suggestions for consideration. Submissions are the author's warranty that the material is not an infringement of the rights of others and that the material/photos may be published without further approval. Editorial material does not necessarily reflect the view of the editor/publisher of *Able Newspaper*. Advertisers are responsible for the content of advertisements. No part of this publication may be reprinted without the permission of the publisher. *Able* is not responsible for errors in advertisements beyond the price of the space occupied by the error. The publisher reserves the right to decline advertising for any reason.



**READ ABLE  
NEWS ONLINE**  
[ablenews.com](http://ablenews.com)

**Stay Connected With Us**

  **Able News**  **@able\_news**

**Interested in Submitting News  
Content or Placing an Ad?**

**Email:** [ablenews@viscardicenter.org](mailto:ablenews@viscardicenter.org)

**Call:** 516-465-1416

The deadline for the December/January issue is November 15.



# Letter From the Editor

By Emily Ladau

Time has truly flown since I first took on the role of Editor of *Able News* back in February of this year. This work continues to be a privilege I don't take lightly, as I know this publication has long been a go-to source of disability news and information. Whether you've been reading this newspaper since the beginning, or you joined our community more recently, I'm so glad you're here.

So many of you have shared that getting the print version of *Able News* in the mail is a highlight of each month, and I absolutely hear you on that. In an increasingly digital world, holding a newspaper can

feel like an added dimension to connecting with the world around us. That said, as the media landscape continues to change, our task is to keep up with the changes. Beginning with next month's issue, *Able News* will be shifting to a fully online presence.

While it may seem like a sudden decision, signs have been pointing in this direction for quite some time. Many of our readers have expressed a preference for a digital format, especially because it's an easier way to stay informed about timely disability news. Publishing online will allow us to report on important topics at a quicker pace,

and open up new opportunities for how we can communicate with our readers.

I'm truly looking forward to this new chapter in our story. Our goal is to continue serving as a trusted resource for the broadest possible audience, and expanding our presence in the digital realm will help make that possible. We've proudly launched a new, fully accessible *Able News* website, and we're excited to be introducing a new subscription plan to support our pathway to continued growth.

I invite you to visit us often at [AbleNews.com](https://AbleNews.com) and consider becoming a subscriber so you can



stay connected to all the latest disability news! My hope is that you'll stay with us as we navigate ahead, because our readers are one of the most important parts of our story. Let's turn the page, together.

## New York Disability News

# Long Term Care Ombudsmen Offer Support for Disabled and Elderly

By Craig M. Rustici, Director of Disability Studies at Hofstra University

Who advocates for a resident in assisted living who wants to leave the facility for the afternoon to visit friends, or who cannot reach the elevator controls when seated in a wheelchair? One person who can help is a volunteer Long Term Care Ombudsman, trained and certified by New York state.

The Older Americans Act requires each state to establish an independent Office of the State Long Term Care Ombudsman, and New York administers its program through the State Office for the Aging. Suffolk County's ombudsman program is housed at the Family Service League, and the Family and Children's Association houses Nassau County's program.

Ombudsmen advocate for and empower disabled or elderly residents in skilled nursing and adult care facilities, as well as smaller "family type" homes. For example, they investigate and work to resolve resident complaints, promote resident and family councils within facilities, inform the public about resident rights and policy issues, and represent residents' interests before governmental agencies or community organizations. They can help a resident fight an unwanted discharge, press a facility to improve responsiveness to call lights, or lobby officials to increase the personal care funds

allocated to each long-term-care resident.

However, with approximately 1,400 long-term-care facilities state-wide and only 95 full- and part-time staff, the State Ombudsman must call upon certified volunteers to participate in this work. To be certified initially, both volunteers and paid staffers must complete a 36-hour training program, including time spent shadowing an experienced ombudsman. To remain certified, they must complete 18 continuing education hours each year. Volunteers spend 2-4 hours per week in a single facility, observing, interviewing residents, and attending resident council meetings.

New York needs more volunteer ombudsmen. In Suffolk County, there are 131 long-term-care facilities and just 21 volunteer ombudsmen. In Nassau County, the situation is much the same: 104 facilities and just 13 volunteer ombudsmen.

AARP Long Island and Hofstra University are partnering on a pilot program to create a pipeline of students to address this need. During a recent information session, Bernard Macias (Associate State Director for AARP), Jennifer Carpentieri (Administrator of the Gurwin Healthcare System in Commack), and Claudette Royal (New York State Ombudsman) addressed 40 Hofstra University

students, explaining the requirements, challenges, and satisfactions of serving as a volunteer ombudsman. "I truly believe this program will provide a rewarding experience for students who choose to participate while, even more importantly, providing vital support for the residents in facilities," observed Royal.

Edward Flynn (Hofstra alumnus and President of the Resident Council at the Glengariff Rehabilitation and Healthcare Center in Glen Cove) described how he had worked with his facility's volunteer ombudsman to improve residents' access and quality of life there. Following that, Hofstra faculty explained how this community service could fit into academic programs such as exercise physiology, disability studies, sociology, and health science. In the proposed program, students will develop skills in advocacy, mediation, and problem solving, earn academic credit for their training and volunteer experience, and, crucially, promote the rights and



Corinne Kyriacou, PhD, Vice Dean of Hofstra's School of Health Sciences, hands a microphone to Edward Flynn, President of the Resident Council at the Glengariff Rehabilitation and Healthcare Center in Glen Cove. Photo credit: Alex Ferreira.

quality of life of people all too often invisible to much of our society. Corinne Kyriacou, PhD, Vice Dean of Hofstra's School of Health Sciences said, "Facilitating this ombudsman initiative is already so rewarding—my faculty colleagues across disciplines see the value, and many students showed up to the info session, indicating interest and asking great questions. I am hopeful that we can channel our students' compassion and commitment to social justice to make a difference in the lives of Long Island's long term care residents."

For more information about the ombudsman program, as well as requirements and opportunities to volunteer, go to <https://aging.ny.gov/long-term-care-ombudsman-program>



## Renegades Series Shines Spotlight on Disabled Creatives

By Christopher Alvarez



The five featured creatives in the "Renegades" series. From left to right: Brad Lomax, Celestine Tate Harrington, Daniel K. Inouye, Judy-Lynn del Rey, and Thomas Wiggins.

The Public Broadcasting Service (PBS) was the first television network to incorporate closed captioning in the 1980s, followed by descriptive audio in the 1990s. Today, PBS remains committed to making educating, inspiring, entertaining, and engaging content accessible to the public. In partnership with the ReelAbilities Film Festival, PBS premiered their exciting new disability-focused docuseries, "Renegades."

