Blind Student Participates On Artemis I

By Jeremy Morak

Three years ago, 15-year-old high school student Matthew Cho lived a happy, everyday teenage life until he was diagnosed with a brain tumor, resulting in two surgeries to remove the malignant mass.

When Cho awoke after the second surgery, he was left completely blind. The sudden loss of sight shocked him and his family and created a challenging roadmap that required mental fortitude and painstaking hard work to get his life back on track.

He transferred to the New York Institute, a school designed to help students with disabilities, and started receiving services at Lighthouse Guild.

Three years later, at 18-year-old, he’s getting set to graduate high school, has continued his passion for playing and teaching music and just returned from NASA’s Johnson Space Center in Houston, Texas, where he participated. Continued on page 15
Gov Launches Caregiver Initiative

In recognition of the recent National Family Caregivers Month, Gov. Kathy Hochul had urged state workers to complete a survey on their experiences balancing their jobs with caregiving tasks and encouraged private employers to do the same. Hochul hoped to raise awareness of unpaid working caregivers and the statewide resources available to help them.

“In addition to making historic investments to expand our long-term care workforce, I am excited to be giving back to the more than four million unpaid caregivers who have already dedicated their time and energy to caring for loved ones,” she said. “By recognizing this work as the valuable and crucial caregiving it is, individuals can better connect with the many state and local resources and supports specific to their needs.”

Recognizing the unique stresses on working caregivers, the State Office for the Aging and the State Department of Labor launched a project to survey state employees and gain insight on the impact of caregiving on the workplace. The initiative also promoted “Caregivers in the Workplace,” a 32-page guide providing information to help employers support working caregivers.

New York State has more than four million unpaid caregivers. These are family members, friends or neighbors who provide uncompensated care and support to someone else, such as a spouse, an older parent, children or someone with chronic or other medical conditions.

Unpaid caregivers perform a range of tasks for loved ones, such as accompanying them to medical appointments, providing help with bathing and dressing, shopping assistance and meal preparation, transportation, bill paying, household chores and more. Yet more than 50 percent of individuals in this role do not identify themselves as caregivers.

AARP estimates that the services provided by unpaid caregivers would cost roughly $32 billion annually.

New York has led a multi-strategy approach to assist family caregivers, through historic investments in the long-term care workforce, respite and social adult day care services offered through state and local offices for the aging, a landmark paid family leave program, paid sick leave laws and more. Individuals needing support caring for an older adult or person with disabilities may contact the NY Connects helpline at 1-800-342-9871 or contact the NY Connects person with disabilities may care for an older adult or a child at the same time, 85 percent experienced mental health symptoms and 52 percent reported suicidal thoughts, according to the U.S. Centers for Disease Control and Prevention.

Other data from the National Alliance for Caregiving and AARP found that 70 percent of working caregivers suffer work-related difficulties due to their dual roles; and 69 percent of caregivers reported having to rearrange their work schedule, decrease their hours or take unpaid leave in order to meet responsibilities.

For individuals providing care to an older person and a child at the same time, 85 percent experienced mental health symptoms and 52 percent reported suicidal thoughts, according to the U.S. Centers for Disease Control and Prevention.

Other data from the National Alliance for Caregiving and AARP found that 70 percent of working caregivers suffer work-related difficulties due to their dual roles; and 69 percent of caregivers reported having to rearrange their work schedule, decrease their hours or take unpaid leave in order to meet responsibilities.

Correction

In a story [COMMUNICATING – SILO And Sheriff Introduce ASL Aids] in the December 2022 issue of Able Newspaper incorrectly reported that the Suffolk Independent Living Organization (SILO) sponsored an event introducing visual cards for communication with the deaf community and the Suffolk County Sheriff’s office. The event was actually sponsored by the Town of Islip Disability Advisory Board.

The Deadline For The February Issue of Able Newspaper Will Be Jan. 10
The NYC Department of Homeless Services (DHS) is falling short in meeting the needs of homeless New Yorkers, particularly those with mental health and substance abuse issues, according to an audit released by State Comptroller Thomas DiNapoli. The audit examined DHS’ assessment and placement of clients and found that far too often the assessments were insufficient in assessing when they had mental illness or substance abuse issues and individuals were placed in a shelter that could not give them the help they needed.

**Must Do Better**

“The Department of Social Services must do a better job helping some of the city’s most vulnerable people,” DiNapoli said. “My latest audit shows that too often the department did not properly place homeless individuals with specialized needs in appropriate shelters where they could receive the support they need to get back on their feet and on the path to stable housing. DHS’ shortcomings can have serious implications.”

As part of DHS’ intake process, clients are assessed to help determine which of its five types of shelter best meets their needs - general, mental health, substance abuse, employment, and senior. General shelters do not offer specialized staffing or services, while the other options offer specialized staffing and services or amenities.

