



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

SILC UPDATE

It's my favorite time of the year, Summer, which also means the NCIL Conference is near. Theo Braddy, the Executive Director of the National Council on Independent Living, has extended an open invitation to individuals and organizations alike to join us in NCIL's March and Rally, taking place on Wednesday, July 26, 2023. The March will commence at the Grand Hyatt Washington from 9:30 a.m. to 11:00 a.m., followed by the Rally at the Capitol from 11:00 am to 12:00 Noon.

This open invitation is specifically for the July 26th event, where we will march and rally at the Capitol. During the March and Rally, we will advocate for three major causes:

- Securing funding for all Centers for Independent Living through NCIL's 5 for 5 campaign, which aims to raise 500 million dollars to support the 5 core services
- Prioritizing Home and Community Based Services by advocating for the passage of the HCBS Access Act and Better Care Better Jobs Act.
- Offering Disaster Relief support for individuals with disabilities in crisis by urging the passage of READI and supporting the ACL legislative items that provide real-time funding for the Aging and Disability Network during emergencies.

Here at home, we have completed the Technical Amendment to the State Plan for Independent Living and are awaiting approval. We are also planning a first of its kind car show featuring vehicles modified with accessible equipment. Although the freedom car show features vehicles with accessible equipment, we want all car, truck, and bike enthusiasts to join us. If it's unique or unusual we want to see it. All years, makes, and models welcome! For more information on the Freedom Car Show see page 6 or visit <https://wvsilc.org/car-show>.

The Freedom Car Show is to raise money for accessible modifications for people with disabilities who cannot afford them. So come; show off your ride, win trophies, and have fun!

MISSION

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

From the desk of

Jerry Boyko, Executive Director

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WIN 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





Application for a State Recreational Area Campsite Discount Card for a Totally and Permanently Disabled West Virginia Resident

Source: WVStateParks

Application for a State Recreational Area Campsite Discount Card for a Totally and Permanently Disabled West Virginia Resident. You could get 50% off camping at some of West Virginia's State Parks. Must provide proof of disability.

Click: [Application](#)

'It's humiliating,' Advocate for disabled furious after wheelchair destroyed on JetBlue flight



Source: CBS news

BOSTON - Colleen Flanagan, an engagement and outreach specialist in Boston Mayor Michelle Wu's Commission for Persons with Disabilities was ready. On April 17th, she flew down to Washington, D.C. on JetBlue to meet with Senator Bob Casey of Pennsylvania. She was there to advocate for better home and community-based services for the disabled.

The trip turned into something different altogether.

"Traveling with a disability is never easy, especially if you have to bring a wheelchair" she said, foreshadowing the events that were about to unfold.

After landing at Reagan National Airport, the Jamaica Plain resident was wheeled in an "aisle chair," a chair used to transport people with disabilities onto and from airplanes to the jetway. Flanagan recorded the moment her power wheelchair was presented to her.

She can be heard on the video, sobbing "I just can't believe this happened."

"The joystick was completely smashed, the side was all the way dented in," she explained later to WBZ-TV. Somehow the chair was so damaged in transit that it wouldn't even turn on. Even worse, she had to wait in the terminal for three hours just to get a loaner.

"It's humiliating, it's frustrating, it doesn't seem fair," she said.

Flanagan says JetBlue's response has been hurtful as well. The airline apologized for the damage but hasn't said when the wheelchair will be returned or if it will even pay for all of the damage.

"After it's assessed, they will let the wheelchair vendor know what they will pay," she explained. "I'm not even to the repair stage."

Sadly, Colleen isn't alone. Every day, an average of 29 wheelchairs are damaged on flights. In 2019, more than 10,000 were broken. She wants visibility, accountability and, above all else - her own chair back.

"They gave me travel vouchers, which I also found insulting because I'm not very eager to travel with them in the future," she said.

WBZ reached out to JetBlue, asking specifically when Flanagan can get her chair back, if the company will pay 100% of the cost of repair and return, and what its protocol is on securing mobility devices. The airline has yet to respond. ■



FACT SHEET: Biden-Harris Administration Announces Most Sweeping Set of Executive Actions to Improve Care in History

Source: [whitehouse.gov](https://www.whitehouse.gov)

Today, President Biden will announce the most comprehensive set of executive actions any President has ever taken to improve care for hard-working families while supporting care workers and family caregivers. Joined by people with disabilities, family caregivers, long-term care workers, early educators, veterans, and aging advocates, the President will sign an Executive Order that includes more than 50 directives to nearly every cabinet-level agency to expand access to affordable, high-quality care, and provide support for care workers and family caregivers.

Too many families and individuals struggle to access the affordable, high-quality care they need. The cost of child care is up 26% in the last decade and more than 200 percent over the past 30 years. For the elderly or people with disabilities long-term care costs are up 40% in the past decade. The result is many Americans – particularly women – stay out of the workforce to care for their families, making it hard for businesses to attract and retain a skilled workforce and for the economy to grow. A [BCG brief](#) forecasts losses of \$290 billion each year in gross domestic product in 2030 and beyond if the U.S. fails to address the lack of affordable child care.

At the same time, many workers providing this critical care find themselves in low-paying jobs with few benefits. Care workers, who are disproportionately women of color, struggle to make ends meet, and turnover rates are high. In addition, at least 53 million Americans serve as family caregivers—including over 5 million caring for service members or veterans—and many face challenges due to lack of support, training, and opportunities for rest.

President Biden believes that we must secure significant new federal investments to transform care in this country. That's why he and Vice President Harris called for investments to support high-quality, affordable child care, preschool, and long-term care in their fiscal year 2024 budget. While Congress considers those proposals, the President is taking immediate action to make care more affordable for American families, support family caregivers, boost compensation and improve job quality for care workers, and expand care options. Specifically, his Executive Order will:

Make child care and long-term care more accessible and affordable for families, including military families. The acute challenges families face in accessing affordable, high-quality care are well documented. In 2019, 76% of families with young children who searched for care reported difficulty finding adequate child care, and military families consistently cite access to high-quality child care as an impediment to military spouse employment and family economic security. More than three-quarters of home and community-based care service providers are not accepting new clients, leaving hundreds of thousands of older Americans and Americans with disabilities on waiting lists for home and community-based services or struggling to afford the care they need. The President is taking action to make child care and long-term care more affordable by directing federal agencies to:

- Identify which of their grant programs can support child care and long-term care for individuals working on federal projects, and consider requiring applicants seeking federal job-creating funds to expand access to care for their workers. This builds off of the [historic child care requirement](#) for semiconductor employers seeking significant federal funding under the CHIPS and Science Act of 2022 to submit a plan for how they will help

(See *WhiteHouse* on p6)

Senate Confirms Gallo To Lead Federal Special Education Office

Source: [stonline](#)

The U.S. Department of Education's incoming assistant secretary for special education has ties to the school bus industry.