"'Renegades' is part of American Master's VIA Initiative," said Stephen Segaller, Vice President of Programming for The WNET Group. "The V is for visibility—stories about the disability com-

munity, I is for inclusion—stories told by the disability community and A is for accessibility—making content as accessible as possible to the widest possible audience."

Each episode of "Renegades" is hosted and narrated by Lachi, a blind musician and disability rights advocate. The series includes five 12-minute short films created and produced by a team of d/Deaf and disabled filmmakers, showcasing the lives of diverse lesser-known historical figures with disabilities, exploring not only their impact on and contributions to U.S. society, but also the concept of disability culture.

One core concept of disability culture is the mantra "Nothing About Us Without Us," meaning that people with disabilities must be centered in any conversation about disability. Charlotte Mangin, the executive producer of "Renegades," first learned about this concept from producer Day Al-Mohamed. Al-Mohamed is disabled, and Mangin is not, but there was an opportunity for everyone to learn from one another. "I was teaching them what I knew about filmmaking, what I know about working for PBS," Mangin said. "And they were teaching me so much about the disability community, disability history, how to communicate in different ways, so, I had to really be very thoughtful about how to communicate my knowledge and [that] was really fascinating to navigate all of that."

The five individuals profiled to celebrate disability and promote inclusion in this first season of "Renegades" were Thomas Wiggins (1849-1908), Daniel K. Inouye (1924-2012), Judy-Lynn del Rey (1943-1986), Brad Lomax (1950-1984) and Celestine Tate Harrington (1955-1998).

As a journalist, I really enjoyed learning Del Rey's story. As PBS

highlights, Del Rey was "a woman with dwarfism who revolutionized the world of science fiction by editing and publishing books from sci-fi writers." I strive to one day add some of her accolades to my resume. While the film did not have archival b-roll footage, director Jeremy Chin said that the absence of this pushed him to "approach this project with reverence and give Del Rey the tenderness and care it deserved."

According to Al-Mohamed, less than two percent of Hollywood films represent the disability community in an authentic way by giving people with disabilities speaking roles or using actors who actually have a disability. "Renegades" is an important step toward changing this by increasing public knowledge of disability history, and encouraging cross-cultural understanding between non-disabled people and those with disabilities.

"Nobody's showing this. Nobody's talking about that," said Isaac Zablocki, director and co-founder of the ReelAbilities Film Festival. "You've got to raise the voices."

To watch the full "Renegades" series, visit: [pbs.org/wnet/americanmasters/shorts/renegades/](https://pbs.org/wnet/americanmasters/shorts/renegades/)

## KEEP ABLE NEWS COMING YOUR WAY!

ONLY \$1 AN ISSUE

**One-Time Ever Able News Digital Subscription Offer. Just \$11 A Year.**

We bring you disability news like no other source!

Subscribe and Get Able News in Your Inbox Each Month!  
Be the First to Read About:

- ★ Policies and legislation impacting you and the disability community at large
- ★ Community resources, things to do, and places to go
- ★ Timely national, state, and local news
- ★ Stories from the disability community
- ★ Culture, technology, and health/wellness
- ★ Ways to connect, learn, and advocate



It's easy to subscribe! Subscribe today by scanning the QR code or visit [AbleNews.com](https://AbleNews.com)

Enter promo code **GODIGITAL**

**AbleNews**  
THE NEWSPAPER FOR, BY, AND ABOUT PEOPLE WITH DISABILITIES  
ISSUE 07 | AUGUST 2024

**New Patchogue Food Pantry Staffed by Disabled Volunteers**  
By Christopher Alvarez

**IN THIS ISSUE**

- Page 1-3 New York Disability News
- Page 4 Disability Entrepreneurship
- Page 6 Disability History
- Page 7 Events and Learning Opportunities

Sign Up to Receive the Digital Edition of Able News! Scan the QR code below.



# Disability History

## Thanksgiving 1967—Gratitude for Progress in Disability Rights

By Warren Shaw, Disability Historian

*(The following is adapted from my book-in-progress, "Never Stand Alone: Tales of the Ancestors," a history of disability activism in the City of New York. It is a tribute to my parents, disability pioneers Julius and Mollie Shaw, who would have celebrated their centennial birthdays in 2024.)*

The year 1967 was drawing to a close. It was the holiday season, and Thanksgiving in my house was one of our most beloved days. For me and my sister Jenina—twins, then nine years old—Thanksgiving wasn't like other holidays. Macy's Thanksgiving Day Parade ran just a block away and we always went there with Dad.

The day dawned with drizzle, but it stopped early enough that there was no risk of Dad's crutches slipping. Unlike the way we ran ahead and skipped around with Mom, we always stuck close to Dad as he ambulated, and within ten or fifteen minutes we arrived. Dad let us wriggle our way to the front. We had a perfect view. Dad somehow remained standing on his crutches the entire time, through pirates' boats, the big balloons, and the Brigadoon float, until Santa as

always brought up the rear, signaling the parade's end.

We made our way back home and went upstairs, chilled and damp and delighted. The air was heavy with the heat of cookery, the table as festively set as plastic dishes and repurposed shrimp glasses would allow. Mom called us to the table, where we encountered a splendid array of beautifully browned turkey and all the trimmings, especially my favorite, the wonderful jellied cranberry sauce. Mom even lit candles.

My parents, Julius (Julie) and Mollie, had a great deal to be thankful for that night. For two people who had sought all their lives to be relevant, to know meaning and purpose despite their lifelong disabilities and near-poverty, the year 1967 had been fruitful beyond imagining.

Accomplishments included barrier-busting corrections to Lincoln Center, forming the new Architectural Barriers Committee, getting accessibility into the draft new Building Code, election to Democratic County Committee, an equal-rights proposal for the State Constitution, the campaign

for a City disability agency, working (even if not always easily) with dozens of officials and other activists. They went up against City Hall, did the Barry Gray radio show, got an endorsement from Senator Bobby Kennedy—and most of all, they'd reached a glorious victory over the towaway edict, in which the City had abruptly invalidated parking permits (and prohibited parking) all over Midtown.

Beating the towaway had changed everything. After half a dozen years of tending their little political spark, the fire had finally and wildly flared. Something permanent, something lasting was under way; they were certain of it.

Julius was hale and hearty at age 43, a crutch- and wheelchair-using man with a secure job, surrounded by wife and children, and tilting not at windmills, but at real political change. Surely, he had reached the far shore of meaning, belonging, and action.

