

**Friends of WVSILC:**

- 2 Larry Paxton
- 3 Leo Mulvey
- 3 Zoey Harrison
- 8 Synchron
- 11 Keith Mills

THE **EDGE**  
 SUMMER 2021 - WVSILC - PO Box 625 - Institute, WV 25112



## SILC UPDATE

Summer has been long and hot and looks like it will continue to be. The SILC held a retreat in early August and developed a strategic plan that will help the SILC move forward AND compliment the goals and objectives in the State Plan for Independent Living (SPIL). One of those goals is to increase public awareness of independent living, particularly of centers for independent living (CILs), and increase the demand for more CILs in more areas of the state. A key effort to achieve that goal is the rebranding of Independent Living (IL) and the CILs.

The rebranding project will provide a clear image and understanding of what CILs are and how they are unique and different from other things labeled "independent living" and "assisted living". Branding CILs will also greatly help with the efforts to increase understanding and support for CILs statewide. The CILs are meeting regularly with a consulting group that has a lot of young, fresh ideas and great progress is being made. We hope to be able to share the new brand in our next newsletter and start using it in printed materials and on-line as we educate the public and policymakers about the need for more CILs to build the network statewide as outlined in the SPIL.

As we move toward the fall season we had hoped to return SILC operations to the SILC office. But the continuing rise of COVID-19 cases and positive testing put the brakes on that plan and staff will continue to work remotely for the time being. Please take all the recommended measures to protect yourself and your family and Stay Safe!

### MISSION

*"To ensure persons who have disabilities have access to community-based resources that promote personal choice and facilitate the achievement of their independent living goals."*

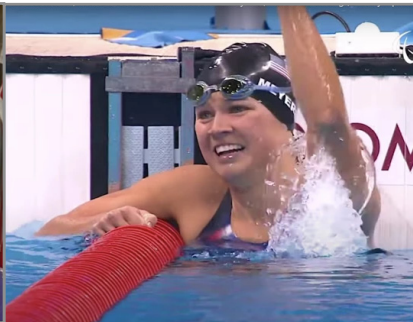
From the desk of:

Ann McDaniel  
Executive Director

## IN THIS EDITION:



Job Bill to Help People with Disabilities Passes p.2



Deaf-Blind Paralympian Withdraws from Tokyo Games p.4

# ADA 31

What is the Americans with Disabilities Act (ADA)? p.5



WV Statewide Independent Living Council: A Strategic Reset p.10

### WV Centers for Independent Living

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

**Northern WV CIL**  
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





## Mourning the Loss of ACIL Executive Director

Source: [WVGazetteMail](#)

LARRY E. PAXTON, 66, of Clendenin passed away on Wednesday, June 23, 2021 at Thomas Memorial Hospital. He was the youngest of 10 children to the late Oral Otha Paxton and Elva Naomi (Schoolcraft) Paxton. He was also preceded in death by four brothers, Clifford, Garland, Emory and Clifton Paxton and three sisters, Helen, Naomi and Garnet.



After a vehicle accident in 1973 left him paralyzed, Larry went on to beat the odds and completed comprehensive rehab at WV State Rehabilitation Center in Institute to reclaim his independence. He went on to graduate from WV State College, earning a degree in social work. Larry was the Executive Director of the Appalachian Center for Independent Living and spent his entire career serving others with disabilities and fighting for equal rights and fair treatment. He was the 1985 recipient of the Jefferson Award for Public Service and received many other acknowledgements and awards in his field. Larry enjoyed country music and loved to sing. He came to know many local musicians whom he called friends, and they in turn called him "Brother Larry". He was known for his wit and humor and always had a joke or funny story ready to tell.

He will be greatly missed by his family, friends and co-workers.

Left to cherish his memory are his nephew and caregiver of 37 years, Darren Paxton and Darren's wife, Stephanie Paxton of Clendenin; brothers, Roger Paxton of Elkview and Michael Paxton of San Antonio, TX; and many other nieces and nephews.

Darren and Stephanie would like to thank Larry's long-time friend, Jim Burdette for his dedication to Larry all these years.

A Memorial service will be from 6 to 8 p.m., Friday July 9, 2021 at Matics Funeral Home Inc. ■

## Bill to Help People with Disabilities Get Meaningful Jobs Passes

Source: [WSAZ](#)

CHARLESTON, W.Va. (WSAZ) - When it comes to disabled people and the opportunities they have to land a job, some say West Virginia could do a better job.



A bill is headed to the governor's desk aimed to help people get a good job.

Making meaningful jobs for people with disabilities a reality in West Virginia is what state Delegate Dianna Graves, R- Kanawha, wanted when she sponsored the bill.

"West Virginia has one of the highest percentage based on population of people that are disabled and we are the lowest in percentage based on people that are gainfully employed," Graves said.

