

New Horizons

Housing That Supports Independence

Drugmaker Moves To Include People With Disabilities In Clinical Trials

by Shaun Heasley | reprinted from DisAbility Scoop / August 16, 2022

People with disabilities are often excluded from clinical trials, limiting what's known about how new treatments will affect those with various conditions. Now a major drug company is looking to change that.

Bristol Myers Squibb says it will work with a nonprofit called Disability Solutions on recommendations to "effectively improve access, engagement, speed of enrollment, and participation of people with disabilities in clinical trials, to ensure all patient groups are reflective of the real-world population and aligned with the epidemiology of the disease studies."

The so-called Disability Diversity in Clinical Trials, or DDiCT, initiative is part of a broader effort from the company — one of the world's largest pharmaceutical makers — to increase inclusion and diversity.

"Through this work, Bristol Myers Squibb can set the standard and stage for access to life-changing and life-saving medicines for people with disabilities," said Dr. Samit Hirawat, executive vice president and chief medical officer for global drug development at the company. "The long-term goal of our DDiCT program is to develop and pilot trials that are accessible to the widest variety of patients."

In announcing the initiative, officials with Bristol Myers Squibb pointed to a 2018 article in the Journal of the American Medical Association, which found that in 338 phase III and IV studies 12.4% of people with intellectual or developmental disabilities were left out because of exclusion criteria.

"People with disabilities are omitted from conversations about diversity and inclusion, despite being the largest underrepresented group in the world and the only underrepresented group anyone can join at any given moment. Therefore, it's essential that we broaden the scope of medical trials and research," said Tinamarie Duff who leads Bristol Myers Squibb's Disability Advancement Workplace Network.

The issue came to the fore earlier this year when the Centers for Medicare and Medicaid Services proposed a plan to limit access to a controversial new Alzheimer's drug to those participating in clinical trials. Even though the lifetime risk of Alzheimer's is over 90% for people with Down syndrome, the proposal indicated that people with the chromosomal disorder would be excluded from participating.

Amid pushback from advocates, CMS reversed course and removed the Down syndrome exclusion from the final determination.



Tracee Battis
Executive Director

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Present Locations

Legacy Robbinsville

Project Freedom at Hamilton

Project Freedom at Lawrence

Freedom Village at Woodstown

Freedom Village at Hopewell

Freedom Village at Toms River

Freedom Village at West Windsor

Freedom Village at Westampton

Freedom Village at Gibbsboro

Freedom Village at Town Center South

Opening Soon

Freedom Village at Hamilton Woods

Inside Six Flags' Efforts To Make Its Parks More Inclusive

by Matthew Griffin, reprinted from The Dallas Morning News/TNS | August 24, 2022

Six Flags America has taken two big steps to make its parks more accessible to people with physical disabilities and autism, concluding years of effort by the amusement park chain and mirroring a broader movement toward accessibility in the entertainment industry.

"I believe everybody has the same philosophy that we do, that we want to be open to everybody that wants to come and enjoy our properties," said Jason Freeman, vice president of public safety and risk management.

Six Flags outfitted its rides at U.S. parks with specialized harnesses that allow people with physical disabilities to access them, the company announced last month.

It also had its parks in the U.S. and Mexico accredited as certified autism centers, a designation overseen by the International Board of Credentialing and Continuing Education Standards that means the amusement park chain has taken steps to better accommodate people with autism. The company's Canadian location is in the process of becoming certified.

It took about five years and cost over \$1 million to develop the harness and install it at all parks, Freeman said. The device will make it possible for people missing limbs or fingers and those who can't fit in a traditional harness or brace themselves in the same way as others to be safely strapped in for rides.

"There are some restrictions, but 98% of the general public can ride all of our rides," he said.

Six Flags parks began working to become certified autism centers in 2019, but delays related to the COVID-19 pandemic meant it took three years for all of them to earn the distinction.

For parks to become certified, 80% of Six Flags' public-facing staff had to be trained in accommodating visitors with autism. The company also added low-sensory areas to its parks, allowing people with sensory sensitivities to take a break when they need to, and created sensory guides for attractions.

Without those kinds of accommodations, someone with autism might have to spend hours planning for a theme-park trip, credentialing board president Meredith Tekin said.

