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New Horizons

Housing That Supports Independence

36th Anniversary
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An Airline Broke An Activist's Wheelchair. Her Death Months Later Amplified Calls For Change

Reprinted from DisAbility Scoop / article by Emily Alpert Reyes, Los Angeles Times TNS / January 18, 2022

LOS ANGELES — Flying to Washington, D.C., was supposed to be just another adventure for Engracia Figueroa.

Figueroa, 51, had survived getting hit by a train decades ago and made clear her life was far from over. In Los Angeles, she rolled in her wheelchair to acting gigs and vegan restaurants, learned to surf, and pressed for change as an activist.

Before the Washington rally where she advocated for public investment in caregiving, Figueroa had phoned one of her sisters and marveled at the sunny day ahead. She was especially excited about the trip after being hemmed in during the COVID-19 pandemic.

Figueroa returned to L.A. to find that her motorized wheelchair — a custom device that cost tens of thousands of dollars — had been broken.

At Los Angeles International Airport, she waited roughly five hours in a manual wheelchair that did not fit her body, which reopened an old sore, according to her attorney, Joshua Markowitz.

Roughly three months later, she was dead, after worsening illness that included skin grafts, hospitalizations and an emergency surgery to pare away infected bone and tissue, according to family members and her lawyer.

Whether the incident led directly to her death, as Markowitz has argued, is poised to become the subject of litigation. United Airlines did not comment on such claims but has expressed condolences to her friends and family. The U.S. Department of Transportation is also investigating what happened, Secretary Pete Buttigieg recently informed her family.

In a statement, United said that "while each customer and their baggage is important to us, we are particularly focused on taking care of special items like wheelchairs and scooters, which are essential for those traveling with them."

Regardless of how her case might play out in court, Figueroa's death has amplified calls to fix a system that disability activists have called archaic and dangerous. Hand in Hand, the advocacy group she was rallying with in Washington, launched a petition calling for airlines to stop breaking wheelchairs. Paralyzed Veterans of America has invoked Figueroa as it pushes for stricter rules about accessibility on airplanes.

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Paralyzed Veterans of America has called for strengthening the air carrier law. Charles Brown, its national president, said he was once dropped on the jet way while being transferred to an aisle chair — an incident that fractured his tailbone and led to a dangerous infection like the one that Figueroa suffered, putting him in the hospital for months.

The industry group Airlines for America declined an interview. In a statement, it said U.S. airlines are committed to providing “the highest level of customer service” to passengers with disabilities and are working with disability groups and manufacturers to address guidelines for safely handling wheelchairs.

Unlike other forms of transportation such as buses, air travel was excluded from the Americans with Disabilities Act, the landmark law that protects the civil rights of people with disabilities. It was passed four years after a federal law regulating air travel — the Air Carrier Access Act — that prohibited discrimination against people with disabilities was enacted.

Federal reports show that more than 6,500 wheelchairs and scooters were damaged on commercial flights between January 2020 and August 2021. That amounts to roughly 1.3% of wheelchairs and scooters put on planes in that time. When big airlines first began reporting the numbers before the pandemic, they averaged 26 broken or lost devices a day.

Losing a wheelchair can cut off people with disabilities from work and school. It can be a financial blow, with wheelchairs costing up to $50,000. And it can jeopardize health: Pressure sores can develop within hours as blood flow is cut off to a particular area, leading to the death of tissue and putting people at risk of infections, said Emily Metzger, a specialist in neurologic physical therapy at Ronald Reagan UCLA Medical Center.

Such wounds are a particular risk for people with spinal cord injuries, who do not feel the immediate discomfort that prompts other people to shift in their seats as bones press against the skin.

Figueroa died while recovering from an emergency surgery for an infection that had reached her hip bone, Markowitz said. Her family was still waiting on her autopsy as of early January.

Her sister Sandi Porter yearns to see what Figueroa was writing about her life. Navarro is puzzling over a recent dream in which Figueroa gave her a cryptic warning about circles. She wants to ask her, “What do you mean?”

Mahoney said her sister “loved life. And that’s why this is so hard.”

“She was just getting started,” she said.

