May 2020

New Horizons Housing That Supports Independence

Disability Advocates Say Billions Needed For Community-Based Services

by Michelle Diament | Reprinted from April 27, 2020 Disability Scoop

As federal lawmakers weigh another coronavirus relief bill, disability advocates say nothing could be more important than increasing funding for home- and community-based services. A coalition of advocacy groups is pressing Congress to rubber-stamp emergency grant funding to support people with developmental disabilities living in their own homes or small group homes in the community.

The request comes as lawmakers craft their next major relief bill in response to the COVID-19 pandemic, which is expected to be considered in May.

"Broadly, in the packages that have passed, the very specific needs of the (disability) community have been all but ignored," said Nicole Jorwic, senior director of public policy at The Arc. "It's more important than ever to fund home- and community-based services because right now, it's a safety issue."

Jorwic noted that coronavirus has spread rampantly at large facilities housing people with developmental disabilities. She cited institutions in Massachusetts, Texas and Illinois where half of residents have tested positive.

The Consortium for Citizens with Disabilities, a coalition representing dozens of disability advocacy groups, is pushing Congress to incorporate a proposal that would allocate extra funds to each state equivalent to 15 percent of their current spending on Medicaid home and community-based services. The money could be used to help people with developmental disabilities who are on waiting lists or those who are in institutional settings who qualify and wish to be in the community.

In addition, advocates want direct support professionals, or DSPs, designated as essential personnel so that they can access personal protective equipment, a necessity given that these workers are often unable to maintain six feet of distance while doing their jobs. And, advocates want extra money for hazard pay, overtime, training and recruitment incentives for DSPs.

All told, the price tag for the home- and community-based services grants being sought is probably around \$50 billion, Jorwic said, though advocates are still waiting for an official estimate from the Congressional Budget Office. "Without additional resources, aging adults and people with disabilities will be forced out of their homes and communities and into congregate settings, at grave risk to their health — as demonstrated by severe and persistent outbreaks in nursing facilities, institutions and other settings that are proving a danger to the health of people with disabilities." reads a <u>letter</u> to lawmakers from the Consortium for Citizens with Disabilities. "We know that we must act now to prevent much of the worst impact of this outbreak."

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

Seems like forever that we have been able to go to a retail store or go out to a restaurant for dinner. Because of the COVID-19 virus, Only essential businesses are allowed to stay open, with staff working shifts so as not to have a crowd of people in one office or conference center at a time. Many small businesses are closed such as hair salons, barber shops, spas, and small retail boutiques, with many pizza shops and small



Now some folks would say that the closing of the State was a drastic action, and something maybe the Governor didn't have to do. Of course, it is always easy to second guess, after the fact and be a Monday Morning quarterback. However the fact remains that New Jersey has been one of the hardest hit states, along with New York, that have suffered the greatest effects of this pandemic. Next to New York, New Jersey has had the most cases per capita of infection and I believe the most deaths due to this virus, than most other states in the US. This COVID-19 Virus is nothing to fool around with, and not something to take lightly.

So, for a month now, we have been inside, sheltering in place, many working from home when we can. For Project Freedom Inc. we have shut our community centers and put staff on rotating work schedules so that we could avoid any large groupings, and thereby reduce our chances of interaction. Staff still monitors the phones and we are only really attending to emergency maintenance issues. Now that the weather is getting warmer, there will be grass cutting and outside maintenance being done at the properties, so that work needs to be kept up with, otherwise it can get out of hand. PFI staff is still available for help if tenants need anything, and continue to check on many of our tenants.

So, as of the Governor's latest news conference, he has laid out several conditions that would need to be in place, before he will lift the "stay at home order". These conditions are a reduction in new COVID-19 cases, more testing of healthcare workers and then from the public in general, along with the reduction in hospitalizations. The Governor is still undecided if he will allow schools to reopen this current school year, which really needs to be done, for most people to go back to work. What is feared most, is for the virus to have a comeback, when business is open again, thereby losing all the gains achieved by staying at home.