The Senate confirmed Glenna Wright Gallo on Wednesday by a 52-44 vote, paving the way for the 25-year career educator to join the Biden administration next week to lead the Office of Special Education and Rehabilitative Services at the U.S. Department of Education.

President Joe Biden nominated her in November 2021.

"Her commitment to meeting the needs of the special education community and strong track record of improving outcomes are exactly what we need at this critical moment in our recovery from the pandemic, and I look [forward] to working with her to raise the bar for students with disabilities and their families," said Education Secretary Miguel Cardona in a statement.

Known for her collaboration, Gallo was a panelist on a 2017 STN EXPO Reno general session on school choice and the impact on student transportation. At the time she had just finished her term as the 2016-2017 president of the National Association of State Directors of Special Education. She was also transitioning from her position as state director of special education for the Utah State Board of Education to join the Washington Office of the Superintendent of Public Instruction (OSPI) as assistant superintendent, where she oversaw the implementation of federal and state rules and regulations that govern special education and related services as well as historic funding for special education programs.

She left OSPI last summer to become chief executive officer of Gallo Consulting.

A graduate of the University of Nevada at Las Vegas with a bachelor's degree in special education, she began her career as a special education teacher and team leader at Jordon School District in Utah before becoming an

(See *Education* on p12)



Flip Writer AAC

Source: [FlipWriterAAC](https://www.flipwriter.com/)

Designed for adults and children with speech or hearing impairments, Flip Writer allows users to type messages displayed on two displays (one facing inward and one facing outward). ■

NaturalReader

Source: [play.google.com](https://www.naturalreader.com/)

NaturalReader is text to speech app that reads text, PDF, webpages, and eBooks aloud to you with our quality, natural-sounding voices.

NaturalReader is an essential tool for those with dyslexia and other reading difficulties. Open up your ears to a new reading experience with over 50 voices in over 20 languages. Just sit back, relax, and let us read to you.

NaturalReader is a great app for all kinds of readers. Adjust the speaker's speed and background color to suit your own preferences. Use it to multitask and enjoy listening on the go while running, commuting, or any household tasks.

Open up any email attachments with NaturalReader to get your important documents to read to you instantly. You can also connect to your Dropbox, OneDrive, or Google Drive account to easily access and listen to your files from your device. Keep up with your favorite webpages with our built-in browser. ■

Disability is an art - an ingenious way to live.
~Neil Marcus

2023 Freedom Car Show

1st Annual
Freedom car show
 Haddad Riverfront Park
 600 Kanawha Blvd. Charleston, WV

October 14, 2023
12 pm - 10 pm
 Free to the Public
Roll In
9 am - 12 pm

Relative Obscurity
REBELLION

Prizes
 Trophies:
 Best of Show
 People's choice
 Best Newest
 Best Oldest
 Furthest Traveled
 Oldest Owner
 Youngest owner
 Band's choice
 Sponsor's Choice

Live local music!
Food vendors
Accessible equipment dealers
Games
50/50 Raffle

Register now at: <https://wvsilc.org/car-show> (\$25 or day of show \$35)
 For additional information call 304-766-4624 or email wvsilc@wvsilc.org

Source: [WVSILC](https://www.wvsilc.org/)

Haddad Riverfront Park, 600 Kanawha Blvd., Charleston, WV

The first annual car show featuring vehicles that have been modified with adaptive equipment to help people with disabilities be mobile. You can expect to see 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.

Although the freedom car show is featuring vehicles with accessible equipment, we want all car, truck and bike enthusiasts to join us. If its unique or unusual we want to see it. All years, makes, and models welcome!

After all, this event is to raise money for accessible modifications for people with disabilities who cannot afford them. So come; show off your ride, win trophies, and have fun. There's no better way to help your brothers and sisters in wheels become mobile!

If you want to see car modifications you've never seen before, you don't want to miss this one-of-a-kind event!

Who are we and why a car show?

Established under federal and state legislation, WVSILC functions both independently and as a partner with the West Virginia Independence Network (WIN) and the West Virginia Division Of Rehabilitation Services (WVDRS) to ensure that West Virginians with disabilities have access to Community-Based

(See Freedom on p6)

Disability Programs At Risk In Federal Budget Battle, Advocates Warn

Source: [disabilityscoop](#)

After the U.S. House of Representatives passed a plan this week to slash federal spending and raise the nation's debt ceiling, advocates say access to Medicaid and other disability programs could be imperiled.

The move comes as the government heads toward defaulting on its debts, potentially as soon as this summer, unless Congress acts. Republicans have been refusing for months to raise the debt ceiling — the amount of money that the government is permitted to borrow — without cutting spending. Meanwhile, President Joe Biden has insisted that he will not negotiate over the debt limit.

Now, however, the measure passed by the House serves as a means for Republicans to pressure Biden to come to the table. And, the situation has disability advocates increasingly on edge.

"I have never been more concerned about the budget negotiations than I am at the moment," said Kim Musheno, vice president of public policy at the Autism Society of America. "The House of Representatives leadership is demanding significant cuts to programs important to people with disabilities and families in exchange for lifting the debt ceiling for one year, in essence using the full faith and credit of the country as a cudgel to demand cuts to programs important to American families."

The bill approved by the House known as the Limit, Save, Grow Act would impose work requirements on many Medicaid beneficiaries, compromising access to health care and home and community-based services for people with disabilities, advocates say.

Medicaid beneficiaries with disabilities and their parents and caregivers may qualify for exemptions under the plan, but determining who is eligible for an exemption and cutting through the red tape to secure one would add a significant burden and increase the odds that people will lose their coverage, disability advocates say.