Amazon Debuts Show Starring Actors With Autism

by Shaun Heasley | January 18, 2022 / reprinted from Disability Scoop

The creator of television’s “Parenthood” is back with a new show about a group of 20-somethings with autism all of whom are played by actors who are on the spectrum themselves.

The series “As We See It” comes from Jason Katims who was behind the family drama “Parenthood” that included a character with Asperger’s syndrome and aired from 2010 to 2015 on NBC.

The new half-hour show on Amazon’s streaming service, Prime Video, follows roommates Jack, Harrison and Violet as they try to make friends, find love and get jobs. It’s based on the Israeli series “On the Spectrum.”

“With the help of their families, aide and sometimes even each other, these roommates experience setbacks and celebrate triumphs on their own unique journeys towards independence and acceptance,” Amazon said of the series.

Rick Glassman, Albert Rutecki and Sue Ann Pien, who play the three roommates, all identify as being on the autism spectrum. In addition, Katims said that “all neurodiverse roles were cast with neurodiverse actors” and “two neurotypical roles were cast with neurodiverse actors.”

Beyond the actors, Katims said that crew members working on “As We See It” in the writers’ room, editing room, production office and on set were neurodiverse.

Katims made clear that the lead actors were not playing versions of themselves, but that they “bring an emotional authenticity to their portrayals.”

NYC Gallery Displays Works By Artists With Special Needs

Reprinted from DisAbility Scoop article by Ellen Moynihan, New York Daily News/TNS | January 21, 2022

The opening reception for "ArtABILITY: an Inclusive Exhibition Celebrating Artists with Special Needs" is held at Agora Gallery in New York City on Jan. 13. (Gardiner Anderson/New York Daily News/TNS)

NEW YORK — A Manhattan gallery known for displaying works by world-famous names is hosting a rare exhibit by a unique group of relative unknowns: artists with autism and other special needs.

ArtABILITY: An Inclusive Exhibition Celebrating Artists with Special Needs, at the Agora Gallery on W. 25 St. in Chelsea, features 40 artists and students at RISE in Spirit, a nonprofit that partners with Spirit of Huntington Art Center to provide art education and art therapy for veterans and people with physical and cognitive impairments.

“Even though we have some Salvador Dalis in the front, the most special art in the gallery is from them,” said Rairis Martins, exhibition coordinator at the Agora Gallery.

“It’s a true honor for me, it’s a big deal,” said Michael Baumann, 23, of Center Moriches, L.I., whose depiction of the Empire State Building is exhibited. “I’m very proud of myself for what I’ve accomplished.”

The 250 works in the show range from drawings and watercolors to mixed media pieces and digital art. Many of them are in bright colors, some are exuberant abstracts and others are quieter figurative works.

Art history is also taught at the cultural center, which shows in the work. Some are done in the styles of Georgia O’Keeffe and Keith Haring, featuring large, ornate flowers and dancing figures.

“People with developmental disabilities, autism, they’re just like you and I, they want to make decisions and express themselves,” said Charles Evdos, executive director of RISE Life Services. “This gives them therapy, basically. Some of them, they’ve come out of their shell, they’re talking to people, smiling.”

As delighted as the artists and their families are, they aren’t the only ones.

“Each of them has their story,” said Martins. “They are, quite frankly, amazing. One of the kids even cried seeing his work in the gallery. It’s such a special event.

“We’re just so proud and happy to be able to have their art here.”

From Norman's Desk

Last month what is being described as "landmark legislation" was signed into law by Governor Phil Murphy after passing the NJ Legislature nearly unopposed._The new law updates the NJ WorkAbility to remove a major barrier to employment and career advancement of New Jerseyans with disabilities.

NJ WorkAbility is the state's Medicaid Buy-In program that allows people with disabilities who work to keep Medicaid if their incomes exceed the normal limits.

People are describing this law as "landmark" because of the extraordinary efforts by people with disabilities, advocacy groups, and government Councils worked together for its passage and enactment. In my 40 years as an advocate, I can count on my hand how many times this type of coalescing around disability legislation by the entire Disability Community.

It was a very empowering and thrilling process to go through with different forms of advocacy being utilized, and it demonstrates how working together can bring about positive change.