So, Lets all continue to do our part. Wash our hands, wear our masks, stay 6 feet away and avoid any large crowds. By doing so, we will protect ourselves as well as one another. And, also keep the faith. We will get through this in time for sure... America has done it in the past, and we will continue in the future.

Timothey & Doberty





From Norman's Desk

It is May! It is time for my annual rant as we near Hurricane Season.

It is time to focus on the looming hurricanes season and the predictions by the Colorado State University tropical study program. This year is no different—especially because we are in the tail end of the first wave of a pandemic.

Yes, I wrote "the first wave." Historically, pandemics come in three waves, and the severity of those waves vary. Dr. Anthony Fauci, the director of the National Institute of Allergy and Infectious Disease, has already stated that the next wave

of COVID19 will hit this Fall and will be more severe.

Fall is also the peak of hurricane season, and the idea of a major hurricane crashing into to the US during another severe wave of COVID19 is frightening. But it needs to be anticipated and planned for with the lessons we have learned the past three months. We have already seen tornado rip through states this past month complicating the fight against COVID19.

As I write this, the American Red Cross is sheltering nearly 900 people in four states hit by tornados. Luckily, hotel rooms were available for a better sheltering option than public schools during this outbreak. Imagine Super Storm Sandy happening now or a major extended power outage.

So now is the time to prepare for both the second wave and foreseeable disasters as we look to opening back up again. If you realized that you should have done a specific task or tasks before the COVID19 shutdown, use that knowledge to prepare yourself better for the next wave and other potential disasters.

That prediction came true over five years ago with Hurricane/Super-Storm Sandy slamming into New Jersey. This year's predictions by Colorado State University's team, now his for a "slightly below" average season for 2019.

This is the 37th year that the hurricane research team at the Department of Atmospheric Science, Colorado State University has issued the Atlantic basin seasonal hurricane forecast. Dr. William Gray, Ph., launched the report in 1984 and continued to be an author on them until his death in 2016. He team is now headed by Dr. Philip J. Klotzbach.

Dr. Klotzbach's team's initial prediction is:

A total of 16 named storms with eight hurricanes and four of them becoming major hurricanes.

Last year's prediction was 13 named storms, five becoming hurricanes, and two reaching the major threshold. Thus, the prediction for this year is for more storms with a greater potential of severity.

The actual number for the 2019 season was 18 named storms; three of these storms turned into hurricanes with two being "major" in power and scale. So they under-estimated the number of storms but overestimated their severity.

The prediction also estimates the probabilities of at least one major hurricane making landfall:

For the Entire U.S. coastline – 69% (Last year it was 48%) For the U.S. East Coast including Peninsula Florida – 45% (28% last year)

With this year's prediction in mind and remembering what we have just gone through, it is not too early to start thinking about severe weather and being prepared for it. The first step is being more aware of both the potential threat and the "emergent" or imminent threat. Here is what FEMA recommends that people with disabilities do to address that need.

Severe Weather Preparedness for People with Disabilities

It is important to know in advance what steps you need to take to keep yourself and your family safe.

Do you know the best way to get emergency alerts and warnings? If you have a disability that affects your communication, identify the best ways for you to access emergency information in advance. What television stations in your area offer live captioning? Can you sign up for text, email, or telephone alerts through your municipality? Keep phones and communication devices charged, and always have a backup way of learning about emergencies. Some options for alerts and warnings are listed below.

- Television stations with live captioning
- Emergency Weather Radio (some can support strobe lights, bed shakers and text readouts)
 - Wireless Emergency Alerts If you are in an area where the alerts are available and have a cell phone that is equipped to receive them, you may automatically receive a text message when an emergency alert is issued.
- Smartphone applications Many smartphone apps will provide text and audio weather alerts. You can set the locations and types of alerts you would like to receive.
- Social Media If social media is accessible for you, look for local emergency management agencies and news stations that also use social media to broadcast alerts and warnings. Save these organizations to your 'favorites' or begin 'following' them in advance.
- Local warning systems Many localities have emergency alert services that will provide alert information to you in a format of your choice. Most locations can send messages to email addresses, mobile phones (text or voice), landline phones, TTYs and Braille readers. Contact your local emergency management agency to learn what options may be available in your community.
- Support network- Talk to trusted friends, family and neighbors and create a plan to notify each other of emergency information.

