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Waiting Lists May Be Eliminated For Disability Services Provided By Medicaid

Reprinted from March 22, 2021 Disability Scoop by Michelle Diament

Work is underway on legislation that could fundamentally transform the nation's system of home- and community-based services, eliminating waiting lists and allowing people with disabilities to move across state lines without forfeiting critical services and supports. A draft bill unveiled this month known as the HCBS Access Act would require Medicaid to provide home- and community-based services to everyone who is eligible and establish a minimum set of services that states must offer. The bill is also designed to help states create a network of providers and workers to deliver such supports.

The plan is being put forth by U.S. Rep. Debbie Dingell, D-Mich., along with Sens. Maggie Hassan, D-N.H., Bob Casey, D-Pa., and Sherrod Brown, D-Ohio.

The lawmakers said the "discussion draft" is a "first step to creating HCBS support for all those who are eligible and choose HCBS" and they are seeking feedback in the coming weeks from stakeholders before moving forward with introducing a formal bill.

"The HCBS Access Act would be a huge paradigm shift," said Nicole Jorwic, senior director of public policy at The Arc who's advocating for the legislation. "It's not an overstatement to say this would be a game changer for services and supports for people with disabilities." Since home- and community-based services originated in the early 1980s, they have been optional. States provide the services through Medicaid waivers, which vary greatly from one place to another and are limited meaning that people with disabilities often spend years on waiting lists before they can access supports. The waivers are tied to the state where a person lives, so if an individual moves, they often must start the waiting list process anew. By contrast, Medicaid guarantees institutional services to those who qualify.

Under the draft legislation, that would change. Home- and community-based services would be mandatory in the Medicaid program, much like institutional services already are. "For the 850,000 people on waiting lists, this would be life changing," Jorwic said. "When you pull that many people into this system, you're not only helping the people getting the supports and services, you're also helping family caregivers who are currently filling the gaps in the services system."

The draft bill would send more federal funding to states and create a basic menu of required home- and community-based services nationwide that states could choose to enhance. Advocates say this would eliminate confusion for families and simplify things for states, which currently operate a range of waiver programs, each with their own target populations and rules.

The lawmakers have also indicated that they intend to include provisions in the bill to strengthen the workforce that provides support to people with disabilities in the community, but they are currently short on specifics about that piece of the plan.

"The current system is an artifact of a law that is over 55 years old and never envisioned community-based supports for older adults and people with disabilities," reads a note to stakeholders from the offices of Hassan, Brown, Casey and Dingell. "It is time to establish a baseline criteria for the delivery of HCBS across the country and to make those foundational services an entitlement under Medicaid."

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"My Two Cents"

By Tim Doherty, Executive Director

Tenant Writes "Heartfelt Thanks" to PFI Lawrence Staff

It isn't often that we get a thank you from tenants for something done by our PFI staff, that has helped or affected their lives. That is why I was surprised to get a very nice phone call from one of our Lawrence tenants, Peggy Newman with regard to something she needed to tell me. So, when I did get to talk to her, she very much wanted to let me know how she felt about our office staff, Robin Brown and Brianne Foley and how they helped her cope and get through this past year, with Covid and all the issues we all faced.

In Peggy's own words, "There aren't enough Thank you's for me to express my thanks for all your help and kindness. They say there are angels among us, and I am glad that I found mine. Life's struggles are so constant in this age, that we live in. That's why God has sent two beautiful angels to care for us. Their names are Brianne and Robyn. Thank you Jesus, for putting them in my path. They make each day a blessing".

Peggy is a long time resident of our Lawrence community. She can be seen whizzing around the complex, usually helping another tenant by walking their dog, or running an errand for another tenant. Peggy usually participates in our activities, when we have been able to put them on, and is very outgoing and sociable. Peggy uses a power chair to get around, but like so many others, has been a prisoner in her own home, so I was glad to hear that Robyn and Brianne were able to help her during this time.