So, what's the big deal? The new law expands access to NJ WorkAbility in the following five ways:

1. **Complete removal of the Unearned Income Limit, previously at 100% of the Federal Poverty Level (FPL in 2022 is $1,074/month for an individual). Previously, individuals with disabilities became ineligible, usually because of the following components of Unearned Income:**

    - **retirement, disability, or survivors' benefits, received based on parents' work records**
    - **paid leave and unemployment benefits**
    - **two-thirds of Child Support received by adult disabled children from parents who are divorced**

2. **Complete removal of the Earned Income Limit, previously at 250% of the Federal Poverty Level.**

3. **Continuation of Medicaid coverage through WorkAbility for one year after a job loss. The new law allows unemployed WorkAbility enrollees to focus on job search and their return to work.**

4. **Complete disregard of spousal incomes and assets in financial eligibility determination of the individual.**

5. **Removal of the upper-age limit for WorkAbility enrollees. Currently, individuals ages 65 and older are not eligible for NJ WorkAbility.**

The new law does not change WorkAbility's asset limit, currently at $20,000 for an individual. Primary home, a car, and assets in 401 (k) / IRA are not countable in WorkAbility's financial determination. ABLE account is another option for eligible individual's asset accumulation.

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CDC Director Apologizes To Disability Advocates For 'Hurtful' Comments

Reprinted from DisAbility Scoop / by Michelle Diament /January 18, 2022

Centers for Disease Control and Prevention Director Rochelle Walensky apologized to disability advocates after calling it "encouraging" that most vaccinated individuals who have died from COVID-19 "were unwell to begin with," but they say the CDC needs to do more.

Walensky drew ire from many with disabilities after an appearance earlier this month on ABC's "Good Morning America" where she discussed a new study looking at the effectiveness of COVID-19 vaccines.

"The overwhelming number of deaths, over 75%, occurred in people who had at least four comorbidities, so really these are people who were unwell to begin with, and yes, really encouraging news in the context of omicron," Walensky said during the appearance. "We're really encouraged by these results."

Individuals with comorbidities like Walensky described, however, are people with disabilities and their lives and the risks presented to them by COVID-19 shouldn't be dismissed, disability advocates say.

The CDC director's remarks spurred an uproar on social media and led nearly 150 disability advocacy groups to sign a letter to Walensky demanding an apology and calling for policy changes. Specifically, the letter says that the CDC should factor the impacts on those most at risk in decisions about COVID-19 isolation guidance and that the agency should ensure that recommendations and response efforts generally are inclusive of people with disabilities.

"Describing the deaths of people with four or more comorbidities as 'encouraging' because they were 'unwell to begin with' encapsulates the exact problem that we, people with disabilities and our family members and allies, have faced the entire pandemic: The public health response to COVID-19 has treated people with disabilities as disposable," reads the letter. "The CDC is not the only agency that has failed to address the needs of people with disabilities during the pandemic, but your comments highlighted a trend of long-standing policy failures that have slowly eroded the trust of the people with disabilities in the pandemic response."

The angry reaction to Walensky's comments is the culmination of long-running concerns from advocates that the needs of people with disabilities during the pandemic have been all but ignored by the federal government. Bethany Lilly with The Arc said that previous outreach to the CDC director from disability advocates regarding access to vaccines and boosters, for example, did not garner a response.

Walensky met with representatives from The Arc, the Autistic Self Advocacy Network, the American Association of People with Disabilities and seven other organizations Friday afternoon to apologize for what the CDC described as a "hurtful, yet unintentional, statement pertaining to COVID-19 deaths and comorbidities." The CDC said that Walensky also committed to regular meetings between senior leaders at the agency and disability groups.

Now, advocates say they want a public apology from Walensky as well and they're looking for the agency to follow through on policy changes that reflect their concerns.

Maria Town, president and CEO of the American Association of People with Disabilities, called the dialogue with Walensky "long overdue."

"I do hope this is a turning point," Town said.

By Jeremy Einbinder / reprinted from Disability in Focus Blog / April 13, 2021

One of the ways in which people with disabilities might known that a product is easy to intuitively use or an environment is intuitively easy to navigate is how little it needed to be adapted specifically to their needs.