"Medicaid is a lifeline for people with disabilities," said David Goldfarb, director of long-term supports and services policy at The Arc of the United States. "Navigating these complex and extreme benefit tests will be particularly difficult for people with intellectual and developmental disabilities, over 45% of which have a co-occurring health condition. In addition, many of the exemptions for the rule are vague and highly subject to the stigmas and biases of those with the power to determine eligibility. Millions of people who rely on these safety net programs will fall through the cracks in a system that is already difficult to grasp — and these changes will compound that problem."

The Biden administration has warned that the bill could jeopardize Medicaid coverage for 21 million Americans. Additionally, officials said that it would reduce support for students with disabilities equivalent to axing over 48,000 teachers and related services providers.

The plan is not expected to see life in the Senate and the White House has already said that Biden would veto the measure. Nonetheless, disability advocates



WIN Success Story

I am pleased to introduce you to Kim Winter. He is a consumer at the Appalachian Center for Independent Living. Kim graduated from the WV School for the Deaf and Blind in 1977. Upon graduation, he worked as a dispatcher for the Kanawha County Ambulance Service. Kim worked for the WV Division of Highways as a Telecommunicator for 32 years prior to his retirement. Aside from being a wonderful singer, Kim is also an ultimate WVU fan, and he has served as a deacon at his church for the past three years.

Quote by Kim Winter. "ACIL helped me to increase my independence through independent living skills training. After moving, I learned my way around through mobility and orientation training. I also learned various other skills that have helped me to be more independent. I was able to successfully complete the goals that I set for myself and am enjoying my newfound independence." ■





(Freedom continued from p4)

Resources that promote personal choice and facilitate the achievement of their Independent Living goals.

The WIN has 3 Centers throughout the state; Appalachian Center for Independent Living, Mountain State Center for Independent Living, and LiveAbility (formerly Northern WV Center for Independent Living). The network provides Independent Living Services under the State-funded Community Living Services Program (CLSP).

CLSP assists individuals with disabilities to function more independently in their homes and communities. Funded under the State Plan for Independent Living with State and Federal Independent Living dollars to support West Virginians with Disabilities, CLSP services include:

- Home Modifications for Accessibility
- Assistive Devices and Equipment
- Communication Services
- Durable Medical Equipment
- Vehicle Modifications

Due to the disproportionate number of people with disabilities in WV, the wait to receive services from CLSP is a mind-numbing 3 to 5 years. Additionally, available funding first goes to home modifications and other items supported by the program. If any funding remains, vehicle modifications will then be addressed. There is rarely any funding remaining for vehicle modifications, which represents freedom, or lack of, for people with disabilities.

All proceeds generated from the car show will be used solely for vehicle modifications for people with disabilities. If you are unable to attend or sponsor the car show, please consider giving to CLSP through our GoFundMe Campaign so the program can provide freedom to people with disabilities who have no means of transportation for lack of adaptive equipment.

You can follow West Virginia Statewide Independence Living Council on our Facebook page to get update on the Car show and other events.

<https://www.facebook.com/WVSILC> ■

(White house continued from p3)

employees access affordable child care. These actions help employers delivering major federal projects recruit and retain a robust, skilled, and diverse workforce.

Lower costs for families benefitting from the Child Care & Development Block Grant (CCDBG) program, including by directing the Department of Health and Human Services (HHS) to consider actions to reduce or eliminate families' co-payments for child care.

Ensure the federal government is a model employer by supporting its own workforce. The Executive Order directs the Office of Personnel Management to conduct a review of child care subsidy policy and consider setting standards for when and how federal agencies should provide child care subsidies to federal employees. Additionally, all federal agencies will review opportunities to expand employee access to child care services through federal child care centers, child care subsidies, or contracted care for providers.

Provide support for our service members and their families by directing the Department of Defense to take steps to improve the affordability of child care on military installations.

Improve access to home-based care for veterans. To meet our sacred obligation to our veterans and their families, the Executive Order directs the Department of Veterans Affairs (VA) to improve access to home-based care for veterans who require support with activities of daily living, like bathing and getting dressed, by giving them more decision-making power over who delivers that care and when. VA is directed to consider expanding its Veteran Directed Care program to all 172 VA Medical Centers by the end of Fiscal Year 2024. This program provides veterans with a budget to hire personal care assistance including from family members. VA will also consider piloting a new self-directed care program in no fewer than 5 new sites that provides veterans with a budget for personal care assistance while reducing administration burdens related to managing care. Further, VA will consider adding 75 new interdisciplinary teams to its Home-Based Primary Care program to serve an additional 5,600 veterans in their homes.

Boost job quality for early educators. Early care and education professionals are among the lowest-paid workers in the country. Child care workers earn a median wage of less than \$18 an hour, while the typical nonsupervisory worker in the U.S. earns over \$28 an hour. While the average salary of a public preschool teacher and kindergarten teacher is about \$49,000 and \$60,000, respectively, the average annual salary for Head Start and preschool teachers is about \$35,000. To address this, HHS will take steps to increase the pay and benefits for Head Start teachers and staff. HHS will implement policies so that more child care providers benefiting from CCDBG receive higher reimbursements for the children they serve. Additionally, the Department of Education (ED) will encourage grantees of the Child Care Access Means Parents in School (CCAMPIS) program—which supports thousands of student-parents across the country pay for care while going to school—to improve the quality of the services they provide, including higher wages for child care workers.

Enhance job quality for long-term care workers. The President is committed to improving the quality of long-term care jobs in this country so that Americans can get the reliable, high-quality care they deserve—whether it is in their homes and communities or in nursing homes. To advance the President's long-term care priorities, the Executive Order directs HHS to consider issuing several regulations and guidance documents to improve the quality of home care jobs,

(See White house on p8)

Impact of Child Disability on the Family

Source: [medscape](#)

Abstract and Introduction

Families with disabled children represent a sizeable share of all American households. Living with a disabled child can have profound effects on the entire family, which in turn can affect the health and well-being of the child who is disabled. Much needs to be learned about how children's health affects their parents, siblings, and other family members and about how family characteristics and resources modify those associations. Numerous programs and organizations provide resources for disabled children and their families, but the system is extremely fragmented and difficult to navigate. This commentary reviews what is known about the effects of child disability on the family, provides an overview of the complex needs of and multitude of resources available to families of disabled children, and concludes with suggested directions for practice, research, and public policy.

