



THE IL EDGE
 WINTER 2023 - WVSILC - PO Box 625 - Institute, WV 25112

SILC UPDATE

As 2022 comes to an end and 2023 begins, we reflect on the past and look forward to the future. 2022 brought many changes to the WVSILC office. The most noticeable change is the people you will see when you visit our office. Two of the faces you are so accustomed to seeing over the past many years are no longer here. Since the retirements of Ann McDaniel and Kathi Young, several staff changes have been made, but we have now found the right people to fill the void. Both Trish Cash and Tonya Barnett joined us in 2022 and have been doing an excellent job supporting the council, committees, and operations of the WVSILC.

The new year promises to be exciting; we have just released a new website which includes the same useful information as the old website but has a few new features as well. You can subscribe to our newsletter, so you'll get the latest news, events, and issues on disability rights emailed directly to your inbox. On the "Events" page, you will see all the upcoming events held by the WVSILC and our partners. We have also added an online store that you'll find on the "SILC Merch" page, so check it out and look for new products to be released.

Towards late summer or early fall we plan on having the first annual car show featuring only vehicles that have been modified with adaptive equipment. There will be vehicle related vendors, first responders, food vendors, live music, and of course – trophies! Come and see cars that have been modified in ways you've never seen before. The purpose of the car show is to educate first responders and the public, provide awareness, and raise money to help people with disabilities get the vehicle modifications they need to be mobile.

Join us as the new year gets underway for a new look, a new dedicated team, and new creative ways to address the issues of the day.

From the desk of

Jerry Boyko

MISSION

"The mission of the WVSILC is to promote the value, equality, full-inclusion, and freedom of choice of all West Virginians with disabilities."

WV Centers for Independent Living

Appalachian CIL
 Elk Office Center
 4710 Chimney Dr.
 Charleston, WV 25302
 304-965-0376

Liveability
 601-603 East Brockway Ave.
 Suite A & B
 Morgantown, WV 26505
 304-296-6091

109 Randolph Ave.
 Elkins, WV 26241
 304-636-0143

Mountain State CIL
 821 Fourth Ave.
 Huntington, WV 25701
 304-525-3324

329 Prince St.
 Beckley, WV 25801
 304-255-0122





Independent Living Day



At the Capitol

You are invited to the second Independent Living Day at the Capitol!

Thursday, January 19, 2023

Celebrating Independent Living programs, highlighting unmet needs, and introducing the WV Independence Network (WIN)

Activities for the day include:

- 9:00-3:00 Exhibits/Displays
- 10:00 Rally & Introduction of WIN
- 11:00-1:00 Floor Sessions
- 1:00-3:00 Visit Legislatures



Source: [Mental Distress](#)

ADULTS WITH DISABILITIES REPORT FREQUENT MENTAL DISTRESS* ALMOST 5 TIMES AS OFTEN AS ADULTS WITHOUT DISABILITIES

Screen patients for mental health concerns

* Frequent mental distress was defined as 14 or more mentally unhealthy days in the past 30 days, using the 2018 Behavioral Risk Factor Surveillance System

CDC.GOV bit.ly/MMWRMentalDistress MMWR

Buckhannon, WV becoming more accessible

By Brenda Dasher from [Liveability](#)

Buckhannon WV is working hard to make their town more accessible.

While working with consumers with independent living skills at the Manor in Buckhannon WV, I was approached by several of the tenants that live there. They were concerned about the town's sidewalk issues. The sidewalks, like most in small towns, had not been made truly accessible during the time of the construction of the sidewalks. Not to mention the wear and tear that they have.

After speaking to the tenants and realizing that the sidewalks were their only way to get around most of the time, I decided to see what I could find about the city.

I asked several people who I should contact, and I always came up with the name Jerry Arnold. When I approached Jerry, he was very interested in what consumers had to say about which sidewalks needed attention the most.

Since then, Jerry has also organized hands-on training for his coworkers. This was to be able to see what it was like to be in a wheelchair, blind, deaf, or any other disability, and try to get around town safely. I believe this was a true eye-opener for all involved. What better way to realize what people with a disability go through on a daily basis than to participate in this activity? I always say if it doesn't affect you or someone you love you have no reason to pay attention.

Jerry and his crew at the City of Buckhannon continue to change and update the sidewalks of the city. This will better serve not only people



(See Accessible p3)

The hidden extra costs of living with a disability

Source: [The Conversation](#)

Disability is often incorrectly assumed to be rare. However, global estimates suggest that one in seven adults has some form of disability.

The term “disability” covers a number of functional limitations – physical, sensory, mental and intellectual. These can range from mild to severe and might affect someone at any time across the lifespan, from an infant born with an intellectual impairment to an older adult who becomes unable to walk or see.

What is perhaps less well-known is that studies consistently show that people with disabilities are disproportionately poor. They are more likely to become poor and, when poor, are more likely to stay that way, because of barriers to getting an education, finding decent work and participating in civic life. Taken together, these barriers significantly and adversely impact their standard of living.

However, a new body of research reveals another major barrier, previously missing from most studies: People living with disabilities also face extra costs of living. Our team’s recent review of the evidence suggests that living with a disability may cost an additional several thousand dollars per year, adding up over time to be a significant financial burden on households.

