New York is Shirking Its Obligation to Provide Wheelchair-Accessible Taxis

By Rebecca Williford, President & CEO, Disability Rights Advocates

The bad news is that the New York City Taxi and Limousine Commission (TLC) is failing to comply with a 2014 agreement to make at least 50% of their yellow taxi fleet accessible to people who use wheelchairs. The good news is that this is exactly the kind of problem Disability Rights Advocates (DRA) was built to solve, and we are taking action to hold the TLC accountable.

If you’re a wheelchair-user and have tried to hail a yellow cab in New York recently, your experience likely went something like my most recent experience at Kennedy International Airport. I got in the line for a cab. I had to wait significantly longer than other taxi-goers for an accessible vehicle. The first driver who showed up said his ramp was broken and he couldn’t transport me. I watched other passengers pile into that taxi, and I waited for another accessible taxi to arrive. When another accessible taxi showed up, the same thing happened. I watched again and again as non-wheelchair-users filed into inaccessible vehicles. Going on 40 minutes later, I still didn’t have a ride.

We know that this is completely unacceptable, so let me tell you what DRA and our partner organizations are doing about it. In 2011, DRA filed a class-action lawsuit against the TLC on behalf of a coalition of people with disabilities including Taxis for All Campaign, United Spinal Association, 504 Democratic Club, and Disabled in Action, challenging the TLC’s dismal lack of wheelchair-accessible taxis. In 2014, after 4 years of legal proceedings, we reached a historic, court-enforceable settlement agreement in which the TLC promised to make at least 50% of its taxis accessible for wheelchair-users. At that time, the fleet was more than 98% inaccessible, and this agreement represented outstanding progress in accessible transportation for people with disabilities in New York. The judge in that case, U.S. District Court Judge George Daniels said of the settlement: “We should not minimize the importance of this historic moment. Decades from now, most will take it for granted. But this is one of the most significant acts of inclusion since Jackie Robinson joined the Brooklyn Dodgers. It is an act of a city that equally values all of its residents and visitors.”

Fast forward nearly ten years. While there are certainly more
Advocates Call on MTA to Improve Congestion Pricing Disability Exemption Plan

By Emily Ladau

Photo: An accessible New York City bus.

The Metropolitan Transit Authority (MTA) recently announced details of two exemption plans that would allow people with disabilities and organizations that provide transport for people with disabilities to apply for an exemption from the central business district toll, known as congestion pricing.

According to a press release from the MTA, the Individual Disability Exemption Plan (IDEP) would enable public and private organizations that transport people with disabilities (such as Access-A-Ride or ambulette services) to apply to register for exemptions for their qualifying vehicles.

Many disability advocates feel the MTA’s plan, which was updated from a previous iteration, still misses the mark. Jessica Murray, an organizer for Rise and Resist Elevator Action Group, shared: “I’m relieved that there’s a revised approach to the plan for implementing the disability exemption, which would have been unfair to the many disabled New Yorkers who don’t drive. Unfortunately, it still falls short for those who might rely on multiple vehicles to get around.”

Murray is among the signatories on a letter submitted to the MTA on March 11 by New York-based disability advocacy groups urging them to further revise the IDEP. While the organizations remain in support of congestion pricing and its promise of funding accessibility improvements throughout New York city’s transportation system, they offered multiple recommendations to the MTA for changes to the plan.

Included in these recommendations are a request to make the exemption person-centered instead of vehicle-centered, linking a person’s cell phone to their exemption. Additionally, the letter asks for flexibility in the provision of exemptions, an option to apply for the exemption remotely, and clearer communication with Access-A-Ride riders.

Ultimately, advocates remain hopeful that the MTA will improve upon its disability exemption proposal to deliver on their promise of avoiding undue financial burden on New York’s disability community.
School cafeterias are often a land of chicken nuggets, pizza, and salads. Equally ubiquitous as the standard school lunch fare is the poster showing first aid for choking. In addition to back blows and chest compressions, these posters feature the classic image of a person choking and a second person standing behind them with their fists above the victim's abdomen, thrusting downward. This move is known as the Heimlich Maneuver.

Unfortunately, this choking solution doesn't work for every population—especially people with disabilities. According to a 2023 resource from the Virginia Department of Behavioral Health and Developmental Services, people with neurodevelopmental disabilities are at high risk for choking. Other contributing risk factors include structural abnormalities of the mouth or throat; difficulty moving the tongue around the mouth; face, mouth, or neck muscle weakness; and having a cleft lip, cleft palate, or other anomalies of the mouth or throat.

 meal is being served in a crowded cafeteria, it can be difficult for someone in a wheelchair to obtain assistance in a timely manner. In such situations, having an anti-choking device can make a significant difference.

Schools would have to develop policies and have device usage training for school nurses and staff including airway management and removal of any obstruction using an airway clearance device.

Meanwhile, there are already laws on the books that provide for equal access to healthcare and educational settings, this bill is essential to clearly ensure safety in an educational setting for all students. Visit equalfirstaid.org to learn more about you can support Equal First Aid in advocating for this legislation.