Integrated employment means people with disabilities can work in their communities for a competitive wage.

Advocates for the bill say most states have passed bills encouraging it and now, overwhelmingly, the West Virginia House and Senate passed a bill, too.

"What this does, it is creates a task force that looks at how well are we doing in the state with integrated employment what could we be doing better," said Delegate Graves.

House Bill 2290 now goes to Gov. Jim Justice's office. If it is signed, the task force would work to raise expectations.

Christy Black's 17-year-old daughter Gracie has Down syndrome. Christy, an advocate for the bill, works with the West Virginia Developmental Disabilities Council.

"Society does unfortunately have a lower expectations about what a person with a disability can or can't do," Black said.

She said Gracie worked at a store in Culloden, the community where she lives. Through working there, Gracie found out she enjoys flowers but also found out a lot of things about herself, too.

"She also found that guess what? ... She wants to work, she wants to get married, she wants to build a house, she wants everything that everybody else wants," Black said.

Christy has been working hard to get this bill through for a few years.

"Early on sometimes parents are told not to have expectations for their children, so it's really a lot about changing those expectations but creating policies to make sure people do get that opportunity," Black said.

# 12-Year-Old Fights to Make Restrooms More Accessible to People with Disabilities

Source: [GoodMorningAmerica.com](http://GoodMorningAmerica.com)

A 12-year-old girl from Michigan is fighting for new legislation to make public restrooms more accessible to people with disabilities.



“Good Morning America” first shared Zoey Harrison’s story in 2018 when she helped “save recess” after her mom invented the Bodycoat -- a special coat for children who use wheelchairs.

Now, Zoey, who uses a power wheelchair herself, has been meeting with state and federal officials to get two bills passed.

“I’m excited to make a change,” Zoey told “GMA.” “I’m happy people are listening to me.”

Zoey said bathroom floors are not particularly clean and in order for her to change her clothes, her parents have to lay towels on the ground.

“It’s very wet and it stinks,” said Zoey, who was crowned Miss Wheelchair Michigan in 2019, ABC affiliate WZZM reported.

The first bill Zoey introduced to State Representative Graham Filler in 2019 focused on increasing accessibility in public restrooms, WZZM reported. The second suggested adding locations to accessible restrooms to the Michigan’s government website so people with disabilities know where the most suitable ones are and plan trips with their families.

Mom Jennifer Harrison of Ithaca, Michigan, told “GMA” that she adopted Zoey when she was a 1-year-old. Zoey has cerebral palsy.

“I’m so amazed by her,” Harrison said. “It doesn’t stop her from reaching her goals to help a whole bunch of people and she’s not shy or afraid to speak up.”

Earlier this month, Zoey met with Congressman John Moolenaar and presented her ideas. Moolenaar, the representative for Michigan’s 4th congressional district, invited Zoey to come to Washington, D.C., later this year.

“It went really good,” Zoey said. “He said, ‘Those are great ideas. He said, ‘I never knew that was a problem.’”

Zoey would also like to see more family restrooms and create maps so people know the locations.

She hopes to visit amusement parks, restaurants, stores and examine the

(See 12-year-old next column)

(Jobs continued from p2)

With the bill’s passage Christy’s work begins to educate the public about what people with disabilities can do and to change expectations so thousands with disabilities like her daughter Gracie can be in their communities doing what they love.

The task force would use federal dollars already available to the state. ■

(12-year-old continued from previous column)

facilities. If they meet Zoey’s approval as well as that of the checklist’s under her proposed bills, those places would receive an official “Z-seal of approval.”

Zoey plans to be a 911 operator when she grows up.

Her message to fellow kids: “Always be kind and helpful and no matter what, you can make a difference.” ■

## The Loss of Leo Mulvey – Advocate and Friend



Leo Mulvey, 84 of Huntington, passed away June 25th at St. Mary’s Medical Center. Visitation and funeral services were conducted at the Reger Funeral Chapel in Huntington on June 29th. Notable

leaders in Huntington and Cabell County law enforcement and the Fire Department, including Fire Chief Jan Rader, were present and the Huntington Fire Department and vehicles honored Leo by participating in the procession to Forest Lawn Memorial Gardens.