Numerous forces have come together to increase the rates of American families living with disabled children. Advances in neonatal care technology have dramatically increased the survival rates of very low birth weight infants and infants with severe birth defects who are at high risk for long-term health problems or cognitive deficits. Diagnoses of autism and attention deficit disorders have multiplied. De-institutionalization, the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and improvements in assistive technology have resulted in greater proportions of disabled and chronically ill children being mainstreamed—that is, living at home and attending school. These trends suggest that more households than ever before include disabled children.

The number of disabled children in the United States is an extremely difficult figure to ascertain due to definitional ambiguities and because adequate data by which to derive estimates are sorely lacking. The terms “chronic illness,” “disability,” and “chronic condition” tend to be used interchangeably and are often proxied by measures of activity limitations. Disability can be defined broadly, to include most types of physical, developmental, and emotional disorders, or it can be defined more narrowly in terms of specific conditions and degrees of severity. Because a national health information database does not exist for the US, estimates of the prevalence of and changes in rates of disabled persons are generally based on survey data. Estimates are therefore subject to potential biases stemming from non-response, limitations and changes in question wording, and respondent reporting. Regardless of data source, trend analyses are subject to confounding by changing patterns in diagnosis.

Based on the best US data sources currently available, disability rates of non-institutionalized children have at least doubled since 1960. Thus, regardless of the exact definition or magnitude, it is clear that disabled children constitute a sizeable fraction of all children (between 6% and 18%, depending on the definition and data source), and that a large and growing number of American families now include children with some type of disability.

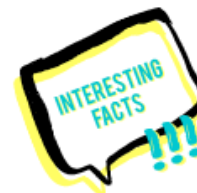
Implications for the Family

Living with a disabled child can have profound effects on the entire family—parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning. On the

(Advocates continued from p5)

advocates are alarmed by the effort to compromise services for this population.

“Access to health care coverage is a matter of life, death and independence for millions of Americans with disabilities, older adults and their families and friends,” reads a recent letter from more than 160 disability and aging groups to leaders of the House and Senate. “It is never acceptable to cut services for low income individuals with disabilities, adults, older Americans and children, including in debt ceiling or budget negotiations.” ■



Bendy Straws

Although the straight paper straw was a marvel all in itself when it was created in 1888, in the 1930s a man named Joseph Friedman tweaked the design to make drinking straws bend in the middle. He came up with the idea when he noted his petite daughter's inability to enjoy her milkshake at a soda fountain while using the straight variety. He put a screw inside a straight straw and wrapped some dental floss around it to create a corrugated effect. Although this tool wasn't originally created for people with disabilities, hospitals were some of the first places to embrace them as they were helpful to bed-ridden patients trying to drink something. Now, everyone loves bendy straws.

Now you know



(See Impact on p12)



We The People with Disabilities

Show your patriotism and your support for people with disabilities with this one-of-a-kind "We The People With Disabilities" T-Shirt
Following link to get yours now: [T-shirts](#)



WV Statewide Independent Living Council

"We The People With Disabilities" T-shirt
\$20.00 - \$22.00



Scan to Pay

(Whitehouse continued from p6)

including by leveraging Medicaid funding to ensure there are enough home care workers to provide care to seniors and people with disabilities enrolled in Medicaid, as well as build on the minimum staffing standards for nursing homes and condition a portion of Medicare payments on how well a nursing home retains workers.

Support family caregivers. Without adequate resources, family caregiving can affect caregivers' physical and emotional health and well-being and contribute to financial strain. These negative consequences are felt most acutely by women, who make up nearly two-thirds of family caregivers and who drop out of the workforce at higher rates than men. To provide greater support to family caregivers, the Executive Order directs HHS to consider testing a new dementia care model that will include support for respite care (short-term help to give a primary family caregiver a break) and make it easier for family caregivers to access Medicare beneficiary information and provide more support to family caregivers during the hospital discharge planning process. Additionally, VA will consider expanding access to the Program of Comprehensive Assistance for Family Caregivers and provide more mental health support for caregivers enrolled in that program. These actions build on the [2022 National Strategy to Support Caregivers](#).

Advance domestic workers' rights. Care workers should be supported, valued, and fairly compensated, and care workers should have the free and fair choice to join a union. In particular, domestic workers providing care for our loved ones are often underpaid and subject to discrimination and abuse. To provide greater protection for these workers, the Department of Labor will publish a sample employment agreement so domestic child care and long-term care workers and their employers can ensure both parties better understand their rights and responsibilities.

Ease construction of early childhood facilities for Tribes. There are approximately half a million American Indian and Alaska Native children under the age of 13 who potentially need child care so their parents can work. Nearly half are below the age of five. To help the families of these children access high-quality child care, HHS will streamline the process for tribal grantees of federal child care assistance and Head Start to apply for and construct or improve early childhood facilities.

Engage affected communities. To make the delivery and design of federal care assistance and programs work better for families, the care workforce, and people seeking care, the Treasury and the Departments of Defense, Agriculture, Labor, Health and Human Services, Education, and Veterans Affairs, will engage with parents, guardians, and other relatives with care responsibilities; individuals receiving long-term care; State and local care experts; care providers and workers; employers; and labor unions. The Executive Order also encourages the Administrator of the Small Business Administration to consider conducting similar engagement.

The Biden-Harris Administration's record on Care

The Administration invested over \$60 billion from the American Rescue Plan (ARP) Act in the care economy, including \$39 billion to help child care providers keep their doors open and to provide child care workers with higher pay, bonuses, and other benefits—reducing turnover and attracting new staff. To date, these efforts have helped 220,000 child care programs, which employ more than one million child care workers with the capacity to serve 9.6 million children. In addition, the Administration invested \$25 billion in ARP funds to

(See Whitehouse on p9)



(Whitehouse continued from p8)

to help states strengthen their Medicaid home care programs, including over \$9 billion in spending to boost wages for home care workers as well as improve overall job quality.