Snug in their home, Mollie felt a deep repose. Life with Julius was a wild ride, but it was never dull. The two of them had certainly thrown the dice for this new political movement, whatever it



A family photo from the author.

was. Their children were at their side. Everything she'd ever really wanted was right in front of her. Perhaps, for the severely epileptic, accidental youngest daughter of a shattered family, the old anxieties were finished, nothing more than antique furniture. And for that, she was extremely thankful indeed.

Dinner done and table cleared, over Nescafé coffee and frozen chocolate pie, the eyes of Julie and Mollie locked deeply. He leaned over, their noses slid past, and they began a long, heart-skipping kiss. They sent the kids off with permission to watch TV. And on this Thanksgiving night, cocooned in the tattering, racketing City, hovering in our second-story home, there came a quiet and beautiful evening for Mollie and Julie.

Monday, the battle would begin afresh.

ABLE  RIDE

## ABLE-RIDE is Proudly Serving Nassau County

Providing Quality Accessible Transportation

To apply for service or to find out more information, please call **516.228.4000** or visit us at **www.nicebus.com**



**nice**™ NASSAU INTER-COUNTY EXPRESS

Able-Ride is a service of NICE, which is powered by Transdev



# NYC Blind and Low Vision Athletes Compete in 2024 Blind Baseball International Cup

By Jeremy Morak



Team USA heading into the field. All team members are blindfolded, which is why they have their hands on their teammates' shoulders, symbolizing how important trust and teamwork is in this sport.

The United States was one of eight countries represented at the second annual World Blind Baseball International Cup this past September. The newly formed tournament that began in 2022, hosted by the World Baseball Softball Confederation (WBSC), took place at Farnham Park in Buckinghamshire, England.

An adaptation of traditional baseball, Blind Baseball utilizes audible cues in the ball and at the bases to assist blind and visually impaired athletes. The sport ensures an even playing field for players with varying degrees of vision impairment by requiring everyone to be fully blindfolded whenever they are on the field — including batting, running and fielding.

Team USA is comprised of players from three local New York City teams: the Lighthouse Guild Lightning, Harlem Jazz, and New York Lions. After the U.S. National Team secured a bronze medal in the first-ever WBSC Blind Baseball Cup in 2022, this year's team was poised to build on its success. "I spent the time between earning a bronze medal and this tournament really training hard and spreading awareness nationally about this sport. We dedicated our team to ensuring practices were efficient and players were as prepared as possible," said 2024 Co-Captain and Harlem resident Kiana Glanton. "Our league, the U.S. Blind Baseball Association,

in partnership with Lighthouse Guild, hosted eight clinics in the past two years spanning from New York City, Orlando, Florida, and even in Bologna, Italy, aimed at elevating our skill level while also introducing the sport to new athletes."

As popularity has continued to grow for the sport since the 2022 tournament, the level of competition undeniably increased at this year's Cup. The U.S. team went a respectable 2-2 in their four games and had an opportunity to compete in the medal rounds. Nevertheless, they lost a nail-biting back-and-forth game to Great Britain 7-6, ending their hopes this year. As Glanton reflected on the experience, "I watched our team learn to trust each other and trust our ability in a way that we had not experienced before. If our performance was based off of energy and intent, we would have taken home the gold. However, the heartbreaking loss was attributed to a lack of proper facilities and consistent training in the United States."

This year's gold medal winner was Team Cuba, who edged out the reigning champions from Italy 2-1 in a thrilling championship match. The United States placed fifth out of eight after defeating Team China 7-1. While the coaches and players of Team USA were disappointed with the outcome, Glanton is confident and excited about the future of

Blind Baseball as it grows in the United States. Glanton added, "It's tough to have not placed higher, but the United States has only gotten hungrier to improve. Our team represents so much more than the blind community. We represent athletes who have

chosen to work hard and never give up."

For more information about the 2024 WBSC Blind Baseball International Cup, visit: <https://www.wbsc.org/en/events/2024-blind-baseball-international-cup/home>



**Lighthouse  
Guild**



## Lighthouse Guild is Here for You!

**Low Vision Services:** Low vision exams and recommendations for tools and exercises for reading, working, and socializing.

**Behavioral Health:** Individual and group therapy and medication management.

**GuildCare Adult Day Health Care** program specializing in care for people with vision loss. Includes nursing care and therapeutic activities.

**Vision Rehabilitation & Technology** offers occupational therapy, assistive technology training, orientation & mobility, college prep and career services, and the latest technology solutions via in-person, telephone, and video sessions.

**Learn more: call 800-284-4422 or visit [lighthouseguild.org](https://lighthouseguild.org)**

**Tele-Support Groups** for parents, teens, young adults, and adults via online or by phone. Led by a licensed professional, offering support in coping with vision loss, finding resources, and networking opportunities. Register at [lighthouseguild.org/adult-tele/](https://lighthouseguild.org/adult-tele/)

We are a Medicare and Medicaid provider and accept many insurance plans. We are licensed by the NYS Office of Mental Health (OMH).



# Disability Resources

## Disability EmpowHer Network: Empowering Disabled Girls and Young Women

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

Each summer for four years running has been a season of empowerment and mentorship for those involved with EmpowHer Camp. EmpowHer Camp is the signature program of Disability EmpowHer Network, a non-profit run by and for girls and women with disabilities that connects, motivates, and guides them to grow, learn, and develop to their highest potential and have the confidence to lead.

EmpowHer Camp is just one of the many ways Disability EmpowHer Network is fulfilling its mission, and its cycle starts each year right here in New York State when a select group of Young Leaders (disabled girls and young women aged 13-18) are invited to the Adirondacks for one week to have fun, explore, connect, and learn about disaster preparedness and basic survival skills and leadership skills, and connecting with mentors. As a two-time Mentor participating in Stage 1 of EmpowHer Camp, I can tell you that rustic lean-to camping without cell service provides a great foundation for pushing ourselves



Top: Disability EmpowHer Network cohort in Washington, D.C. Bottom: Photos of the Young Leaders at EmpowHer Camp.

to acquire new skills, stretch the boundaries of our independence, and facilitate a greater understanding of and propensity for interdependence. I left Camp with a better understanding of myself

and eagerness to see the Young Leaders' progress on their goals and projects, which were in support of emergency preparedness.

After Stage 2 (Projects and Mentorship), Young Leaders

come together again with their Mentors for a Stage 3 Leadership Reunion in Washington, D.C. The Class of 2024 had their reunion trip in July, lining up with the anniversary of the Americans with Disabilities Act. While in D.C., the Young Leaders reconnect with their friends and mentors to present their yearlong projects, assess their growth as leaders, and set new goals. They also work on skills important for employment such as mock interviewing, resume building, and conducting meetings (with members of Congress and their staff, no less). I've had the pleasure of supporting the Leadership Reunion for three years and am astounded by the level of growth we all achieve. I'm excited for the growing alumni network at Disability EmpowHer Network and the lifelong mentorship and support it will offer for girls and women with disabilities in the years to come.