The Conversation is a news organization dedicated to facts and evidence

Calculating the cost

People with disabilities may have more basic necessities than people without. Governments draw poverty lines at a level of income that they believe is sufficient to meet a minimum standard of living. Someone at the poverty line presumably has just enough resources to house, clothe and feed themselves at an acceptable level, and participate in the basic activities of being a citizen. Increasingly, countries provide cash benefits or food transfers to people below this poverty line so they are able to reach this minimum standard for basic resources.

The problem is that people with disabilities have extra costs of living that people without disabilities do not have. They have higher medical expenses and may need personal assistance or assistive devices, such as wheelchairs or hearing aids. They may need to spend more on transportation or modified housing, or be restricted in what neighborhoods they can live in to be closer to work or accessible services.

When this is the case, then some people with disabilities might appear “on paper” to live above the poverty line. But in reality, they don’t have enough money to meet the minimum standard of living captured in that poverty line.

In our recent review of the literature, we found that people with disabilities in 10 countries face large extra costs of living. These costs can range widely, from an estimated US\$1,170 to \$6,952 per year. In a developing country such as Vietnam, for example, the estimate stands at \$595 for additional health costs alone.

with disabilities but everyone. He is always ready to listen when someone has an issue with a sidewalk.

Thank you, Jerry Arnold and crew, for really listening to the people in Buckhannon WV.



Why Advocate?

“Unless someone like you cares a whole awful lot, Nothing is going to get better. It's not.”
- Dr. Seuss, *The Lorax*



How to becoming a advocate

By Lynsay Frye

For me advocating is about helping with intellectual and Developmental Disabilities in children until they get older and learn about advocating for themselves. Teaching them how they can speak up for their rights. You just need to give them guidance while advocating for them. You can use your voice to speak up.

Advocate for them by talking to individuals with Disabilities, not criticize them and never take their power from them, it is discouraging. We are like you and you are just like us. Please don’t judge us. By advocating we will make a difference in the world.



FuelService

Source: [FuelService](#)

This app helps disabled drivers find and get assistance refueling their vehicles. Refueling can be challenging for people who are in wheelchairs and other disabled drivers, but FuelService aims to solve that challenge by showing you which gas stations have attendants who can help.

Use the app to search for and choose a gas station from a list or map. The app will then contact the gas station to see if they can assist you. Once you arrive, the app notifies the attendant you have arrived and shows you how many minutes it will be before they come out to help. It even includes a rating system to help you choose gas stations that have provided good assistance to others.

Even if you do not have a smartphone, you can still use FuelService. You can also use FuelService by dialing our interactive voice service or by sending an SMS TXT message. Just enter the gas station number and pump number. FuelService then contacts the station for you and lets you know the

Access Now

Source: [Access Now](#)

The world isn't designed for everyone in mind. Millions of places all around the world are still inaccessible to people with disabilities. That's why we're building a movement that celebrates access by connecting people to inclusive, welcoming places for all.

Access Now is a community-driven app that pinpoints accessible locations on an interactive map. You can look up restaurants, museums and attractions and view their accessibility ratings; accessible, partially accessible, patio access only and not accessible. You can also rate locations and even add your own to help others in the community.

Federal Panel's Shift to 'Neutral' Autism Language Prompts Backlash

Source: [Disability Scoop](#)

As an influential federal autism committee considers moving to “neutral, strengths-based” language, some advocates are pushing back arguing that stripping words will merely “sanitize” the realities many families face.

Every year, the government's Interagency Autism Coordinating Committee — a panel of government officials and members of the autism community that's charged with advising the secretary of health and human services and coordinating federal autism activities — is tasked with updating its strategic plan. The plan guides priorities for autism research, services and supports and is relied on by both federal agencies and private organizations.

With work underway on the latest iteration, committee leaders have signaled their intention to shift the type of language that's included. The updates were incorporated in response to feedback in a survey of IACC members earlier this year.

“There were some comments on language considerations, which we summarized as moving away from deficits-based language and towards more neutral, strengths-based, inclusive language while also balancing the importance of maintaining accuracy when referring to issues that may be scientific, medical or clinical in nature,” Susan Daniels, executive secretary of IACC, said during the committee's spring meeting.

Sam Crane, legal director at the Quality Trust for Individuals with Disabilities and a member of the IACC, said that the current draft the committee is considering contains “significant changes,” many of which are “for the purpose of reducing stigma and reflecting the community's prioritization of well-being over a ‘cure.’” She noted that the changes are in line with efforts to refocus research on improving quality of life.

Now, however, some advocates are not on board. The National Council on Severe Autism recently wrote to the IACC criticizing the plan.

“There is nothing inclusive about neutral or strengths-based language that specifically excludes or denies realities of autism, particularly severe autism,” the group wrote. “While the IACC neutralizes language about autism, families on the other hand rely on medical necessity, and the neural and behavioral impairments, disorders and pathologies underlying it, to attain desperately needed supports. For most of us in the real world, impairments, dysfunctions, deficits, disorders, dependency, and not ‘strengths,’ define the daily experience of autism.”

The group argues that altering the language around autism limits the ability to address significant issues like self-injurious behaviors, the rise in autism prevalence and the need for services and housing.