The stabilization funding provided through the ARP saved child care in this country. One in three child care programs who received stabilization support [report](#) that they would have been forced to close permanently without these funds.

These grants likely have had effects beyond the child care workforce and providers as access to child care is critical for parental employment, particularly for women. The President's Council of Economic Advisers analyzed this relationship in their most recent [Economic Report of the President](#), and found that mothers' employment has recovered more quickly in areas with greater child care capacity supported by ARP stabilization grants. In those areas, employment among mothers with young children outpaced that of mothers in lower ARP-supported areas throughout 2022 and rebounded to pre-pandemic levels by mid-2022.

The FY 2024 President's Budget builds on these investments and proposes investing \$600 billion over 10 years to expand access to high-quality, affordable child care and free, high-quality preschool. This funding will enable States to increase child care options for more than 16 million young children. The proposal lowers costs so that parents can afford to send their children to high-quality child care while also paying child care providers wages that reflect the value they provide families and communities.

The President's Budget also includes \$150 billion over the next decade to improve and expand Medicaid home care services—making it easier for seniors and people with disabilities to live, work, and participate in their communities. This funding would improve the quality of jobs for home care workers and support family caregivers. The Administration is also promoting the use of apprenticeship programs and partnering with employers, unions, and others to recruit, train, and keep long-term care workers on the job while also helping them advance their careers as registered and licensed nurses. Just this month, the President also signed the first-ever [proclamation](#) designating April as National Care Worker Recognition Month, to honor the efforts and sacrifices of our child care and long-term care workers.

The Administration is committed to getting caregivers the resources and respect they deserve. The National Strategy to Support Family Caregivers outlines nearly 350 actions the federal Government can take to support family caregivers' health, well-being, and financial security. And the ARP provided \$145 million to help the National Family Caregiver Support Program deliver counseling, training, and short-term relief to family and other informal care providers. The Administration has also expanded the VA Program of Comprehensive Assistance for Family Caregivers to veterans of all service eras so more veteran caregivers have the financial and mental health support they deserve. Through the First Lady's Joining Forces initiative, the Administration has partnered with more than 50 public and private sector organizations to launch the ["Hidden Helpers"](#) Coalition to serve the 2.3 million military and veteran children in caregiver homes. ■

National Museum of American History Launches History of Disability Online

Source: [Smithsonian](#)

The Smithsonian's National Museum of American History will launch "EveryBody: An Artifact History of Disability in America" to explore themes and events related to the history of people with disabilities in the U.S. and offer a new perspective on American history. This online exhibition is a first-of-its-kind image compilation that provides access to objects and stories related to the history of disability that have been collected at the museum for more than 50 years. The information is presented in English and Spanish, and the website is designed to be accessible to all users, including those using specialized software for vision or hearing impairments. All pages on the website follow federal accessibility guidelines, which are outlined on the site's Accessibility Statement page. The website is available at everybody.si.edu.

"Many stories and events related to people with disabilities never make it into the history books or shared public memories," said Katherine Ott, curator of medical science at the museum. "Knowing this history deepens the understanding of the American experience and reveals how complicated history is."

The website explores such themes as identity and stereotypes; the importance of place, laws and legislation; home and daily life; technology, institutions and schools; eugenics; and work. Featured objects include prosthetics, adapted kitchen utensils, activists' buttons and T-shirts, Section 504 (a federal law guaranteeing rights to persons with disabilities) protest artifacts, medical devices, text telephones for the deaf and Braille writers, wheelchairs, design plans for improving accessibility in public spaces and about 300 snapshots, tintypes and cabinet cards. Each image has descriptive detail.

Through incomparable collections, rigorous research and dynamic public outreach, the National Museum of American History explores the infinite richness and complexity of American history. The museum helps people understand the past in order to make sense of the present and shape a more

(See [Smithsonian on p11](#))



Bill to create alert system for missing people with cognitive disabilities on 1st reading in West Virginia State Senate

Source: [wowktv](#)

CHARLESTON, WV (WOWK) — A bill to create an alert system for missing people with a mental or cognitive disability is on its first reading in the West Virginia State Senate as of Thursday.

House Bill 3188, or the Purple Alert Plan, passed the House of Delegates on Feb. 24.

The bill says these alerts can be extremely effective in finding a missing person with a cognitive disability. Sending these alerts would let the public know details to look out for.

“It puts the information out there to the general public so they would be able to get this individual help if they were to see them,” James Thompson, a Purple Alert Plan advocate, said. “They can get in touch with law enforcement, EMS or whoever they need to get this person home safely.” ■



you just lost The Game by 9GAG.COM

More work needed to address negative attitudes to disability - ESRI

Source: [rte.ie/news](#)

More work is required to address negative attitudes towards disability, according to an ESRI study.

The finding comes after 2,000 adults were asked about their opinion by the Economic and Social Research Institute on a range of different disability policies.

They were divided into two groups.

One group was asked directly about their support for policies, while another group could express their opinion more anonymously.

Some people withdrew their support for disability policies when assured of their anonymity, particularly around policies that helped disabled people meet the extra cost of living associated with having a disability.

The study, which was funded by the National Disability Authority, revealed that support for increased social welfare payments for disabled people was lower (66%) when respondents had more anonymity.

It found 77% showed support for increased payments when they were asked directly.

When assured of their anonymity, 1 in 20 drivers admitted to parking in an accessible parking spot without a permit.

Conversely, more anonymity sometimes led to greater support for disability policy.

The study revealed that more people supported prioritising disabled people for social housing when they were given greater anonymity (71% vs 61%).

This could reflect a preference for people with disabilities compared to others who might compete for limited social housing stock, according to the ESRI.

Anonymity also made a bigger difference to people with higher levels of educational attainment.

The survey 76% supported increased social welfare payments when asked directly, compared to 59% when given more anonymity.

The ESRI said this finding suggests that respondents who are better educated may be more likely to respond to standard surveys in ways that they view are socially desirable.

A second experiment showed that support for disability policies is much lower when questions specify how policies will be funded or potential trade-offs.

There was almost universal support (98%) for children with disabilities to get the support they need using a standard survey question, but this dropped to 85% when the question specified the policy would be funded through budget reallocation.