Leo was born on August 18, 1936, in Wheeling, W.Va. He is survived by a host of family and friends including the Cabell County Sheriff’s Office and the Huntington Fire Department. Leo was a long-time consumer at Mountain State Centers for Independent Living in Huntington and proud member of the Fair Shake Network. He was very active in advocacy in the community and at the State Capitol. Leo knew his was around and

(See Leo p8)



## G.T. v. Kanawha County Schools

Source: [Bazon Center](#)

January 27, 2020 – The Bazelon Center and other advocates represent The Arc of West Virginia and parents of an autistic child in a class action in federal court in Charleston, West Virginia, alleging widespread failures by Kanawha County Schools (KCS) to educate children with disabilities, including autism, intellectual and developmental disabilities, mental health issues, and Attention Deficit Hyperactivity Disorder (ADHD). The class action complaint asserts that KCS—the public school district serving the Charleston metro area—has failed to provide behavioral supports to students with disabilities and is instead punishing them by sending them home instead of educating them. Attorneys for The Arc of West Virginia and the parents—the Bazelon Center, Disability Rights of West Virginia, Mountain State Justice, The Arc of the United States, and the law firm Latham & Watkins LLP—allege that KCS has violated federal laws protecting students with disabilities.

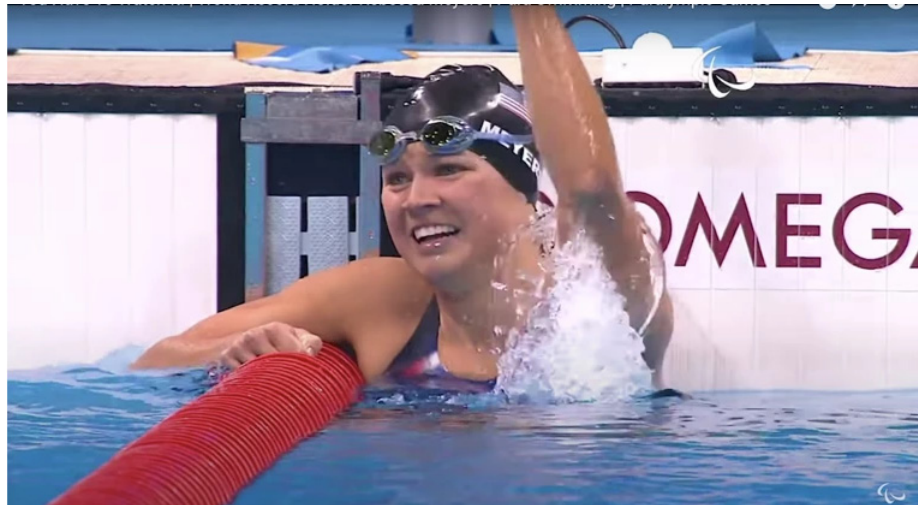
Data from the West Virginia Department of Education shows that over 1,000 children with disabilities enrolled in KCS were removed from their classrooms during the 2018-2019 school year after their schools suspended them. This number does not include all of the additional students with disability-related behaviors whose schools asked their parents to take children out of the school before the end of the school day, or to keep them at home, without formally suspending them. It also does not include students with disabilities who were expelled from school for their behavior; those who were separated unnecessarily from mainstream classrooms and moved to segregated classrooms where they interact only with other students with disabilities and receive an inferior education; or those who were placed on “homebound” status where they may receive only a few hours of tutoring each week. These students are not receiving critical behavioral supports that can help them be successful in the general education classroom with their classmates without disabilities.

The complaint alleges that KCS is: 1) violating the Individuals with Disabilities Education  
Page 4 (See KCS p6)

## Deaf-Blind Paralympian Withdraws from Tokyo Games After Being Denied Personal Care Assistant

Source: [christianpost.com](#)

A deaf and blind swimmer who is a three-time gold medalist withdrew from the Tokyo 2020 Paralympic Games because of a COVID-19 restriction that prevents her from bringing a personal care assistant to help her navigate an unfamiliar environment.



Deaf-blind Paralympian Becca Meyers celebrates in the water at a swimming competition.

The U.S. Olympic and Paralympic Committee denied Becca Meyers’ need for a personal assistant due to COVID-19 personnel restrictions imposed by the Japanese government.

The 26-year-old was born with Usher syndrome, a rare genetic disorder resulting in a combination of hearing loss and visual impairment. She is a six-time Paralympic medalist, world record holder and winner of three gold medals and a silver medal at the Rio Games in 2016. Meyers also won silver and bronze medals at the London Games in 2012.

Meyers received a response from the USOPC saying they would begin searching for her replacement after she submitted her withdrawal letter Sunday night, ESPN reported.

Meyers detailed her disappointment with the USPOC’s unwillingness to offer accommodations for her disabilities in a piece published Tuesday in USA Today.

“The Paralympic Games are supposed to be a haven for athletes with disabilities,” she wrote. “The one place where we are able to compete on a level playing field, with all amenities, protections and support systems in place.”

“After COVID-19 put last year’s Games in Tokyo on pause, we all expected and were forced to deal with the reality that this summer’s Paralympic Games would be altered in many ways,” she continued. “But then I learned this summer that U.S. Olympic & Paralympic Committee denied a reasonable and essential accommodation for me to be able to compete at the Games.”

