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# **Coronavirus Forcing Occupational Interapy To Go Virtual** By Megan Woodward, Reprinted from the Carroll County Times/TNS | July 21, 2020

BALTIMORE — Health care institutions across the country have turned to telehealth technologies to continue providing care during the coronavirus pandemic, and one infant with cerebral palsy has seen some benefit from that remote treatment, her mother says.

Crystal Dorsey, a New Windsor resident, has a 10-month-old daughter, Natalie, who had two strokes while Crystal was pregnant. Natalie was born with spastic hemiplegia cerebral palsy and has struggled to use the left side of her body and complete movement with her left arm. Natalie started receiving occupational therapy via telehealth from the Specialized Transition Program at the Baltimore-based Kennedy Krieger Institute when she was 8 months old to help improve her strength. She was first treated in the institute's neuro-developmental clinic, similar to a neonatal intensive care unit (NICU) for medical needs, prior to transferring to the STP.

The Specialized Transition Program at Kennedy Krieger is an intensive interdisciplinary outpatient program and serves children and adolescents who have neurological or orthopedic conditions by providing them with comprehensive daily therapy, such as physical, occupational, or speech therapy. Andrejow, the department telehealth lead of the program, said that because of the pandemic, therapists had already started to provide therapy via telehealth when they brought Natalie on board. "When this first started in March, we switched our entire caseload to telehealth," Andrejow said. "A full day's worth of patients that all of our therapists would typically see in clinic were switched over, so essentially 100 percent of our patients are telehealth and have been for a number of months."

Natalie participated in the Specialized Transition Program's infant constraint induced movement therapy program with Andrejow as her lead therapist for one hour every day for four weeks. The program is designed to set patients up for success so they get positive experiences using the ligament that's more difficult for them to operate.

Crystal said Natalie's improvement has drastically increased since her telehealth appointments began. She has gained more control over her body movements and has been using her left arm with little to no encouragement from her therapist. Crystal said she could feel a difference in Natalie's body just from picking her up after a week's worth of daily sessions, and Natalie has also learned to roll over on her own using her weaker side.

Andrejow said she and her colleagues have generally seen progress with the Specialized Transition Program and there were not too many concerns when the department moved completely to telehealth. Families have continued to be just as interactive in their children's appointments, as they would have been in person.

Kennedy Krieger intends to continue providing services via telehealth, even after the pandemic has ceased. "I think Kennedy Krieger serves so many families who have lived out of state and typically have to travel to come see us," Andrejow said. "Having an opportunity where telehealth might be a beneficial way to serve some of these families so that they don't have to have the expensive burden of traveling to see us would be an awesome opportunity.

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### **"My Two Cents"** By *Tim Doherty, Executive Director*

So, we are coming to the end of our summer this year, and what a year it has been. This Covid19 Virus has turned our world upside down; however it seems to be subsiding, at least, in the eastern part of the country for those of us in New Jersey and New York. Let's hope that it continues. So here are some of the things we tried to do and get done this summer:

During this time of lockdown, Project Freedom has tried to continue with

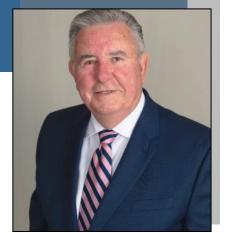
"Business as Usual" while setting up protocols to keep everyone safe. This meant, closing the offices of our sites, with only having limited staff hours, staff working on and off days, and only responding to emergency maintenance situations. Of course the grass still had to get cut, and sanitizing needed to be done, so those things continued. Unfortunately we did have to stop all our recreation events and other programs for tenants. These we hope to be able to operate again, once the governor provides guidance.

Over the summer, we did provide our tenants at Robbinsville, Lawrence and Hamilton with certain essentials and a purchase grocery card so that they could stretch their existing funds. We also provided masks to anyone who needed them and continue to do so. Our other sites, worked with outside social agencies who provided food bags and other essentials to our tenants at those sites as well, so that no one should be without some help.

The construction of our new Robbinsville "Town Center" location has been pretty much on schedule, with only minor disruptions, such as waiting for all our windows. We are still waiting on the final nine windows, but are able to work around those issues, so as to continue progress.

One issue should be mentioned for our present tenants. Those of you who have been laid off or have had your work hours cut and now are finding it hard to make your monthly rent, please call your office manager to let us know. You are still responsible for the rent; however, we will try to work with you to develop a strategy that can avoid eviction by establishing a payment plan. This way you can avoid all the hassle of eviction or debt collection.

Finally, one thing we should all realize is that we are in this together....this virus affects everyone, the rich and the poor, the disabled and non-disabled, the young and the old. Let's take the time to check on our neighbors and relatives, ask how they are doing...do they need anything....how can we help? By doing that we can keep each other safe and hopefully, when things settle down and society opens up again, we will be able to come together once again.





### From Norman's Desk

This month marks nineteen years since the attacks of September 11<sup>th</sup>. It is also National Preparedness Month is recognized each September to promote family and community disaster and emergency planning now and throughout the year. The 2020 theme is: **Disasters Don't Wait. Make Your Plan Today.** 

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.