**Looking At Background**

To try to understand the impact that shelter placements can have on clients’ outcomes, auditors looked at the background information of the 17,244 homeless individuals and examined their current shelter/program assignment, length of stay at current facility, assessment screening scores (e.g., mental health, substance abuse, alcohol abuse) and medical diagnosis. Of these, auditors found 3,022 who were diagnosed with serious mental illnesses who should have qualified them for a mental health shelter. However, 26 percent were not placed in a mental health shelter.

Some individuals with known mental health diagnoses were placed in a general population shelter rather than in a specialized shelter. In one instance, a client was diagnosed with schizophrenia and bipolar disorder. Despite being recommended for a mental health shelter, the client was placed in a general health shelter and transferred to three other non-mental health shelters following violent incidents.

After multiple psychotic and violent incidents, the client left a shelter and was charged with murdering a person in a robbery about six weeks later.

Another client with schizophrenia was found dead from probable suicide months after being placed in a general shelter. Prior to his death, he suffered multiple psychotic episodes and was found to not have taken his medication, but there was no change in his shelter placement.

Auditors also found that clients with known substance abuse issues were routinely placed in shelters that did not have specialized staffing and services. Out of the 1,061 clients identified as having alcohol or substance abuse issues, 90 percent were not placed in a substance abuse shelter.

In one case, a client assessed with alcohol dependence had 60 separate drug-and-alcohol-related incidents while in general shelters in 2021, including one in which he threatened a roommate with a box cutter while intoxicated. Despite the incident, the client remained in a general population shelter.

Placements were also an issue in senior shelters. A large percentage of homeless seniors, 43 percent, were placed in general, non-senior shelters. Although DHS officials attributed this to a small number of beds available in senior shelters, auditors found that 28 percent of the beds were given to younger clients.

**Standard Procedures**

It is recommended that DHS create and implement standard operating procedures to ensure individuals are diagnosed, placed in, and/or transferred to the most suitable shelter; work to identify clients who would benefit from services in specialized shelters; review current placements and consider transferring clients into shelters that better serve their needs; and consider what actions to take for clients who might be a danger to themselves or others.

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**Highlighting Need For Student Protections**

Sen. Edward Markey (D-Mass.) has sent a letter to the Department of Education (DOE) and the Department of Justice (DOJ) stressing the need for stronger policies to avoid limiting students’ access to higher education based on their disability through the use of involuntary medical leaves of absence involuntarily (MLOAs).

Involuntary MLOAs, often due to concerns related to mental health, require a student to take leave for much of an academic term or year and be removed from campus. Students with disabilities might be subject to undue academic, financial, medical and emotional burden, which can interfere with their ability to return to school and complete their education.

In his letter, Markey highlighted the urgency of the mental health crisis and asked DOE and DOJ to strengthen non-discrimination protections and affirm access to higher education for students with disabilities by issuing guidance to college and university administrations regarding involuntary MLOAs.

“No student should be denied access to education because of their disability,” he wrote. “Students do not only lose their access to higher education when their school imposes an involuntary MLOA, they also can lose access to health, social, and financial supports such as friends, professors, advisors, and any medical professionals treating the student.”

Markey requested DOE and DOJ to respond in writing.

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**Custom Plates Support Anti-Stigma**

The New York Department of Motor Vehicles is offering a license plate in support of mental health awareness that features the slogan “Healthy Minds, Healthy New York.

The plate is available to order online, at a DMV office, by phone or through the mail, although online orders process faster.

The custom plate fee varies if the plate number is assigned by DMV or if personalization is requested. The fee is in addition to the annual registration fee. The plates are billed every two years when registration is renewed. $25 of the annual fee supports the Mental Illness Anti-Stigma Fund.

The initial fee for an assigned license plate is $85 and the annual renewal fee is $56.25. Personalized plates are $116.25 initially with an annual renewal cost of $87.50.

To order, one must have a valid New York State registration that does not expire within 60 days.
New York’s Public Health and Health Planning Council has approved regulations that will guide the implementation of two laws passed in 2021. An average of 3.5 hours of care a day for each nursing home resident is now required. Prior to the law’s passage there were no minimum staffing requirements in New York. In order to meet these standards, most nursing home owners will have to hire more caregivers.

Nursing home owners must now spend 70 percent of their revenue on quality resident care, with 40 percent of that for staffing. The regulations were passed unanimously; industry representatives testified in opposition and stated their need for more funding in order to follow the law.

Gov. Kathy Hochul has signed legislation to protect patients facing steep medical bills that can lead to wage garnishment or liens against their property.

“No one should face the threat of losing their home or falling into further debt after seeking medical care,” Hochul said. “I’m proud to sign legislation today that will end this harmful and predatory collection practice to help protect New Yorkers from these unfair penalties. With medical debt a burden for far too many, this is an important step to address this crucial issue.”