Paradoxically, the less something needs to be “made accessible” in order to use, the more accessible it might be. In a world dominated by an unconscious ideal of how someone’s body “should” work, or how someone “should” think or learn, that able-bodied neurotypical society has never abandoned since the advent of social classes, instances of life which do not have to be re-molded in order to satisfy our needs or wants is crucial. This is universal design. Coined by architect Ronald Mace, universal design is, according to the National Disability Authority, “the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability.” It continues, “An environment (or any building, product, or service in that environment) should be designed to meet the needs of all people who wish to use it. This is not a special requirement, for the benefit of only a minority of the population. It is a fundamental condition of good design.”

The prevailing approach to accessibility seems to be one of workarounds. That is, a society which is by default inaccessible and, through patchwork, made incrementally more accessible as an add-on, or an afterthought. For example, a building with an accessible entrance in the back, away from everyone, or a small lift to combat stairs where a ramp could have been easily placed. The ramp would be an example of universal design. The seven principles of universal design, according to the National Disability Authority, are as follows,

PRINCIPLE ONE: Equitable Use
The design is useful and marketable to people with diverse abilities.
It provides the same means of use for all users: identical whenever possible; equivalent when not. It is appealing to all users. It does not stigmatize them, and it equally ensures their privacy, security, and safety.

PRINCIPLE TWO: Flexibility in Use
The design accommodates a wide range of individual preferences and abilities, such right or left-handed access and use, accuracy, facilitating the user’s accuracy and precision, and facilitating their pace.

PRINCIPLE THREE: Simple and Intuitive Use
Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.
It is as simplistic as possible and consistent with user expectations and intuition. It also accommodates a wide range of literacy and language skills, and arranges information consistent with its importance, and provides effective prompting and feedback during and after task completion.

PRINCIPLE FOUR: Perceptible Information
The design communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities. with sensory difference.

(continued page 7)

Using different modes (pictorial, verbal, tactile) for redundant presentation of essential information, the design contrasts essential information and surrounding and makes the essential information as easy to understand as possible, and yet also presents a variety of ways information can be described. This is especially helpful for people

PRINCIPLE FIVE: Tolerance for Error
The design minimizes hazards and the adverse consequences of accidental or unintended actions.
This design minimizes hazards and errors, built in such a way so that the user does not have to be overwhelmingly vigilant.

PRINCIPLE SIX: Low Physical Effort
The design can be used efficiently and comfortably and with a minimum of fatigue, such as use in a neutral body position and the minimizing of repetition.

PRINCIPLE SEVEN: Size and Space for Approach and Use
Appropriate size and space are provided for approach, reach, manipulation, and use, regardless of user's body size, posture, or mobility.
This essentially ensures that a user, spectator or viewer is comfortable sitting or standing and can participate all the same, having all the room needed for any assistive device.

Universal design is slowly beginning to work its way into the mainstream, with companies starting to recognize its importance. Nike's GO Flyease shoe is the company's first hands-free sneaker, which will be made available on April 30. Although it doesn't explicitly promote people with disabilities in its advertising, it is clear that a sneaker that does not require use of one's hands may be extremely useful to the disability community.

Elsewhere, TechCrunch, an online newspaper covering high tech and start-up companies recently held a paneled discussion on universal design. A representative of the company said,
"We learned that on one level the notion of accessibility is very simple: making products that everybody can use. However, from a company-building point of view, it's also important to think about accessibility from an internal tooling and processes perspective. It's not enough to have accessible products for your users. If the software tools or ways of working at your startup exclude people with various disabilities, it's infinitely harder to design accessible products anyway, as prospective or existing employees with disabilities will be prohibited from doing their best work."

There is an immense challenge of shifting entire infrastructures and designs from being "adapted" to being universally applicable to as many people as possible. However, universal design is a simple and all-encompassing principle that could be the guiding force behind disability liberation and hopefully the destruction of systemic ableism.

An article on the website Popular Science written by Eleanor Cummins and titled, "Designing spaces with marginalized people in mind makes them better for everyone," explains how.
"Today, these shallow slants," referring to curb cuts, "are an essential feature of the pedestrian landscape across the United States."