(Negative continued from p10)

Support dropped further, to 64%, when the policy was to be funded through a tax increase.

The ESRI said 84% of people said that they supported a proposal to build more wheelchair accessible infrastructure on a standard survey question.

However, when trade-offs were made explicit, such as reducing parking infrastructure or cycling infrastructure, support was lower, at 77% for parking and just 67% for cycling.

Despite differences in support depending on how questions were posed, a highlight from the study was that the majority of people supported most policies that aim to enable disabled people to participate fully in society, even with full anonymity.

Support was stronger among respondents most familiar with disability issues, such as those with lived experience of disability or whose partner or child has a disability.

Dr Shane Timmons, who is the lead author of the report, said the results show that while public support for disability is high, standard surveys may overstate it.

“The link between being close to someone with a disability and support for policy suggests that increasing the inclusion of disabled people in communities and workplaces and informing the public about the challenges of having a disability may improve attitudes to disabled people and supportive policies.”

The Director of the National Disability Authority Dr Aideen Hartney, welcomed the research said the findings made it clear that more work needed to be done to address negative attitudes towards disability to achieve equal rights and opportunities for persons with disabilities in Ireland. ■

(Smithsonian continued from p9)

humane future. It is currently renovating its west exhibition wing, developing galleries on business, democracy and culture. For more information, visit americanhistory.si.edu. The museum is located at 14th Street and Constitution Avenue N.W., and is open daily from 10 a.m. to 5:30 p.m. (closed Dec. 25). Admission is free. For Smithsonian information, the public may call (202) 633-1000.

EveryBody: An Artifact History of disability

<https://everybody.si.edu/>



Portable Air Conditioner

A hot day can cause pain and fatigue for people with physical disabilities. A person with spinal cord or traumatic brain injury has a lower ability to sweat, the body's primary method of cooling itself, and is more vulnerable to heat-related illnesses. There are also some disabilities that cause heat sensitivity. An individual's disability will be worsened by heat. Using a portable air conditioner allows one to enjoy the outdoors, including sitting outside, picnicking, and gardening.

Summer Time

I	G	W	A	T	E	R	M	E	L	O	N	C	F
K	A	O	L	B	A	S	E	B	A	L	L	R	I
R	R	U	H	C	A	E	B	E	U	A	S	I	R
A	D	T	S	L	R	E	W	O	M	M	E	C	E
P	E	D	H	E	P	L	M	I	W	S	I	K	W
I	N	O	O	D	S	O	M	B	B	V	L	E	O
C	B	O	R	A	T	C	O	O	U	A	F	T	R
N	W	R	T	N	O	A	E	L	T	C	E	S	K
I	O	S	S	O	R	M	R	P	T	A	R	R	S
C	R	S	T	M	M	P	O	D	E	T	I	E	B
P	R	I	S	E	S	I	B	I	R	I	F	W	I
N	R	R	L	L	O	N	M	M	F	O	G	O	R
X	A	L	E	R	T	G	B	U	L	N	T	L	D
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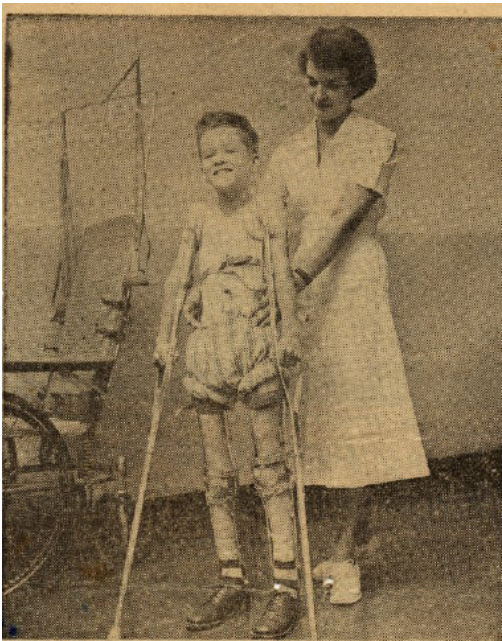
- GARDEN
- SWIM
- CAMPING
- VACATION
- CRICKETS
- RELAX
- OUTDOORS
- BUTTERFLY
- FIREFLIES
- PARK
- HOT
- SHORTS
- LEMONADE
- FIREWORKS
- BEACH
- PICNIC
- POOL
- MOWER
- BIRDS
- WATERMELON
- STORMS
- FLOWERS
- BASEBALL
- HUMID





Poster child newspaper clipping, 1950

Ron Mace, in a typical “poster child” pose, wears rolled-up pajama bottoms to expose his leg braces. He beams at the camera while a smiling nurse approves that “he can stand alone.” Mace later helped create the field of Universal Design.



Staff Photo by Frank Jones
HE CAN STAND ALONE—Polio victim Ronald Lawrence Mace, son of Mr. and Mrs. William H. Mace, Winston-Salem, is learning to walk again at Central Carolina Convalescent Hospital in Greensboro. He is being assisted by Nurse Helen Raynsford. Ronald has been there since Aug. 28, 1950.

(Impact continued from p7)

positive side, it can broaden horizons, increase family members’ awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child can have far-reaching effects as we describe below. The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.

For parents, having a disabled child may increase stress, take a toll on mental and physical health, make it difficult to find appropriate and affordable child care, and affect decisions about work, education/training, having additional children, and relying on public support. It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning. The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure. Having a disabled child may also affect parents’ allocation of time and financial resources to their healthy and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility, and short- and long-term contributions to the household, and the siblings’ health and development. Finally, having a disabled child in the family may affect the contributions of time and financial resources on the part of the child’s grandparents or other extended family members, the relationships of those individuals to the core family, and the financial, physical, and emotional well-being of those family members. All of these potential effects on families have implications for the health and well-being of disabled children.

Surprisingly little is known about the ripple effects of child disability on the family. Population-based research, particularly on demographic or economic outcomes, is scant. Existing studies indicate that having an infant with a serious health condition or health risk increases the likelihood that parents divorce or live apart; that the mother does not work outside of the home; and that the mother relies on public assistance. It also leads to a reduction in the father’s work hours. Another study found that parents with disabled children have lower rates of social participation than parents without a disabled child and that they are less likely to have large families.