The legislation amends the civil practice law and rules to prohibit health care providers from placing home liens on an individual’s primary residence or garnishing wages to collect on medical debt. Nearly half of American adults struggle to afford health care costs, and more than 50,000 New Yorkers have been sued for medical debt over the past five years; this problem is most pervasive upstate. Previously, hospitals or health care facilities in New York state were able to impose and enforce liens on a patient’s primary residence to satisfy a judgment in a medical debt lawsuit, leading to housing instability and financial consequences for vulnerable New Yorkers.

“I want to thank Gov. Hochul for signing my bill into law to protect New Yorkers from facing liens on their homes or wage garnishment by medical institutions in their effort to collect medical debt. We must work together to eradicate medical debt from our State and I am thrilled that we are taking this important first step,” State Sen. Gustavo Rivera said.

“New Yorkers struggle with health care costs even when they have insurance. People seeking care end up with bills to cover ever-increasing out-of-pocket costs, including high deductibles, copays and the various fees insurance doesn’t cover. People’s homes and income should not be threatened to satisfy medical debt. I thank Gov. Hochul for signing S.6522A-A.7363A into law to help protect patients from these egregious practices,” Assemblymember Richard Gottfried said.

The Suffolk Independent Living Organization (SILO) staff attended a Public Hearing at the Williams H Rogers Legislation Building to advocate for Economic Development, Planning and Housing in December.

The hearing was held for comment on bill IR 1839 - A Local Law to Improve the County’s Affordable Housing Programs for Veterans and IR 1840 - A Local Law to Improve the County’s Affordable Housing Programs for Individuals with Disabilities.

Six SILO staff members stepped up one by one and spoke about their experiences locating affordable, accessible housing for people with disabilities and veterans. Housing Specialist, Marianne Franck spoke about a program participant who is a Navy veteran and the experience and housing struggle.

SILO’s director of IT, Oscar Salgado, a former U.S. Army Veteran told his emotional story of his housing struggles before and after leaving the military and said, “We hope to see these bills passed.”

Other members of the community also spoke at the hearing.
New York Gov. Kathy Hochul (D) recently announced $9 million in state funding for an educational loan repayment program to help community mental health agencies recruit and retain psychiatrists and psychiatric nurse practitioners.

Administered by the New York State Office of Mental Health (OMH) and the Higher Education Services Corps of New York State, the Community Mental Health Loan Repayment Program will provide loan repayments of up to $120,000 for psychiatrists and $30,000 for psychiatric nurse practitioners, provided they remain employed by licensed community mental health programs for three years. Both existing and newly hired providers at licensed community mental health programs are eligible to apply. Worker-awarded funds through the program must fulfill a three-year service obligation to their employer and will receive one-third of their total award annually during those three years.

“Part of the largest ever investment in health care, the Community Mental Health Loan Repayment Program will allow us to build a more equitable health care system,” Hochul said. “This funding will provide our partners in communities across the state with the resources they need to attract top-tier workers and then keep them employed in our state, so we can grow our workforce and ensure all New Yorkers have access to the highest quality of care.”

Eligible psychiatrists may receive up to $120,000, while eligible psychiatric nurse practitioners may receive up to $30,000. Providers may apply for loan repayment on behalf of their staff, with applications reviewed on a first-come, first-served basis for as long as funding remains available.

“Community-based mental health care providers continue to be impacted by the nationwide shortage of healthcare workers, and the demand for psychiatrists and psychiatric nurse practitioners continues to grow,” said OMH Commissioner Anna Brown. “The Community Mental Health Loan Repayment Program will help our partners meet this growing demand by helping to attract and retain these essential professionals.”

Inpatient and comprehensive psychiatric emergency programs eligible for the program include licensed providers of Article 28 hospital inpatient psychiatric units, Article 31 freestanding inpatient hospital programs and comprehensive psychiatric emergency programs.

Also eligible are licensed Article 31 outpatient programs, including assertive community treatment teams, continuing day treatment, children’s day treatment, partial hospitalization, personalized recovery-oriented services, and mental health outpatient treatment and rehabilitative services.

The repayment program complements Hochul’s $20 billion, multi-year plan to improve and grow New York’s health care infrastructure and workforce. The plan includes $1.2 billion for health care and mental hygiene worker retention bonuses, and $500 million for cost-of-living adjustments to raise wages for human services workers.

Additionally, OMH has also distributed more than $21 million in federal funds since fall 2021 for recruitment and retention incentives. This funding was provided through the American Rescue Plan Act of 2021 and time-limited expansions of the Community Mental Health Services Block Grant program and Federal Medical Assistance Percentage share of funds for Medicaid programs.

For details about the student loan repayment program one may visit www.omh.ny.gov/omhweb/rfp/2022/cmhlrp/index.html.