(See Paralympian p5)

# ADA 31



## Americans with Disabilities Act

### Celebrate the ADA! July 26, 2021

#### Celebrate ADA31 (1990-2021) and ADA Anniversary (July 26, 2021)

The Americans with Disabilities Act (ADA) was signed into law on July 26, 1990 by President George H.W. Bush.

## What is the Americans with Disabilities Act (ADA)?

Source: [ADA National Network](#)

The Americans with Disabilities Act (ADA) became law in 1990. The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. The purpose of the law is to make sure that people with disabilities have the same rights and opportunities as everyone else. The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. The ADA is divided into five titles (or sections) that relate to different areas of public life.

In 2008, the Americans with Disabilities Act Amendments Act (ADAAA) was signed into law and became effective on January 1, 2009. The ADAAA made a number of significant changes to the definition of "disability." The changes in the definition of disability in the ADAAA apply to all titles of the ADA, including Title I (employment practices of private employers with 15 or more employees, state and local governments, employment agencies, labor unions, agents of the employer and joint management labor committees); Title II (programs and activities of state and local government entities); and Title III (private entities that are considered places of public accommodation).

### Title I (Employment)

#### *Equal Employment Opportunity for Individuals with Disabilities*

This title is designed to help people with disabilities access the same employment opportunities and benefits available to people without disabilities. Employers must provide reasonable accommodations to qualified applicants or employees. A reasonable accommodation is any modification or adjustment to a job or the work environment that will enable an applicant or employee with a disability to participate in the application process or to perform essential job functions.

*(Paralympian continued from p4)*

Meyers said she has been "let down" by the USOPC in past competitions, namely the 2016 Paralympic Games in Rio. She claimed that the staff was not adequately equipped to care for a death-blind athlete and the special needs of other paralympic athletes.

Meyers said she opted not to have an assistant at the Rio Games and promised she would never put herself in that situation again. Her mother, Maria, is now her personal care assistant and helps her navigate life with a disability..

"What happens if there is an emergency in the middle of the night? What if we need to be moved from one venue to another quickly? Masks and distancing have made it incredibly difficult for me to make out what people are doing or saying. If I don't have someone I can trust, how can I trust that I will be safe?" the Paralympian wrote.

Since she cannot have an assistant help her navigate Tokyo safely, competing in the event is out of reach for her this year.

"Every single Paralympian has earned the right on this team to compete for our country," she wrote.

"The Paralympic movement has never had a bigger platform on the world's stage than it is going to have this summer," she continued. "Advertisers, brands and networks are all celebrating athletes with disabilities. Showcasing us breaking barriers, defying odds, overcoming adversity. What you don't see though, is that many of those barriers and adverse situations are being created by our own Paralympic structure."

Meyers said the decision not to compete was "agonizing" because she trained five years to make it back to the Paralympic Games.

"I'm disgusted," Meyers told ESPN. "As an athlete, I did everything correct for this organization. I won medals. I trained so hard, especially during the postponement and pandemic. I wanted to be the best athlete. I feel like I was kicked in the teeth. Like, they just don't care about anyone. ■



(KCS continued from p4)

Act (IDEA) by failing to provide children with disabilities with the special education they need to receive a “free appropriate public education” in the least restrictive environment; and 2) violating the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and the West Virginia Human Rights Act by failing to educate children with disabilities in the most integrated setting appropriate to their needs, and denying them equal educational opportunity.

In 2017, the U.S. Supreme Court held unanimously in *Endrew F. v. Douglas County School District RE-1* that the “IDEA demands more.” Specifically, the Court provided a new and more demanding standard for what schools must do to adequately educate students with disabilities, requiring that school districts provide students with disabilities the opportunity to meet “challenging objectives” with “appropriately ambitious” special education. For virtually all children, this means receiving instruction and services in the general education classroom, with appropriate supports, alongside students without disabilities. In addition, in 1999, in *Olmstead v. L.C.*, the Court held that the ADA prohibits the needless isolation or segregation of people with disabilities. The ADA applies to public schools, which cannot unnecessarily segregate students with disabilities, nor deny them equal opportunities.

#### **UPDATE**

#### **Bazon Center’s West Virginia Lawsuit Certified as a Class Action**

On August 24, the lawsuit, *G.T. v. Kanawha County (W.Va.) Schools*, filed by the Bazon Center for Mental Health Law, Mountain State Justice, Disability Rights of West Virginia, The Arc of the United States, and the law firm, Latham Watkins LLP for two Kanawha County students with disabilities was certified as a class-action lawsuit. Judge Irene C. Berger of the United States District Court for the Southern District of West Virginia, Charleston Division granted the order.