As an ambulatory wheelchair user, spouse and parent of two able-bodied children, I am constantly trouble-shooting situations before they happen. Being prepared is the only option. The value of acquiring and having these anti-choking devices in our first aid kit is three-fold. If I am the person choking, I may not be able to position myself to have abdominal thrusts performed. Additionally, I may be with my young children who would not be able to perform such a move on an adult. Alternatively, if one of my children, my husband, or a guest began to choke, logistics and strength might render abdominal thrusts impractical or ineffective.

The anti-choking device's lightweight design and easy to understand instructions make it a much more accessible process to save someone who's choking. As the primary caregiver in my family, the limited amount of strength required to build the manual pressure required to dislodge an object from the airway means I am taking action in a choking situation in my home, whether it involves my ever-growing children, first-responder husband, or myriad guests, regardless of how my body is feeling that day.

Having an anti-choking device empowers me, and it can empower so many people with and without disabilities.
New Proposed Rule Would Make Air Travel Safer and More Accessible

By Christopher Alvarez

As disabled travelers’ refusal to fly has surged in the last few years, the federal government is taking aim at airlines for mishandling wheelchairs, proposing to make damages and delays automatic violations of the Air Carrier Access Act (ACAA).

“There are millions of Americans with disabilities who do not travel by plane because of inadequate airline practices and inadequate government regulations, but now we are setting out to change that,” said U.S. Transportation Secretary Pete Buttigieg. During a White House Town Hall with disability advocates and aviation workers on February 29, Secretary Buttigieg announced a new proposed rule from the U.S. Department of Transportation (DOT) that would ensure airline passengers who use wheelchairs are traveling safely and with dignity.

“We have decided that it’s too hard to accommodate them, the world shrinks and importantly it shrinks for that traveler and it shrinks for everybody else who would benefit from having that traveler with them,” Secretary Buttigieg said.

The proposed rule comes after 11,527 wheelchairs and scooters were mishandled last year, according to a DOT report. In this proposed rule, the term “mishandled” is defined as being lost, delayed, damaged, or stolen.

Victoria O’Brien was left stranded at Kennedy International Airport for three hours because her wheelchair was stolen.

In 2022, O’Brien, a graduate student at the University of Arizona, was coming back home for summer break on an American Airlines flight when her wheelchair went missing. She said a flight crew member told her they had seen the wheelchair at the jet but didn’t know it was hers. Moments later, a man asking for a wheelchair for his wife was seen pushing O’Brien’s chair. “It was there and then it magically wasn’t,” said O’Brien.

American Airlines said she had to wait 30 days for them to investigate the matter. It took them three months to replace the $6,000 wheelchair.

“This proposed rule is so critically important,” said Senator Tammy Duckworth of Illinois, a wheelchair user and strong advocate for accessible travel. “People don’t realize that [my wheelchair] is a part of my body. If this is broken, you’ve broken my legs.”

“People who travel with mobility devices deserve better and under this rule once it’s finalized, they will get better,” added Senator Duckworth.

O’Brien couldn’t agree more. She says this proposed rule, once put in place, would “create a whole new world for people with disabilities,” adding that this was “needed a long time ago.”

Many disability advocates believe the proposed rule should go even further, however, as they want to be able to bring their own wheelchairs on the plane. Asked about the timeline for allowing that, Secretary Buttigieg said, “that is the ‘Holy Grail’ and we are working toward it.”

Jim Sinocchi, a wheelchair user and disability inclusion professional, said getting wheelchairs on planes was one of his main focuses when he served as Chair of the Air Carrier Access Act Federal Advisory Committee, but the debate always circled back to safety and cost competitiveness. “If you can put one or two wheelchairs per flight, that’s great, but the airlines will lose two seats and there’s a shortage of money,” he said. “[But] I think at the end game, you lose two seats but you get people on planes with dignity. To get to the state of nirvana is another 20 years out. So I think we’re making the right steps now but I think there’s more to do.”

As a frequent traveler, O’Brien is “scared” for the safety of her wheelchair every single time she gets on a plane. “My wheelchair is my freedom. It lets me be independent, travel, and see the world,” she added. “We are already disabled, we should not be disadvantaged as well. We have to have equal access and equal rights just as everyone else.”

According to a DOT spokesperson, “The proposal will be published in the Federal Register, after which the public will have 60 days to provide comments. The Department views this issue as a priority and will work expeditiously to review the public comments and determine how to proceed consistent with federal requirements.”

Comments on the proposed rule can be filed on regulations.gov, docket number DOT-OST-2022-0144, until April 28th.
Inclusive Fashion Revolution

By Christopher Alvarez

In recognition of Women’s History Month, The Metropolitan Museum of Art closed out its “Women Dressing Women exhibit” by hosting a panel of experts and advocates working in the fashion industry to discuss accessibility, sustainability, and the collective nature of design.

Panelists included Sinéad Burke, CEO and Founder of Tilt ing the Lens, and Grace Jun, CEO and Board Member of Open Style Lab (OSL).

For the “Bodily Agency” section of “Women Dressing Women”, Burke produced a “life mold” from her body to achieve an authentic likeness for a mannequin dressed in collaboration with colleagues of Proportion London for the National Museums Scotland’s 2019 exhibition, “Body Beautiful: Diversity on the Catwalk.” This garment celebrates rather than polices the body beneath and introduces needs not always considered in fashion, such as pregnancy and disability.