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Diabetes Leading Cause Of New Blindness In Adults

According to the 2022 National Diabetes Statistics Report from the Centers for Disease Control and Prevention (CDC), more than 11 percent of the U.S. population (approximately 37.3 million people) has diabetes.

The study also found that 38 percent of adults 18 and older in the U.S., some 96 million people, have prediabetes. Diabetes is the leading cause of new blindness among adults from 18 to 64, according to a Prevent Blindness news release.

Daniel LaRoche, a New York City eye specialist, said, “To help prevent diabetes, it is essential to have an excellent diet with salads, vegetables and fruits and reduce bread and rice intake. Exercise 30 minutes a day. Meditate for 15-30 minutes a day. Drink green tea and reduce sleep apnea and snoring by sleeping on the side and not directly on your back. Controlling weight helps to reduce diabetes and retinopathy.”

Many people with diabetes may not know about the damaging effects the disease can have on vision. “Regular dilated eye examinations are essential to detect diabetic retinopathy early and provide vision saving treatments when ready,” he added.

LaRoche is a glaucoma specialist who wants people to be aware that glaucoma, cataracts, retinal degeneration and retinopathy can begin to surface between the ages of 40 and 70.

“Over time, these diseases can lead to blindness, so it’s best to address them as soon as possible,” said LaRoche. “We have new treatments with earlier surgical options that can help preserve or restore their vision with faster recovery times.”

Glucoma is the leading cause of blindness in African Americans and people from the Caribbean, and the simple way to prevent the devastating effects of glaucoma is to maintain regular eye visits.

“Eyesight or human vision is one of the most important senses,” LaRoche said. “As much as 80 percent of what we feel comes through our sense of sight. By protecting the eyes, people will reduce the chance of blindness and vision loss while also staying on top of any developing eye diseases, such as glaucoma and cataracts.”

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Silverstein, 73, who died Nov. 17.

Bobby played a critical role in advancing disability policy.

Prior to working on Capital Hill, he was co-founder of a law firm that focused on public policy analyses for Federal, State, and local officials and representation of persons with disabilities and their families. He was also the staff director of a congressionally-mandated study of Title I of the Elementary and Secondary Education Act at the National Lawyers Committee for Civil Rights Under Law.

He served in both the U.S. House of Representatives, as counsel to the Subcommittee on Select Education of the Committee on Education and Labor, and Senate, as staff director and chief counsel for the Subcommittee on Disability Policy of the Senate Committee on Labor and Human Resources and chief aide to Sen. Tom Harkin, who sponsored the Americans with Disabilities Act (ADA).

Silverstein spent his adult life in Washington, D.C. and was probably America’s foremost expert on the interface of law with disability. He was a bi-partisan consensus-builder in making the ADA a reality and was known as the “behind-the-scenes architect of the ADA” and more than 20 disability-related bills that were enacted into law.

After leaving government service, he continued his public policy work as director of The Center for the Study and Advancement of Disability Policy where his work was used for NCD’s 2006 “Creating Livable Communities” report. Most recently he served as principal at the law firm of Powers Pyles Sutter and Verville.

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Celia Brown died after a bout of breast cancer in December at the age of 59. According to colleague and friend Harvey Rosenthal, CEO New York Association of Psychiatric Rehabilitation Services (NYAPRS), Brown skillfully straddled the worlds of government and advocacy. She was referred to as the Mother of the consumer/survivor/ex-patient movement.

A psychiatric survivor and advocate for people with psychiatric disabilities, she was the first Peer Specialist for the New York State Office of Mental Health, where she provided technical assistance and support to people with psychiatric disabilities and their families.

She subsequently rose to the position of Regional Advocacy Specialist for the Bureau of Recipient Affairs at the New York City Field Office, New York State Office of Mental Health where she facilitated training on peer supervision, wellness and recovery approaches in community mental health agencies.

Brown served as the President of the Board of MindFreedom International and served as their main representative to the United Nations. She worked with other disability organizations on the Convention on the Rights of People with Disabilities.

According to The National Association for Rights Protection and Advocacy (NARPA) “she traveled to Finland, New Zealand and Geneva and marched on the roads of Ghana, West Africa to lift the stigma and disenfranchisement of Ghanaians with disabilities to change its laws... She has presented nationally and internationally on topics such as self-help, peer counseling, advocacy, trauma and cultural competency.”

“Celia possessed unparalleled wisdom and skill navigating historically oppressive systems while simultaneously “changing the narrative” within these same hierarchies,” said Jonathan Edwards, Peer Support Workforce Advocate and Researcher, Colleague and Long-time Friend. “She was a tireless advocate, possessed a buoyant spirit and was intentional about supporting others. Celia sought to change systems one person at a time and never deemed any cause insurmountable.”