"We're all human beings. We all want to be understood and welcomed," she said. "And if we take a few small steps, in this case in an entertainment space, we can welcome so many more individuals and families."

The credentialing board has provided its certified autism center designation since 2016. Although Six Flags is the first theme park chain to ensure that all of its parks have the designation, companies like SeaWorld and LegoLand have worked with the board to earn the status at some of their locations.

It's not just theme parks. Sporting venues have added sensory-friendly spaces. Johns Hopkins University's Peabody Institute held its first sensory-friendly concert in 2019.

"Organizations are finally realizing, 'We need to do more to make sure we can welcome these visitors and attract more people to us, but also improve that guest experience,'" Tekin said.

The Americans with Disabilities Act does not require amusement park operators to create specialized technology like Six Flags' harnesses to make rides accessible. In general, it allows for safety restrictions that sometimes exclude people with disabilities.

Some people have sued amusement parks, including Six Flags, after being barred from rides because of physical disabilities. Freeman wrote in an email that Six Flags doesn't comment on litigation related to the theme park industry or itself but that the harness was "developed for the sole purpose of allowing as many as guests as possible to ride our rides safely."

The steps Six Flags has taken go above and beyond the company's legal obligations to make parks accessible, he said.

Thousands May Join Class Action Suit Over Special Education Delays

by Tina Kelley, reprinted from NJ.com/TNS | August 26, 2022

In 2019, parents of 10 children with disabilities filed suit against the New Jersey Department of Education for taking too long to resolve disputes about how their children should be educated. Now, a federal district judge has ruled that their case could become a class action suit, potentially including an estimated 15,000 families who say students have been harmed over the years by administrative delays.

In his ruling this month, U.S. District Judge Noel L. Hillman allowed two groups of parents to proceed in class action suits — those asking for the state Department of Education to fix its broken dispute resolution system for current and future students, and one seeking justice for students in past years who were kept waiting too long.

According to a report by the New Jersey Special Education Practitioners, the average time for cases to be resolved was 212 days, as of 2018, while more recently, lawyers said, that has increased to an average of nine months, with about 1,000 families requesting hearings a year.

Under the federal Individuals with Disabilities Education Act, disputes between parents and school districts regarding placements of special education students must be resolved in 45 days, not counting adjournments, but the U.S. Department of Education issued a letter in 2019 saying that in the 2016-17 school year, **less than 5% of the 1,300 due process complaints were resolved on time in New Jersey.**

Of the families in the suit, five had waited more than 300 days for a resolution to their cases, with one waiting 791.

The Department of Education did not respond to a message requesting comment this week.

The judge also appointed John Rue & Associates, a special education law firm headquartered in Princeton, N.J., to represent both classes.

“The NJDOE’s due process system is systematically flawed,” Rue said. “It ignores and routinely violates the 45-day rule—a rule that recognizes time is of the essence when it comes to educating children.”

The shortage of administrative law judges has contributed to the backlog, according to Rue. He added that the Office of Administrative Law, the state agency handling such cases, could not estimate how many more judges would be needed to speed up the cases. And while the state appropriated \$6 million in its last budget to address the backlog, that funding will not go specifically to new administrative law judges on special education cases, as originally planned.



Several advocacy organizations have joined in the suit, including SPAN Parent Advocacy Network; Advocates for Children of New Jersey; Council of Parent Attorneys and Advocates; Disability Rights New Jersey; Educational Law Center; NJ Special Education Practitioners; and Volunteer Lawyers for Justice.

In an earlier ruling that the case should proceed, Hillman noted that the parents had made “plausible claims” that the system “is profoundly broken and routinely violates the federal laws designed to insure that our most vulnerable children remain the priority we all should agree they are.

From Norman's Desk



This month marks 21 years since the attacks of September 11th. For many, the memory of that awful September day in 2001 is fading, but my memories are still vivid down to my shirt and tie. The day started out so bright, beautiful, and refreshing, but it ended so dark and frightening. The feeling of anger and uncertainty spread around us like a cloaking fog.