To learn more about what Disability EmpowHer Network is doing in New York and beyond, visit: <https://www.disabilityempowhernetwork.org/>

## New App Supports Caregivers

By Christopher Alvarez

Bees are often seen as guardians of the natural world because they pollinate flowers and crops, helping them grow. Marcy Handler, Director of Strategic Initiatives at Abilities First, and her team had the same helping-hand mentality when they came up with the name "Abilibee" for their new resource app. "The brand that we wanted was the sage, someone who kind of knows everything and someone who was more community minded," Handler said. "The bee has always been a symbol of wisdom and the perfect community is the beehive."

With funding support of a two-year \$400,000 grant from the New York State Council on Developmental Disabilities, Abilities First—a nonprofit provider of education, vocation, residential and community-based services that serves over 1,100

individuals with intellectual and developmental disabilities (I/DD) and their families—recently launched their comprehensive, all-in-one lifeline app to guide users through critical New York State system changes and life transitions.

From Early Intervention to adulthood, Abilibee includes step-by-step transition guidance through New York State system changes, simplifying how to care for individuals with I/DD and ensuring no one faces the challenges of disability support alone.

The app's key features include a comprehensive resource library, a communication log to keep contacts and notes all in one place, planning tools for effective advocacy, daily check-ins to track progress and well-being, and even positive affirmations to encourage holistic wellness.

As Jeffery Fox, President and CEO of Abilities First, shared, "[We] wanted to bring clarity to complexity. We wanted to help you out with what comes next. And we wanted to share some great resources."

Handler noticed a common theme when speaking with parents, advocates and providers that led to the app's inception: wanting deeper conversations and access to answers. "Everybody really wants to have better conversations about their options and their planning," said Handler. "Less playing catch up every time a new person joins the team, less asking and answering the same questions over and over again."

The app, aimed at empowering and guiding individuals with I/DD and the people who support them, is available for the New York State public to register and

use at [abilibee.org](http://abilibee.org). With over 200 users already benefiting from Abilibee, it will soon be made available for download on the App Store and Google Play with new features including enhanced security to be HIPAA compliant, a directory for recreational activities happening in the area, a file cabinet feature to keep important documents in one place, and a discussion board where people can meet and talk about their needs or concerns.

As a mother of a child with disabilities herself, Handler understands that there can be challenges. "Parents don't always see the progress they make every day. It's stressful and it takes a lot. But there's joy in it too and we wanted everybody to feel that," she said. "That's why I wanted to make [the app] yellow and sunny and happy, to get them to feel some of the joy."

RAISE  HEALTH

# LUNG CANCER AFFECTS WOMEN DIFFERENTLY THAN IT DOES MEN

**In fact, nonsmoking women are 2x more likely to get lung cancer than nonsmoking men—but knowledge is power.**

For Lung Cancer Awareness Month this November, join us to learn about women’s unique risk factors, prevention and screening, hosted by Northwell’s Katz Institute for Women’s Health, Cancer Institute, and Imaging.



Scan to learn  
about our events



**Northwell**<sup>SM</sup>



# Community Events

## November 7

1:00-7:00pm

### Atypical Architectures: Design For Diverse Abilities

This symposium at the New York Institute of Technology (16 W. 61st St., 11th-floor auditorium) aims to recenter the imagination of architecture on atypical users and non-idealized bodies through a dialogue on design practices that may carry the potential to improve the experience of the built environment for all. Learn more and register: <https://www.nyit.edu/events/atypical-architectures-design-for-diverse-abilities/>



## November 15

6:00pm

### The Ride Ahead Film Screening

Join ReelAbilities and DOC NYC at the Marlene Meyerson JCC Manhattan for the NYC premiere of "The Ride Ahead," a documentary that shares a heartwarming, enlightening journey about Gen Z life with a disability. Learn more and purchase a ticket: <https://reelabilities.org/newyork/event/the-ride-ahead/>

## November 8-10

2:00pm and 7:30pm



Enjoy this timeless classic in the Herricks Players newly renovated theater at 999 Herricks Rd. New Hyde Park, NY, which has plenty of wheelchair accessible seating and an easy-access entrance. Tickets are available at [herricksplayers999.com](http://herricksplayers999.com) or by calling 516-317-4242. Discounts are available for seniors, children, and groups of 10+.

## November 19

11:00am-2:00pm

### Reach for a Star Luncheon

For over 40 years, this luncheon has raised funds to support the after-school and adaptive sports programs at the Henry Viscardi School. This year's featured performer is Jarrod Spector, a Broadway icon. After setting a record of 1,500 performances as Frankie Valli in "Jersey Boys," Spector was nominated for a Tony Award for his portrayal of Barry Mann in "Beautiful: The Carole King Musical." He most recently played another iconic real-life character, King George III in "Hamilton." The event features an elaborate cocktail hour, a sit down lunch, and a Chance Raffle/Silent Auction. Learn more and purchase a ticket: [viscardi-center.org/event/annual-reach-for-a-star-luncheon](http://viscardi-center.org/event/annual-reach-for-a-star-luncheon)

## November 12

3:00pm

### Tech Access: Exclusive Product Updates for Wheelchair Users

United Spinal's Tech Access partners will review eye gaze, voice, and movement commands, and other exciting accessibility features. Register: <https://unitedspinal.org/swtcon/>

## November 19

7:00pm

### Out of My Mind Film Screening

Join ReelAbilities at the Marlene Meyerson JCC Manhattan for a screening of the new Disney movie "Out of My Mind," a story about Melody Brooks, who is navigating sixth grade as a non-verbal wheelchair user who has cerebral palsy. Learn more and purchase a ticket: <https://reelabilities.org/newyork/event/out-of-my-mind/>

## December 3

7:00pm

### Facing the Falls Film Screening

Join ReelAbilities at the Marlene Meyerson JCC Manhattan for a screening of "Facing the Falls," the story of international disability advocate Cara Elizabeth Yar Khan's 12-day expedition through the Grand Canyon. Learn more and purchase a ticket: <https://reelabilities.org/newyork/event/facing-the-falls/>

# Connect, Learn, and Advocate

## Ongoing Through End of 2024

### Improving Gynecologic Resources for Accessibility, Collaboration, and Education

Are you a person with a disability, healthcare provider, or advocate wanting to increase accessibility in OB/GYN offices? You're invited to join this study. Learn more and participate: <https://redcap.link/igrace>

