New Housing That Supports Independence



Norman A. Smith Editor Judy Wilkinson Co-Editor

Tracee Battis Executive Director

Norman A. Smith Assoc. Executive Director

Robert Fasulo Construction Manager

Stephen J. Schaefer Chief Financial Officer

Anne Hamlin Dir. of Housing Development

> Marilou Chinchilla Human Resources

Jacklene Elsowiny Regional Manager Freedom 1, Town Center South & Hamilton

Freedom 1 Robbinsville Dee Ferra Property Manager / SS Coordinator

> *PF at Hamilton* Tanja Silver Social Services Coordinator

> *Town Center South* Jacklene Elsowiny Social Services Coordinator

Frank Sciarrotta Regional Manager & Compliance Manager Lawrence, Hopewell & West Windsor

> *PF at Lawrence* Brianne Devlin Social Services Coordinator

Freedom Village at Hopewell Cecilia Funk Social Services Coordinator

Freedom Village at West Windsor JoAnne Sherry Social Services Coordinator

Dara Johnston Regional Manager Westampton, Gibbsboro & Toms River

> Freedom Village at Westampton Dara Johnston Social Services Coordinator

Freedom Village at Gibbsboro Wendy Pritsky Social Services Coordinator

Freedom Village at Toms River Laurie Solymosi Social Services Coordinator

Freedom Village at Woodstown Sammi DeMaris Social Services Coordinator

NJ Affordable Housing could see \$300M Infusion Under Murphy Budget Proposal

Reprinted from NorthJersey.com by Ashley Balcerzak

Using \$305 million in federal funds, the governor wants to propel across the finish line close to 50 fully affordable housing projects that have been approved in towns' fair housing court settlements but haven't been built due to lack of funding. Combined, they total about 3,300 units. "The Affordable Housing Production Fund will provide real stability for communities," Murphy said. "It will ease the burden on municipalities. And it will short-circuit potential lawsuits by developers. But, most importantly, it will get working families into homes."

Among the projects that could be eligible, according to the nonprofit Fair Share Housing Center:

- Columbus Way in Paramus: About 90 affordable units for low- and moderateincome families on a property
- near Garden State Plaza and the Gennarelli Sports Complex
- 11 Main Street in Millburn: 75 affordable family apartments proposed in downtown Millburn, Essex County
- 720 Eighth Street in Union City: 101 affordable apartments for seniors

Richwood-Aura Road development in Harrison Township: 84 accessible affordable homes for people with disabilities being developed by the nonprofit **Project Freedom**, **with 21 units set aside for people with developmental disabilities**. "This fund seems promising, and we hope that it's a down payment on providing the housing affordability and security that we know New Jersey's working families and seniors need," said Staci Berger, president and CEO of the Housing and Community Development Network of New Jersey. With rising costs for such construction supplies as lumber and drywall, it can be very difficult to finance properties for low and moderate income families, said Tracee Battis, director at Project Freedom, a nonprofit that develops and operates housing for people with disabilities.

The project in Harrison requires \$26 million in development costs, and the nonprofit plans to apply for federal tax credits to help cover the price tag. "Any kind of gap funding is helpful because it's so tight to build these projects ... they need every penny they can get," Battis said. "Tax credits are very competitive. Financing can mean the difference between us getting this project done in a year or having to wait much longer."

Under a series of New Jersey Supreme Court rulings called the Mount Laurel decisions, municipalities are required to provide their "fair share" of affordable apartments to low and moderate-income families. After the state's top court declared that the statewide agency meant to oversee this process was "nonfunctioning," municipalities were to negotiate in Superior Court the numbers of affordable units they need to offer during a specific time range with the nonprofit Fair Share Housing Center. The settlements include proposed housing sites or developments that will contain the discounted apartments.

To see the interview online with our own Executive Director, Tracey Battis, click on this link: <u>https://www.njspotlightnews.org/video/murphy-proposes-new-affordable-housing-fund-its-long-overdue-advocates-say/</u>

Page 2

Ed Department Prods Schools On Compensatory Services For Students With Disabilities

Reprinted from DisAbility Scoop / February 22, 2022 by Michelle Diament

Amid a rise in complaints, federal education officials are reminding schools across the nation about their obligation to provide compensatory services to students with disabilities.

