

New Horizons

Housing That Supports Independence



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Disability Discrimination In Health Care Under Scrutiny

Reprinted from DisAbilityScoop by Shaun Heasley | January 19, 2021

Federal officials are weighing a rewrite of regulations designed to ensure that people with disabilities do not face discrimination from medical providers amid persistent concerns about unequal access.

The U.S. Department of Health and Human Services' Office for Civil Rights is issuing a request for information on disability discrimination in the health care and child welfare systems.

The move comes as the agency said that it "is aware that significant discrimination on the basis of disability against persons with disabilities persists in the nation's health care system and in its child welfare system." In addition to reports of discrimination that have surfaced during the course of HHS OCR's own activities, officials said that they've heard about issues from researchers, advocates and disability organizations.

As a result, HHS OCR is reviewing existing relevant regulations and mulling revisions.

Now, the agency is looking for feedback on what any updates should address. Specifically, officials said they would like information about disability discrimination in the context of organ transplants, life-saving or life-sustaining care, suicide prevention and treatment, crisis standards of care, health care value assessment methodologies, child welfare and the availability of auxiliary aids and accessible medical equipment.

HHS OCR said it wants input from people with disabilities, their families, providers, disability advocates, hospitals, child welfare agencies and other stakeholders. In addition to information on discrimination, the agency indicated that it would like to hear about the costs and administrative burdens related to various approaches to tackling the issue.

We believe that persons with disabilities should not be discriminated against in vital health and human services including organ transplants, suicide prevention, the provision of life-saving care and child welfare," said Roger Severino, director of HHS OCR. "We believe the American public agrees that persons with disabilities deserve full protection under law and we seek public input on achieving that goal with respect to the most consequential, life-altering contexts."

Once the request for information is published in the Federal Register, the public will have 60 days to submit comments.

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“My Two Cents”

By Tim Doherty, Executive Director



“ Remembering Project Freedom’s Angel – Jack Rafferty ”

It was sad for everyone in Hamilton and Mercer County to learn of Jack’s passing this February. He did so much for the citizens of Hamilton Township and for a little organizations like Project Freedom. Many people may not know the full true story, of how Project Freedom got established. Much of who we are today, couldn’t have been done, without Jack’s help. So, here’s the story.

We all know that Project Freedom was Norman Smith’s dream for achieving his independence. When he returned home from college, living once again, with his elderly parents, he felt his life was taking a step back, rather than a step forward with a new life. He had successfully lived in New York, at college with his roommate, and knew that he could accomplish anything he put his mind to, if only given the supports he needed.

So, Norman along with Frieda Applegate, started the Nottingham Recreation Center for the Physically limited. They organized a day program and then began to think about the other needs such as housing. Long and short, Norman gathered community support with others, including myself, who had family members with a disability. Along the way, Jack Rafferty, the mayor of Hamilton heard about Norman’s efforts and over the early years provided meeting space for his program activities. Eventually Jack ran and won a single term in the New Jersey Legislature, and as part of that membership was able to get a single grant for \$ 150,000 for Project Freedom. After several years of fundraising, bingos, and the like, it was this grant that really gave Project Freedom the ability to hire an architect and seriously talk about housing.

That effort became reality in 1990, when Project Freedom was able to win tax credits that year and ultimately build our first Project Freedom on Hutchinson Rd in Robbinsville. We tried to find land in Hamilton, however none was available at the time. We did finally build in Hamilton in 2000, when we purchased land from St. Anthony’s on Kuser Road.

Along the way, many people helped get Project Freedom where we are today, but it was that initial support from our Hamilton Angel, Jack Rafferty, that really got us going. In subsequent years, Jack would come to our yearly gala’s and helped with our ongoing fundraising. He was so proud when we were able to finally bring our housing to Hamilton, and build our 48 units there on Kuser Road. As Mayor of Hamilton Jack helped so many other non profits and community organizations in Hamilton. I know that he is personally responsible for the success of the Hamilton Y and all that they offer Hamilton consumers. Jack Rafferty will always be remembered as our Angel.

A handwritten signature in blue ink that reads "Timothy J. Doherty". The signature is fluid and cursive, with a large 'T' and 'D'.



From Norman's Desk

This month is the 37th anniversary of Project Freedom's incorporation as an organization in New Jersey. It was our first serious step toward bringing an idea into concrete reality.