“Judge Berger’s decision that the case should focus on all children removed from their classrooms for behavior related to their disabilities will expand its impact to hundreds of Kanawha County’s students.” Lewis Bossing, Senior Staff Attorney of the

(ADA31 continued from p5)

This portion of the law is regulated and enforced by the U.S. Equal Employment Opportunity Commission (link is external). Employers with 15 or more employees must comply with this law. The regulations for Title I define disability, establish guidelines for the reasonable accommodation process, address medical examinations and inquiries, and define “direct threat” when there is significant risk of substantial harm to the health or safety of the individual employee with a disability or others.

#### **Title II (State and Local Government)**

##### *Nondiscrimination on the Basis of Disability in State and Local Government Services*

Title II of the ADA prohibits discrimination against qualified individuals with disabilities in all programs, activities, and services of public entities. It applies to all state and local governments, their departments and agencies, and any other instrumentalities or special purpose districts of state or local governments. It clarifies the requirements of section 504 of the Rehabilitation Act of 1973, as amended, for public transportation systems that receive federal financial assistance, and extends coverage to all public entities that provide public transportation, whether or not they receive federal financial assistance. It establishes detailed standards for the operation of public transit systems, including commuter and intercity rail (e.g., AMTRAK).

This title outlines the administrative processes to be followed, including requirements for self-evaluation and planning; requirements for making reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination; architectural barriers to be identified; and the need for effective communication with people with hearing, vision and speech disabilities. This title is regulated and enforced by the U.S. Department of Justice.

#### **Title III (Public Accommodations)**

##### *Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities*

This title prohibits private places of public accommodation from discriminating against individuals with disabilities. Examples of public accommodations include privately-owned, leased or operated facilities like hotels, restaurants, retail merchants, doctor’s offices, golf courses, private schools, day care centers, health clubs, sports stadiums, movie theaters, and so on. This title sets the minimum standards for accessibility for alterations and new construction of facilities. It also requires public accommodations to remove barriers in existing buildings where it is easy to do so without much difficulty or expense. This title directs businesses to make “reasonable modifications” to their usual ways of doing things when serving people with disabilities. It also requires that they take steps necessary to communicate effectively with customers with vision, hearing, and speech disabilities. This title is regulated and enforced by the U.S. Department of Justice.

#### **Title IV (Telecommunications)**

This title requires telephone and Internet companies to provide a nationwide system of interstate and intrastate telecommunications relay services that allows individuals with hearing and speech disabilities to communicate over the telephone. This title also requires closed captioning of federally funded public

# People With Disabilities May Face Greater Challenges When Returning To In-Person Work

Source: [NPR](#)

The adoption of flexible work arrangements during the pandemic has helped some employees for whom working from home is ideal. Will this trend continue for the post-pandemic work force?

AILSANG CHANG, HOST:

A significant number of Americans like working from home, including me, and poll after poll has shown this. But now, as vaccinations rise and COVID infections drop, employers are busy making plans to return to the office. But for some, working remotely has meant the difference between working and not working at all. NPR's Anna Sirianni reports.

ANNA SIRIANNI, BYLINE: Kristen Parisi had a tough time getting to work in New York City before the pandemic.

KRISTEN PARISI: It's nearly impossible to get to the office if you use a wheelchair or really have any type of mobility disability. The cities where the best jobs are are still our most inaccessible cities.

SIRIANNI: A number of barriers made it hard for Parisi, a writer and disability advocate, to navigate her wheelchair through the city. Bad weather, heavy doors, unreliable subway station elevators - they all made every trip to the office a challenge. Some days there were just too many obstacles, and she would have to turn around and go home.

PARISI: And I would have to make those tough calls to make that awful email to my boss saying, I'm going to have to work from home today. Please understand. People looked at you as though you were trying to take advantage of a system that just wasn't built for you.

SIRIANNI: Even when she could get into work, parts of the office weren't built for her, either.

PARISI: I went for a year where I couldn't reach the microwave at work. So if I needed my coffee reheated or my lunch heated, I had to ask someone to do that for me, which is an incredibly - I don't want to call it humiliating, but it makes you feel very exposed.

SIRIANNI: Parisi left her job at a PR firm in 2018. She says she applied to more than a thousand jobs with no luck. But that changed in 2020, when COVID started closing cities.

PARISI: Some of my friends said, oh, you know, you're still applying for jobs every day. I said, I'm applying for more now than ever because maybe places are going to be more open to the idea of long-term remote work.

SIRIANNI: She was right. Parisi found a job at a marketing firm in January 2021 that would allow her to work from home permanently. She says working from home has helped her be more productive and avoid painstaking commutes. But with case counts dropping and vaccination rates rising, some employers are thinking about getting everyone back in their cubicles. Others are OK

(See Work next column)

(ADA31 continued from p6)

## Title IV (Telecommunications)

This title requires telephone and Internet companies to provide a nationwide system of interstate and intrastate telecommunications relay services that allows individuals with hearing and speech disabilities to communicate over the telephone. This title also requires closed captioning of federally funded public service announcements. This title is regulated by the Federal Communication Commission.