“I actually think that language is a central concern of these debates, as it determines how policy makers and the public more broadly perceive autism,” said Amy Lutz, vice president of the National Council on Severe Autism, who spoke out at the IACC's October meeting against the move toward neutral

Yale Discriminates Against Students Like Me With Mental Health Disabilities. That's Why I'm Suing.

Source: [Yale](#)

In September 2019, I showed up to my Yale University psychiatrist's office in tears. After getting As in most of my classes my first year, my depression and insomnia escalated at the start of my sophomore year, leaving me unable to fall asleep until only a couple hours before I needed to go to class. I was desperate for help.

I asked if some of my absences could be excused as long as I kept up with my coursework. I was told that the university's office of mental health and counseling had a policy of not writing notes in support of disability accommodations because students could be lying about their symptoms—the same symptoms my psychiatrist had prescribed me an antidepressant and antipsychotic to treat.

I'm now a Yale junior. Last month, I was one of two named plaintiffs, as well as a Yale mental health advocacy group called Elis for Rachael, who filed a class-action lawsuit against the university for failing to accommodate and discriminating against students with mental health disabilities.

I did not want to spend my time at Yale suing them. It's terrifying to go up against an elite, powerful institution wielding an endowment larger than the GDP of 103 countries. But despite scores of students begging for change, Yale has made minimal attempts at reform. For years, students and alumni have organized to ask that Yale make it easier to access mental health treatment on campus, address distrust of mental health services, and make medical withdrawal and reinstatement policies less punitive. These focused efforts have resulted in little change. Every second we wait puts students' lives at risk.

People with mental health disabilities have federally protected civil rights, just like those with physical disabilities. Under the Americans With Disabilities Act, universities must provide academic accommodations and other reasonable modifications for students with all forms of disabilities. Our lawsuit argues that Yale has failed to do so.

As plaintiffs, we are not seeking monetary relief. All we are asking is for Yale to change their policies. I chose to be named in the lawsuit because I didn't want other students to go through the agonizing experience I did.

After being denied support by the school psychiatrist that fall, my mental health rapidly worsened. I knew that part-time enrollment was not permitted by Yale's policies, but I also knew that I couldn't finish the semester with a full course load—especially without any accommodations. Everywhere I turned for help, I was met with dead ends. I felt trapped. With no other choice, I submitted a request to withdraw.

Once my medical withdrawal was formalized, Yale seemed mostly concerned with getting me off campus. I had 48 hours to move out of my dorm. I lost 75 percent of my tuition and housing fees for the semester, despite having withdrawn only a third of the way into the term. My access to student health insurance was revoked. I was officially banned from engaging in any campus

(Yale continue on p6)

"Long COVID" as a Disability Under the ADA, Section 504, and Section 1557

Source: [HHS.gov](#)

Yes, long COVID can be a disability under the ADA, Section 504, and Section 1557 if it substantially limits one or more major life activities. These laws and their related rules define a person with a disability as an individual with a physical or mental impairment that substantially limits one or more of the major life activities of such individual ("actual disability"); a person with a record of such an impairment ("record of"); or a person who is regarded as having such an impairment ("regarded as"). A person with long COVID has a disability if the person's condition or any of its symptoms is a "physical or mental" impairment that "substantially limits" one or more major life activities.

This guidance addresses the "actual disability" part of the disability definition. The definition also covers individuals with a "record of" a substantially limiting impairment or those "regarded as" having a physical impairment (whether substantially limiting or not). This document does not address the "record of" or "regarded as" parts of the disability definition, which may also be relevant to claims regarding long COVID.



Come check out WVSILC new website.
<https://wvsilc.org/>

New and approved website filled with information to learn about West Virginia Statewide Independent Living.



(Yale continue from p5)

(Cost continued from p3)

without prior permission. I was left isolated and abandoned when I was most in need of help. It felt as though even Yale's facade of caring about my well-being evaporated the second I was no longer their problem to deal with.

After six months and attending an intensive outpatient therapy program, I felt stable, optimistic, and ready to reenroll. But the reinstatement process proved to be another daunting series of obstacles. The application consisted of a personal statement, three letters of support, interviews with Yale administrators, and a coursework requirement (which has since been eliminated) to earn grades of B or higher in two classes at an accredited four-year institution, which I also had to pay for. There is a cruel irony in taking time off school to prioritize my mental health only to be told that I have to take classes regardless—I just wasn't allowed to do so at Yale.

All of this was meant to prove that I had been "constructively occupied" during my withdrawal, so that Yale could assess not just whether I had been effectively treated but also that I had used my time off "productively," per their policies. But I didn't take time off to be productive; I needed to heal. Yale's process made me feel as though my mental health challenges were a weakness, a moral failure, a character flaw that I had to fix to earn my spot back.

I returned to campus aware that I was on thin ice. As Yale stipulates for most students who withdraw for any reason, I knew that if I failed a single course in my first year back, the university could kick me out, this time involuntarily. This pressure was compounded by an exhausting and demoralizing fight to receive disability accommodations as I was passed around between administrators and staff for weeks.

Pressure cooker universities demand perfection and punish anything less, treating mental health disabilities as evidence of defectiveness rather than approaching students with compassion and care. The end goal is to produce the leaders of tomorrow, even if that means sacrificing their well-being.