In the life of any organization, there are moments in time when an individual makes a big difference. Project Freedom has had many, but in those early years when the path to success was fraught with obstacles, one political person was truly Project Freedom's first angel.

John K. "Jack" Rafferty was mayor of Hamilton Township when the "Project Freedom" concept was first conceived. By sheer happenstance, I was invited to write for Jack's unsuccessful run for governor, and as I have written many times, that brief opportunity gave me visibility and credibility to promote the idea of what Project Freedom became.

In fact, our name came out a meeting with Jack when he asked Frieda Applegate and me what we were going to call this "house" we wanted to build. Frieda looked at me, and with very little thought "Project Freedom" popped out of my mouth. And that became our marketing tool before we incorporated.

A couple years later, Jack became Assemblyman Rafferty, and he was able to secure \$150,000 state grant for Project Freedom through legislation. This was fuel for our planning engine as it empowered us to get architectural plans and hire all the professionals for the development phase of a building project.

Jack did that for us at a time when we were spinning our proverbial wheels. From there, we had a path to move forward. The path had more pitfalls and obstacles, but we had a way forward and professionals to help.

I'm remembering this because my friend Jack Rafferty passed last month. He is mourned by many in New Jersey as a decent and dedicated family man, public servant, and politician who loved his community.

In an online remembrance of Jack, I contributed these thoughts:

"Jack Rafferty was a friend; he was a friend to me, a friend to Project Freedom, and a friend to the disability community. I was a small part of Jack's gubernatorial campaign, and this opened doors for me to co-found Project Freedom. When Jack was in the legislature, he secured seed money that enabled our first complex to be planned. Jack established one of the first Mayor's Office for Disabilities in New Jersey during a time when we had very limited community visibility. He truly was an angel to Project Freedom, and for that reason we gave Jack our first Angel Award."



Right to left: Norman Smith, Bill Mathesius, Tom Keane and Jack Rafferty

We will miss Jack, but his legacy continues every time we open a new community. Rest in Peace, my friend.

Norman A. Smith, Associate Executive Director -
Follow us on Twitter @TheFreedomGuys
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To COVID-19 Vaccines Uneven For Those With IDD

by Michelle Diamant | February 18, 2021

People with developmental disabilities are at significantly greater risk of dying from COVID-19, but whether or not individuals have access to vaccines is coming down to which state — or even which county — they live in.

Disability advocates say that access has increased. As of December, just 10 states specifically addressed people with developmental disabilities in their COVID-19 vaccine rollout plans, according to the American Network of Community Options and Resources, or ANCOR, which represents disability service providers across the nation. To date, ANCOR said that has grown to at least 31 states.

“We are really pleased that there has been an improvement in the number of states,” said Donna Martin, director for state partnerships and special projects at ANCOR.

Martin indicated that she’s also heard of individual counties that have elected to prioritize people with developmental disabilities independent of their state.

Research shows that people with developmental disabilities face a three times higher risk of dying from COVID-19. Accordingly, disability advocates have been pushing for months to ensure that this population receives early access to life-saving vaccines. But, when the Centers for Disease Control and Prevention failed to specify those with developmental disabilities in its recommendations for priority groups, advocates were left to plead their case with individual states.

As a result, in some places like Tennessee, vaccines were made available in the highest priority group to all adults with developmental disabilities who are unable to live independently. However, states like California and North Carolina moved people with disabilities down on their priority lists in favor of other groups, leaving advocates to fight to regain quicker access. California subsequently reversed course under intense pressure from advocates. Still, other states like Mississippi, Idaho and Arkansas “have been pretty silent” about people with developmental disabilities, Martin said.

Disparities remain even in many places where individuals with developmental disabilities are being prioritized, with access given to those in residential settings like institutions and group homes, but no accommodation for those living with family or in other community-based situations. “There is such great variability from state to state and even county to county that we cannot really provide a solid assessment of how it is going,” Martin said. “My prevailing concern is that while many states have shifted to include people with IDD in their ‘priority groupings,’ this grouping tends to represent people with IDD in (long-term care) and/or group homes. The population is divided into subsets — group home versus community — wherein people with equally elevated risk of severe outcomes do not have equal access to the vaccine.”