## November 13

9:00am-12:00pm

### AHEAD Symposium: Achieving Health Equity through Access for All with Disabilities

Join NYU College of Dentistry for a virtual symposium on disability and health policy, focused on improving access to dental care for people with disabilities. Speakers will include Jim Brett, chair of the President's Committee for People with Intellectual Disabilities, and Congressman Seth Moulton, along with disability advocates, health professionals, and other policymakers. Register: [dental.nyu.edu/ahead](http://dental.nyu.edu/ahead)

## November 21

1:00pm

### Webinar: The Impact of the November Election on Disability Policy

Join an esteemed panel of speakers for a critical post-election discussion on the outcomes and explore how they will shape the future of disability policy. This is a vital opportunity to engage with experts and stakeholders in a bipartisan context on the path forward for disability inclusion and advocacy. Register: <https://nod.org/events/>

# Learn Which Breast Cancer Screening Guidelines are Right for You

By Nina Vincoff, MD, Chief of Division, Breast Imaging



*The Katz Institute for Women's Health (KIWH), the only network of experts devoted to every aspect of women's care, is putting women first. The below content was originally published in its entirety on the Katz Institute for Women's Health's website and exemplifies its commitment to raise health for all women.*

Recent decades have seen remarkable progress in breast cancer identification and treatment. Thanks largely to improved screenings that can detect cancer in its early stage, the breast cancer mortality risk decreased by 40% from 1987 to 2010.

It's simple: by catching cancer early, we often have the tools to help patients treat their illness and go on to lead normal, happy lives.

Unfortunately, we don't always catch it early, partly because the current breast cancer screening guidelines are vague, sometimes contradictory, and based on "average risk." But who is average when it comes to breast cancer risk? The reality is that several factors

should be taken into consideration when calculating a patient's risk of breast cancer, including:

**Family history:** Certain types of breast cancers are hereditary. If you have a family history of cancer, including breast and ovarian cancer, you may have a higher risk of developing breast cancer. When possible, understanding your history can help you and your provider determine when and how frequently you should get screened for cancer.

**Race and ethnicity:** Some types of breast cancer are more likely in Black women and those with an Ashkenazi Jewish background. For reasons we don't completely understand, Black women are 40% more likely to die from breast cancer than non-Hispanic white women, more likely to carry the BRCA gene, and more likely to develop the very aggressive form of breast cancer called "triple negative." Black women are also more likely to have breast cancer diagnosed before age 40. For those reasons, Black women need

to discuss their risk with their doctor and determine what age to start screening. Age 40 might not be early enough.

**Age:** Most current guidelines recommend starting breast cancer screenings at age 40. But this doesn't account for the 9% of breast cancer cases that occur in women younger than 45—and are often more aggressive and difficult to treat than the ones found in older women. If you have an Ashkenazi Jewish background or are Black, have a relative who was diagnosed with early breast or ovarian cancer, or received radiation therapy to the chest as a child, it's smart to talk to your provider about starting screenings before age 40.

**Lifestyle and personal history:** Certain lifestyle or medical incidences in your past may impact your risk of breast cancer, including smoking, excessive alcohol intake, as well as your pregnancy, breastfeeding, and menopause history. Taking these into account can help you determine your personal risk.

**Breast type:** Every woman's breasts are different, and about half of all women have "dense breasts." The only way to know if your breast tissue is dense is to have a mammogram. It's not something your doctor can feel. Dense breasts make mammograms harder to read and increase your risk of developing breast cancer. If your breasts are dense, you might benefit from additional screening with ultrasound or MRI.

Given how many factors are at play when it comes to breast cancer risk, it's simply impossible to define a one-size-fits-all risk of the disease. Instead, it's critical that you and your health care provider look at your personal risk.

Cancer is scary, but letting it go undetected because of confusing guidelines is even scarier. By taking measures to assess your personal risk factors and receive the proper screenings, you'll be giving yourself the gift of a better chance of living a long, full life.



## Musicians with Disabilities Shine at The Danny Awards

By Steven McCoy

October 19 was a night to remember at The Town Hall in New York City. People from all walks of life came together for the Danny Awards, an unforgettable celebration of disability, music, and empowerment, hosted by Daniel's Music Foundation (DMF), an organization dedicated to promoting inclusion and empowerment through music.

The Danny Awards has been making an impact for five years. This year's event was particularly noteworthy, as it garnered the attention and support of the Recording Academy committee members. Their participation highlights the significance of the Danny Awards and further emphasizes the importance of creating platforms for artists with disabilities to showcase their incredible talents.

As the show kicked off, it quickly became evident that this was not just another awards show. The powerful performances by the talented artists from the Just Call Me By My Name® record label left an indelible mark on the audience, bringing many to tears and evoking a strong sense of connection. Music proved to



Ruth Lyon performs at The Danny Awards.

be the ultimate unifier, breaking down barriers and fostering understanding among all those present.

Cazerny Bussey, a music artist and founder of the nonprofit Even Though I'm Blind, reflected on the powerful event: "Being a blind musician myself, I could connect with the artists and their music on a deeper level—it felt like we were all sharing in something powerful, pushing through challenges with endurance. The Danny Awards continue to show that no matter our challenges, our

gifts can shine through."

One of the night's talented performers, Gifted Hands, expressed his gratitude, saying, "It felt so good to perform for an audience who resonated with the lyrics to my song. I appreciated how everyone paid attention. The applause was the cherry on top."

After the event, guests and I gathered at a nearby restaurant to share experiences and discuss the powerful impact of the night's performances. Emotions continued to run high as people reflected on the challenges faced

by individuals with disabilities and the importance of creating inclusive spaces for self-expression.

Accessibility was a top priority at the event, earning high praise from guests who appreciated the Foundation's commitment to ensuring that everyone could enjoy the show, regardless of their abilities. The attention to detail and thoughtful planning demonstrated the organizers' dedication to promoting understanding and reducing isolation for individuals with disabilities.

The lasting impact of this extraordinary event will continue to inspire and motivate those who were fortunate enough to be a part of it. Daniel Trust, co-founder and president of Daniel's Music Foundation, shared his enthusiasm about the event, saying, "The vision behind The Danny's is to highlight the amazing talent that thrives in our community, and Saturday's show did exactly that! We are thrilled to have these incredible artists join the DMF community and look forward to creating additional opportunities for them to share their talents with the world."

## Inclusive Casting: Shining a Spotlight on Disability

By Jake April

This past summer, thousands of the world's best disabled athletes competed on an international stage in Paris at the Paralympic Games. While the Paralympics has provided athletes with disabilities the opportunity to showcase their physical capabilities since 1960, disabled actors have often struggled to find opportunities to capture spectators' attention with their talents.