## Title V (Miscellaneous Provisions)

The final title contains a variety of provisions relating to the ADA as a whole, including its relationship to other laws, state immunity, its impact on insurance providers and benefits, prohibition against retaliation and coercion, illegal use of drugs, and attorney's fees. This title also provides a list of certain conditions that are not to be considered as disabilities. ■

(Work continued from previous column)

with employees staying at home. Ruth Colker is a professor of constitutional law and disability discrimination at the Ohio State University. She says that employers are usually focused on business decisions like how to save money or boost productivity, while employees are focused on personal decisions.

RUTH COLKER: Those business decisions, which may or may not be made to allow more of workers in general to work from home, don't speak to the question of what happens when a person with a disability says, I know everyone else has to go to the office, but I want to work from home.

SIRIANNI: That question will likely end up in court. Colker says it will be a heavy legal lift for people who want to keep working from home because courts have historically sided with employers, saying they can require in-person work. If they do, Colker says companies should know that a clean office full of vaccinated people still won't be safe for everyone.

COLKER: When we think about a post-COVID world, whatever that might look like, there are going to be some people for

(See Work p9)



(Leo continued from p3)

Leo knew his was around and who to talk to and everyone at the Capitol knew Leo! He would find who he needed to talk to and would pull in people to help make them understand what he supported and what they needed to do. He was also very active in his community and was a proud fan of the WVU Mountaineers ■

(KCS continued from p6)

Bazon Center, said "Judge Berger's opinion makes clear that KCS's failures to support its students with disabilities are systemic, and that systemic changes are needed. We hope that KCS will work with us to address the problems that Judge Berger has identified."

The judge suggested the parties try to negotiate a resolution. If parties are unable to resolve their differences, the trial will be scheduled August 2022.

[Read Judge Berger's August 24, 2021 Memorandum Opinion and Order \(PDF\) here.](#)

**COURT**

U.S. District Court for the Southern District of West Virginia

**DATE FILED**

January 24, 2020

**STATUS**

Ongoing

**PLAINTIFFS**

G.T., by his parents Michelle and Jamie T., on behalf of himself and all similarly situated individuals, and The Arc of West Virginia.

**DEFENDANTS**

Kanawha County Schools and Ron Duerring, Superintendent, Kanawha County Schools, in his official capacity. ■



# 20-person biotech firm beat Elon Musk's Neuralink - gets OK to test brain chip implants in humans with paralysis

Source: [Business Insider](#)



A competitor to Elon Musk's Neuralink has edged out its rival in getting permission for a trial to implant chips in people.

The brain data transfer company Synchron has gotten the green light from the FDA to begin a human trial of its brain chip, according to a press release issued Wednesday.

The company will begin what is called an early feasibility study later this year at New York's Mount Sinai Hospital. The study will examine the safety and efficacy of its flagship product, known as the Stentrode motor neuroprosthesis, in patients with severe paralysis. Synchron is hopeful that its device will allow the patients to use brain data to "control digital devices and achieve improvements in functional independence." The study, called the COMMAND trial, will enroll six patients.

The FDA's go-ahead "reflects years of safety testing performed in conjunction with FDA," Synchron CEO Thomas Oxley said in the release.

"We have worked together to pave a pathway forward, towards the first commercial approval for a permanently implanted [brain-computer interface] for the treatment of paralysis," he added in the release. "We are thrilled to finally be launching a U.S. clinical trial this year."

The company says its device will allow patients to "wirelessly control external devices by thinking about moving their limbs," which can help with activities ranging from texting and emailing to online shopping and accessing telemedicine.

"Synchron's north star is to achieve whole-brain data transfer," Oxley continued. "Our first target is the motor cortex for treatment of paralysis, which represents a large unmet need for millions of people across the world, and market opportunity of \$20B."

The device gets to the brain via blood vessels in a minimally invasive procedure of around two hours that Synchron says is similar to the placement of stents in the heart. The company adds that the procedure can be done in "widely available angiography suites" and that there are no wires coming out of the body after the device is implanted.

Synchron also says there is no robotic assistance required for its procedure, unlike competitor Neuralink, which previously unveiled a robot designed to implant its chips.

Synchron currently has a separate clinical trial underway outside of the US, with four patients in Australia having already received the implant. The company published a study last year showing that the first two patients from this study



# Biden Plan To Boost Disability Services In Limbo

Source: [DisabilityScoop](#)

President Joe Biden's effort to get people with disabilities off waiting lists by infusing billions into Medicaid home and community-based services looks stalled for the moment, but the plan may soon get new life.

The proposal to inject \$400 billion into the community-based services system came as part of Biden's American Jobs Plan, a wide-ranging infrastructure proposal introduced in March.