That feeling is around us again as COVID-19 has changed our lives, and the future is uncertain as we all work through this "new normal."

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 U.S. 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.

This 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.

In the same manner how many people with disabilities have died from COVID-19 may never be accurately known. We do know that nearly40% 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 that September day. I also honor the nearly 200,000 persons who have died in this pandemic.

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

Norman A. Smith, Associate Executive Director - ProjectFreedom1@aol.com Follow me on Twitter @normansmith02 Follow Project Freedom on Twitter @TheFreedomGuys "Like" us on Facebook.com/ProjectFreedomInc Visit us at www.ProjectFreedom.org



### *30 Years After Americans With Disabilities Act, A Look Back And Ahead*

Reprinted from July 31, 2020 Disability Scoop, The Courier/TNS | by Amie Rivers

DES MOINES, Iowa — President George H.W. Bush was on board, and former U.S. Sen. Tom Harkin of Iowa and his colleagues made sure it passed the U.S. Senate. But in early March of 1990, the Americans with Disabilities Act, a civil rights bill for individuals with disabilities, was stalled in the House of Representatives.

"It got stuck in a lot of different committees," Harkin remembered. "We were all worried that we weren't going to get the bill."

It wasn't until members of ADAPT, a disability activist organization, showed up at the U.S. Capitol and staged a protest for the television cameras — taking themselves voluntarily out of their wheelchairs and climbing the Capitol building steps however they could — that attention became focused on the cause.



President George H.W. Bush signs the Americans with Disabilities Act during a ceremony on the South Lawn of the White House on July 26, 1990. (TNS)

"To me, that remains an iconic moment," Harkin said.

"When the evening news carried that and it became global, I think that just provided the spark — that last little thing we needed to convince people in the House and others that we needed to get this bill through."

The protest worked, and the Americans with Disabilities Act was signed into law July 26, 1990.

But even as he celebrates the law he introduced 30 years ago — meant to give those 1 in 5 Americans with a disability the opportunity for full participation in society — Harkin bemoans the goals that have not all been achieved, citing unemployment, technology that failed to serve people with disabilities and inaccessible housing. "The younger generation — the ADA generation — don't be satisfied with what you got. We've got a ways to go," Harkin said.

Harkin and other former legislators gathered on a Zoom call as part of a week of events surrounding the ADA anniversary by RespectAbility, a national disability advocacy nonprofit.

Tucker Cassidy, a disability rights activist who lives in Waterloo, said the fact the sessions were being held virtually due to the coronavirus pandemic was a boon to the disability community.

"Everybody knows what a Zoom conference is now," Cassidy said. "If we can make them more accessible, we will show up. It's just that, if you've got the door locked, how are people going to get in?" The same is true with telehealth and beginning to happen with education, he noted.

But many other facets of his life are still barricaded: It took Cassidy 12 years to find an accessible apartment through the Department of Housing and Urban Development, for example. Now that he owns his own home, he tried shopping in person for furniture at a Waterloo furniture store and couldn't get his chair through the door. The owner apologized, Cassidy noted, but also said that the building had been renovated within the past year. But because it was "historic," building owners could ignore accessibility provisions in the ADA.

"They didn't even think about that fact. They didn't take the opportunity to make it an accessible building," he said. "It blew me away: Here we are 30 years later, and we're still having to run into stuff like that. In short, we have a long way to go."

### **Disabled People Love Clothes Too** But #disabledandcute influencers say the

fashion industry has been slow to embrace them. Reprinted from the New York Times /July 26, 2020 / Updated Aug. 6, 2020

I have always believed that fashion is the window to the soul. As a Black disabled woman with cerebral palsy, a neurological disorder that affects movement on the right side of my body, I have gone through what I call the stages of fashion grief.

First, there was denial, which led to pretending fashion did not matter to me. Anger, depression, bargaining and acceptance came when I realized that I was no longer going to deny myself the things that allowed me the opportunity to share myself with the world. Especially when I realized just how much fashion was a part of my story. In "The Pretty One," my collection of essays published last year, I talk about my journey to see my self-worth and how it led to my Twitter hashtag #disabledandcute, used by like-minded people to share pictures of ourselves and to declare that we are just as cute and worthy as anyone else.

I am not alone in my love for fashion. Disabled people, including the fashion plates among us, have always had to make wardrobe hacks to navigate features like zippers, buttons, shoes and irritable fabric tags. Stylish clothing for disabled people goes by many names: Accessible fashion, functional fashion, universal and inclusive fashion. I use accessible and inclusive fashion interchangeably and sometimes together because they best fit what I believe fashion should be after, not just function but style, too.

We have always known that clothes must function for our bodies. Increasingly, the fashion world is seeing this too. But it's only a start.

Three decades after the passage of the landmark Americans With Disabilities Act, disabled people want to be able to have freedom of self-expression through fashion rather than accepting scraps from an industry that has been very slow to embrace us and our needs.