With such inconsistency across state lines, Johns Hopkins University’s Disability Health Research Center and the Center for Dignity in Healthcare for People with Disabilities at the University of Cincinnati Center for Excellence in Developmental Disabilities launched a new dashboard this month to track where people with disabilities fall in each state’s prioritization. The tool, which is being updated weekly, breaks down when vaccines are available to people with disabilities in four different groups — those in long-term care settings like nursing homes, individuals in other congregate settings such as group homes, people with chronic conditions and other groups. Depending on the state, this last category can include those receiving direct support in the community, people with intellectual or developmental disabilities or those who benefit from certain Medicaid programs.

Sabrina Epstein, a student at Johns Hopkins who has Ehlers-Danlos Syndrome, came up with the idea to track vaccine prioritization across states after finding it difficult to determine when she would qualify. “We want people to be able to use this tool to identify if they or their family or friends qualify for a vaccine in their state and to advance advocacy efforts,” Epstein said.

Meanwhile, the National Council on Disability, a federal agency charged with advising the president and Congress on disability issues, is pressing governors to step up and ensure that people with disabilities have better access, no matter where they call home. “As you are aware, persons with disabilities are disproportionately affected by the COVID-19 virus,” NCD Chairman Andrés Gallegos wrote in a letter this month to New York Gov. Andrew Cuomo in his capacity as chair of the National Governors Association. “As the distribution and allocations of the vaccine continues, we urge you to emphasize to governors and health departments that more equitable frameworks must be determined that incorporates persons with disabilities with IDD, those with limited mobility, and those with underlying health conditions in priority groups, regardless of their setting.”

Bipartisan Disability Caucus forms after pandemic exposes flaws in NJ's system of care

By Gene Myers / Reprinted from NorthJersey.com / Dec 15, 2020

Legislators have promised to come together to focus on disability issues at the end of a rough year for New Jerseyans with disabilities.

Senate President Stephen Sweeney will chair a newly formed bipartisan Disability Caucus. "This bipartisan caucus presents the opportunity to further improve health care, education, transportation, housing and employment for New Jersey citizens with disabilities. I look forward to working with my colleagues and the many advocacy groups across this state who are committed to helping people with disabilities live self-determined, fulfilling lives so we can move New Jersey forward for everyone," Sweeney said in an email.

The formation of the caucus comes not a moment too soon, said advocates who spent the pandemic lobbying for essentials like hospital rights, protective gear and access to food. "We need to be served as a population," said Javier Robles, chair of the New Jersey Disabilities COVID-19 Action Committee, which published a report condemning the state for failing to protect its most vulnerable residents.

In March, companies that run group homes for people with developmental disabilities said their lobbying for protective gear fell on deaf ears. In August, health care professionals who serve the same population said their clients were isolated too long as they remained in quarantine even as everyone else was emerging from lockdowns. Six months from the start of the pandemic, thousands of residents were still waiting for permission to go back to their jobs, which in some cases were already being done by people without disabilities.

"The Caucus will establish a platform in which legislators and their staff can be educated on key issues and where they have a place to reach out to organizations and self-advocates who have lived these experiences as they are considering issues, said Mercedes Witowsky, executive director of the New Jersey Council on Developmental Disabilities.

Her group had been pushing to establish a caucus for a year, Witowsky said, and if there were such a thing as a silver lining to the pandemic it was that it highlighted flaws in the systems set up to help residents with disabilities, who make up 24.6% of New Jersey's population, according to the CDC. That lit a fire, and lawmakers announced the Caucus in a Dec. 1 live stream.

"This unfortunate pandemic and emergency has exposed many cracks in the systems of care to our disability community," said caucus member Assemblywoman Valerie Vainieri Huttie, a Democrat representing the 37th District.

Maybe that's why more than a couple of dozen lawmakers from both sides of the aisle in the House and Senate chose to take part in the Caucus, said Witowsky. It's slated to meet four times next year, with the first meeting to focus on "COVID and the disability community" in late January. But Witowsky hopes the effects of the caucus will be greater.

"As they go back to their work, they include disability matters in their conversations, in drafting legislation. It's also a way that our community self advocates, advocates and family can identify with leadership in the state," Witowsky said. "They will know that Senator [Thomas] Kean supports the caucus and is a founding member and when they have an issue they will go to Senator Kean's office. The Senate and Assembly members who signed on signed on knowing that they were making a commitment to disability issues," he said.