However, opportunities to be on stages and screens are expanding thanks to many who stand up for marginalized groups. One such person is Danielle Pretsfelder Demchick, who in 2022 began her own casting company, DPD Casting, with the following mission: "We believe in manifesting change in how the real world is reflected in today's media by advocating for and elevating underrepresented and

misrepresented communities."

Born into a family of advocates, Demchick grew up observing her mother working as a speech pathologist and her uncle serving as one of the top experts at the National Center for Learning Disabilities. "I grew up around a lot of laryngectomies and a lot of people who had strokes because my mom brought me to all of her nursing homes when she was working and didn't have child care," Demchick remembers.

She was also surrounded by inclusion throughout her education. Demchick went to a high school for performing arts, and one of her classmates was Zack Gottsagen, an actor with Down Syndrome whose breakout role was in the film "The Peanut Butter Falcon."

"I'm not someone who stays quiet if I think something is an

injustice or unfair," Demchick said. "I decided I needed to be a part of the change." In 2015, Demchick officially became a part of the revolution as a member of the Casting Society of America (CSA) Diversity Committee, and today serves as a Board Member and Co-Vice President of Advocacy.

Demchick is determined to flip the script. She expresses that the change in the industry should not only be reflected by the actors and actresses who perform, but also in the training that casting directors receive. "Something that's really important to me is that all of my peers understand how you ask for an accommodation, why you ask for an accommodation, what an accommodation does. [An accommodation] makes something better as opposed to just taking away."

As Demchick recalls, "You look at 20 years ago, you know, there were [disabled] people that would be in a movie here or there...but there really weren't a lot of examples. And now you can name people [with disabilities] that make a living acting."

One young actor in particular, casted by Demchick, stole the spotlight as Tiny Tim in "A Christmas Carol" on Broadway in 2019—Sebastian Ortiz.

"When I met [Ortiz], he was adorable," Demchick recalls of the actor, who has cerebral palsy. "I saw that he had that potential, and he kept training. He's a really hard worker...and when he's on set, he is magical."

Ortiz, indeed a talented actor, sees himself in superheroes like Spiderman. "I'm somewhat like them. Because, like me, they

*Continued on page 16*

## Shifting Systems

# Fighting for the Right to Healthcare

By Rebecca Williford, Esq., President & CEO, Disability Rights Advocates (DRA)

Access to healthcare is a basic civil right and an active topic of debate in our current presidential election cycle. Inequality in healthcare for those of us with disabilities is not covered enough and has dire consequences. As many of us with disabilities unfortunately understand and experience, too often we cannot get into our healthcare facilities, get the interpretation we need to understand our providers, access information about our prescriptions—the list goes on. DRA has been tackling this illegal inequity for decades, case after precedent-setting legal case.

In early September, DRA, along with Access Living, filed a lawsuit against a Preferred Open MRI in Chicago for refusing to offer Ramon Canellada, a wheelchair user, equal access to medical services. After he waited for 30 minutes in the lobby of the healthcare facility, a staff person came out and informed Mr. Canellada that

they were unable to provide him with MRI services because he used a wheelchair. In the words of Mr. Canellada: “It is no surprise that people with disabilities complain about access to healthcare when we have to fight tooth and nail just to get seen.” The kind of discrimination that Mr. Canellada experienced is illegal, and every time DRA fights and wins a case like this against a discriminatory provider, the healthcare industry moves closer towards equality.

This latest lawsuit is one of many DRA has brought since our inception in 1993—all designed to ensure that people with disabilities have the same access to healthcare services as their non-disabled peers.

In 2016, DRA reached a settlement in a case representing the Bronx Independent Living Services and multiple individuals against Union Community Health Center and St. Barnabas Hospital, securing healthcare access for

people with disabilities. The settlement resulted in a comprehensive plan that included alternative formats for blind patients, American Sign Language for d/Deaf and hard-of-hearing patients upon request, organizational training that promotes best practices to meet the needs of patients and visitors with disabilities, height-adjustable medical equipment, and more.

In 2015, DRA and partners reached a settlement with Kaiser Permanente, setting in motion changes to health care services that increased accessibility for patients who are blind and low vision including, adopting new policies and practices regarding the provision of information in alternative formats such as braille, audio, large print, and talking prescription labels.

The list of DRA's lawsuits and victories in the healthcare space goes on, and each case and resulting precedent brings us closer to a world where people



Photo of the author.

with disabilities don't have to fight for basic, life-saving healthcare services. As always, if you're interested in learning more about DRA and our legal work defending the civil rights of people with disabilities, you can visit us at [dralegal.org](http://dralegal.org).

## Empowering Individuals with Disabilities

Are you facing discrimination in the workplace due to your disability? Are public places inaccessible, hindering your mobility and rights? Have you suffered a personal injury and need legal support? Look no further than Bell Law Group, PLLC. With over 20 years of dedicated service, we've been the beacon of justice for individuals with disabilities. Our team of experienced lawyers is committed to fighting for your rights.

### We specialize in:

- Workplace discrimination, including failure to accommodate cases.
- Public accessibility cases, ensuring businesses comply with ADA and NY State Human Rights Law.
- Personal injury cases, advocating for your rightful compensation.

At Bell Law Group, PLLC, we understand the challenges faced by individuals with disabilities. That's why we're passionate about being your voice in the legal system.

Contact us at 516-280-3008 or find us on the web at [www.BellLG.com](http://www.BellLG.com)





# Civics League Conversation

## The Toll of Advocacy on Mental Health

By: Sharifa Abu-Hamda, Civics League for Disability Rights (CLDR)

A common phrase you'll hear in the disability community is, "I'm tired of being tired." Constantly advocating for accessible, quality healthcare, transportation safety, and supplies necessary for my well-being often feels like weathering a never-ending storm. It's deeply exhausting to navigate a world not designed for me. What's more challenging is the toll advocacy has taken on my mental health.

As a wheelchair user with a physical disability living in New York, it's becoming extremely difficult, year after year, to live the way I want in my community. People with disabilities continue to face threats at every corner, all of which weigh heavily on our minds. The state chose to implement a single fiscal intermediary to administer the Consumer Directed Personal Assistance Services (CDPAS) program, which is designed for and with people with physical disabilities, to allow aides to perform life-sustaining services in the community. Budget cuts continue to reduce funding for crucial services, and the state is reducing the number of people in the Health Home program, displacing people with disabilities.

According to the National Center for Biotechnology Information, an estimated 17.4 million adults with disabilities reported frequent mental distress across the United States. Among adults with disabilities, those with both cognitive and mobility disabilities—55.6 percent—most frequently reported mental distress. This comes as no surprise because our nightmare never ends.