We used a method called the standard of living approach, which estimates extra costs based on the gap in assets owned by households with and without disabilities. Extra costs accounted for a large share of income, from a low of 12 percent in Vietnam to 40 percent for elderly households in Ireland.

Comparing the costs of disabilities across countries is challenging. Recent studies measure what is actually spent, not what needs to be spent. Estimated costs might be less in developing countries not because it is less expensive to accommodate the needs of people with disabilities in those countries, but because the goods and services needed are not available. If wheelchairs or hearing aids are nowhere to be found, then a person cannot spend money on them.

This could lead to the paradoxical finding that, as a country starts becoming more inclusive, the measured costs of living with a disability could increase. But hopefully, at the same time, the ability of people with disabilities to work and go to school will also increase.

Unanswered questions

There is much we still don't know about what it costs to live with a disability. In our comprehensive review of the literature, we found only 20 studies that estimated increased costs of living with a disability. The vast majority were from developed countries.

We need better information on how these extra costs may vary by type of disability, and how they may be affected by efforts to remove barriers to participation. For example, how would building a fully accessible public transportation system impact the extra transportation costs that people with disabilities face?

Our work also suggests we may need different income tests for people with disabilities when it comes to social protection programs. For example, should the income limit for receiving cash transfers or subsidized housing be higher for families with disabilities because they face these extra costs? Some countries, such as Denmark and the United Kingdom, provide benefits to support families with disabilities who bear these costs.

Another important question is whether these benefits are adequate. Do they allow people with disability and their families to reach at least a minimum threshold for standard of living? To what extent does this improve their participation in society or the economy?

Supporting people with disabilities

To address these questions, we need to monitor these issues over time. For that, we need more and better data on disability in different countries linked to good data on income, assets and expenditures. We recommend adding well-formulated disability questions to the standard household surveys currently used by most countries to chart their citizen's wellbeing. The best example of such questions was developed under the aegis of the U.N. Statistical Commission via the Washington Group on Disability Statistics.

It's also important to undertake qualitative research. For instance, focus groups and in-depth interviews would help researchers better understand the needs of people with disabilities in their own terms.

(Cost continued from p6)

Policymakers also need to make social programs sensitive to the issue of extra costs associated with disability – for instance, in income tests and benefit amounts or through social health insurance programs. Our review has led us to believe that even well intended anti-poverty efforts and social protection schemes that do not take into consideration the additional costs of living with a disability will leave millions of people who have disabilities, and their families, in poverty.

Legislative Days at the Capital Charleston, WV

David Stewart Legislative Training Day Tuesday, Jan. 17, 2023
Jan Lilly-Stewart Disability Advocacy Day Wednesday, Jan. 18, 2023
Independent Living (IL) Day at the Capital Thursday, Jan. 19, 2023



Appalachian Center for Independent Living (ACIL) will assist in accessible transportation to and from the Capital for Legislative Training Day, Disability Advocacy Day and Independent Living (IL) Day for individuals living in Kanawha County, WV.

Contact Cody
Phone: (304) 965-0376
To schedule transportation

What Is Long COVID?

Many people recover fully within a few days or weeks after being infected with SARS-CoV-2, the virus that causes COVID-19. But others have symptoms that linger for weeks, months, or even years after their initial diagnosis. Some people seem to recover from COVID-19 but then see their symptoms return, or they develop new symptoms within a few months. Even people who had no symptoms when they were infected can develop symptoms later. Either mild or severe COVID-19 can lead to long-lasting symptoms.

Long COVID, long-haul COVID, post-COVID-19 condition, chronic COVID, and post-acute sequelae of SARS-CoV-2 (PASC) are all names for the health problems that some people experience within a few months of a COVID-19 diagnosis. Symptoms of Long COVID may be the same or different than symptoms of COVID-19. Long COVID can also trigger other health conditions, such as diabetes or kidney disease.

What causes Long COVID?

Scientists don't know for sure what causes Long COVID, but research is providing some clues.

- SARS-CoV-2 particles may become active again, causing symptoms to reappear.
- Overactive immune cells may release high levels of inflammatory substances that can injure organs and tissues.
- The infection may cause the immune system to start making autoantibodies that attack a person's own organs and tissues.

Symptoms may also be caused by a combination of these and other factors. Research into these factors is ongoing.

Why are Long COVID symptoms so varied?

Scientists are uncovering risk factors for Long COVID and reasons why symptoms vary from person to person. Some factors that may be important include:

- Female sex
- Older age
- Severity of initial COVID-19 illness
- Immune response to initial infection
- Not being fully vaccinated against COVID-19



(See COVID p9)



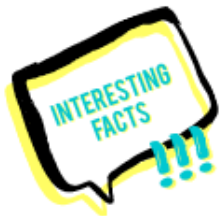
(Autism continued from p4)

language. “If neurodiversity advocates are successful in this new drive to purge discourse of words like ‘severe,’ ‘challenging,’ ‘disorder,’ ‘risk,’ etc., then they will also control the kinds of research that are funded and the supports and services that are provided to individuals like our kids.”

Officials with the National Council on Severe Autism said leaders of several autism groups and some prominent researchers have privately applauded their efforts to speak up, but have not come out publicly against the IACC move to neutral language.