At the time, the White House said "these investments will help hundreds of thousands of Americans finally obtain the long-term services and support they need, while creating new jobs and offering caregiving workers a long-overdue raise, stronger benefits, and an opportunity to organize or join a union and collectively bargain."

But right from the start, Republicans opposed the home and community-based services plan arguing that it had no place in an infrastructure bill. And, the proposal is missing from a bipartisan infrastructure deal that Biden endorsed this week.

"It is frustrating that an issue that is nonpartisan — because constituents need HCBS in every district, in every state — is getting left out due to semantics," said Nicole Jorwic, senior director of public policy for The Arc, who noted that the community-based services component continues to poll better than any other part of the American Jobs Plan.

Despite the setback, however, Jorwic and other advocates say they expect that the extra funds for home and community-based services will be included in a budget reconciliation bill that could be passed in the coming months by Democrats alone.

Just this week, Democrats in Congress unveiled legislation to make Biden's plan a reality. Known as the "Better Care Better Jobs Act," the bill would offer states a 10 percentage point increase in the matching funds they receive from the federal government for home and community-based services if they meet certain requirements. In addition, it includes incentives for states to strengthen the direct care workforce.

The measure, backers point out, is already co-sponsored by 40 of the nation's 100 senators.

The legislation cannot come soon enough, said Sarah Meek, senior director of legislative affairs at the American Network of Community Options and Resources, or ANCOR, which represents disability service providers across the nation. She said that workforce shortages before the pandemic meant that providers were often unable to open new lines of service, but those issues have been exacerbated and now some agencies don't have the staff to continue serving existing clients with disabilities.

"We're at a breaking point and something like this has to happen," Meek said.

■

*(Brain Chip continued from p8)*

were able to "control their devices to text and type through direct thought."

Synchron competitor Neuralink made headlines in April when it released a video showing its chip at work in a monkey. The clip showed a macaque named Pager playing video games with its mind six weeks after receiving the implant in its brain.

Neuralink founder Elon Musk tweeted at the time that the company's first device would "enable someone with paralysis to use a smartphone with their mind faster than someone using thumbs." In a subsequent tweet, Musk added that later versions of Neuralink's products would succeed in "enabling, for example, paraplegics to walk again." ■

*(Work continued from p7)*

disability-based reasons that, even though they may have been vaccinated, the vaccine may not be effective. I think employers should realize going forward there may be some employees for whom a physical workplace will unfortunately continue to be too dangerous.

SIRIANNI: And while some workers have already figured out work arrangements or found new jobs that let them stay home, people in the disability community are contending with sky-high rates of unemployment.

COLKER: I can think of some anecdotes where some people who have been looking for work for a while have had a little more success during COVID. But given the terrifically high unemployment rate in the disability community, those anecdotes are not likely to tip the needle in a way that's dramatic.

SIRIANNI: Tipping the needle will come one worker at a time. Kristen Parisi knows what her post-pandemic work life will look like.

PARISI: I feel very lucky that I never have to have that stress of making that hour-and-a-half to two-hour commute again.

SIRIANNI: But for so many others facing similar challenges, things are much more uncertain. ■



# WV Statewide Independent Living Council: A Strategic Reset

On August 3rd, 2021 the WVSILC held a retreat at Stonewall Jackson Resort for a Strategic Planning session with the Centers for Independent Living (CILs) in WV to better understand the priorities and needs of the CILs around Core IL Services.

Our goal is to build upon and strengthen the Independent Living Network in WV by identifying expected results of the retreat and putting them in action.

### Expected Results:

- Identify the core value concepts to guide WVSILC
- Understand the roles of CILs and WVSILC and the possibility of the network
- Hear from WV’s Centers for Independent Living
- Establish a new vision and mission for the organization
- Understand the environment
- Establish 3-year strategic priorities
- Select Year 1 priorities for action
- Identify next steps, time lines, and persons responsible

Representatives from each CIL presented the priorities and needs of the CILs around Core IL Services as well as how the SILC can help. After the presentations, SILC members were invited to ask questions to better understand the needs of the CILs. A facilitator was brought in to help engage participants and bring out ideas to create a plan that will strengthen our IL Network.

## Centers for Independent Living (CILs) & Statewide Independent Living Council (SILC) WV’s Network of Possibility

### Independent Living Centers

WV has 3 CILs; Mountain State, Appalachian, and Northern West Virginia. Each CIL is responsible for providing Five (5) core services to people with disabilities. The 5 core services are:

1. Advocacy – ILC’s provide services around both individual and systems advocacy. The goal is to empower people of all ages with disabilities to reach their highest level of achievement by teaching them to advocate for individual and systems changes that result in access, choice, equality, inclusion, integration, and independence. Systemic advocacy attempts to change laws and attitudes surrounding disability. Personal advocacy is a type of problem-solving designed to protect personal and legal rights and ensure a dignified existence.