“I’m so proud that a mannequin of a body of a little person exists,” said Burke, explaining that she wished she had encountered it as a little girl. “I needed to see that mannequin. I needed to see a physical representation of somebody who was proud of their body not despite the fact that it was different, but because it was different.”

Burke is working to change perceptions of the disability community. For a Vogue magazine cover she appeared on last year, she chose three key words: dynamic, daring, and disabled. “The rationale behind [the words] is because often when we talk about disability, particularly through a non-disabled lens we are either inspirations, or there is this need to distance ourselves from the language of disability,” Burke said. “I’m a proud dwarf woman and a little person.”

Burke and her all-disabled team in Europe create equitable and systemic change through the lever of accessibility. Burke’s Tilt ing the Lens consultancy recently teamed up with the Parsons School of Design to create a program that will fully fund three disabled students to become disabled designers, starting in September 2024. “I want to ensure disabled people will thrive in spaces like this,” Burke shared.

Grace Jun is also hard at work bringing accessibility to the fashion industry. She started the nonprofit organization OSL ten years ago at the Massachusetts Institute of Technology as a public service project. Today, the organization is leading the way in education for a more inclusive future through co-design with the disabled community. OSL’s annual 10-week incubator teams up designers, engineers, occupational therapists and people with disabilities to make style accessible for people of all disabilities. “From shoes to accessible shopping to wearable technology, we find ways to investigate barriers where the doors are closed and not accessible for most people,” said Jun.

New Yorker Xian Horn, an OSL participant, had two obstacles she wanted to tackle when heading out on a cold or rainy day: holding an umbrella while she walks using ski poles as canes, and putting on a coat while seated without it getting caught on the chair. This motivated her to ask OSL for a customized raincoat “that didn’t look like a Disneyland poncho.” During OSL’s first semester at Parsons in 2016, Horn was able to see her much-needed garment blossom when “team Xian,” a group of six women, designed a couture coat with a higher coattail and purple wings inside of it to represent her nonprofit, Give Beauty Wings. “I had a team of women who not only cared about the coat I needed but also incorporated my advocacy into the garment,” Horn said. “They did so much more than create a garment, they made me feel loved and that is priceless!”
Eunice Fiorito’s Lasting Legacy on the NYC Disability Rights Movement

By Warren Shaw

Eunice Fiorito was a charmer—a blind, tall, red-headed woman, always beautifully dressed and scented, with a Midwestern twang that put you right at ease. But beneath that sugary crust she was bold as brass. If there was someone she wanted to meet, she was known to ask a sighted friend to aim her in the right direction, and she would literally walk right into them! Then she’d turn on the *savoir faire* and jawbone until she got her way. Usually, she made a friend.

Eunice and my family spent a lot of time together when I was young. The first time I met her, around 1969, around age ten, Eunice piled into the passenger seat of my parents’ car, an aged gray Rambler station wagon. She immediately turned round and trained all of her attention on me. I’d recently gotten a gift of a gold and ruby ring, and I was very proud of it. When I mentioned it to her, she squealed “Oh, let me see it,” proceeding to “ooh and aah” over it. Eunice nicknamed me “Turnip,” for some reason, and was an honored guest at my bar mitzvah in 1971.

Eunice was part of the second wave of founders of the modern New York City Disability Rights Movement, along with people like Anna Fay and Marilyn Saviola. And she was probably the first to come to the movement with relevant professional credentials. A native Chicagoan who lost her sight as a teenager, Eunice came to New York City and earned a master’s degree in social work from Columbia University, graduating in 1960.

She was living at the 34th Street YMCA at the time, where she became friends with Anne Emerman, later a Director of the Mayor’s Office for People with Disabilities. They traveled the city together. As Anne described it to me, “I was the eyes, she was the power.”

In 1970, Eunice became Coordinator of the Mayor’s Advisory Committee on the Handicapped. As the only salaried member of that body, she did so well that in 1972, when Mayor Lindsay upgraded the Advisory Committee into the Mayor’s Office of the Handicapped (MOH, today known as the Mayor’s Office for People with Disabilities, or MOPD), Eunice was named its first Director.

The upgrade showcased Eunice’s willingness to confront her employer. She staged a one-woman sit-in on the steps of City Hall, campaigning for the upgrade day after day. Then she surprised the mayor by bringing hundreds of activists to a meeting where the press was present. She forced an exasperated Lindsay to give in.

A few years later, during the Fiscal Crisis, Eunice fought successfully to keep MOH from being defunded and shut down, staging a rally and pizza party, again in front of City Hall.

During the OPEC Oil Embargo, in the Spring of 1974, Eunice took MOH to its most radical moment, helping coordinate a huge demonstration against the State’s gas rationing program, because it did not provide an exemption for disabled drivers. Hundreds of demonstrators turned out, right in front of Governor Malcom Wilson's midtown Manhattan office. After being rebuffed by the Governor’s staff, they poured out onto the street and blocked traffic on Sixth Avenue for hours, in the middle of a workday—WITHOUT a permit! Mayor Abraham Beame was furious.

And then, in 1977 Eunice went national, as a leader of the Section 504 Sit-Ins, perhaps the greatest direct action in the history of American disability activism.

Section 504 of the Rehabilitation Act of 1973 prohibited discrimination against people with disabilities in any program or activity that received federal funding—libraries, schools, public transportation and the like. Section 504 had the potential to be revolutionary, but it wasn’t self-enforcing—implementing regulations had to be passed first. By 1977, four years after Section 504 passed, no regulations were in place; there was only a draft.