Alycia Halladay, chief science officer at the Autism Science Foundation and a member of the IACC, said she would like to see “more flexibility in the terminology being used” in the draft of the 2021-2022 strategic plan. But she said that she appreciated the IACC staff’s efforts to integrate a broad range of perspectives given that this is a “very contentious issue.”

The IACC is supposed to update its strategic plan every year in accordance with the Autism CARES Act, but the last update was in 2019. Subsequently, the committee did not convene for two years after all of the members’ terms expired and there was a delay in appointing a new committee.



Typewriter/Keyboard

Everyone these days has at least one keyboard, but that wasn’t always the case. The typewriter was the brainchild of an Italian inventor named Pellegrino Turri. He noticed that his friend, Countess Carolina Fantoni da Fivizzano, couldn’t write letters by hand, due to her blindness. So, in 1608 he developed the first-ever incarnation of the typewriter, which involved keys and metal arms with raised characters. Turri also invented carbon paper as a way to provide ink for the machine. The typewriter has since morphed into the computer keyboard.

Now you know

Paralyzed Dachshund Walks Again After Being Gifted Wheelchair for Christmas

Source: [Newsweek](#)

A paralyzed dachshund is back on his feet after receiving the perfect gift this holiday season—the chance to walk again.

Trey, who lives with his owners in College Corner, Ohio, lost the use of his hind legs back in October. The adorable young pup and his family have visited chiropractors and other specialists in the months since, hoping that some sensation would return.

“We honestly don’t know what happened to leave him paralyzed,” his owner Patty Rader said. “We left him unattended, which we have several times. We got home and noticed he wasn’t acting like his usual self.”

After a few days, they decided to take him to their veterinarian to find out what was wrong. “We could tell he was hurting,” Rader said, recalling how Trey was “whimpering and he didn’t want us to touch him.”

She said she initially thought he might have sustained a leg injury, having stepped on it funny. They never expected the vet to tell them their dog had been left paralyzed from his midback down.

According to figures published by the North Carolina State University College of Veterinary Medicine, spinal cord injuries are common among dogs and account for around 2 percent of all cases presented to a veterinarian.

While options are available to help dogs adapt to the challenges presented by injuries of this kind, it can still be a struggle, with pet owners often in need of help.

For Rader and her husband, that help came in the form of the “Letters to Chewy Claus” program, an initiative set up by Chewy, the online pet food and pet product retailer, over the holiday season.

The idea was simple: pet owners submit a holiday gift list for their four-legged friend via a pet-friendly website. Chewy Claus then reviews submissions to determine who has been naughty or nice and, ultimately, make their Christmas wish come true.

For Trey and his family, that wish was simply to walk again. “My mommy and daddy love me more than all the sand at all the beaches, but I know they are struggling,” Trey’s letter to Chewy Claus read [the letter was written by a friend of the Raders].

“What I really want for Christmas is to be able to run and play again but my heart tells me what I need are essentials for paralyzed pups like myself.”

More than 65,000 letters have already been submitted, with Chewy pledging to donate one pound of food to pets in need for every one sent. But while the competition may have been fierce, Trey’s plea did not go unanswered.

With December 25 fast approaching, he and his parents were surprised with their very own Christmas miracle: the gift of a wheelchair to get their beloved

(Dachshund continues on p11)



WV Dept. of Health and Human Resources under federal civil rights investigation

Source: [News and Sentinel](#)

CHARLESTON — The West Virginia Department of Health and Human Resources is under additional scrutiny after federal officials launched a civil rights probe into how the agency handles issues involving intellectual disabilities.

According to a Nov. 14 letter sent to Disability Rights of West Virginia (DRWV), the U.S. Department of Health and Human Services' Office for Civil Rights said it will open an investigation into DHHR based on complaints that Disability Rights submitted.

"After careful consideration, we have determined that we will open an investigation into the complaint filed by DRWV," wrote an official with HHS whose name was redacted. "Please be assured that our office is committed to resolving your complaint as expeditiously as possible."

Disability Rights filed a complaint with HHS alleging that DHHR was unlawfully discriminating based on disability. DHHR is accused of not properly administering the state's Intellectual and Developmental Disabilities (IDD) waiver program.

"In the complaint, (Disability Rights) alleges that DHHR fails to administer services, programs and activities in the most integrated setting appropriate to meet the needs of qualified individuals with disabilities," the letter stated. "As a result, (Disability Rights) states that certain individuals found eligible for services under the IDD Waiver ... did not receive services needed to avoid the risk of institutionalization and are now needlessly segregated in state-operated hospitals."

"The West Virginia Department of Health and Human Resources' (DHHR) Bureau for Medical Services is cooperating with the U.S. Department of Health and Human Resources' Office of Civil Rights in an investigation of allegations of discrimination based on disability," Adler said.

"The DHHR does not tolerate discrimination of any kind and works diligently to prevent discrimination from occurring in any service, program or activity which is administered by the agency," Adler said.

DHHR and Disability Rights have butted heads publicly recently over issues at hospitals operated by DHHR and the lack of input sought from Disability Rights in the \$1 million McChrystal Group report recommending organizational changes at DHHR.