The U.S. Department of Education's Office for Civil Rights issued a new <u>fact sheet</u> last week doubling down on the responsibilities schools have under Section 504 of the Rehabilitation Act of 1973.

Even during the COVID-19 pandemic, the law requires that students with disabilities are provided appropriate evaluations and services, the guidance indicates, adding that the right to a free appropriate public education remains intact "regardless of the challenges schools face."



In circumstances where students do not receive the services they should, federal officials say that schools must convene a group to determine if compensatory services are required. This could mean making up for physical therapy that a child lost out on during school closures or services for a student who did not receive a timely evaluation, according to the fact sheet.

"Providing compensatory services to a student does not draw into question a school's good faith efforts during these difficult circumstances," the guidance indicates. "It is a remedy that recognizes the reality that students experience injury when they do not receive appropriate and timely initial evaluations, re-evaluations, or services, including the services that the school had previously determined they were entitled to, regardless of the reason."

Decisions about whether compensatory services are warranted and to what degree should be made by people who are knowledgeable about the student, federal officials said. They ought to consider the frequency and duration of missed services, if the services that were provided were appropriate to the student's individual needs as well as the child's performance and rate of progress, among other factors.

An Education Department spokesperson told Disability Scoop that the agency was prompted to issue additional guidance after seeing an increase in complaints to the Office for Civil Rights alleging a failure to provide FAPE.

"The new fact sheet differs from previous guidance in that it directly addresses the requirement to offer compensatory services, acknowledging that these services may be necessary even when a school has acted in good faith in working with students and their families to provide equal access and FAPE," the spokesperson said.

A survey of parents across the country released last fall by the Council of Parent Attorneys and Advocates, or COPAA, <u>found that</u> only 18% of students with disabilities had been offered compensatory services despite widespread concerns from families about learning loss, regression or slower than expected progress toward goals since the onset of the pandemic.

"We do continue to hear that families are struggling," said Denise Marshall, CEO of COPAA, which works to advocate for the rights of students with disabilities and their families. "I certainly hope the guidance helps — and I urge families who don't find that to be the case and are still struggling to submit OCR complaints."

Chase Bank Took \$2,500 Intended For ABLE Account, Then Wouldn't Give It Back

Reprinted from The Oregonian/OregonLive/TNS | March 15, 2022 by Mike Rogoway

PORTLAND, Ore. — When Jeanne Tindall went to the bank last October with \$2,500 in pandemic relief funds on behalf of a man with a disability who she helps cares for, she envisioned him someday using the money to pay for future care, or maybe for therapeutic horseback rides.

Tindall has been legal guardian to the Oregon man, named Stephen, since the late 1980s. He is 46 and lives in a group foster home near Portland because he has a cognitive disability and cannot care for himself. So Tindall helps, managing his finances and make sure he's getting what he needs. The aid money could be helpful down the road, so Tindall took it to her local Chase Bank branch in Albany and put it into a guardianship account on Stephen's behalf.

In November, Tindall went back to the bank to shift the money into an ABLE account, a special category of savings designed to enable people with disabilities to set aside money without reducing their eligibility for government aid programs. Chase refused to move the money, though, notifying Tindall that Stephen's account had "insufficient funds."

So Tindall spent three months seeking to pry the money back from Chase. She says the bank refused to hand it over, providing a variety or explanations ranging from fraud concerns to questions about who was authorized to access the account.

Recently, Chase relented and restored Tindall's access to Stephen's account. The bank's reversal came one day after The Oregonian/OregonLive inquired about the situation. In a statement, Chase said it couldn't restore Tindall's access to the money without additional documentation about her guardianship. But Tindall said she provided all that information when she opened the account.

To Tindall, the three-month struggle for access to the funds points to how difficult it is to resolve problems with large corporations — especially for people with disabilities, and for their advocates. At times, Tindall said she would spend well over two hours on hold trying to get answers from Chase. Once, when she went to check Stephen's account online, it listed a negative balance totaling \$1 billion. Tindall took a screenshot to document that absurdity.