Studies in the psychology literature indicate that a number of specific child health conditions are associated with poor mental health outcomes of parents and siblings. A recent meta-analysis indicates that peer activities and cognitive development scores are lower for siblings of children with a chronic illness compared to controls.[11] Virtually nothing is known about siblings’ long-term economic, demographic, and physical health outcomes. Another potentially important but under-explored area is how child disability affects the well-being of grandparents and other extended family members and how the responses of those individuals to having a disabled child in the family affect the child’s

(Education continued from p3)

education specialist and later the state and federal compliance officer at the Utah State Board of Education.

Gallo holds an MBA from Western Governors University and an administrative leadership certificate from Utah State University. ■

Resource Needs

Most children grow up, leave the household, and become independent. For some disabled children, however, care may be life long—extending in some cases beyond the parents’ death. Even when a disabled child is able to transition to independence soon after reaching adulthood, enormous resources may be required to get to that point. On top of the competing demands of raising their other children, holding down jobs, and sometimes even caring for their own

(See Impact on p15)



'Unbelievably excited' - wheelchair users react to new Delta airplane Seat design

source: [CNN](#)

Hamburg, Germany (CNN) —

A new airplane seat concept that allows wheelchair users to stay in their own chair throughout a flight was revealed this week by a subsidiary of US airline Delta, a move welcomed as a “huge step” by potential customers.

“Unbelievably excited,” is how power wheelchair user and avid traveler Cory Lee described his reaction after a working prototype of the design was demonstrated by Delta Flight Products (DFP) at the Aircraft Interiors Expo (AIX) in Hamburg, Germany, a symposium spotlighting airplane cabin innovations.

DFP’s concept seamlessly converts to and from a traditional airplane seat. The built-in seat folds up to allow a wheelchair to be docked into place. The seat would be installed into pre-existing aircraft seat track systems, so would not involve any structural change to the airplane.

When the seat’s in wheelchair mode, flyers are still able to use the tray table – the center console that houses the tray table rises to the appropriate height when the seat conversion takes place.

Rick Salanitri, DFP president, told CNN Travel at AIX that the goal is to make the conversion seamless.

Though still only a prototype, the design is already generating significant buzz among wheelchair users who could be among potential customers. It’s hoped that the concept could enter commercial use within 18 months if it passes testing and is adopted by airlines.

“For decades, people with disabilities have been fighting for more accessible air travel, and this feels like a huge step (or a giant roll) toward real inclusivity,” Lee told CNN Travel via email.

Lee’s visited 43 countries and counting, documenting his adventures on his blog. He loves exploring the world, but said at present air travel is “tremendously difficult” for him.

As airlines can’t typically accommodate powered chairs, Lee usually has to use a non-electric, airport-owned one, which he can’t control himself. This, he said, leads to a “scary” loss of independence.

This discomfort continues when he boards a plane and must be lifted by staff into an aisle wheelchair, and then again onto an airplane seat.

“During those transfers, I’ve nearly been dropped on several occasions,” said Lee.

(See Design on p14)

Becoming an Intern at ACIL

By: Canada Richardson

Hello, my name is Canada Allagas and I am proud to be an intern at ACIL.

I want to share my journey of becoming an intern here with you. In the fall of 2022, I was pregnant with my third child while attending college. I was excited to hear about a practicum program that would allow me to gain hands-on experience in my field of study. However, when I approached one of my professors to inquire further, I was faced with discrimination based on my pregnancy. The professor believed that I wouldn’t be able to handle an internship along with three children and thought I would quit. This unfair treatment violated my rights and was a clear violation of Title IX policy. Title IX is a federal law that prohibits discrimination based on sex in education programs and activities that receive federal financial assistance. It applies to all educational institutions that receive federal funding, including colleges and universities, as well as K-12 public schools. Despite the discrimination I faced, I refused to give up and sought help from my school’s Title IX coordinator, who was incredibly supportive. With her assistance, I was able to secure a different supervisor for my internship, who is an amazing individual and helped me to get set up with ACIL.

It’s important to never be afraid to advocate for yourself or others, and to speak up against discrimination. By standing up for our rights, we can create a better future for ourselves and for others.

As an intern at ACIL, I am grateful for this opportunity to work alongside such talented and dedicated professionals. I am eager to learn and contribute as much as I can during my time here. ■

“Get up, stand up, Stand up for your rights. Get up, stand up, Don’t give up the fight.”

~Bob Marley, Jamaican singer



WV Navigator

Source: [WVNavigator](#)

(Design continued from pg13)

You may be able to get health insurance from your job, through the state's expanded Medicaid program, the VA if you're a Veteran, Medicare, or through the Health Insurance Marketplace, which offers options for people to get health insurance who can't get it through another qualifying source.

ACA Navigator is a grant-funded program that provides free health coverage enrollment assistance to people who are uninsured. Our certified Navigators help consumers enroll in qualified health plans through the Health Insurance Marketplace or, if eligible, Medicaid. We also help determine eligibility for health coverage and financial assistance for health coverage. This program is operated by First Choice Services and is funded by a grant from the Center for Medicare and Medicaid Services, a division of the United States Department of Health and Human Services.

Facts About ACA Marketplace Insurance

- Financial help is available.
- Preventive care is free.
- Application help is available — and free.
- You can't be turned down for coverage for having a pre-existing condition.
- The costs and benefits of each plan must be explained in easy-to-understand language — with no fine print.
- All health insurance plans have to cover important benefits, like doctor visits, hospitalizations, prescriptions, and more.

1-844-WV-CARES

Monday - Friday | 8:00am - 6:00pm (ET)

Video on WV Navigator: [WSAZ](#)

Medicaid

Depending on your income and family size, you and your family members may qualify for Medicaid or the Children's Health Insurance Program (CHIP). If you qualify for Medicaid or CHIP, you can enroll at any time. ■

Once on board, Lee spends the whole journey concerned that his personal wheelchair may be damaged during flight ("It has been damaged so badly that I couldn't even drive it out of the airport on two different occasions," he explained.)

Lee's experiences are not unique. Air travel is infamously inaccessible, with disability activists vocal about the dehumanizing and dangerous air experience for wheelchair users.