Every year since the attacks, I choose to pay tribute to the three elements that create my memory of that day. First, I honor the life of my friend and colleague Colleen Fraser who died on Flight 93 with those other selfless heroes who may have saved the Capitol or the White House and thousands of other lives. Colleen was a fighter, and she was in good company that morning fighting to take back that plane.

Second, I remember the lives of the 343 FDNY firefighters who died that day. Most knew going into those buildings that some of them would not come out alive. They knew this instinctively by virtue of their experience and profession. They still went in with police officers and EMS personnel to save those who could not save themselves. They went in to save people with disabilities.

And, yes, thirdly, I remember those people with disabilities who died that day in those towers. I was not watching the horror on television that morning. I had a meeting at 10:00, and during that meeting I spoke of Colleen and wanting to connect her with someone. Later, someone told me of the collapse. My very first thought was that many firefighters had just died; my immediate second thought was that many people with disabilities had died as well.

For the third year I also pay tribute to the doctors, nurses, medical support staff, direct care staff, and first responders who put their lives on the line trying to save others from COVID-19. They also ran toward danger to help other, and many paid with their health or their lives.

How many people with disabilities died that morning in September may never be known. We do know that the corporations and government agencies housed in those towers hired people with disabilities. We do know that some people with disabilities made it out because they had a plan, their company had a plan, or some colleague or friend took the initiative to get them out. We do know that others stayed behind not wanting to burden friends, not wanting to get in the way, or just having unwavering faith that the FDNY would get to them. We also know that loyal friends stayed behind with them. We know that some people with disabilities who stayed were rescued but many died with their rescuers.

Summarily, the number of people with disabilities have died from COVID-19 may never be accurately known. We do know that over 25% of the COVID-19 deaths occurred in nursing homes where many people with disabilities are forced to live. We do know that people with disabilities living in the community have been isolated by the lack of community-based direct support workers. We do know that the government is not tracking the deaths of people with disabilities as a COVID-19 statistic.

Every victim of these national tragedies needs to be remembered and honored. I feel a personal duty to honor Colleen, The 343, and those almost nameless people with disabilities who stayed behind.

As I say each year, let us all remember the victims and the heroes of September 11th, 2001, by getting prepared and staying prepared. You never know how a bright, beautiful, and refreshing day may end.

It is also National Preparedness Month to promote family and community disaster and emergency planning now and throughout the year. The 2022 theme is "A Lasting Legacy" with the rather long tag line of "The life you've built is worth protecting. Prepare for disasters to create a lasting legacy for you and your family."



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Robbinsville Township Hotdog Party

On August 30th, the Mayors Alliance of Robbinsville Twp hosted a party at Town Center.

Everyone enjoyed the delicious hotdogs, chips, beverages and frozen ice as the kids made bubbles and bounced in the bouncy house.

Here are a few shots of the festivities.



Norman, Joy Tozzi, Tracee Battis and Ravi Patni from the Robbinsville Twp Planning Board



Mary and "Z"



Bubbles and bouncing



After Institutionalizing Son, Mom Fights To Bring Him Home

Reprinted from The Seattle Times/TNS | July 21, 2022 by Hannah Furfaro

SEATTLE — On his 330th day in the hospital, Charlie Edgmon repeats a well-worn refrain to his mother Carmin. I just want to go home.

Institutionalizing Charlie was never Carmin Edgmon's plan. But for years, she and her son have been locked in a cruel and dangerous cycle. Violent outbursts at home — Charlie once smashed out windows in the family home, and he regularly threatens to kill people and himself — usually lead to a visit by police, to the ER, or to juvenile detention. Charlie is always sent back to his home in Covington, without any new help to change the pattern.

When Charlie threatened to hit Carmin with a rock last summer, she reached a breaking point. Charlie couldn't come home, she decided, until there was a plan to keep their family safe. He's lived inside a locked stabilization unit at Seattle Children's ever since.

While many Washington youths are living inside hospitals waiting for an inpatient psychiatric bed, as The Seattle Times has reported, Charlie's situation illustrates how hospitals have also become a warehouse for young people whose families believe they can and should live at home with proper support.