2. Information and Referral (I&R) – Information and referral is the art, science, and practice of bringing people and services together. If individuals or families do not know where to turn, or need more information, I&R can help connect them with the information, tools, and resources they need.

3. Independent Living Skills– ILC’s provide information and instruction which lead to mastery in the following areas: health and safety, community resources, meal planning and nutrition, self-advocacy, sexual awareness, Personal Assistant management, household management, recreation and leisure, and money management. The integration and full participation of individuals with

(See Reset p11)



(Reset continued from p10)

4. Peer Counseling – ILC's provide support and role models for people who want to live more independently. Personal experience with disability often places ILC staff in a unique position to understand and effectively teach people who experience disabilities while providing a role model for success.

5. Transition – ILC's provide services that facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life.

### **What is WV SILC?**

The WV State Independent Living Council (WVSILC) is a 31-member council, appointed by the Governor, to primarily persons with disabilities from across the state. Twenty-four (24) appointees are voting members and seven (7) are ex-officio, non-voting members representing state agencies and/or providers. All council members are appointed by the Governor.

- A majority of both the voting members (13 or more) and of the total members (16 or more) must be individuals with disabilities who do not work for a center for independent living or any state agency.
- A term of appointment is three years and council members may serve two full terms consecutively.

WVSILC functions as a partner with the Division of Rehabilitation Services (DRS) and the Centers for Independent Living (CILs). Together they work to ensure the statewide existence of:

- appropriate planning;
- adequate financial support;
- coordination of services;
- coordination of efforts; and
- other assistance to appropriately address, the independent living needs of West Virginians with disabilities.

WVSILC is a non-profit, 501(c)3 organization. Non-profits (NPs):

- Can apply for grants to fund work that is aligned with their mission;
- Can receive donations and give tax exemption notes to donors;
- Can expend a percentage of unrestricted funds to lobby at the state and federal levels;
- Must file an annual report (IRS form 990) with the IRS and post online;
- Are governed by a board of directors; and
- Voting members appointed by the Governor serve as the board of directors of WVSILC.

WV's Network of Possibility

- Educating policymakers about funding needed to implement the SPIL
- Advising the Governor and Legislature about issues impacting persons with disabilities in West Virginia
- Creating projects and moving forward ideas that will enhance the ability of people with disabilities to live independently
- Assuring compliance with applicable state and federal laws governing independent living ■

## **Passing of Keith Mills**

Keith Howard Mills 46, of Huntington, passed away Monday August 9, 2021 in Cabell Huntington Hospital. He was born January 4, 1975 in Charleston, WV to Cynthia Ann Mills who preceded him in death.

Keith was a consumer at Mountain State Centers for Independent Living in Huntington and was an active member of the Fair Shake Network. The highlight of each year was attending the WV Legislative Session and advocating for the rights of persons with disabilities. He was a loyal Marshall fan faithfully attending games and events. Keith loved his bird Tweetie and enjoyed cornhole, NASCAR, Marshall football and the Crabb Family concerts. He had many friends, loved taking photos with people, and never forgot the name of someone he met.

Keith was employed at Goodwill, Captain D's for almost 9 years and recently Kentucky Fried Chicken. He volunteered at the Storehouse Food Pantry in West Huntington. He devoted many hours to reading and math classes at Tri-State Literacy Council. Keith was an active member of his church, Trinity Orthodox Presbyterian Church in Huntington, and recently Providence Reformed Presbyterian in Barboursville where a memorial service was held August 24, 2021. ■



WVSILC  
P.O. Box 625  
Institute, WV 25112-0625

NONPROFIT  
ORGANIZATION  
U.S. POSTAGE  
PAID  
INSTITUTE, WV  
Permit No. 6

## UPCOMING EVENTS

### WV STATEWIDE INDEPENDENT LIVING COUNCIL, INC. MEETING SCHEDULE

**September 2, 2021 Executive  
Committee  
1:00 PM, ZOOM**

**October 6, 2021  
Council Meeting  
9:00 AM - 5:00 PM  
Sleep Inn, Cross Lanes WV**

**November 3, 2021 Executive  
Committee  
1:00 PM, SILC Office**

**December 1, 2021  
Council Meeting  
9:00 AM - 5:00 PM  
Sleep Inn, Cross Lanes WV**

**amazon**smile  
You shop. Amazon gives.

AmazonSmile is a simple and automatic way for you to support your favorite charitable organization every time you shop, at no cost to you. When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to WVSILC. To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device and choose WV Statewide Independent Living Council

 **facebook** Like us: [www.facebook.com/wvsilc](http://www.facebook.com/wvsilc)

 Follow us @wvsilc