"These institutions may put things in place to 'protect the person with the disability' but what that does is often make negative assumptions about their capabilities or who they choose to have in their lives," Cooper said.

While it's important to protect people with disabilities against exploitation, Cooper said it's also important to distinguish between measures that help and those that just create obstacles. The Americans with Disabilities Act requires public institutions provide "equal access" to people with disabilities, and that includes that ability to establish bank accounts.

"They proceeded as though I had no power or position, or worse, that I was fraudulently posing as if I did," Tindall said. "For me and many people, that one piece of paper ... is the one bit of power and control available to protect the person we care about — and we are talking about some of the most vulnerable people in our society." And if documenting her guardianship was an issue, Tindall said she cannot understand why Chase would have allowed her to open the account in the first place.

"If corporations like Chase can pressure and mistreat guardians (and by default, the wards) and then turn around and say it was the guardian's fault for not giving them, 'the paperwork they needed,' then the bully wins," Tindall said.

From Norman's Desk

My readers know that I often write about weather and being prepared for weather events that can cause havoc with all our lives but especially the lives of people with disabilities. Sometimes readers ask why. Why worry about the weather?

This past February, the Mt. Holly office of the National Weather Service (NWS) put out a summary of 10 impactful weather events for 2021. I was shocked that we had as many as 10 significant weather events, and I'm willing to bet that most of you don't remember more than three.

We all probably remember Hurricane Ida, but do you remember Tropical Storm Elsa that spun out two tornados in eastern NJ? How about the "everyday" severe thunderstorms on July 1st that caused "straight line wind damage through-

out south Jersey. Then we had Fred, Henri, and Ida impacting us within two weeks of each other causing major flooding.

Winter weather had its impacts as well. The three-day winter storm at the end of January dumped 24 inches of snow in the northwestern parts of NJ. This storm was listed as the third most impactful event, but who actually remembers it?

Coming in second was the July 29th tornado outbreak with 10 confirmed tornados with one EF3 tornado and two EF2s. Thankfully, there were no fatalities and no serious injuries, but there was widespread damage.

Of course, coming in as the most impactful was Hurricane Ida with historic flooding and seven more tornados (1 EF3, 2 EF3).

Any one of these 10 impactful weather events could have turned uglier with far greater impacts on all our lives. This is why I write about weather awareness and preparedness. To paraphrase what I say every September, you never know how a bright, beautiful, and refreshing day may turn dark and stormy.

For more "weather readiness" information, go to: <u>https://www.ready.gov/severe-weather</u> or <u>https://www.projectfreedom.org/norms-emergency-preparedness-desk/</u>





Page 5 They Weren't Wanted at the Paralympics. They're Excelling Anyway By David Waldstein / reprinted from The New York Times March 8, 2022

ZHANGJIAKOU, China — Until the moment Cécile Hernandez of France was handed an official racing bib and a time slot on Saturday, she still feared that race officials would forbid her to compete. Only the day before, after months of legal wrangling, she sat in her room in the Olympic Village, listening via video conference to a court proceeding in Germany in which an opposing team's national delegation questioned her level of disability.

Her lawyer had assured her that all would be fine, that all she needed to worry about was zooming as fast as possible down the Genting Snow Park snowboarding course at the Beijing Paralympics. But with legal jargon still clattering around her mind — along with an image from one of her social media accounts that was used as evidence against her — Hernandez's anxiety spiked in the form of insomnia, worry and tears.

Hernandez, who has multiple sclerosis, overcame her stress and lack of sleep to win the gold medal in the women's snowboard cross event on Monday. The bronze medalist was the American snowboarder Brenna Huckaby. Hernandez's fellow plaintiff in a bitter legal dispute with the International Paralympic Committee over whether the two could race in the Beijing Games at all.

A spokesman for the Paralympic committee referred to a statement it issued last month that said it was "disappointed" at a court ruling that allowed the women to race. He added that the organization was planning to increase opportunities for female athletes in Winter Paralympics, including, for the first time, six medal events for female snowboarders at the Milan-Cortina Paralympics in 2026.