As opposed to the public thinking that curb cuts are especially designed for people with disabilities, the article posits that curb cuts are fully integrated into general society, as a normal part of design, a design that not only works for people with disabilities but for everyone else as well.
The "curb-cut effect," which is the phenomenon of universal applicability, shows that supporting marginalized groups of people often ends up helping much larger swaths of society.

"Whether it's applied to accessible design, investments in social welfare, or pioneering legislation, study after study shows the effect has the power to uplift us all," Cummins says.
It is possible to have a world in which the differences in the way people navigate the world and perform their activities of daily life become smaller and smaller, and stigmatize people less and less. There is no possible environment that is too accessible, or one that marginalized able-bodied neurotypical people, so let's make this world as accessible as humanly possible. That starts with the principle of universal design.

A Catch-22 Trips Up Some In Legal Guardianship Who Try To Regain Independence

Reprinted from DisAbility Scoop article by Carter Barrett/Side Effects Public Media | January 11, 2022

Ten years ago, Nicholas Clouse was riding shotgun in his friend's Camaro when the car jerked and he felt himself flying through the air. Clouse's head slammed against the passenger-side window.

The traumatic brain injury he sustained in the wreck led to severe memory loss, headaches and insomnia. Clouse, who was 18 then, didn't recognize his friends and family.

Shortly after the crash, Clouse's mother and stepfather petitioned to be his legal guardians, which meant they'd make all his financial and health decisions. They said the situation would be temporary. A judge in Indiana made it official.

Years after recovering, Clouse wanted to make his own choices again — to put gas in his car, buy his daughter diapers and take his wife out for dinner without needing permission. But he ran into opposition. His parents didn't want to give up their power, Clouse said, and he had to find a way to fight for his rights.

Clouse testified at a U.S. Senate committee hearing focused on guardianship reform. Over time, Clouse's traumatic brain injury improved. He started working as a welder, met his future wife — and got his parents' permission to marry her. Clouse wanted out of the guardianship, he said, but he faced a catch-22. To regain his independence, he needed to get advice from a lawyer. But to hire a lawyer would require his parents' approval since they controlled his finances.

Clouse eventually found pro bono legal representation through the advocacy group Indiana Disability Rights. In January 2021, Clouse and his lawyer filed a petition to end the guardianship. According to court documents, his parents responded by insisting on a psychological evaluation of Clouse's decision-making ability. The evaluation determined guardianship was unnecessary and dampening his ability to make independent decisions.

Eight months later, in August, Clouse's parents agreed to end the guardianship.

In recent years, court decisions have shifted state policies toward less restrictive options that give adults with physical or intellectual impairments more independence and provide them with support for making decisions. Advocates for people with disabilities say this change is long overdue, and some argue the system needs a complete overhaul.

"People with significant disabilities have long been discriminated against because people think that they (lack) the ability to make decisions," said Derek Nord, director of the Indiana Institute on Disability and Community.

Guardianship cases often involve people with disabilities, older adults, people recovering from an injury or medical condition, or people with severe mental illnesses.

An official count does not exist, but the National Center for State Courts estimates that about 1.3 million adults in the U.S. are in legal guardianships. In Indiana, where Clouse lives, 11,139 adults are in permanent guardianships, according to state officials.

A task force formed to examine the use of legal guardianships in Indiana reported that no medical evidence of incapacity was presented in 1 in 5 guardianship cases in the state. The 2012 report also says that in cases in which evidence was presented, the medical reports were often incomplete or illegible.

Guardianship differs from most other legal proceedings in that the burden of proof tends to fall on the person with a disability, who must convince the judge that the arrangement is unnecessary, Dinerstein said.

Less Restrictive Alternatives

In 2019, Indiana joined a handful of other states — including Delaware, Ohio, Texas and Wisconsin — in passing laws to require judges to consider less restrictive alternatives to guardianships.

Supported decision-making is one of these alternatives. Adults in these arrangements consult a support team — which can include friends, relatives, social workers, case managers or paid support members — about big decisions. But unlike in a guardianship, the individual can make the final decision.

"Many of us … run important decisions by other people in our lives who are important to us — family, friends," Dinerstein said. "(Then) you get to decide whether to listen to the advice."