Eunice had co-founded (with Franke Bowe) and was then President of the American Coalition of Citizens with Disabilities (ACCD). ACCD was the most serious effort to date to create a national disability umbrella organization, formed largely on the outrage that followed President Nixon’s veto of the 1972 Rehabilitation Act.

In February 1977, ACCD began organizing protests at the United States Department of Housing, Education, and Welfare (HEW) to press for enactment of regulations to implement Section 504. ACCD sent a letter to President Carter and HEW Secretary Joseph Califano warning that if Section 504 regulations were not issued by April 4, ACCD would hold sit-ins at HEW offices across the country.

Califano met with ACCD on April 4, and although he sounded receptive, he did not agree to sign the draft regulations. The very next day, sit-ins began in multiple locations—most famously in Washington, D.C., where HEW’s offices were occupied overnight—and in San Francisco, where the occupation ran a staggering 23 days, ending only after Califano signed the regulations.

Prominently photographed onstage with Judy Heumann at a big rally, Eunice’s leadership role in the 504 Sit-Ins was a matter of public record. In another demonstration of Eunice’s *savoir faire*, instead of scorning her as a malcontent, HEW named her Vice Chair of a Section 504 task force, then hired her away from New York City. Eunice stayed at HEW for 19 years, until she retired.

Eunice passed away in 1999 at age 69, leaving a legacy of accomplishments, a true force in the NYC Disability Rights movement.

For more of Warren Shaw’s work in disability history, visit disabilityhistorynyc.com
Community Events

April 12-28
Omnium Circus

A world-renowned comprehensively inclusive circus company bringing excitement, thrills, and joy to people of all ages. Accessible to all, every performance incorporates American Sign Language, audio description, sensory-friendly lighting and sound, and a relaxed environment where movement and vocalization are welcome. Performances are April 12-28 at the New Victory Theater, 209 W. 42nd Street in New York City. Buy tickets: omniumcircus.org/event/new-york-ny-new-victory-theater/

April 13
Middle Country Public Library’s Youth Abilities Day

On April 13 from 11:00am-1:00pm, attend a disability resource fair and family fun day at the Centereach Building, 101 Eastwood Blvd., Centereach, NY, 11720. Register at: tinyurl.com/2arwyfkt

April 20
Family Fun Day at the Southampton Fresh Air Home

On Saturday, April 20 from 12:00-4:00pm the Southampton Fresh Air Home (SFAH) is hosting their annual Family Fun Day. This year’s event features reptiles from the South Fork Natural History Museum, dogs from the Southampton Animal Shelter, a magician, face-painter, and games. There will also be a seminar on traveling with medical equipment for parents and family members. Email office@sfaht.org to RSVP.

April 23
2024 AAPD National Community Event

This free virtual gathering, taking place on April 23 at 6:30pm ET, will be an opportunity for or the disability community to come together with business and government leadership to celebrate the progress of disability rights. Register at: tinyurl.com/mppc-j27b

May 13
AHRC NYC 75th Anniversary Celebration

AHRC New York City is celebrating its 75th Anniversary Gala on May 13 at Tribeca 360° beginning at 6:00pm. The event will honor founder Ann Greenberg, whose idea shaped AHRC NYC for 75 years, creating schools, camps, clinics, employment programs, residences, and much more. Experience the evening with a cocktail reception, dinner program, and be part of recognizing outstanding contributions to the intellectual and developmental disabilities community. Buy tickets: ahrcnyc.org/75th-anniversary/

June 24
Achilles Hope & Possibility 4M Presented by TD Bank

The Achilles Hope & Possibility 4M Presented by TD Bank is one of the largest inclusive races of its kind in the U.S., welcoming athletes of all ability levels and wounded, ill or injured veterans. It is operated annually by New York Road Runners (NYRR) and held in Central Park. Register at: achillesinternational.org/hope-possibility

July 1 - August 8
Town of North Hempstead Summer Recreational Program

From July 1-August 8, Town of North Hempstead residents with developmental disabilities can participate in a free summer program with activities including arts and leisure, music appreciation, cooking, an outdoor pool, outdoor recreation, weekly outings, and more. The home base is Clinton G. Martin Park. To register, contact Barry Tussman at Btussman@viscardicenter.org or call (516) 465-1529.

Evert Saturday
Town of North Hempstead Saturday Respite and Recreation Program

This free weekly, full-day program provides year-round supervision and activities for Town of North Hempstead residents, ages 8 and up, with developmental disabilities. This unique experience gives participants an opportunity to socialize with their peers and explore their communities through a range of social, educational, and recreational activities and excursions. The program’s home base is Clinton G. Martin Park. To register, contact Barry Tussman at Btussman@viscardicenter.org or call (516) 465-1529.
Basketball

Team CUNY competed in Marshall, Minnesota on March 14 to make a push to win the National Wheelchair Basketball Intercollegiate Men’s Tournament. They battled Edinboro University in the first game but came up short. They were eliminated from tournament play in a game against the South-west Minnesota State University Mustangs with a score of 69-60. Determined to improve, only good things lie ahead for this program.