Hernandez and Huckaby's legal appeal against the I.P.C., which will not be completely resolved for months, goes to the core of classification — a system that para sports use to equitably organize athletes into groups according to their levels of impairment. The goal is to make each competition as fair as possible, much like categories by age, weight and gender. In para sports, it is a complicated process, far from perfect, and complaints arise among athletes about where they and their opponents are classified. But Hernandez and Huckaby were not challenging their classification. They were fighting for their right to race.

Both Hernandez, 47, and Huckaby, 26, are classified as SB-LL1. An SB-LL1 racer has significant impairment in one leg, like an above-the-knee amputation, or significant combined impairments in two legs. But there were not enough qualified LL1 snowboarders to make the race viable, and the I.P.C. shut it down. So Huckaby asked instead to be placed in the men's LL1 race or in the women's LL2, both ostensibly more challenging categories for her. An LL2 racer has an impairment in one or both legs, with less activity limitation than an LL1 competitor. In all para sports, classification is determined by doctors observing the athletes. The I.P.C. declined her request, even though the racers were moving up in class. The I.P.C. is opposed to athletes of one classification moving into events of another. It could affect the integrity of the competition if athletes were allowed to race in whatever classification they chose.

Huckaby and Hernandez hired Christof Wieschemann, a German lawyer, to handle the case because, with the I.P.C. based in Bonn, German courts had jurisdiction. Wieschemann first won a temporary injunction for Huckaby on Jan. 27, arguing that classification systems of any kind in all sports are designed to "protect the weak against the strong," not the other way around.

Using antitrust statutes and laws protecting equal treatment, he argued that the I.P.C. was bound to provide his clients an opportunity to race, and said the organization had forgotten the underlying purpose of the rules — to promote fairness.

Hernandez won her preliminary injunction on Feb.16, and all that was left was a final hearing in the days leading up to the



qualification run at the Beijing Paralypics.Credit... Chang W. Lee/The New York Times

Games. Hernandez flew to Beijing at the end of February and spent five days practicing on the slopes. But then, on Thursday, her case was back in court for a final scheduled hearing. With just three days until the event, the I.P.C., joined now by Canadian Paralympic officials, was protesting the ruling. The Canadians said Hernandez had an advantage based on her level of impairment, and during the proceeding showed a photo of Hernandez from one of her social media accounts to support the argument.



"My disability does not show up in photos of my body," Hernandez said in an interview. "My legs don't work. I have impairment in my eyes. My brain won't allow my body to work. My whole body is disabled." Huckaby and Hernandez

are next scheduled to compete in the women's banked slalom on Saturday. For both, it is a chance at another hard-earned victory.

Demand For Service Dogs Unleashes A 'Wild West' Market Reprinted from Kaiser Health News | March 2, 2022 by Markian Hawryluk,



Jennifer Arnold, founder of Canine Assistants in Milton, Ga., allows Cheeto to smell a scented swab as part of the dog's training to identify seizures. Researchers have isolated several compounds released when seizures occur. (Robin Rayne/KHN)

Jenni Mahnaz admits she's not much of a dog person. She's mildly allergic and the only pet she had as a child was a hermit crab. But once she learned that specially trained dogs could help her daughters with their medical needs, she was willing to do anything to make it happen.

Her oldest daughter, Suraiya, 6, was diagnosed with autism and sensory processing challenges. Soon after, 4-year-old Phoenix was diagnosed with epilepsy.

"Our family is very likely to end up with two service dogs," Mahnaz said. "I think we're probably looking at \$10,000 per dog."

That's a serious hurdle for the Troy, N.Y. family of five whose income is below the federal poverty line, even though they'll save money by buying pups from a breeder and then paying a local trainer to train them as service dogs.

Organizations charge from \$15,000 to \$40,000 for a fully trained service dog, which they have bred, raised, and trained for a year and a half. None of that cost is covered by health insurance. Other trainers have long waiting lists or won't place dogs with young children.

"This is very expensive for us, but I am my girls' parent, and it is my job to do whatever I can to make their standard of living as good as I can," Mahnaz said. "It is a need for them and it will make a big difference in their lives."