After determining how you will be notified of an emergency, put together an emergency plan and kit. Involve your friends, family, neighbors, support staff and anyone else that you trust to assist you. Determine how you will contact them in an emergency and what they can do to assist you. Think about where you will take shelter in your home if you need to. Also consider any services you need (personal care assistance services, dialysis services, etc.) and how you will access those services in an emergency. Talk to provider agencies about their emergency plans

Learn more about preparing for severe weather at www.ready.gov/severe-weather.



by Michelle Diament | Reprinted from April 28, 2020 Disability Scoop

U.S. Secretary of Education Betsy DeVos will not seek changes to the central tenets of the Individuals with **Disabilities Education Act** in response to the coronavirus pandemic.

In a report to Congress released late Monday, DeVos recommended that lawmakers consider what the Department of Education called "additional flexibilities on administrative requirements."

But, DeVos said in the 18-page document that her agency "is not requesting waiver authority for any of the core tenets of the IDEA or Section 504 of the Rehabilitation Act of 1973, most notably a free appropriate public education (FAPE) in the least restrictive environment (LRE)."

The report came at the request of Congress, which as part of a federal stimulus law approved in late March, gave DeVos 30 days to provide recommendations for any waivers she thought necessary under IDEA to "provide limited flexibility" to states and school districts during the emergency.

Disability advocates were unequivocal that they thought no waivers were needed even as most of the nation's schools remained shuttered. But, groups representing school administrators had reasoned that given the extraordinary circumstances, temporary modifications were justified.

"We undertook this task acknowledging the reality that most students and teachers are at home today; yet, America's teachers want to keep teaching and students need to keep learning," DeVos said in a statement. "While the department has provided extensive flexibility to help schools transition, there is no reason for Congress to waive any provision designed to keep students learning. With ingenuity, innovation and grit, I know this nation's educators and schools can continue to faithfully educate every one of its students."

The Education Department said that the recommendations were rooted in several key principles including that learning must continue for all students, decision-making should be based on what's best for students, parents must be informed of how waivers would impact their kids and services that have traditionally been provided in-person will have to be done differently.

"The secretary determined there is no reason that a student's access to FAPE cannot continue online, through distance education or other alternative strategies," the agency said in an announcement about the report.

DeVos is recommending that Congress allow her agency waiver authority to ensure that children with disabilities can continue receiving services after they turn 3 if the pandemic delays an evaluation that's supposed to happen at that juncture. The secretary is also seeking changes to requirements of IDEA personnel development scholarships and more flexibility in funding for vocational rehabilitation.

"I am pleasantly surprised that it appears that the secretary did not succumb to pressure and chose the high road to leave the important provisions of both (IDEA and the Rehabilitation Act) untouched," said Denise Stile Marshall, CEO of the Council of Parent Attorneys and Advocates, or COPAA, a nonprofit that represents special education attorneys.

Officials with AASA, The School Superintendents Association, as well as the National Association of State Directors of Special Education and the Council of Administrators of Special Education — which had all pushed for temporary IDEA flexibilities — did not immediately offer comment on the report.

Direct Care Workers Struggle To Find Protective Equipment

by Rita Price, reprinted from The Columbus Dispatch/TNS | April 14, 2020

COLUMBUS, Ohio — For a brief, happy moment, it appeared that a distributor of masks would come through with a shipment to a northeastern Ohio agency whose workers care forpeople with disabilities. "And then it was diverted to a hospital," said Pete Moore, president and CEO of the Ohio Provider Resource Association. "We are essential, and we are part of the health-care community, too," he said. "But we are kind of low on the PPE totem pole."