As co-leader of the Civics League for Disability Rights (CLDR), an independent, volunteer-led group of New Yorkers with disabilities who advocate for themselves and their community to emphasize the challenges people with disabilities face, I continue to hear the horror stories of those who have waited months for wheelchair repairs. We hear about struggles with skin breakdowns, pressure wounds, and poor-quality supplies. It's challenging to ignore the mental and emotional fatigue that comes with fighting for basic necessities.

As someone with muscular dystrophy, I currently face my own health challenges and have found myself buying my own supplies to support myself because I'm



Photo of the author.

not receiving what I need to live. I am angry, uncomfortable, and without peace of mind. When you're constantly battling to survive, you lose so much time. When you are limited to how much money you can earn, it's devastating. Without my personal aide, I couldn't work, eat, or travel. There's little breathing room and plenty of uncertainty.

What we need is change—now. The healthcare system is broken, not breaking. To the best of our abilities, we have to prioritize our personal wellness because the truth is, though we are tired,

the fight can't stop. Advocacy, the powerful tool that exhausts us, also empowers us and allows us to be heard.

The Civics League has launched an advocacy campaign aimed at demanding that the New York State Department of Health (DOH) fulfill its longtime promise of establishing a new specialized program to support people with disabilities. We need you to take action with us! Connect with me at [civicsleague@gmail.com](mailto:civicsleague@gmail.com) to join the fight and learn how you can make a difference. Our lives depend on it.

## Advertising & Employment Opportunities

### WATCH

**Watch The Lisa Baxter Show on YouTube.** "Fantabulous" interviews and resources for over 16 years. Sharing is caring is wealth. Help spread kidney awareness: [https://youtu.be/ml\\_6yLjHnM4?si=wJfOzEZs4q-m5AM](https://youtu.be/ml_6yLjHnM4?si=wJfOzEZs4q-m5AM)

### POST YOUR JOB OPENINGS HERE

**Show your commitment to ensuring disabled workers have access to good jobs year-round!** Meet your Diversity, Equity, and Inclusion goals by recruiting qualified candidates with disabilities for your part-time, full-time, or seasonal positions by placing an ad in *Able News*.

### HAIRCUTTING

**HAIRCUTTING** in your home. Call **917-363-6834**

### PLACE YOUR AD HERE

To place an ad in *Able News*, call **Wendy Kates** at **516-465-1587**

### ITEMS FOR SALE

**U-Step Walker for Sale** Specially designed to mitigate chronic disabilities. Size: 28" long x 23" wide x 36" high. Four 360 degree rubber rotating wheels. Cushioned flip top seat. Excellent condition, delivery available. Price: \$400, negotiable. **Contact Boris: 212-362-5278**, [boriswinthrop2011@gmail.com](mailto:boriswinthrop2011@gmail.com)

**Roland GO Piano 88** Keyboard With stand and 6 batteries Size 9D Wall plug; Travel wooden chair; Portable folding wooden table. **Call Peter: 646-621-5271**

# United Spinal Now

## Harris Says Medicare Should Cover Personal Care

By James Weisman, Esq., General Counsel, United Spinal Association

By the time you read this, it's possible this year's presidential election will be over. Regardless of the outcome, there has recently been a remarkable proposal regarding homecare that should not go unnoticed. We can either hold Kamala Harris to her campaign promise, or advocate for Donald Trump to follow suit.

The Affordable Care Act, passed in 2010, protected people with disabilities by making it illegal for insurers to deny coverage or impose waiting periods for applicants with preexisting conditions. Republicans tried to repeal it well over a hundred times by attaching repeal amendments to bills which had to pass. They always said they'd substitute a better plan, but not once in the past 14 years have they produced a bill. As far as I can tell, after reviewing the Trump campaign materials, long term care is unaddressed. (He still supports repeal of the Affordable Care Act.)

Kamala Harris, however, has proposed a change to the Medicare program that would dramatically improve the health and quality of the lives of millions with disabilities and seniors needing homecare services to reside in the community and stay out of nursing homes.

The federal Medicaid program currently pays for personal care for people with disabilities and seniors. The states can opt in or out of Medicaid's homecare program. They are required to pay a participatory share and the nature and extent of services provided depends on the level of state participation. Medicaid requires recipients to be poor and retaining income is difficult. Work incentive programs have not solved this problem.

The Harris proposal would have Medicare cover homecare for seniors and Medicare-eligible people with disabilities. Income would not be an issue. This would

be paid for by negotiating Medicare drug prices and stopping fraud and abuse.

The concept, extremely attractive to seniors, allows them to age in place with, at least partial Medicare coverage. On the TV show "The View," Harris described the "sandwich generation"—people, mostly women, who care for their parents and children. These caregivers also hold jobs outside the home, which Harris said is untenable for families. She proposed Medicare-sponsored personal care assistance. She also proposed adding vision and hearing care to the Medicare benefits package.

Medicare recipients who are not poor enough to qualify for Medicaid but are in need of homecare services pay privately, out of their own pockets. If they need enough care they are eventually impoverished and end up on Medicaid.

Currently, there is a vast shortage of personal care workers for

multiple reasons, including low pay and the fact that Medicaid requires workers to have a Social Security number. The vast majority of care workers are employed by companies that contract with local governments.

Where could all the new homecare workers necessary for Harris's proposal to be successful come from? The Medicare homecare proposal could be enhanced by comprehensive immigration reform. Undocumented workers are currently employed as personal care assistants, mostly by those who self-pay in untaxed cash.

Creating a migrant worker program in the homecare field, with a path to citizenship, enhanced training, and opportunity for advancement would afford seniors and those with disabilities in need of homecare the ability to stay out of nursing facilities and will make the difficult work of personal care assistance more attractive to the labor force—a win for all.

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](mailto:ablenews@viscardicenter.org).

## Around Our Towns



On August 18, Marie Marsilio, owner of Cutting Edge Hair Design in Commack, held "Michael's Down Right Perfect" fundraiser at her salon. Staff volunteered their time and donated 100% of the money raised from hair services and raffles - \$5,300 - to the ACDS Foundation. Marie's son, Michael, is in his 2nd year at ACDS's Pre-school and, according to her, "Michael is thriving at ACDS!" The money raised will directly impact Michael and his peers.



Assemblymember Charles Lavine (D-North Shore) visited The Viscardi Center in Albertson to meet with students from his district who are benefitting from the Henry Viscardi School. Lavine also met with the dedicated team of administrators and staff whose mission is to educate and empower people with disabilities of all ages to take their place as economically secure, fulfilled members of their communities. Photo courtesy of the Office of Assemblymember Charles Lavine.