Brown was a founding member of the National People of Color/Consumer Survivor Network; worked on planning the New York City Conference for Working Peer Specialists; and hosted virtual peer support groups on Saturday afternoons for 14 months during the pandemic.

She co-founded Surviving Race: The Intersection of Race, Disability and Human Rights Coalition in 2014 to explore the intersections between race and disability in the human rights movement.

“Celia inspired her fellow advocates to speak out against inhumane practices, racism and stigma,” said Gita Enders, director of the Office of Behavioral Health Medical and Professional Affairs, NYC Health + Hospitals. “She skillfully and inimitably traversed her multiple roles with grace and discretion.”

Celia was and will always be one of our movement’s most cherished and most influential leaders: a very kind, devoted, determined and humble leader who led the way in the advancement of rights-based advocacy, peer support, trauma informed approaches, cultural competence and humility, peer specialist roles and numerous efforts to combat racism and discrimination,” said Rosenthal.

“Celia is my hero, my Cape Crusader and deserves a send-off that is bigger than just a regular Home-going service,” Brown’s sister Jocelyn Brown said on Facebook. “There will be two ceremonies. One ceremony will be in Ghana, West Africa in the beginning of April where her ashes will live in the waters of our ancestors.

The Brown family is also planning a Memorial Service during Black History Month, to celebrate and honor historical leaders past and present. The date and time will be announced at a later date.”

Brown, a life-long resident of the Bronx, is survived by her long-time partner Kevin Waller, son “Little” Kevin Waller Jr., her Mother Marva, brother Norman Brown, sister Jocelyn Brown and numerous nieces and nephews.
C

hildren’s Specialized Hospital, part of the Children’s Health Network at RWJBarnabas Health, has launched the Living Safely Online Center for Safety, a new website designed to advance safety education and injury prevention for people with disabilities.

As the latest initiative of the hospital’s Living Safely with Disabilities and Special Health Needs program, the website serves as a one-stop accessible hub of safety tools and resources, guidance documents, public service announcements and discussion templates to support community safety conversations between disabled residents, community caregivers and local emergency response teams.

Funded in part by a $250,000 grant from the Department of Human Services, Living Safely with Disabilities and Special Health Needs program, the website serves as a one-stop accessible hub of safety tools and resources, guidance documents, public service announcements and discussion templates to support community safety conversations between disabled residents, community caregivers and local emergency response teams.

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Airport Gets Autonomous Service

A leading developer and service provider of electric mobility chairs, announced today the first permanent installation in North America of its autonomous mobility service at Winnipeg Richardson International Airport.

An estimated one in three travelers will need some form of assistance by the year 2038, making it difficult for airports to meet the additional demands that come with accommodating their needs.

The WHILL autonomous mobility service relieves airlines of fulfilling wheelchair push demands and allows airline passengers to travel more freely by autonomously transporting them to their gates.

After the user selects their destination on a touch screen, the autonomous power chair proceeds to transport the passenger safely and reliably to the desired gate. The service covers the entire route from check-in counter to security checkpoint, and then to the departure gate to provide a seamless travel experience.

The service has been tested during several development trials at the Winnipeg Airport since 2019.

“The addition of their innovative autonomous mobility device as a fully available service at Winnipeg Richardson International Airport is another example of our commitment to providing a more accessible and inclusive environment,” said Nick Hays, president and CEO of Winnipeg Airports Authority.

Previous trials of the autonomous service in U.S. airports have included Atlanta, San Jose and Grand Rapids. WHILL plans to announce partnerships with additional airports in North America in 2023.
POV Present ‘I Didn’t See You There’

P OV, the showcase for independent nonfiction films on the PBS network offers an intimate view of modern urban life, with its contradictions and unexpected moments of joy, from the point of view of first-time filmmaker Reid Davenport in the thought-ful documentary “I Didn’t See You There,” produced by Keith Wilson.

Filmed from Davenport’s physical perspective – a camera mounted to his wheelchair or held by himself – the film serves as a clear rebuke to the norm of disabled people being seen and not heard.

The film makes its national broadcast premiere on POV at 10 p.m., Monday, Jan. 9 and will be available to stream with no PBS Passport membership necessary until Feb. 9 at pbs.org.

“The Beautiful Colors of Jeremy Sicile-Kira,” a short film by UCLA student Aaron Lem-ple, will air immediately following the premiere. The film follows artist Sicile-Kira, who uses painting to transcend his disability and communicate his dreams to others.

In addition to standard closed captioning for the film, POV, in partnership with audio description service DiCap-ta, provides real-time audio interpretations for audiences with sensory disabilities. POV, currently celebrating its mile-

stone 35th anniversary sea-son, is America’s longest running non-fiction series.