Last fall, Project Freedom recognized the work that some other organizations, such as ARM in ARM or the Jewish family Services agency, does with providing food for many of our tenants. I know that both Robyn and Bri make those monthly distributions to all our tenants (Rosario helps as well) so that everyone gets something each month. In addition, it gives them a chance to see how folks are doing, and to lend a hand if needed. Peggy also commented about how she felt that we were all a family who cared about each other, and that she felt "blessed".



So Kudos to Lawrence PFI staff, keep up the good work.

Timothery & Doberty

From Norman's Desk

It is May! It is time for my annual rant as we near Hurricane Season—especially this year. The National Weather Service has officially decreed that Hurricane Season begins on May 15, two weeks earlier than normal, because tropical storms are forming earlier.

It is time to once again focus on the looming hurricanes season and the predictions by the Colorado State University tropical study program. Nationally, we went through an horrendous year in 2020 in terms of Tropical Storms, Hurricanes, and Major Hurricanes, and the pandemic only added to the trauma.

This is the 38th 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 this year is for a total of 17 named storms with eight hurricanes and four of them becoming major hurricanes. This is very similar to last year's prediction was 16 named storms, four becoming hurricanes, and four reaching the major threshold. But they were way off in their April forecast. The actual number for the 2020 season was 30 named storms; 13 of these storms turned into hurricanes with six being major in power and scale. Of the 30 storms, 11 of them made landfall in the US breaking the record of nine set in 1916. Last year was the fifth consecutive year that at least one category five hurricane has formed.

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 the same, but in 2019 it was 48%. For the U.S. East Coast including Peninsula Florida the prediction remains at 45%, up from 28% for 2019.

In sum, it looks like a busy summer and fall with tropical storms, and if Dr. Klotzbach's team has underestimated as they did last year, we may have another horrendous season.

With this year's prediction in mind and remembering what we went through last year 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

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.

Myths and Facts about COVID-19 Vaccines

How do I know which COVID-19 vaccine information are accurate?

It can be difficult to know which sources of information you can trust. Before considering vaccine information on the Internet, check that the information comes from a credible source and is updated on a regular basis. Learn more about this at https://www.cdc.gov/vaccines/vac-gen/evalwebs.htm



Will a COVID-19 vaccine alter my DNA?

No. COVID-19 vaccines do not change or interact with your DNA in any way.

There are currently two types of COVID-19 vaccines that have been authorized and recommended for use in the United States: messenger RNA (mRNA) vaccines and a viral vector vaccine. Both mRNA and viral vector COVID-19 vaccines deliver instructions (genetic material) to our cells to start building protection against the virus that causes COVID-19. However, the material never enters the nucleus of the cell, which is where our DNA is kept. This means the genetic material in the vaccines cannot affect or interact with our DNA in any way. All COVID-19 vaccines work with the body's natural defenses to safely develop immunity to disease.

Can CDC mandate that I get a COVID-19 vaccine?

No. The federal government does not mandate (require) vaccination for people. Additionally, CDC does not maintain or monitor a person's vaccination records. Whether a state or local government or employer, for example, can require or mandate COVID-19 vaccination is a matter of state or other applicable law. Please contact your state government or employer if you have other questions about COVID-19 vaccination mandates.



After getting a COVID-19 vaccine, will I test positive for COVID-19 on a viral test?

No. None of the authorized and recommended COVID-19 vaccines cause you to test positive on viral tests, which are used to see if you have a **current infection**. Neither can any of the COVID-19 vaccines currently in clinical trials in the United States. If your body develops an immune response to vaccination, which is the goal, you may test positive on some antibody tests. Antibody tests indicate you had a **previous infection** and that you may have some level of protection against the virus. Experts are currently looking at how COVID-19 vaccination may affect antibody testing results.



Can a COVID-19 vaccine make me sick with COVID-19?

No. None of the authorized and recommended COVID-19 vaccines or COVID-19 vaccines currently in development in the United States contain the live virus that causes COVID-19. This means that a COVID-19 vaccine **cannot** make you sick with COVID-19. COVID-19 vaccines teach our immune systems how to recognize and fight the virus that causes COVID-19. Sometimes this process can cause symptoms, such as fever. These symptoms are normal and are signs that the body is building protection against the virus that causes COVID-19. Learn more about how COVID-19 vaccines work

People With IDD Can Get COVID-19 Vaccination Help From New Website

By Katie Camero / reprinted from McClatchy Washington Bureau/TNS | April 6, 2021

People with intellectual and developmental disabilities — such as Down syndrome, cerebral palsy and autism — have faced significant hurdles during the pandemic involving education, employment and mental and physical health.