The Rolling Knicks were in Florida on February 10 fighting in the Memorial Rehab Sharks Invitational. Though they didn’t get the results they wanted, longtime player Kevin Grant said, “we are getting better.”

The New York Rolling Fury varsity team is ranked 4th nationally and continues to climb in the rankings. They will be in Richmond, Virginia on April 5 competing in the 2024 Adult and Junior Division Wheelchair Basketball National Tournaments. Coach Christopher Bacon asserted, “if we can keep improving, we have a shot at winning it.” Keep an eye on player Sebastian Milan, who received a full scholarship at the University of Illinois, where he’ll play for the school’s wheelchair basketball team.

The Brooklyn Nets played in the Capital Wheelchair Basketball Invitational Tournament on March 2-3, hosted by the Medstar NRH Punishers. The Charlottesville Cardinals won a close game against the Nets for the first round. The Nets’ accurate shooting by Errol “E” Samuel kept it close but eventually the Cardinals’ inside game and rebounding proved too much. The Cardinals came out on top 47-41. Coach Mendez of the Nets noted, “the Cardinals are a big team, and our guys stayed with them most of the way.” In the second game, the Nets went on to beat the Philadelphia team by 60 points. In the last game of the tournament, the Nets played against the host team, and their superior speed, size, and shooting proved punishing, resulting in a winning final score of 63-23. Felix Castillo Samboy led the team in rebounding while Mike Kelly and Alex Gomez connected for fast breaks. Hector Marambio finished the weekend with 30 points. Coach Mendez concluded, “they developed chemistry as the tournament went on, they worked hard, and when they play together they can compete against anyone.”

St. John’s University and the Wheelchair Sports Federation (WSF) organized the first-ever wheelchair basketball game at UBS Arena in February. Displaying their skills at the halftime demonstration were the Nassau Kings, New York Rolling Fury, and Brooklyn Nets.

Sled Hockey

The Long Island RoughRiders sled hockey team is gearing up for two tournaments in April: 24th Annual New England Sled Hockey Tournament and the 2024 Toyota USA Hockey Sled National Championship.

The WSF New York Sled Rangers defeated their neighbors to the north and south, taking down the Connecticut Wolfpack and grounding the Philadelphia Flyers in league play in February. On March 15, the Rangers competed in the Northeast Sled Hockey League playoffs. Bryan Genovese, who has played center for the Rangers for nearly 20 years, has seen the team go through many cycles. “We are coming together as a team and our younger players have really stepped it up, or should I say ‘armed’ it up!” said Genovese. In the championship game, the Johnstown Sitting Bulls proved too strong to corral and defeated the Rangers 7-1.

Tennis

The Jana Hunsaker Memorial Wheelchair Tennis Tournament will start June 14 at the USTA National Tennis Center in Flushing, NY. Keep an eye on Max Wong, who in 2023 reached a career-high junior ranking of No. 20, and finished the season ranked No. 47.
Workshops on Social Security
The Long Island Center for Independent Living (LICIL) is hosting two workshops (both virtual and in-person) on Social Security, led by Rhonda Morgan, LICIL’s Director of Benefits Advisement. The first workshop, “How to Apply for Social Security,” will be April 12 from 3-4pm ET. Participants will learn what to include and how to organize all documents as well as what to do while waiting for your benefits. The workshop will include how to keep documents in order and where to obtain assistance if your application is denied. On April 26 from 3-4pm ET, the second workshop, “Using SSA.GOV” will teach participants how to create a My Social Security Account, which provides personalized tools for everyone, whether you receive benefits or not. Email Vanessa to register at vanessa@licilinc.org or call her at 616-796-0144 ext. 232.

2024 National ADA Symposium
This three-day virtual training, hosted by Great Plains ADA Center and the ADA National Network, offers 36 sessions covering all areas of the Americans with Disabilities Act presented by nationally recognized experts in issues related to the ADA. All sessions will have live captions and ASL interpreters. Register for the training, happening May 6-8, at: tinyurl.com/muuxwr6k

Resources for Veterans and Employers
The Office of Federal Contract Compliance Programs released new resources to help veterans and employers understand the protections under the Vietnam Era Veterans’ Readjustment Assistance Act (VEVRAA) of 1974. Under VEVRAA, federal contractors and subcontractors are prohibited from engaging in discrimination in employment practices against veterans and requires employers to take action to provide equal employment opportunity in recruitment, hiring, promoting and retaining protected veterans. Access the resources: dol.gov/agencies/ofccp/vevraa

As part of Neurodivergent Celebration Week in New York State, Assemblymember Charles Lavine (D-North Shore) was honored to introduce good friend Josh Mirsky of Jericho on the floor of the Assembly Chamber at a March 18 event. As a member of the Autism Spectrum Disorders Advisory Board, Josh is an advocate for greater understanding and acceptance of those in the neurodivergent community. Josh continues to work on getting a bill passed in the legislature establishing a flag he designed as the official state flag for raising awareness of neurodiversity.
Voting (Accessibility) Matters
by Jeff Peters, Director of Communications, Center for Independence of the Disabled, New York (CIDNY)

Voting matters. But what happens when you want to vote or attempt to vote and face a barrier? What about when you encounter the same barrier repeatedly? This can deter people with disabilities from voting. In fact, did you know that people with disabilities voted at a 7% lower rate than people without disabilities in the 2020 election? This is an issue that we hear about frequently at CIDNY.