According to a letter written to legislative leaders Nov. 11, DRWV Legal Director Michael Folio said his group sent emails to Meghan Bourne, a partner with the McChrystal Group and the lead on the DHHR review, at the end of September through Oct. 17 raising concerns about issues at DHHR.

(Investigation continues on p10)

- The SARS-CoV-2 variant that caused the initial infection
- Preexisting health conditions, such as diabetes, lung problems, autoimmune diseases, or obesity

Health inequities may also increase the risk of Long COVID for some racial or ethnic minority groups and some people with disabilities.

Can Children Get Long COVID?

Children and teenagers can get Long COVID, whether they had COVID-19 symptoms or not.

Multisystem inflammatory syndrome in children (MIS-C) is a serious delayed complication of SARS-CoV-2 infection that may develop in children and young adults. The condition is caused by inflammation of body parts, including

The heart, lungs, kidneys, brain, skin, eyes, and gastrointestinal organs. Children ages 5 to 11 are most frequently affected by MIS-C.

How can I prevent Long COVID?

The only known way to prevent Long COVID is to avoid getting COVID-19.

The Centers for Disease Control and Prevention (CDC) has steps you can take to protect yourself and others from getting COVID-19.

I have COVID-19. How can I reduce my chances of getting Long COVID?

If you are not vaccinated, vaccination after you recover from COVID-19 may help to prevent Long COVID. COVID-19 vaccination may also reduce the likelihood of MIS-C in young people ages 12 to 18.

People who test positive for COVID-19 can check with their health care providers about authorized treatments that may lower their risk of severe symptoms and hospitalization. Scientists are studying COVID-19 treatments to see whether they lower the risk of long-term symptoms.

What can I do if I have Long COVID?

There is no specific treatment for Long COVID yet. You and your health care provider can work together to create a personal care plan to manage your symptoms and improve your quality of life.



(Yale continue from p6)

(Investigation continued from p9)

As traumatic as my experience has been, the horrifying reality is that I am more fortunate than many others struggling with their mental health. I was never involuntarily hospitalized, and I had access to financial support and health insurance outside of Yale. This is not the case for countless students—those who are forced or pressured to withdraw by the university, subject to psychiatric incarceration, escorted off campus by police officers, or left without any form of support once they are cut off from the university, as detailed in our lawsuit.

The impact of Yale's discriminatory policies is most severe on students who lack the privilege I had. Students of color face medical racism. Students from rural areas are cut off from Yale housing and forced to return to places that may lack substantial mental health treatment. International students lose their visas and are unable to remain in the U.S. Students who rely on Yale for health insurance suddenly lose it.

I like to envision an alternate reality where my story played out differently. One where my distress was met with a process of identifying suitable accommodations, such as part-time course loads or virtual attendance, so that withdrawal wasn't my only option. Or if I did have to withdraw, a world in which I was met with support, treatment options, resources, and guidance, rather than cut off from Yale entirely and left to fend for myself. A world where my struggles did not call into question my ability to succeed, where I wasn't forced to prioritize being a Yale student over being a human being.

Ultimately, our lawsuit is striving to take a meaningful step in building a more just world, where students in crisis are met with compassion rather than punishment. But it is only one step; it will take far more effort and advocacy to change cultural norms that punish mental health disabilities and transform university policies into humane ones that work to genuinely foster students' well-being. Because at the end of the day, the question colleges should be asking is not "How can we get rid of you?" but rather, "What can we do to help you?"

Michael Folio said his group sent emails to Meghan Bourne, a partner with the McChrystal Group and the lead on the DHHR review, at the end of September through Oct. 17 raising concerns about issues at DHHR.

According to reporting by West Virginia Public Broadcasting published Nov. 3, DRWV alerted lawmakers to alleged abuse of patients at William R. Sharpe Jr. Hospital, a psychiatric facility operated by DHHR. Accusations included physical and verbal abuse of patients and neglect. DRWV also accused DHHR of failing to provide court-ordered update to the organization.

"At no time did McChrystal Group ever attempt to interview or meet with any person at DRWV," Folio wrote. "At no time after receipt of such information did Ms. Bourne or any person at McChrystal Group seek to interview, meet with or confer with DRWV. At no time did Ms. Bourne or any person at McChrystal Group seek information from DRWV."

Folio also claimed that Shevona Lusk, the chief operating officer for DHHR's Office of Health Facilities, ordered staff in a Sept. 7 written directive to not provide any information to DRWV, an organization that serves as the designated federal Protection and Advocacy System agency that provides third-party monitoring of state agencies that serve the disabled.

"It is hard to fathom that it was a mere coincidence that McChrystal Group did not want relevant information from DRWV and Ms. Lusk wanted to conceal information from DRWV," Folio wrote. "A taxpayer price tag of over \$1M for a 41-page report with little substance, canned rhetoric, empty platitudes and minimal guidance is disheartening. The cost of the 41-page report is roughly equal to 1,139 admission days at a state diversion hospital."

Lawmakers asked about the allegations in Folio's letter during two legislative interim meetings held at Cacapon Resort State Park in Berkeley Springs Nov. 13. Bourne said several outside organizations were interviewed, such as the West Virginia Hospital Association and the West Virginia Behavioral Health Association, though a complete list of groups was unavailable. Bourne admitted that other constituency groups, such as foster families or the disability rights community, were not interviewed.