#### Show Us Your Accessible and Inclusive Fashions

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As long as there has been clothing, disabled people have had to make wardrobe hacks, especially when navigating features like zippers, buttons, shoelaces and irritable fabric tags. We want to see the accessible designs you use to make the world suit your needs. Your submission may be included in a @nytimes Instagram Story.

The clothing brand Levi Strauss & Co. was one of the first major brands to design clothing for disabled people in the mid-1950s with the work of one of its designers, Helen Cookman. She created a pair of jeans with "stretch denim and full-length zippers in the side seams that opened from the top or bottom. Another useful design feature was a special inside half belt buttoning on either side to hold the jeans in place when the seat dropped," according to the company's archives.

Christina Mallon-Michalove, who is head of inclusive design at the advertising agency, Wunderman Thompson, and chief brand officer at Open Style Lab, a design incubator for functional fashion, is a disabled woman herself, with a rare form of amyotrophic lateral sclerosis, or A.L.S., that left her arms paralyzed. She sees accessible fashion for what it is: a requirement that will make the fashion industry even better.

"I know Levi's was the first to create the product and think about it, but when I think about the first that is creating end to end inclusive experiences, that was Tommy Adaptive" said Ms. Mallon-Michalove, referring to the preppy line by the designer Tommy Hilfiger. "When we talk about clothing and style, physically being able to buy the product is just one part of the style experience. We need functional clothing that is also fashionable."

It took years for other brands to follow suit, but today's accessible fashion lines include Target's Cat and Jack, to Zappos to Tommy Adaptive and Open Style Lab.



Christina Mallon-Michalove wearing a jacket that you can put on without the use of your arms. The design was created from a co-collaboration between Ms. Mallon-Michalove and Open Style Lab fellows Claudia Poh, Estee Bruno and Julia Liao.

### **Google Offering New Tools To Help Those With Disabilities** by Shaun Heasley / reprinted from Disability Scoop / May 28, 2020

Google is introducing new technology to simplify smartphones for those with cognitive disabilities and it's beefing up its map program to make it easier to know if destinations are accessible.

The company said this month that it is releasing an app called "Action Blocks" for Android devices that's designed to make routine smartphone tasks — like calling mom or turning the lights off — less cumbersome.

With the app, users can create a one-touch button that displays on their home screen to complete actions that typically require multiple steps.

"For people with cognitive disabilities or age-related cognitive conditions, it can be difficult to learn and remember each of these steps," wrote Ajit Narayanan with Google's central accessibility team and Sharlene Yuan of Android Accessibility in a posting about the app. "Create an Action Block for any action that the Google Assistant can perform, like making calls, sending texts, playing videos and controlling devices in your home."

Separately, Google said that it is also launching a feature in Google Maps called "Accessible Places." When enabled, users see a wheelchair icon prominently displayed to denote if a location has an accessible entrance. In addition to details about entrances, the maps program offers information about whether a place has accessible seating, restrooms or parking. Google Maps will also indicate if it has confirmed that a business or other destination does not have an accessible entrance, the company said.

"With this feature 'rollout,' it's easier to find and contribute wheelchair accessibility information to Google Maps. That benefits everyone, from those of us using wheelchairs and parents pushing strollers to older adults with tired legs and people hauling heavy items," wrote Sasha Blair-Goldensohn, a software engineer with Google Maps, in a posting about the development. "And in this time of COVID-19, it's especially important to know before you go so that you won't be stranded outside that pharmacy, grocery or restaurant."

At present, Google said it has accessibility information for more than 15 million places around the world, a figure that has doubled since 2017. The new offerings come as Google is also bringing improvements to Live Transcribe, an app that provides real-time transcription for conversations, and Sound Amplifier, which clarifies the sounds around you.

Due to COVID-19 (coronavirus) all registered voters in New Jersey will be mailed a ballot for the November General Election beginning October 4.

All voters are strongly encouraged to vote that ballot as soon as possible and return it so it reaches the Election Officials by the deadline.

The state is adding secure drop boxes around the state to ensure voters can drop their ballots instead of mailing if they prefer.

If you would like to vote in person on Election Day that will still be an option.

Registration deadline to vote in November is October 13.

Contact Norman for more information at nsmith@projectfreedooom.org



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Project Freedom Inc. is a 501 (c)(3) not for profit organization dedicated to developing, supporting and advocating opportunities for independent living for people with disabilities

### **Community Comes Together During Blackout**

On August 11<sup>th</sup> 2020, Hurricane Isaias made landfall in New Jersey, causing about 3.7 million power outages across the state. Sadly, Freedom Village West Windsor was one of those affected by this massive outage.

With tenants living without power or air conditioning, the staff at West Windsor and Lawrenceville worked together to provide breakfast and hot coffee for the tenants. The neighbors at West Windsor jumped in to grill hot lunch and dinner for tenants. Staff was also able to set up a generator to allow tenants to charge electronics and medical equipment throughout the day. We would like to extend immense gratitude to the staff and tenants that helped their community during this time. With their help Freedom Village at West Windsor was able to turn a disaster into a community enrichment day.