Voting accessibility matters. We advocate in support of accessible ballots and polling places. We listen to our community members experiences and share them with lawmakers. We conduct polling site surveys. Yet in 2024, we still encounter the same barriers. It

doesn’t have to be this way.

What are some barriers to voting? I hope you haven’t encountered them, but it seems that the odds are likely. Some barriers that I have personally seen include doorways not being propped open; doors held open with furniture or other items; loose materials on the floor such as mats or cords; and not enough room for people to navigate between voting areas. Absentee ballots can be inaccessible and/or confusing. Election workers are often unfamiliar with the Ballot Marking Device (BMD), which is a device that allows people to vote independently. I’ve even seen locations where it seemed like the

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Access Aging

We Cannot Wait for a Master Plan for Aging to Do More

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

When we talk about being "older," specific numbers may come to mind: 50 might be the age at which your local diner offers a "senior citizen" discount. At age 55 or 60 you might be eligible for services through your area agency on aging. Or you may qualify to apply for a housing unit in a "senior living" or retirement community. You might think of 62 if you're considering electing to get Social Security retirement 'early,' 65 comes to mind because we'll be called upon to make choices about Medicare.

We are all getting older every day, and our needs evolve over time. That's why the "Master Plan for Aging" (MPA), and aging services in general, should be of concern to all of us.

In 2022, Governor Kathy Hochul ordered that a Master Plan "shall coordinate existing and new state policy and programs creating a blueprint of strategies to be implemented to ensure older New Yorkers can live fulfilling healthy living and preventative meals and nutrition programs, healthy living and preventative health programs, homecare, caregiver support, transportation, elder abuse prevention, long term care oversight, independent living supports, legal services, and many other things that allow people with disabilities of all ages to live in the community. People who currently need any of these or other supports, or will need them in the next year, simply cannot wait for a completed Master Plan for Aging to be implemented. And what's more, they cannot wait for a Master Plan for Aging if it does not demand budgetary investments far beyond what the State is currently spending.

Funding to support our long-term care services, specifically for hands-on care for those who need it, is a combination of Federal, State, and County funding that has not kept pace with the needs of our aging population. New York is currently fourth in the nation for population over the age of 60 at 4.6 million, with anticipated growth to 5.3 million in less than ten years. Additionally, 1 in 5 older residents live with a disability, and data shows that 70% of individuals over the age of 65 will need some form of long-term care services. Currently, we know that there are 18,000 people on a waitlist for a variety of aging services that area agencies on aging cannot provide. We also know from our friends in the Independent Living network that disabled people of all ages struggle to find accessible housing, accessible transportation, and homecare.

We are urging you to take action to let our state government know that we need to do more now. Contact your Assembly-member or State Senator to ask for more funding for aging services. Fill out a 'postcard' with your AAA or older adult center to say that healthy aging programs are important to you. Visit ny.gov/form/sign-up-for-mpa-updates to sign up for MPA email updates and leave a comment. The Master Plan for Aging is for everyone. While we might eventually have a final draft Plan, we must advocate today to meet the needs of every aging New Yorker and caregiver.

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

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

Voting (Accessibility) Matters

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BMD was treated as an old piece of furniture, pushed to the back and out of sight. And we know that there are so many more barriers that people with disabilities face. Again, it doesn’t have to be this way.

What can you do about this? Register to vote, and then vote! Sometimes we hear “my vote doesn’t matter” or “what difference does one vote make?” It does matter. It can make a difference. You can make a difference. But it won’t happen if you don’t vote. If you can’t make it to the polling place on Election Day, you can take advantage of early voting option or request an absentee ballot. If you have the time and capacity to do so, consider volunteering or supporting something like CIDNY’s polling site surveys. Even just sending a note sharing your voting experience helps.

To find out more about the election in your area, visit elections.ny.gov. Register to vote in New York online at elections.ny.gov/voter-registration-process (and reach out to CIDNY if you need assistance).

Remember, one person can make a difference, and that person could be you.

To get in touch with us, visit cidny.org or call 212-674-2300. If you are interested in volunteering for a polling site surveys, email info@cidny.org.

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Preserving Independence: The Crucial Role of CDPAP

By Marcus Johnson

People with disabilities are currently facing several alarming budget and legislative proposals, including Governor Kathy Hochul's proposed $1.35 billion budget cuts to the Medicaid program in the FY 2024-25 state budget and changes to the Consumer Directed Personal Assistant Services (CDPAS) which would impact people with disabilities. Protecting our access to supports and services is essential.

A recent New York Post article, "How NY’s $6 billion CDPAP Medicaid program has been abused, overused for years," is the perfect example—and reminder—of why people with disabilities must continue fighting and advocating for what we need. While the article addresses concerns about potential misuse and fraud with the Consumer Directed Personal Assistant Services Program (CDPAP), the editorial fails to recognize the broader context and the essential role that CDPAP plays in the lives of thousands of New Yorkers.

CDPAP—a Medicaid-funded program—allows people with chronic illnesses and physical disabilities to hire, train, and supervise their own caregivers. Medicaid then pays these hired caregivers for their services through a fiscal intermediary (FI), an organization responsible for handling administrative costs of the program such as management of employee benefits, payroll, and tax processing. The program was created with the input of people with disabilities who could not receive services they need to live independently from home care agency aides, who are prohibited from providing certain types of care. Without CDPAS, people would need to receive these services either in a nursing home or from a nurse, with both options coming at a higher cost and restricting the autonomy of the consumer to direct their own care.