Demand for service dogs has exploded in recent years as dogs have proved adept at helping children and adults with an increasing range of disabilities. While dogs once served primarily people with vision or mobility impairments, they now help people with autism, diabetes, seizures and psychiatric disorders. That has overwhelmed nonprofit service dog trainers, who generally donate dogs to patients for at most a small application fee. But unmet needs have helped launch a for-profit service dog industry with hefty price tags.

Rapid growth, however, has come with little oversight, potentially subjecting people who have complex medical issues to huge financial barriers, poorly trained dogs and outright fraud. Those pitfalls are only exacerbated by social media, including fundraising sites like GoFundMe that allow families to meet pricing thresholds they wouldn't be able to afford on their own. The flourishing market emboldens trainers to charge more for their services, confident that the funds will be donated.

Some, like the Mahnaz family, gamble by training their own dogs to lower the cost. But trainers say that the success rate for self-trained dogs is lower than their own — and that families could be out thousands of dollars.

"The dog could absolutely fail. We could end up with an adult dog who cannot be a service animal," Mahnaz said. "The reality is we don't have a choice."

The lack of regulations for service dog trainers has opened the door for scores of backyard trainers who may or may not be qualified to train service dogs, said Lynette Hart, a professor of veterinary medicine at the University of California-Davis. There is no certification process for service dogs, either.

"There's a big opportunity for people who are dog trainers to say, 'Oh, I will sell you one for tens of thousands of dollars," she said. "It's a kind of a wild West issue."

But that also leaves families open to getting burned with little recourse.

"Sometimes they're sold a bill of goods," said Sheila O'Brien, chairperson of the North American board of Assistance Dogs International. The group accredits service dog trainers, but the accreditation is voluntary and only nonprofit organizations are eligible. The group has 80 accredited members and 25 candidate programs in North America. But nobody knows how many unaccredited dog trainers are operating in the U.S. "It's so easy to defraud people over the internet. There's a lot of money to be made here," said David Favre, a Michigan State University law professor specializing in animal law. "It's never been controlled, and it's gotten worse."

In 2018, for example, Virginia's attorney general filed a lawsuit alleging a company named Service Dogs by Warren Retrievers charged families up to \$27,000 per dog but often delivered "poorly-trained puppies with significant behavioral issues and inadequate skills or training." The trainer settled the lawsuit last year for \$3 million.

In 2020, North Carolina's attorney general filed a similar suit against the owner of Ry-Con, a nonprofit service dog trainer. The suit alleged that Ry-Con charged families up to \$16,710 per dog despite knowing the dogs were not adequately trained.

Both training companies are now out of business and the former owners could not be reached for comment.

O'Brien estimates the average training cost in the U.S. is \$30,000 per dog. But trainers must also account for the costs of the 60% of dogs who won't make it through the training.

Sometimes dogs wash out because of health or temperament issues. "Some are just lovers and not workers," O'Brien said.

Jennifer Arnold, founder of Canine Assistants, a Milton, Ga. nonprofit training organization, said much work remains after a dog graduates, but many for-profit trainers end their involvement when they sell the dog. Many people need help troubleshooting issues such as housebreaking or leash-walking difficulties.

"Clients can get dogs that aren't prepared, and sometimes, when dogs are prepared, they end up with families who don't follow through," Arnold said. "It's difficult on both sides, but families get taken advantage of a lot more than the other way around."

Canine Assistants has the ability to train and place a maximum of 100 dogs per year but receives about 1,400 applications.

"The need is overwhelming," Arnold said. "It made the industry perfect for folks who want to make a little money."

In most cases, that money isn't coming directly out of patients' pockets.

Kelly Camm, development director with the Xenia, Ohio-based nonprofit 4 Paws for Ability, said only about 5% of families can write the \$17,000 check required for a service dog. The rest rely on their community, family, friends or sometimes complete strangers for donations.

Medical Mutts Service Dogs in Indianapolis trains about 30 service dogs a year, about a third of which are dogs that board with them for training.

"There is no guarantee for any of those dogs to go through," said Eva Rudisile, Medical Mutts' director of client services. "As you start training and you take them out in public places, you start practicing certain behaviors, it's quite stressful. And some dogs, they just can't handle that."