With supplies being gobbled up by medical professionals, safety workers and now the general public, disability services agencies and their thousands of employees are desperate for the masks and other personal protective equipment that they need to reduce the risk of coronavirus infections in group homes and other settings. "It's just overwhelming, the need out there," said Bethany Toledo, executive director of the Ohio Alliance of Direct Support Professionals.

Many workers have no choice but to try to make their own masks. Agencies and county boards of developmental disabilities throughout the state also are accepting donations of purchased or handmade masks from the public and will get them to the workers, Toledo said. "We would welcome that and would help to distribute them as well," said Jed Morison, superintendent of the Franklin County Board of Developmental Disabilities.

Franklin County Emergency Management and Homeland Security is doing a good job obtaining supplies, Morison said, "but there's still a shortage of masks, in particular."

Cassandra Benning-Lewis, a direct support worker in the Dayton area for more than 20 years, is among those sewing as fast as she can. The skill is brand new. "I didn't know anything about sewing," she said. "But I had a machine that had been sitting in the corner collecting dust. And I figured I'd go on YouTube and watch how-to videos until something resonated."

Benning-Lewis is protective of both her clients and colleagues, and frustrated that many don't have what they need to stay safe. "I have a co-worker who has COPD," she said. "She told me, 'I just got off the phone with my sister and I made plans for her to take care of my dogs should something happen to me.""

Benning-Lewis cried that day, as she had when Ohio Gov. Mike DeWine praised direct support workers for standing by their clients with disabilities. "When he mentioned us, tears rolled down my face," she said. "We don't make a lot of money, but we're buying fabric, sewing, we're doing all we can."

Moore, of the provider association, said he knows some workers are using rain ponchos instead of medical gowns. He and others say it shouldn't be that way in the United States. "I certainly hope we can walk away from this crisis with a better understanding of what it takes."

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Students With Special Needs Donate Face Shields Made With 3D Printers by Patrick Lanni, reprinted from NJ.com | April 28, 2020

HASBROUCK HEIGHTS, N.J. — The beeps and whistles stopped long enough for Amelia McGowan to realize exactly what was going wrong. A paper jam ... or in this case a filament jam. For nine hours a day, there's a 3D printer spitting out line after line in an effort to produce face shields for health care workers. It's McGowan's job to make sure the printer runs smoothly, but in the middle of this jam, production has slowed to a halt. There's a service error, and there's only one McGowan in the house who knows how to fix it. It's not mom. It's not dad. It's Amelia, a 13-year-old student with special needs from the South Bergen Jointure Commission, who is one of a dozen teenagers from the district working with 3D printers at their homes to supplement remote learning.

The SBJC provides special education services for nearly 400 students in the area. The public school district, which has schools in six Bergen County towns, educates students from preschool through high school. It also has a post-graduate program for students up to 21 years old.

Earlier this month, McGowan, her family and a group of teachers and administrators from the district donated boxes of face shields to Holy Name Hospital in Teaneck. They were all produced by a group of students who were able to work with the printers from their homes once schools closed last month during the start of the coronavirus outbreak. The students are not only learning how to use the technology, but it has also given them a sense of pride in their work. "Special parents, we don't get the opportunity to watch our kids throw the winning touchdown or get to have the milestones that typical families do so to watch her and watch this independence bloom, to see her have that victorious moment, it's only fueled my need to keep pushing this conversation," said Dr. Stephanie McGowan, Amelia's mother.

McGowan, who also serves as a councilwoman in Rutherford, has been a special needs advocate for the Bergen County town and works as the dean for the School of Education at Felician University. In collaboration with Felician University and No Barriers USA, the South Bergen Jointure Commission has focused on educating its students "beyond the confines of school walls," according to Dr. Michael Kuchar, the district's superintendent.

Shane Miller, the STEM coordinator for the district, delivered the printers to nearly a dozen families and provided step-by-step lessons. Since the initial deployment, additional 3D printers have been donated to the SBJC. The project also caught the attention of New Jersey Gov. Phil Murphy, who shared the story of during a news conference while explaining #NJThanksYou, an initiative which highlights extraordinary acts of selflessness during the coronavirus pandemic. "We are grateful to the whole team," Murphy said.