This pencil drawing submitted to *Able News* by Salman, a participant in Viscardi's Day Habilitation Without Walls program, is just one of many in his sketch book. Salman draws daily and loves to include himself, along with some of his favorite video game characters and pets, in his artwork.



## Disability Pride

# Disability is Not a Dirty Word. Say it. Celebrate it. Share it.

By Easterseals Southern California



**D1\$@B1L\*tY IS NOT A DIRTY WORD**  
Say it. Celebrate it. Share it.

**DISABILITYPRIDE.COM**



Easterseals Southern California's (ESSC) provocative new PSA campaign, D1\$@B1L\*tY is Not a Dirty Word—which launched in the SoCal marketplace during Disability Pride Month in July—was so well received that the non-profit has now taken the campaign national.

Aimed at creating a brash, new dialogue around disability acceptance and inclusion, the PSAs premiered during the 2024 Summer Paralympics Games, televised on NBC in the United States. Throughout the games, the PSAs—with both English and Spanish versions in rotation—were seen on NBC and all affiliated platforms. The spots are also airing in the Los Angeles media market during game coverage by Spectrum's Monday Night

Football, as well as on ESPN and the NFL Network. The D1\$@B1L\*tY is Not a Dirty Word campaign will continue to run throughout the remainder of 2024.

Says Mark Whitley, president and CEO, ESSC, "This disability pride media campaign is by, for, and about people with disabilities. Real authenticity only comes through personal experience and for this important project, people with disabilities are sharing their stories and insights on disability to unite as one voice for change."

People with disabilities and parents of children with disabilities collaborated throughout the campaign development and production process. The campaign features 12 diverse people with many different types of disabilities, all

sharing their unique viewpoints.

"We often fear what we don't understand and conversations around disability are avoided," added Kimberly Cohn, Chief Marketing Communications Officer, ESSC. "The fear of not knowing what to say, how to act or how to behave divides us, not unites us. We whisper it or avoid it altogether, as if disability is a dirty word. Disability is not a dirty word. It's a source of pride. It's part of being human. And for more than 25% of all U.S. residents, it's a part of who we are."

As part of the campaign, ESSC also launched a website amplifying stories both of the people featured in the PSA and other people with disabilities, shining a spotlight on how they embrace

disability pride. Additionally, the website features a quiz on disability language and etiquette, which offers a helpful starting point for expanding knowledge and understanding to be better disability allies.

Says "Days of Our Lives" actress Kennedy Garcia, who appears in the PSA, "People often count me out because I have Down syndrome and don't even give me a chance. That's frustrating, but it makes me stronger. People with disabilities have a story to tell and something unique to offer... just like everyone else. We are changing hearts and minds...one person at a time!"

View the campaign, take the language quiz, and join the social movement at [DisabilityPride.com](https://DisabilityPride.com)



## Meet Christina Sparrock, Mental Health and Anti-Intimate Partner Violence Advocate

By Emily Ladau

### Can you tell us about your story and the advocacy work that you do?

I am an African American woman living with bipolar disorder who has been advocating for the protection of women living with disabilities experiencing intimate partner violence (IPV). Over the past seven years, I have grown uncomfortably familiar with IPV living as a woman with a disability within unsupportive systems.

There is a lack of knowledge and understanding among law enforcement and lawyers, and a lack of community-based organizations that specialize in supporting people living with disabilities experiencing IPV. And victims often fear advocating for themselves due to risk of retaliation. This can lead to victims of IPV feeling helpless and hopeless, increasing rates of anxiety, depression, substance use, anxiety, and suicide.

Better policies can dictate better outcomes. Women with disabilities experiencing IPV should know they are not alone and that it's important to collaborate by forming support groups, sharing resources, and advocating for policies that protect us.

### Why is it especially important for people with disabilities to be educated about IPV?

Although IPV affects one in three women worldwide, it is nearly twice as common among women with disabilities. Countless women with disabilities experiencing IPV endure physical, sexual, emotional, and economic abuse from former or current spouses or partners. The lack of compassion within systems,

the absence of policies, and the scarcity of services increase the distress of, and the health inequities for, women with disabilities experiencing IPV, compared to their non-disabled counterparts. These barriers alone can increase this population's fear of advocating for themselves. IPV should not be normalized, and therefore, advocacy is essential to help women with disabilities find meaningful, fear-free, healthy relationships.

### Much of your work focuses on mental health and well-being. What words of wisdom would you share with people who are navigating mental health challenges?

Stigma and criminalization often hinder people living with mental health challenges from seeking the necessary treatment and support for their emotional well-being. This can be in the form of talk therapy and taking medication, or it can look like meditation, dancing, and cooking. It's important to not give up, and to seek what works best for you and gives you peace and joy. Remember, you are only human, and your goal is to do your best to manage your stress.

### You were a participant in The Viscardi Center's IdeaSpark program. Can you share more about that experience and any advice you'd share on starting a business based on your passion?

I was extremely elated to know that there is a program like IdeaSpark that trains and encourages people with disabilities to become entrepreneurs. The program viewed me as someone with an ability who is deserving of rights and allowed me to realize my



Photo of Christina Sparrock.

dreams by giving me a platform to become an entrepreneur.

Although I worked diligently as a program participant, it wasn't about winning the competition for me. It was about learning a new skill, developing confidence, and believing in myself. I was in a space where the program administrators and trainers were patient and saw my potential even when I didn't. And I was inspired by my fellow students who are living with their disabilities and kicking butt!

### What's next on your incredible journey?

I plan to pursue a Master of Arts in Urban Studies through the CUNY system to become a healthcare policy analyst. I also would like to work with other women living with disabilities experiencing IPV. Together, we can support each other, find resources, and change policies that will help us and others to live free from fear and have a meaningful life.

### Inclusive Casting: Shining a Spotlight on Disability

*Continued from page 11*

are different; they go through differences not everybody has and they get judged because, they're different and that people don't know what their life is like, so they're basically living like a double life. Usually, like, half human, half superhero. And

sometimes, I feel like that. I'm living a double life. I feel like I'm half human, half superhero. But, I get bullied for thinking that... But I know that I'm amazing and those characters inspire me to be who I am and they are brave, strong, and awesome."

And Ortiz knows he will always have support from his family in the face of those who don't see just how awesome he truly is. "My mom and my sister and my dad always tell me: Sebastian, don't listen to them."

Ortiz's star continues to rise,

as he can be seen in photoshoots for French Toast Adaptive and commercials for Montefiore Hospital. Demchick is excited for more of the world to see in Ortiz what she already does: "He's a kid star who just so happens to have a disability!"