Medical Mutts charges \$15,000 to \$17,000 for a program dog depending on what type of disability is involved. It's \$11,000 to board and train a dog. If that dog washes out, the family is out that money. Families that opt for a program dog, on the other hand, are guaranteed to get a dog that completes the training.

"That's the biggest plus for a program dog," Rudisile said. "They don't have the risk of, 'OK, I got a dog and now I'm stuck with it and it's not working."

For the Mahnaz family, that's a gamble worth taking. A friend has set up a GoFundMe page to raise the initial \$4,000 to get their first dog, a goldendoodle, from a breeder. They'll start with basic obedience training and, when the dog is old enough, begin its service dog training.

An autism service dog, they hope, will help Suraiya deal with uncomfortable social situations and settle her down when she is on the verge of a meltdown. Eventually, they'll get a second dog trained to alert them when Phoenix experiences a seizure.

Suraiya, who cannot write yet, has nonetheless created a list of potential dog names that only she can read: Blueberry, Alex, Stardust, Jelly-Jam. Phoenix has settled on Pancake.



Two stories in the Disability Scoop online news feed this week illustrate how the country needs a national push to fulfill one of the key components of the Americans with Disability Act (ADA), reaffirmed by the Olmstead decision, that citizens with disabilities have the right to live in a home in their communities.

On this anniversary of the ADA we owe it to people with developmental disabilities and their families to finally remove the fear of institutionalization.

The first article reports that states are "failing to meet their obligations to transition individuals with disabilities out of institutions and into community settings" as required by the Supreme Court's 1999 Olmstead v. L.C. ruling that unnecessarily segregating individuals with disabilities in institutions is a violation of their rights under the ADA. A 2010 study by the U.S. Senate Health, Education, Labor and Pensions Committee finds that "the number of people with disabilities in nursing homes is on the rise and, as of 2010, just a dozen states devoted the majority of their Medicaid dollars to community-based care." http://www.disabilityscoop.com/2013/07/18/report-lagging-community/18344/

The next day the Scoop ran an article about a federal suit against Florida for its inappropriate use of nursing homes as placements for younger people with disabilities. http://www.disabilityscoop.com/2013/07/23/feds-sue-nursing-homes/18365/

If trends like this continue it poses a risk for any person with a developmental disability no matter what their current situation is. Here in New Jersey that risk is all too real. Even though it is not the state's policy to place someone in crisis in a developmental center or nursing home we all know what happens when an emergency situation arises late in the day or over the weekend. The institution is just down the road. It will only be for a few days until something more appropriate can be arranged. People get busy. The person is deemed to be in a safe environment. Days turn into weeks, months, years. If these "out of sight, out of mind" options are available they will be used. Once used, a person whose family never would have approved of an institution for their son or daughter when they were alive and able to care for them themselves finds themselves in one, possibly for the rest of their lives. That's why everybody in this community should be troubled by these trends and should get involved in advocating for their reversal. Not just those who live in states like New Jersey where institutions are still an integral part of the system—although it is even more important here. Not just those families who are getting older and nearing a time when these crises are more immediate.

What we need is a national commitment; a national policy that ensures that people with developmental disabilities will not be faced with the prospect of being forced into an institution because that happens to be an option. They and their families should not face that threat as they cross state lines and life's thresholds. This violation of one's basic rights should not be subject to what is most convenient or politically expedient in a particular region of the country at that particular point in time. Like other rights protected by other laws, the ADA and its Olmstead clarifications should be applied equally throughout the country. I would go even further and say additional challenges need to be made to eliminate some of the wiggle room in the law so that once and for all people with developmental disabilities can leave the stigma and memories of the institutional era behind forever.

Of course, eliminating the institutional option for people with developmental disabilities doesn't fix all the problems in the community supports system, although it is my opinion that it will infuse that system with much needed resources that can be used to address some of those issues. Of course the ongoing commitment to watchdog and constantly improve those services should continue, as it should have with the old institutional system when it was dominant, before it blew up in scandal and outrage.

What we're talking about here is more fundamental. It is about the fundamental right of every person to not be excluded from their communities simply because they have a developmental disability. It is about their fundamental right to have the same fundamental rights as the rest of us. The only way to ensure that is to eliminate the institutional option entirely, nationwide. It's that simple.