“I shot this film from my lit-eral perspective. As a disabled filmmaker, I first and foremost want to share that perspective with other disabled people in the hopes that it resonates. I also hope that non-disabled people find entry points into the film. There is no place bet-ter than POV for ensuring that ‘I Didn’t See You There’ is seen by a wide audience,” said Reid Davenport, director and direc-
tor of photography for the film.

“POV is the absolute per-fect place for ‘I Didn’t See You There’ to reach so many viewers and start some needed conversations. It’s an incredible honor to follow the footsteps of so many groundbreaking filmmakers whose POV films influenced me including Marlon Riggs, Laura Poitras, and Marshall Curry,” said Keith Wilson, producer.

“I Didn’t See You There” premiered at the 2022 Sun-dance Film Festival where it won the Direction Award - U.S. Documentary and was a Grand Jury Prize nominee. At the 2022 Full Frame Doc-umentary Festival, it won the Grand Jury Prize and was the McBaine Bay Area Documen-
tary Feature Award winner at the 2022 San Francisco Inter-
national Film Festival.

Recent accolades include two 2022 Cinema Eye nomina-
tions for Outstanding Debut and Outstanding Sound Design.

“I Didn’t See You There” will be an official selection of the 2022 ReelAbilities Film Festival in New York.

Resource Center To Assist Those With IDD

ACL has awarded an estimated $3.25 million over five years to create a national tech-nical assistance and resource center that will improve sup-port for people with co-occur-
ing intellectual and develop-
mental disabilities (IDD) and mental health needs so they can live and participate in their communities.

Recently, the U.S. Depart-
ment of Health and Human Ser-
vices released a Roadmap for Behavioral Health Integration. The roadmap, developed in sup-
port of the president’s strategy to address the national mental health crisis, affirmed HHS’s commitment to “providing the full spectrum of integrated, equitable, evidence-based, cul-turally appropriate and per-
son-centered behavioral health care.” It outlined a range of actions to support the pillars of the president’s strategy, in-
cluding the creation of this new resource center that will help to ensure that people with IDD have access to the behavioral health care they need.

The grant was awarded to the National Association of State Directors of Developmental Dis-
abilities Services (NASDDDS) in partnership with the Nation-
al Association of State Men-
tal Health Program Directors (NASMHPD), and the National Association for the Dually Diag-
nosed (NADD).

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A group of Hispanic New York based actors recently presented the world premiere of the immersive production, “Odd Man Out” at the Bristol Riverside Theatre (BRT) in Bristol, Penn. The show was presented by Teatro Ciego (Theatre for the Blind) and Theatre C.

The story was about Alberto Rinaldia played by Gonzalo Trigueros, a blind jazz musician flying from New York back home to Argentina. During the flight, Alberto shared his New York experiences with some of the passengers. However, throughout the show, the theatre was dark in order for the audience to get a taste of Alberto’s world.

Sitting in the dark was unquestionably difficult for most audience members, but preparing to perform in a pitch black theatre was also challenging for a lot of the cast members. Despite the cast’s struggles they ended up empathizing with blind people and their ways of living in a fully sighted world.

“Before I played a blind character, I had to do a lot of research,” said Trigueros. “It helped that our co-director, Facundo Bogarin is blind.”

The rest of the cast and crew were fully sighted.

Being in “Odd Man Out” gave Trigueros empathy for a condition outside of his own. “That’s a beautiful thing about acting; to be able to immerse yourself in the lives of people who are different,” he said.

This was Trigueros’s first time having to take orders and direction from a blind person.

“It was wonderful,” said Trigueros. “I have to admit it was scary to see Facundo move around so well on stage.”

For seven years, Bogarin directed fully sighted actors. “Odd Man Out’s” other co-director Carlos Armesto said that actors always showed him respect because of the confident way that he carries himself.

“He knows what he is doing at all times,” said Armesto.

Andres Montejo, who portrayed passenger Christian, recalled the early days of rehearsing in the dark, “The first day we rehearsed in the dark, I remember lifting my hand very close to my face and I couldn’t tell that it was there. I remember that was a very daunting moment. It took us time to learn how to safely move in the dark without hurting anyone. We started doing different processes of identifying the space with touch and sound. It was a long process of getting comfortable with that. We had a total of 32 rehearsals.”

“It was an incredible experience for me to not only be taught by Facundo but to also deal with him like he was one of us.” He soon stopped looking at him as a blind person but as the show’s co-director. He learned to view people with disabilities like he did everyone else.

The cast hopes to perform this show in New York. A different version of the show was slated to have debuted at the Argentinian consulate in New York City in 2020, but plans fell through due to the pandemic.