Despite little research on the group comprising about 6.5 million Americans, it's well known these individuals face significantly higher risks of coronavirus-related hospitalization and death — yet they have been mostly absent from many states' vaccination priority lists.

To combat what experts deem a public health concern, the National Association of Councils on Developmental Disabilities launched a <u>website</u> last week to help guide people with IDD to trusted resources on COVID-19 vaccines, particularly where to find one in their area.

Those behind "Get Out The Vaccine" said the community is dealing with transportation issues, internet access problems and general struggles with following preventive measures such as social distancing and mask wearing — all factors that can keep them from getting a vaccine appointment.

But Emmanuel Jenkins, who has cerebral palsy, says he won't let those challenges stand in the way. "If cerebral palsy is not going to take me out," he said, "I refuse to let a pandemic, or a virus do the same."

Donna Meltzer, CEO of NACDD, said her goal is to make sure people with disabilities can "get back to living their fullest lives." "So many people have been isolated from their friends, families, coworkers and their community because of this pandemic," Meltzer said in a statement. "We want our community to understand the benefits of the vaccine and feel empowered to make the decision to get vaccinated on their own."

There is no national database that tracks how many people with IDD are getting vaccinated against COVID-19, but some states have their own counts and are taking steps to ensure this population receives priority access while supplies remain limited.

For example, Maryland and Ohio included people with developmental disabilities in their Phase 1b vaccine priority lists, Illinois included people with disabilities in its Phase 1b, and Nevada and Washington included the same group in Phase 1c, according to the Kaiser Family Foundation.

Still, the terminology used within state vaccination plans has left some people with attention-deficit disorders, hearing loss, seizures, stuttering or other developmental delays out from early vaccination guidelines. Most states say people with "high risk medical conditions" should be prioritized, but the category may not include all people with IDD.

Many, if not all, states also prioritized adults living in long-term care facilities, per Centers for Disease Control and Prevention recommendations, however not all people with IDD live in nursing homes. The vague criteria for vaccination "stems, in part, from a continued inattention to this population in research studies," four medical professionals wrote in <u>commentary</u> published in February in The Lancet. "Specifically, national population health data for individuals with IDD is incomplete and strategies to improve vaccination rates in individuals with IDD are under-explored."

The CDC acknowledges that people with disabilities are at higher risk of getting COVID-19, but the only intellectual or developmental condition it lists on its <u>website</u> is Down syndrome. The agency notes "conditions are added when there is enough scientific evidence to support putting them on the list. The list is updated as new information becomes available."

What Risks Do People With IDD Face When Diagnosed With COVID-19? CDC officials say additional health conditions such as diabetes, heart disease or obesity — on top of a disability — can raise risks of getting COVID-19. Part of the reason being that this group is more likely to have such pre-existing health conditions. In fact, life expectancy for this population is nearly 20 years below that of the general public.

A <u>study</u> of more than 65 million patients across 547 health care organizations found that people with IDD were more likely to get COVID-19 (3%), be hospitalized (63%), be admitted to an intensive care unit (15%) and die (8%) from COVID-19 compared to those infected with the virus but without IDD — 1%, 29%, 6% and 4%, respectively. Another <u>study</u> of New York residents showed that risk of death for people with IDD and COVID-19 was nearly eight times higher than that of the general population.

Yet another <u>paper</u> found that people with intellectual and developmental disabilities were more likely to become infected by and die from COVID-19, especially at younger ages, McClatchy News reported last June. This group has "historically grappled with fragmented access to primary and preventive care, social and medical stigma, and marginalization," medical professionals wrote in The Lancet. "These barriers contribute to higher prevalence of co-occurring mental and physical health conditions and rates of mortality, particularly for racial and ethnic minorities, women, and individuals from low-income families." "Given these barriers and resulting health disparities, we can anticipate hurdles for vaccine dissemination and uptake among individuals with IDD," they added.