Founding legislative Disability Caucus members are:

Sens. Sweeney, Anthony Bucco, Kristin Corado, Patrick Diegnan Jr., Thomas H. Kean, Jr., Fred Madden Jr., M. Teresa Ruiz and Troy Singleton; Assembly members Daniel Benson, Annette Chaparro, Nicholas Chiaravalloti, Ronald S. Dancer, Joann Downey, Aura Dunn, Louis Greenwald, Eric Houghtaling, Valerie Vainieri Huttie, Pamela Lampitt, Yvonne Lopez, Nancy Munoz, Carol Murphy, Holly Schepisi, Adam Taliaferro, Britnee N. Timberlake, Anthony Verrelli and Andrew Zwicker.

Teams To Examine Self-Driving Cars For Individuals With Special Needs

By Ed Blazina, reprinted from the Pittsburgh Post-Gazette/TNS | January 26, 2021

PITTSBURGH — John Tague, chairman of the Pennsylvania Transportation Alliance, uses a wheelchair and understands the daily mobility challenges faced by people with disabilities. That's why Tague is excited that a team from Carnegie Mellon University has received a grant to develop a prototype system for autonomous vehicles that will allow anyone to control most vehicle functions — from summoning the vehicle to their location to controlling the windows and the temperature of the air conditioning — from their cellphones.

The team, based in CMU's Human-Computer Interaction Institute, was among 10 across the country that received \$300,000 grants this month from the U.S. Department of Transportation to continue developing their ideas to make autonomous vehicles more practical for people with disabilities.

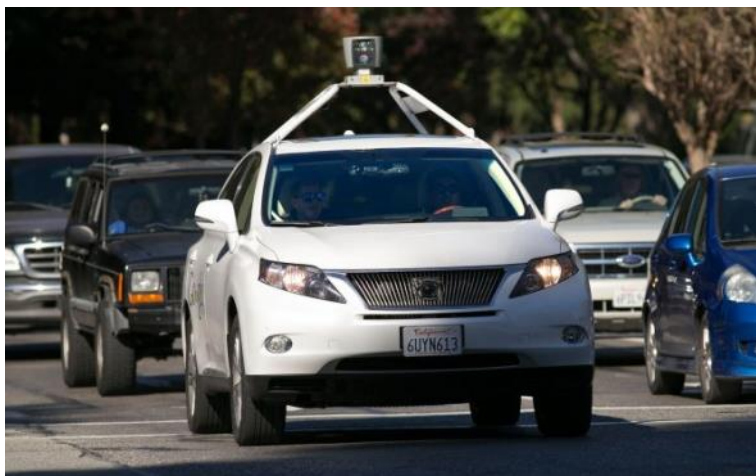
The grant is part the DOT's Inclusive Design Challenge, a competitive program to improve mobility for people with disabilities. Three finalists will split \$2 million to produce their product. Nik Martelaro and Patrick Carrington, assistant professors at CMU, said their first step was to assemble a team of advocates for people with disabilities to determine what would help them use autonomous vehicles. Tague and others told them that many people with disabilities can use mobile phones with a regular keyboard, touch screen, voice commands or Braille keyboard, and linking those with autonomous vehicles would be a great benefit.

"We had ideas that we thought might be good, but we really relied on communications with the community to find out what they need," Carrington said. "We really let that guide us."

Martelaro said it quickly became clear that the mobile phone is "the community gateway" for people with disabilities. The group and designers believe it would be a great benefit if all autonomous vehicles have a common system for communicating with mobile devices. "The phone is already something people have and use," Martelaro said. "How do you leverage that to control an autonomous vehicle? We hope to develop a standard system for all manufacturers."

Student researchers will begin working on the prototype when they return to classes Feb. 1, said Sarah Fox, another assistant professor on the development team. The project will be submitted for another round of judging in March 2022.

Tague said it's a real benefit for people with disabilities to be involved with a product from the development stage rather than trying to adapt something that already exists.



"A lot of times, we don't get to the table until after something has been developed," he said. "Here, we have a chance to have that input at the beginning."

Fully autonomous vehicles may be more than 10 years away. But Tague and the developers say a system that allows people with disabilities to operate items like air conditioning or communicate with other riders will be beneficial even before that happens.

"This (grant) is great for us," Martelaro said. "We get to do the work now. Our goal is to get the tested pattern to the point where the car companies say they can build off of that and produce a system every vehicle can use."

One of Google's self-driving vehicles makes its way in Mountain View, Calif. (John Green/Bay Area News Group/TNS)

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March Madness

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