Speaking during that same meeting, DHHR Cabinet Secretary Bill Crouch criticized DRWV and Folio, a former general counsel for DHHR's Office of Health Facilities, accusing him of drowning DHHR in letters and requests for information. Crouch also denied that Lusk told staff to withhold any information from DRWV.

"One day after (Folio) left and took the job with Disability Rights, we began getting letters," Crouch said. "We can't quite keep up with it...we're trying to get to those. There's no attempt to delay in any way. That is false. What (Lusk) sent out, because we didn't have a general counsel, was if you get a request...for information, please provide that to herself and the interim general counsel...and myself so we could coordinate those responses."

"In one instance, we got a seven-page letter from Mr. Folio complaining that we weren't communicating, and we were trying to hide information. We had five people from Disability Rights of West Virginia talking about those same issues," Crouch continued. "It's almost bordering on harassment. Mr. Folio and the board of Disability Rights needs to look at what Mr. Folio is doing."

During that same meeting Crouch encouraged anyone with any complaint to

(See Investigation p11)

dachshund back up and running.

Footage of Trey taking his first tentative steps thanks to his new wheels was captured on camera by Chewy, with his owner, Rader, left understandably emotional at the prospect of her beloved dachshund returning to something approaching his old self.

As well as a wheelchair, Trey was also gifted an assortment of items designed to improve his quality of life, with Rader admitting they have been "truly blessed" to have received this kind of help. "We weren't sure how we were going to actually come up with money to get him wheels," she said. "It is so amazing."

She's now looking forward to having the Trey they know and love back enjoying his life again. "To know Trey is an absolute blessing," Rader said. "He never meets a stranger. He loves everybody and he'll kiss you and he won't stop until you scold him for it. I would love for everybody to meet Trey,



Michael Folio said his group sent emails to Meghan Bourne, a partner with the McChrystal Group and the lead on the DHHR review, at the end of September through Oct. 17 raising concerns about issues at DHHR. "If they have any specific information, anything, any evidence that Sharpe or out that."

(Mildred Mitchell-Bateman Hospital) or DHHR has done something wrong that is inconsistent with state and federal statute, go straight to (the Centers for Medicare and Medicaid Services) and do it now if you're worried about that."



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Easy to install and use.

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Disability

R	L	E	L	E	D	H	Y	P	S	T	D	L	I
H	M	T	A	I	A	T	I	E	E	W	I	I	H
C	H	R	O	N	I	C	A	L	O	A	I	L	D
W	H	E	E	L	C	H	A	I	R	L	W	L	N
T	I	Y	I	R	D	C	T	D	A	K	I	N	E
N	A	B	E	E	I	L	E	T	C	E	F	E	D
E	O	N	I	D	S	D	E	N	E	R	S	S	E
M	D	T	E	R	A	N	D	A	I	I	S	S	M
R	E	M	T	O	B	N	E	N	R	E	B	B	O
I	A	O	I	S	L	M	E	E	I	N	L	L	C
A	F	C	R	I	E	I	O	A	D	I	I	I	N
P	H	A	N	D	I	C	A	P	N	S	R	N	I
M	H	E	A	L	T	H	S	D	D	O	D	E	G
I	I	N	E	U	R	O	L	O	G	I	C	A	L

- MEDICAL
- MOBILITY
- DISABLE
- HANDICAP
- NEEDS
- NEUROLOGICAL
- HEALTH
- ILLNESS
- WHEELCHAIR
- DEFECT
- LEARNING
- DISORDER
- BLIND
- IMPAIRMENT
- WALKER
- PSTD
- DEAF
- INCOME
- CHRONIC





"No, you don't get a check because your computer is disabled."

Interracial and Gay Marriage Was Codified. But What About Disabled Marriage Equality

Source: [Huffpost](#)

For people with disabilities, marrying a non-disabled person could result in the loss of federal benefits and health insurance.

President Joe Biden signed the Respect for Marriage Act on Tuesday, effectively codifying rights for same-sex and interracial marriages into law. But the historic legislation left out some groups, such as disabled people, who are still fighting for marriage equality.

Activists and members of the disability community are pointing out that a disabled person is unable to marry a non-disabled person without risking the loss of their federal benefits.

Many disabled people rely on programs such as Social Security Disability Income (SSDI) and Supplemental Security Income (SSI), which both provide a monthly stipend to meet basic living needs. The New York Times reported that about 4 million Americans receive SSI. A recipient of SSDI is designated as a "disabled adult child" (DAC) of 18 or older whose benefits are linked to their parents' Social Security.

According to the Disability Rights and Education Fund (DREF), those who receive SSDI can also receive Medicare and Medicaid, which provide essential services that aren't covered by private health insurance. But people with disabilities who receive these benefits are faced with a "marriage penalty," forcing them to live separately from their spouses in order to keep receiving these lifesaving benefits.

If an SSI or SSDI recipient were to marry a non-disabled person or someone who has a higher income, they would run the risk of losing their stipend, Medicare and Medicaid, according to DREF. Even two SSI recipients who get married would face a 25% reduction in benefits.