Experts say the best defense against COVID-19 right now is vaccination; President Joe Biden announced all Americans will be eligible to get COVID-19 vaccines by May 1, although some states are opening up eligibility earlier. However, most advocates agree there's much to be done to ensure people with IDD have the resources they need to access accurate information about vaccines.

The CDC offers resources about COVID-19 that are <u>easy to read</u>, in <u>American Sign Language</u> and for people with <u>limited English</u> proficiency.

So far, more than 56 million people have been fully vaccinated in the U.S. as of April 1, a CDC <u>tracker</u> shows — about 16.9% of the population.

Virtual Special Olympics Brings Smiles To Students' Faces Reprinted from March 24, 2021 Las Cruces Sun-News/TNS by Miranda Cyr,

With a mix of enthusiasm and some shyness, each student involved in the Special Olympics at Mesa Middle School stepped up to the first-place podium and received a red medal for competing. The Special Olympic collaboration between Mesa Middle School and Picacho Middle School had been a work in progress for months.

While ensuring COVID-safe practices, the team of educators worked together to give special education students the opportunity to participate virtually. Classes from both schools spent two months meeting on Zoom to prepare for the modified Winter Olympic events. Karen Sivils, a physical therapist at Las Cruces Public Schools who helped coordinate the Special Olympic events, said the students also learned to sing and sign the National Anthem, practiced the Athlete's Oath, practiced announcing events and learned about sportsmanship.

Last week, the events began with an opening ceremony and ended with an in-person awards ceremony on Friday. "We made it really accessible to a wide range," Sivils said. "We had our kids who are announcers — who are the kids who have more talking skills — they're able to read the scripts. Then, we have kids who can't even walk, and they were able to still participate ... One of the things I love about working with (these) kids is that they've never known anything different for the most part. Their joy and their enthusiasm is just boundless."

This year, Anna Houdeshell, recreation therapist at LCPS who helped coordinate the Special Olympics events, said they decided it would be too difficult to coordinate with general education students without being in-person. But the students enjoyed participating all the same. "Being at home individually has really taken a hit on what students," Houdeshell said. "The opportunity to do something like this, where we can all see each other on Zoom, and you still feel like a team has just been so amazing. This is the first time I've seen these kids in a year."

The group later met in a virtual hot chocolate social Zoom to wrap up the week of Olympic events. "It took a lot from all the staff from both schools to just really communicate to plan this, but all of the staff really, really wanted to work hard and communicate," Houdeshell said. "It's hard for the students I think sometimes to understand the Zoom versus in-person, but they did so well adapting to that."

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CDC Issues COVID-19 Guidance For Day Centers Serving Adults With Disabilities by Shaun Heasley / Reprinted from DisAbility Scoop / April 13, 2021

The guidance comes in two documents — one aimed at administrators and staff and another for participants and their caregivers — that were issued late last month.

"We know these populations are at high risk for severe COVID-19 disease, and this guidance will help center administrators and staff protect themselves and adults receiving their services by promoting and engaging in preventive behaviors that reduce COVID-19 spread and help maintain healthy operations and environments of these facilities," said Rochelle Walensky, director of the CDC.

Federal officials say that day centers for people with disabilities and older adults across the nation should encourage COVID-19 vaccination, hand-washing, mask-wearing and physical distancing when possible. Both participants and staff should stay home if they have tested positive for the virus, have had close contact with someone who has or if they have symptoms.

Nonessential visitors should be limited from day centers, the guidance indicates, as should services and programs that require individuals to be within six feet of each other. In addition, centers are advised to have a plan to isolate and transport anyone who shows symptoms.

The CDC is recommending that day centers modify layouts to allow for physical distancing, install plexiglass barriers and prioritize outdoor activities. Participants should be assigned to small groups that regularly do things together to limit interactions. Meals, drop-offs and other activities should be staggered to avoid crowding. The guidance is meant to supplement, not replace, existing federal and local rules and regulations for day centers, the CDC said.