The New York Post article also highlights the increase in enrollment in CDPAP over the past years and emphasizes the potential for abuse, but neglects to acknowledge the critical shortage of home care workers in New York State, leaving thousands at risk. It’s easy to point fingers at the program, but it’s important to acknowledge the systemic issues that contribute to its challenges.

New York State currently faces the nation’s highest shortage of home care workers. Over 4.6 million New Yorkers will be over age 65 by 2035 — an increase of 29 percent in the next decade. These caregivers are often underpaid and work countless hours, yet provide vital support to individuals who need assistance to live independently. Without a wage increase, the home care worker shortage will hit 1.47 million workers by 2035.

The CDPAP program did not grow by accident. It filled a void simply because there is an absence of viable alternatives for individuals with disabilities or senior adults. The flexibility of the program has allowed many agencies to recruit family workers that otherwise took on caregiving responsibilities as unpaid work. In a population of aging New Yorkers, the numerous ads for CDPAP touting same day payment and getting paid for taking care of grandma made the program attractive and popular.

However, it is critical to note that for many New Yorkers, CDPAP is not a convenience; it’s a lifeline that allows them to remain in their homes and communities surrounded by loved ones.

Focusing on CDPAP enrollment figures without considering these important factors paints a distorted, incomplete portrait of the program’s overall impact and effectiveness. As someone with a spinal cord injury who uses CDPAP, the program, for me, isn’t simply a cost-saving measure—it’s the only option that allows me to maintain my independence and dignity while receiving necessary care in the comfort of my home.

Let’s not lose focus on CDPAP’s importance in providing essential care for an often overlooked and undervalued population. We have to ensure our voices are heard, and that the full story, the painting in its entirety, is on the canvas for all to see.

As co-leader of the Civics League for Disability Rights (CLDR), CDPAP is just one of a number of issues myself and my fellow members advocate for. We invite the community to join us and learn more about how we advocate for ourselves and the disability community, in order to stay engaged and informed on the issues that impact us.

Marcus Johnson is co-leader of the Civics League for Disability Rights (CLDR), 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, email civicsleague@gmail.com.
Meet Author and Advocate Ken Kunken

Storytelling is a key part of creating connections and understanding, and it’s central to our work at Able News. As we continue to build our platform for amplifying stories of the disability community, we’re delighted to introduce this new interview series. To kick things off, we had a conversation with Ken Kunken, a Long Island-based attorney, author, disability advocate, husband, and father. His book, I Dream of Things That Never Were: The Ken Kunken Story, was published late last year. Here, in his own words, Ken shares a bit about his life and the wisdom he’s gathered along the way.

Congratulations on recently publishing a book! What can readers expect?

I had been planning on writing a book for quite some time. I had a lot of people encourage me to do so. I’ve been doing motivational speaking for a number of years and after almost every one of my talks somebody would suggest that I write a book. I’ve been told that what I’ve done with my life since my injury has both motivated people to do more with their lives. I’d really like to get my message out and highlight the importance of family, friends, everybody who has helped me achieve far more than anybody thought I would ever be able to do.

How would you say things have changed for people with disabilities in the time since sustaining your injury?

I had a spinal cord injury back in 1970. I broke my neck making a tackle on a kickoff at a lightweight football game against Columbia University when I had just started my junior year at Cornell University. I had the added misfortune of being injured about 20 years before the Americans with Disabilities Act took effect. When I went back to school after my injury, almost nothing was wheelchair accessible. At Cornell, there was not one ramp or curb cut on the entire campus and every building had steps in front of it. One of my main concerns was just getting to and from class safely and being able to navigate all the physical obstacles that were involved.

We know that discrimination toward people with disabilities remains all too common when it comes to employment opportunities. What guidance would you share with disabled people who are navigating a job search?

It’s great to make it known to as many people as you can that you’re looking for a job and what type of job you’re pursuing so that you may be able to get some guidance from other people who have already been working in that job. I think it’s very important to be realistic in the job that you’re looking for. And I think it’s important that employers be encouraged to hire qualified individuals who happen to have a disability. Everybody benefits by having a more inclusive and diverse workforce.

What disability rights issue is your biggest advocacy priority right now?

For years and years there have been disincentives for somebody with a disability to work. So many individuals with disabilities need Medicaid and Social Security benefits. But when they get a competitive job, they can lose those benefits, which jeopardizes access to attendant care. We have to change this so that people are encouraged to go to work rather than stay home for fear of losing those benefits.

Looking ahead, what’s next in your exciting journey?