“In 2021, we did an at home (virtual) version of “Odd Man Out” in New York. Armesto said that Alberto’s story coupled with the way that the show was presented, intrigued the live audiences.
Book Looks At ADA’s Past And Future

Journalist Ben Mattlin, of California, recently published “Disability Pride: Dispatches From A Post-ADA World,” a book that traces the lives and work of the generation that came of age after the Americans with Disabilities Act (ADA) was passed in 1990.

He utilizes interviews and reporting to illustrate the immense advancements that have been made since the ADA was enacted to legally prohibit discrimination, increase access and offer accommodations for the millions of Americans who are disabled. However, he also explores all the progress that is still needed, including acceptance, representation and support for those facing marginalization.

Mattlin was born in the early 1960s with spinal muscular atrophy and has been a lifelong wheelchair user. Therefore, he has experienced life before and after the ADA, and has seen a lot of change in disability rights and activism through the decades.

He writes about his observations of a new and profound shift in how individuals and groups with disabilities were being viewed, how they viewed themselves and how they were organizing to make change. Mattlin said that he set out to learn more about the current generation who were breaking new barriers and making an impact in areas that had previously seemed inaccessible to much of the disability community.

“The disability community had grown into something I no longer knew much about but to which I felt intrinsically akin,” he said.

The book also explores the shift towards disability heritage, recognition and celebration. It also examines the history of the ADA’s passing, improved health outcomes and longer life expectancy, the sociopolitical climate, autistic self-advocacy, the rise of disability studies, increased visibility, improved representation in the media for those with marginalized body types and facial features and the power of social media. Mattlin also delves into issues such as the right-to-die movement, institutionalization and subminimum-wage labor.

“Despite the progress that’s been made, as good as things may seem at times, there are still too many obstacles, still too much subjugation and cruelty, still too great a need to make life better, safer, more accessible, more just,” he said.

Yet, in the end, Mattlin finds reasons to remain hopeful. Writing that the disability community has never given up on the fight for equity, he looks optimistically toward the future of the flourishing movement.

Mattlin’s other books include “Miracle Boy Grows Up” and “In Sickness and In Health.” His work has appeared in the New York Times, Los Angeles Times, Washington Post, Chicago Tribune and USA Today.

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WEBINAR ADDRESSES ADA AND ABA REGS AT DETENTION FACILITIES
Unique security features can pose challenges to designing accessible detention and correctional facilities. The next webinar in the U.S. Access Board’s free monthly series will take place from 2:30 to 4 p.m., Jan. 5 and will provide an overview of the Americans with Disabilities Act (ADA) and Architectural Barriers Act (ABA) accessibility requirements for detention and correctional facilities.

Presenters will review provisions addressing holding cells and housing cells with mobility and communication features, visiting areas and medical care facilities along with some additional requirements established by the U.S. Department of Justice.

One may visit www.accessibilityonline.org for information or to register. All webinars include video remote interpreting (VRI) and real-time captioning. Questions can be submitted in advance of the session or can be posed during the live webinar. Webinar attendees can earn continuing education credits. The series is hosted by the ADA National Network in cooperation with the U.S. Access Board.

PUBLIC INVITED TO ONLINE MEETING OF U.S. ACCESS BOARD
The public is welcome to attend the next meeting of the U.S. Access Board, which will be virtually, from 1 to 2 p.m., Wednesday, Jan.11.

The meeting agenda includes brief reports from standing and ad hoc board committees, the executive director and federal agency updates.

Attendance will be through the Zoom.gov platform or by phone (listen-only mode).

For further information, one may contact Marie Buna at events@access-board.gov.

The meeting link is https://www.zoomgov.com/j/16176955865 and the meeting ID is 161 769 55865.

To dial in, one may call 646 828-7666.

UNITED NATIONS TO REVIEW DISABILITY-INCLUSIVE AGENDA

The priority theme is “Creating full and productive employment and decent work for persons with disabilities such as the way forward, a disability-inclusive development agenda toward 2015 and beyond; World Program of Action for Youth; the Madrid International Plan of Action on Aging; and family issues, policies and programs.

Information is available by visiting www.un.org.

REGISTRATION OPENS FOR ADVOCACY CONFERENCE
Individuals with Down syndrome, their families and other advocates may now register for the Down Syndrome Advocacy Conference in Washington, D.C. April 17 through 19.

This three-day event will bring attendees together to advocate for legislative priorities that impact the Down syndrome community. Heather Avis of The Lucky Few and Matthew Schwab will be the keynote speakers.

For information and to register one may visit www.ndss.org.
Lighthouse Guild And Bionic Sight Form Partnership

Bionic Sight’s technology focuses on restoring sight to patients with advanced-stage blindness due to retinal degenerative diseases, such as retinitis pigmentosa. The technology is based on discoveries by researchers and developer Sheila Nirenberg, a professor at Weill Medical College of Cornell University and the founder of Bionic Sight. She unraveled the code the retina uses to tell the brain what a person is seeing.