Efforts have been made to omit these penalties. For example, Rep. Jimmy Panetta's Marriage Equality for Disabled Adults Act would eliminate the requirement that a DAC beneficiary must remain unmarried to receive SSDI and health care. The bill was introduced by the California Democrat in January and is in committee, according to Forbes.



Capital Crawl

On March 12, 1990, over a thousand disability rights activists gathered outside the U.S. Capitol to peacefully demand passage of the ADA. "At the end of the rally, 60 activists including 8-year-old Jennifer Keelan-Chaffins, abandoned their wheelchairs, crutches, and other mobility devices and crawled up the steps of the capitol building in a demonstration of not only their convictions but also to highlight the daily struggles people with disabilities face due to a lack of inclusivity."



Nickole Cheron's Story

Source: [CDC.gov](https://www.cdc.gov)

In 2008, a rare winter storm buried Portland, Oregon under more than a foot of snow. The city was gridlocked. Nickole Cheron was stuck in her home for eight days. Many people would consider that an inconvenience. For Nickole, whose muscles are too weak to support her body, those eight days were potentially life-threatening.

Born with spinal muscular atrophy, a genetic disease that progressively weakens the body's muscles, Nickole is fully reliant on a wheelchair and full-time caregivers for most routine tasks. Being alone for eight days was not an option. So Nickole signed up for "Ready Now! pdf icon[PDF – 4.8MB]external icon," an emergency preparedness training program developed through the Oregon Office of Disability and Healthexternal icon.

"The most important thing I learned from 'Ready Now!' was to have a back-up plan in case of an emergency situation," she said. "When I heard the snow storm was coming, I emailed all my caregivers to find out who lived close by and would be available. I made sure I had a generator, batteries for my wheelchair, and at least a week's supply of food, water and prescription medication."

Nickole said the training was empowering, and reinforced her ability to live independently with a disability. She felt better informed about the potential risks people with disabilities could encounter during a disaster. For example, clinics might close, streets and sidewalks might be impassable, or caregivers might be unable to travel.

Among the tips Nickole learned from Oregon's "Ready Now!" training are:

Develop a back-up plan. Inform caregivers, friends, family, neighbors or others who might be able to help during an emergency.

Stock up on food, water, and any necessary prescription medications, medical supplies or equipment. Have enough to last at least a week.

Make a list of emergency contact information and keep it handy.
Keep a charged car battery at home. It can power electric wheelchairs and other motorized medical equipment if there is an electricity outage.
Learn about alternate transportation and routes.

Understand the responsibilities and limitations of a "first responder" (for example, members of your local fire department or law enforcement office) during a disaster.

"This training shows people with disabilities that they can do more to triage their situation in a crisis than anyone else can," she said. "'Ready Now!' encourages people with disabilities to take ownership of their own care."

If you would like to share your personal story, please contact us at Contact CDC-INFO at <https://www.cdc.gov/ncbddd/disabilityandhealth/stories.html>



Feta & Roasted Red Pepper Stuffed Chicken Breast

(Mediterranean Inspired this quick and east stuffed chicken breasts recipe)

- ½ Cup crumbled feta cheese
- ½ Cup Chopped roasted red bell pepper
- ½ cup chopped fresh spinach
- ¼ cup Kalamata Olives, pitted and quarter
- 1 tablespoon Chopped Fresh Basil
- 1 tablespoon Chopped Fresh flat-leaf parsley
- 2 cloves garlic, minced
- 4 (8 ounce) boneless, skinless chicken Breast
- ¼ teaspoon salt
- ½ teaspoon ground pepper
- 1 tablespoon extra-virgin olive oil
- 1 tablespoon Lemon Juice

Directions:

Step 1

Preheat oven to 400°F. Combine feta, roasted red peppers, spinach, olives, basil, parsley, and garlic in a medium bowl.

Step 2

Using a small knife, cut a horizontal slit through the thickest portion of each chicken breast to form a pocket. Stuff each breast pocket with about 1/3 cup of the feta mixture; secure the pockets using wooden picks. Sprinkle the chicken evenly with salt and pepper.

Step 3

Heat oil in a large oven-safe skillet over medium-high heat. Arrange the stuffed breasts, top sides down, in the pan; cook until golden, about 2 minutes. Carefully flip the chicken; transfer the pan to the oven. Bake until an instant-read thermometer inserted in the thickest portion of the chicken registers 165°F, 20 to 25 minutes. Drizzle the chicken evenly with lemon juice. Remove the wooden picks from the chicken before serving.



UPCOMING EVENTS

WV STATEWIDE INDEPENDENT LIVING COUNCIL MEETING SCHEDULE

February 1, 2023 - Full Council Meeting

9:00 AM - 4:00 PM

WV Division of Rehab Services and Hybrid/zoom

March 1, 2023 - Executive Committee

1:00 PM -

SILC Office - Hybrid/Zoom

April 5, 2023 - Full Council Meeting

9:00 AM - 4:00 PM

WV Division of Rehab Services and Hybrid/zoom

May 3, 2023 - Executive Committee

1:00 PM

SILC Office - Hybrid/Zoom

June 7, 2023 - Full Council Meeting

9:00 AM - 4:00 PM

WV Division of Rehab Services and Hybrid/zoom



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