Clinical staff say Charlie's been ready to discharge for months. But for at least a year the family has struggled to access something, anything, that would help him manage life at home. The kind of services that could make that happen — help with hygiene, behavior supports, anger management, a crisis response team, volunteer opportunities to give him a sense of self-worth — weren't made available by several state agencies, Carmin said. Eventually, Carmin says, she was told by state agencies that sending Charlie to a residential psychiatric facility — likely out of state — was her only choice.

Then, she learned that Charlie and thousands of young Washingtonians like him have a legal right to care that helps them live safely at home and out of an institution. A class-action lawsuit, settled nearly a decade ago, determined the state is legally compelled to create a system of support for youths up to age 21.

But Charlie's experience raises new and serious doubts about how well Washington is living up to its promise. His case, which is detailed in a new federal lawsuit filed in March against the state, also illustrates the extreme lengths to which families go to guarantee rights that are already firmly enshrined in state law.

"It's never a good sign if it takes a federal lawsuit for an individual to get services that exist on paper," said Susan Kas, an attorney with Disability Rights Washington who is representing Charlie and was involved in the original class-action suit. "I think that's a really good question for the people in the system ... why did you have to get sued to do this?"

The program created to meet the terms of the settlement is called Wraparound with Intensive Services, or WISE. It was supposed to create access to outpatient services no matter where youth are first identified as needing help — whether that's the child welfare system, the juvenile justice system, or the medical system.

The state and federal government together invest more than \$120 million a year — or about \$3,500 per youth per month — in WISE, which serves youth ages 0 to 20 who qualify for Apple Health. Last fall, after years of judicial monitoring to ensure the state did what it was supposed to do, a district court judge agreed with the parties and ruled that the state had finally met the terms of the settlement.

But experts who initially advised on WISE say the state took shortcuts that hollowed out the range — and intensity — of support it's supposed to offer. A recent independent review, for example, found that WISE care coordinators meet face-to-face with each family for less than an hour per month, on average. The review also cited concerns about "rapid staff turnover," delays in treatment and inconsistencies in the way WISE staff are trained.

State data suggests the program is doing a particularly poor job of serving the most vulnerable youth, with the most severe mental health conditions, while focusing instead on easier-to-manage cases.

"It was even worse than I feared," said Eric Bruns, professor of psychiatry and behavioral sciences at the University of Washington School of Medicine, and a former WISE adviser, said of the review. In 2015, Bruns wrote a letter to the state warning of several problems with the program, including a lack of high-quality services, engagement with families, and training. Bruns, who directs two national children's care coordination centers,

stopped advising Washington government officials, he said, “when the state signaled that certain of those recommendations were not going to be part of the way that WISE operated.”

It’s a total mess,” said Tyler Sasser, an attending clinical psychologist in the psychiatry and behavioral medicine department at Seattle Children’s. He regularly refers patients to WISE as a matter of practice, but “What’s actually needed is not available. It’s not even offered,” he said, noting that evidence-based services like parent training aren’t accessible through WISE. And persuading families to stay enrolled in WISE can be difficult, he said, because they get frustrated by the lack of services. The cost, he says, is that families “spiral deeper and deeper.”

WISE served just over 6,100 youth last year, state data shows, and by certain measures, the program appears to help many of those who are enrolled. But not everyone who wants services has them: the state served below its target number of 3,345 youth per month during every month of 2021. And as of June, at least 518 Washington youth were waiting to get into the program.

Government officials acknowledge the program has shortcomings, and note that it’s difficult to attract and keep mental health providers, who are in drastically short supply across the state’s mental health system. Families might wait three or more months to get enrolled, officials say.

But even then, they’re not guaranteed access to the kind of care they need.

Charlie’s family, who enrolled in WISE nearly three years ago, is still waiting.

Charlie was born with a genetic condition that’s caused him to develop several brain tumors over his short life span. He’s also prone to severe seizures and has undergone a life-altering surgery — a functional hemispherectomy that separated one side of his brain from the other — to stop them.

He’s lost muscle mass in his face, which gives him a smirky smile that Carmin finds cute. And he walks with an uneven gait, which Carmin affectionately calls “his penguin.” He also has low cognitive abilities. While he’s incredibly close with his mother, a single mom with two other twin children, he’s acted out violently toward her during moments of rage.