Nirenberg has won numerous awards for her work, including a MacArthur Genius Award. She and Bionic Sight are using it to develop a new approach for treating blindness.

"Lighthouse Guild’s mission includes both providing exceptional services today for people who are visually impaired and creating a future of unlimited potential for our clients and patients," said Calvin Roberts, president and CEO of Lighthouse Guild. "By investing in breakthrough technologies and therapies, Lighthouse Guild can help impact the direction of medical innovation."

"Lighthouse Guild and Bionic Sight have a shared commitment to utilizing technology to transform the lives of people who are blind or visually impaired," Nirenberg said. "Our goals are naturally aligned. Through this partnership, we will be able to continue exploring and implementing innovative approaches and treatments."
The Artemis I mission aboard the Orion spacecraft was, in November, the first uncrewed rocket ever sent to space. Alexa, the AI voice of Amazon, powered the rocket. Earlier this year, Amazon and Lockheed Martin announced plans to integrate Alexa into the Orion spacecraft for Artemis I, the first of several NASA missions intended to bring the first woman and the next man to the Moon.

On Dec. 9, Cho was chosen to represent Lighthouse Guild at NASA's space station to join the virtual Artemis crew and tour the facility. During the tour, Cho learned about the process that astronauts must go through to prepare for missions, and the conditions they face while in space. He was also able to touch the various materials that are part of the astronaut suit to protect them from the extreme conditions. “The coolest part of the tour was feeling the material of the astronaut’s suit,” he said.

From the Artemis command center at Mission Control, he communicated directly with Alexa, asking questions about the mission and giving commands.

Some of the questions included asking Alexa how many miles away Orion was from Earth and how fast the rocket was traveling. He also commanded Alexa to change the light within the spacecraft to green and got Alexa to recite a fun space rap.

“It was a truly emotional experience,” said Cho. “I felt, WOW. I got to be one of three people in the whole world, in the whole country that talked to Alexa while she was in space.” Talking about the experience, he explained, “It just feels like I’m in a totally different world, like I’m in outer space. It’s just a wonderful opportunity. I feel that being part of this, listening to everything as a visually impaired person, it reminds me just how far technology has come and what’s in store in the future.”

The first Artemis mission ended on Dec. 11 when it splashed down off the coast of San Diego.

The U.S. Access Board’s webinar on accessible amusement rides is now available in the archives.

This webinar provided information on accessible amusement rides, including reviews of technical provisions for rides that include a wheelchair space, ride seats designed for transfer and transfer devices. Additionally, board staff Bill Botten and Bobby Stinnette addresses requirements for accessible routes, que lines, parking and passenger loading areas, signage, sales and service counters.

This webinar includes video remote interpreting (VRI) and real-time captioning. The webinar series is hosted by the ADA National Network in cooperation with the board.

The webinar may be viewed at www.accessibilityonline.org/ao/archives/111019. Other archived copies of previous board webinars are also available on the site.
USABA has announced the names of the 10 athletes chosen for the first-ever USA Blind Soccer Men’s National Team that will begin international competition in 2023. This is the first step on the journey to competing at the Los Angeles 2028 Paralympic Games.

The team was named after a four-day selection camp held in Chula Vista, Calif. The roster features eight athletes with visual impairments along with two sighted goalkeepers.

The eight athletes with visual impairments named to the team are Noah Beckman (Columbus, Ohio), Cody Kirchner (Columbia, S.C.), Ahmed Shareef (Staten Island, N.Y.), Ricardo Castaneda (Fort Worth, Texas), Kevin Brown (Fallis Church, Va.), Antoine Craig (Richmond, Va.), David Brown (Chula Vista, Calif.) and Alvaro Mora Arellano (Phoenix, Ariz.).

The two sighted goalkeepers selected are Brandt Herron (Palm Coast, Fla.) and Kyle Knott (Brevard, N.C.).

Senior Sofia Lopez, 17, not only led her team from the Florida School for the Deaf and the Blind recently to the High School Goalball National Championships, but she was also named Most Outstanding Player in the girls’ competition, despite not scoring a single goal from her center position.

She was chosen because her performance exemplifies how a center can be instrumental to their team’s success without being the leading scorer. “Being at center I am more like the quarterback of the team,” said Lopez. “There is no need for me to be the one to score all the goals. I think my main job at center is to lead our team and defend anything that comes our way. I think just being supportive and positive is what really helped me win the title of MVP.”

This was Lopez’s second national championship, but she has been playing goalball since the age of six. This year’s experience has bolstered her outlook on where the sport could take her. “I never thought there was a future for me in goalball, but after this year’s nationals, I feel like all these opportunities are coming up and there is no way I can turn them down,” she said.

If everything goes to plan I will be traveling next summer for a tournament, and maybe I’ll even consider training and practicing to get to the Paralympic levels.”