I’d been working as an assistant district attorney in Nassau County. I’d been there for more than 41 years. I’ve decided now is the right time for me to fully retire. What’s next? I have three sons in college and I’m looking forward to watching their growth and helping them in any way that I can. I’m also looking forward to doing more speaking about my book so that I can encourage people, whether they be people with disabilities, family members of people with disabilities, friends of people with disabilities, employers or just the public in general to learn more about disability. We must continue moving toward a society that values everyone, including people with disabilities.
Navigating Tax Season: Tips for People with Vision Disabilities

By Jeremy Morak, Marketing Manager, Lighthouse Guild, and Dorothy Delayo, Lighthouse Guild Volunteer

Tax day is coming up on April 15. This time of the year can be stressful for anyone, but for individuals who are blind or visually impaired, tax preparation can be challenging and inaccessible. The process can feel overwhelming, from gathering documents to completing forms, and ensuring that information is entered correctly. However, with proper preparation and the right resources, filing taxes can be manageable, reducing stress and creating a sense of independence.

One resource available to individuals who are blind or visually impaired is Lighthouse Guild’s Tax Preparation Program. Dorothy Delayo, who has been volunteering in this program for the past three years, offers useful tax filing tips:

**Organization is Key**
Start by gathering all necessary documents, such as income statements, receipts, and tax forms, and organizing them in a way that is easy to keep track of. Assistive technology such as electronic magnifiers can help identify different documents. If you’re not sure if a specific document will be necessary, bring it anyway. It’s better to have too many documents than not enough. Stay on top of records and finances all year, rather than waiting until filing season. Keep your information in a safe and secure location that’s easy to access. Your ID card and social security card are necessary for filing as well.

**Find Trustworthy Resources**
One of the most important aspects of using a tax preparation resource is feeling comfortable with the person handling your sensitive financial information. Seek out organizations that specialize in working with people who are blind or visually impaired. Places such as Lighthouse Guild are not only able to help scan documents to ease the process of filing taxes, but they are also more equipped to work with specific unique situations that other financial institutions might not have experienced in the past. Preparers at these types of institutions are more inclined to go through all documents slowly, answer questions to the best of their knowledge, and ask the right questions to help ensure information is accurate and accounted for.

**Plan Ahead**
Avoid the stress of last-minute filing by starting early and setting aside dedicated time to work on your taxes. Waiting until the last minute leads to rushing and unnecessary worrying and can often cause mistakes in preparation. If you plan on submitting medical records, keep a list of receipts throughout the year and set aside time to go through each expense. Slowly and carefully create a list of necessary documents, including identification information, financial statements, tax forms, and pay stubs. Before meeting in person, go through this list several times. Don’t hesitate to reach out to preparers beforehand to ask any clarifying questions.

Remember that you are not alone – support and assistance are available to help you through the process. Keeping a level head, slowing down, and calmly working through potential hurdles will ensure that forms are completed correctly and on time. By following these steps and using available resources, individuals who are blind or visually impaired can successfully navigate tax season with confidence.
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Serving the Community Since 1979
Disability In The Media

WBFO, Buffalo’s NPR Station Continues Commitment to Disability Reporting
By Emyle Watkins

When I went to school for journalism, two things became clear to me. I loved journalism, but it was an industry that wasn’t built with people like me in mind. I had a lot of people who encouraged me to hide or not disclose my disabilities to avoid discrimination. I didn’t have mentors who openly identified as disabled. And frankly, some of the “best practices” we learn in journalism school don’t work for some of the people with disabilities we’re interviewing, like interviews in person, not providing questions ahead of time, or not doing interviews via email.

Three years ago, I found myself deciding I no longer wanted to hide who I was or go along with the status quo in journalism. I grew up with a disabled parent and at the time was coming into my own disabled identity, and knew my community wasn’t getting the coverage it deserved. And while I was looking for an opportunity to do this work, the right place for it also found me.

My former editor at WBFO, part of Buffalo Toronto Public Media, where I had interned at in college, asked me to apply for a news reporter position. I didn’t know until the interview they were looking for a disability reporter and they didn’t realize it was my dream job.

I was very clear to them what I felt disability reporting should look like, and they matched my vision and provided me the resources I would need to succeed. For the first time I was in a newsroom that followed the National Center on Disability and Journalism Style Guide. I was given a paid mentor who was a retired disabled journalist and editor. And I was able to be open about my own experiences at work.

Since then, WBFO has allowed me the opportunity to develop and lead our Disabilities Beat, which covers disability rights, equity, and culture. We focus on what barriers exist to people with disabilities in having equity in education, employment, transportation, housing, and their broader communities. We’ve taken on new approaches to interviewing, focused on using language that better represents the diversity of the disability community, and done deep-dive investigations into discrimination and local government. We’ve held elected officials accountable for their failure to use American Sign Language interpretation during vital communications, exposed potential violations of the Americans with Disabilities Act, and highlighted a workforce crisis that is threatening independent living options for many in New York.

However, I would say the most valuable thing our initiative has done is show that this coverage matters. It’s highlighted that journalism can adapt to better cover marginalized communities and more accurately represent the lived experiences of people with disabilities. And lastly, it’s shown that it matters that people like me, who are disabled, are in journalism and leading this work.

Our community deserves to see and hear people who understand us on the news, and it makes a difference when the person you’re sharing your story with can relate on a personal level. We’ve shown that disability equity isn’t something we should only be discussing in the stories we tell, but in our newsrooms as well.

Over the next two years, WBFO is going to continue expanding this work. We’re committed to improving the accessibility of our content, adding new accommodations for guests we interview and have just introduced a new eight-minute weekly segment during our most popular weekday hours. That’s just the start of many plans we have, and I hope you’ll check out the work we’re doing by visiting WBFO.org.