At Seattle Children’s, he’s taken the antipsychotic risperidone and is often lethargic and confused. He’s been there so long, his therapist Ivyanne Smith says, that his aggression is waning as his mood slips toward despair.

“I hear him every day crying to his mom or crying to me saying, ‘I just miss home. I want to go home, it’s been too long,’” Smith said.

Had Charlie been offered outpatient care early on, it’s less likely his family would have reached the crisis point that caused his hospitalization, said Carmin’s former attorney Lindy MacMillan, of the Northwest Justice Project.

And once he was at Children’s, “It was never laid out for (Carmin) that there are legal entitlements that Charlie has that would allow him to come home, and come home safely,” she says.

Using Medicaid data that approximates youth demographics and health conditions, the state projected that of all young people who may need WISE, about 23% would be 18-20 years old. But in practice, this age group makes up only 3.1% of WISE enrollees; meanwhile, about 40% of youngsters in the program are ages 5-11, twice as many as projected.

Similarly, about half of the state’s children with bipolar disorder who might need WISE are likely missing out on services, the state data shows. And the program serves a disproportionately high number of those with mental health conditions that are sometimes less severe, such as anxiety, ADHD and impulse control problems; Sasser notes that it’s likely some kids with ADHD have multiple diagnoses, however, which would make their treatment plan more complex.

Those ages 18-20 are harder to attract into WISE because they have more rights over their own care, and they may not want to be told what to do, said Tina Burrell, a Health Care Authority acting supervisor who has been involved in implementing WISE since 2014. Burrell said HCA is now paying a youth peer to do outreach to this age group.

As Charlie passes one year locked inside Seattle Children’s, he has missed every holiday, celebrating his 18th birthday, and his high school graduation. Every week, his mom still joins a Zoom call with upward of 40 people from various state agencies, medical providers — and lots of lawyers — to talk, and talk and talk about what’s next.

A couple of days each week, a caretaker from an outpatient provider called Good Intentions visits his hospital room to work with him on behavior. Carmin sees this new service as a small win.

But the fight’s not over, she said, until Charlie comes home.

DISABILITY RIGHTS NEW JERSEY

ADVANCING JUSTICE. ADVOCATING INCLUSION.

The Richard West Assistive Technology Advocacy Center (ATAC) of Disability Rights New Jersey serves as New Jersey's federally-funded Assistive Technology Act project, through a sub-contract with New Jersey's Department of Labor and Workforce Development. Its purpose is to assist individuals across New Jersey in overcoming barriers in the system and making assistive technology more accessible to individuals with disabilities throughout the state of New Jersey.

WHAT IS ASSISTIVE TECHNOLOGY?

Assistive Technology is any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized that is **required** to increase, maintain, or improve the functional capabilities of any person with disabilities, be it for school, work and/or for play. AT ranges from low-tech to high-tech devices or equipment. Examples include: computer, glasses, reacher or grabber, pencil grip, closed captions, wheelchair, ramp.

HOW WE HELP

ATAC provides funding to sub-contractors throughout New Jersey in order to effectively provide the core services of the Assistive Technology Act.

DEVICE DEMONSTRATIONS

ATAC can provide opportunities for New Jersey residents with disabilities to become familiar with specific types of AT by comparing the functions and features of devices through hands-on exploration.

DEVICE SHORT TERM LOANS

ATAC provides a library of AT devices available to New Jersey residents with disabilities to borrow, for a limited time period, to try before you buy. That way you can decide if a device is right for you before purchasing.

DEVICE RE-UTILIZATION

Through a partnership with Goodwill Home Medical Equipment, ATAC supports the reuse of assistive technology, to get equipment out of the basements and storage facilities and into the hands of New Jersey residents with disabilities who can use it (at a significant cost savings to the individual).

TRAINING ACTIVITIES

Across New Jersey, ATAC performs a range of training opportunities for stakeholders. These activities are provided in accordance with the requirements of the Assistive Technology Act. Our staff conduct webinars, conferences and technical assistance support.

CONNECT WITH THE ATAC STAFF

To learn more about the services provided by ATAC or Assistive Technology resources available to NJ residents with disabilities, visit the ATAC website. Email our staff at ATAC@disabilityrights-nj.org or call (609) 292-9742.