To produce this new seat design, DFP partnered with UK-based consortium Air4All. Air4All comprises aviation design company PriestmanGoode, advocacy group Flying Disabled, aerospace company SWS Certification and wheelchair design company Sunrise Medical.

Flying Disabled's Christopher Wood kickstarted the consortium a few years ago. His two adult children are wheelchair users who love to travel, and Wood's seen firsthand the issues they encounter on airplanes.

"I did research to try and create a solution," Wood tells CNN Travel at AIX. First, he looked into working with nonprofits. Eventually he concluded he needed to go directly to an aviation company. He approached Priestman Goode and Air4All was formed.

"I found like minded people," said Wood.

Somewhere along the line, DFP – described by Salanitri as "a product development company inside of the airline" – and Priestman Goode started talking about the concept.

"We thought the idea had some merit," said Salanitri. DFP bookmarked the idea, and then revisited it when they were approached by Delta Air Lines customer service team to see if they could develop "some sort of carrier that they could put customer wheelchairs in."

That was an "aha" moment, said Salanitri.

"Well, we came across this other idea here," he recalled saying.

That was around 18 months ago, and the product's been in development ever since.

DFP said it brought in a disability focus group to weigh in every step of the way. One of the key pieces of feedback, said product innovation manager Tyler Anderson-Lennert, was the height of the center console, which now elevates when the seat is in wheelchair mode.

"This has been done with some serious backing from the community to give their feedback," added Flying Disabled's Wood, who said it was important that this wasn't an airline "lecturing to the community," but rather a collaborative, instructive process.

At AIX, the DFP team has spent the past few days demonstrating their seat to aviation industry insiders. Wood said the reaction has been "genuine enthusiasm."

What's perhaps most striking at first look is that the seat maintains the same aesthetic whether it's in its traditional airplane seat mode, or in its wheelchair conversion. The team wanted to make it "stylish" and they've succeeded.

The conversion process, as demonstrated to CNN Travel by DFP engineers, is also incredibly swift and smooth, taking around 90 seconds.

(See Design on p17)

(Impact continued from p12)

aging parents, adults raising a disabled child can face a host of daunting challenges.

The most obvious resource needs involve health care. Disabled children require not only high quality primary care, but they often require multifaceted specialized care on a long-term basis. Ideally, children with complicated cases will have a team of specialists who work together in a coordinated fashion. If the condition is rare or difficult to diagnose, the family may need to consult specialists on a regional or national level. Even routine transportation may become a problem when the child has mobility issues, especially for poor or inner-city families who rely on public transportation. The family's dwelling may be inadequate to accommodate the child's physical limitations and expensive modifications may be necessary.

Disabled children often have complex educational and child care needs as well as unique recreational and social needs. They may need early intervention programs for physical, developmental, and/or emotional rehabilitation. Later, specialized education programs or facilities may be needed. Into the teen years and adulthood, transition programs and specialized job training can help many disabled individuals become independent, although supported employment on an ongoing basis may be necessary. Specialized child care is often needed, as are appropriate recreational and social activities for the disabled child.

Resource Availability

The good news for families of disabled children is that there are numerous programs and organizations that provide resources they may need. Medical care may be financed by private insurance companies, Medicaid or the State Children's Health Insurance Program when the family is eligible, state Medicaid waiver programs for specific types of disabilities, state programs for children's catastrophic illness, state and local departments of disability, and charitable organizations and programs at various levels of government that provide assistance for medication, medical or assistive devices, home modifications, or services such as physical, occupational, and speech therapy. General financial or in-kind assistance may be available from the Supplemental Security Income program or from need-based programs such as Temporary Assistance to Needy Families, the federal Food Stamps program, public housing, and the Supplemental Nutrition Program for Women, Infants, and Children. Programs such as the Special Olympics and the Ronald McDonald summer camp provide opportunities for children with special needs to get exercise and socialize. Resources that assist family members directly include respite care, counseling, parent and sibling groups, and support groups surrounding specific types of diagnoses, as well as national clearinghouses (often provided by foundations focusing on specific diseases) for information about available resources.

The Individuals with Disabilities Education Act (IDEA) requires states to implement early intervention programs that provide therapeutic, educational, and case management services from infancy through age 2 for children with, or at risk for, developmental delays. These can be administered by state departments of education, health, or human services. It also requires school districts to provide handicapped preschool programs beginning at age 3 and a free and appropriate education in the "least restrictive environment" when the child reaches school age (parents and school districts may not always agree about what such an environment would entail). School districts vary in the quality of services they offer to disabled children, and it is all too common to hear of families relocating, when they are able, to areas with school districts

(See Impact on p16)



Baked Parmesan Yellow Squash Rounds

Baked Parmesan Yellow Squash Rounds... an easy and delicious squash recipe requiring just two ingredients: yellow squash and grated Parmesan!

Prep Time 5 minutes
Cook Time 15 minutes
Total Time 20 minutes

Servings 2 to 4 servings

Equipment:

- 13- x 18-inch Half Sheet Pan

Ingredients:

- 2 medium-sized yellow summer squash
- Garlic salt & freshly ground black pepper
- 1/2 cup freshly grated Parmesan cheese

Instructions:

1. Place an oven rack in the center position of the oven.
2. Preheat the oven to 425°F.
3. Line a baking sheet with foil (lightly misted with nonstick cooking spray) OR parchment paper.
4. Wash and dry the squash, and then cut each one into 1/4-inch thick slices.
5. Arrange the squash rounds on the prepared pan, with little to no space between them. Lightly sprinkle the squash with garlic salt and freshly ground black pepper.
6. Use a small spoon to spread a thin layer of Parmesan cheese on each slice of squash.

Bake for 15 to 20 minutes, or until the Parmesan melts and turns a light golden brown. ■



(Impact continued from p15)

that offer better services for their children. Head Start, a completely separate program under the Department of Health and Human Services, provides grants to local public and private agencies to provide early intervention and preschool programs for children age 0–5 years and some additional services for participants and their families. The goal of Head Start is to increase the school readiness of disadvantaged children, broadly defined to include children with disabilities. However, the services discontinue after age 5 and are not necessarily coordinated with the services that states and school districts are required to provide under IDEA.

The bad news is that in trying to address the often complex needs of their disabled children, parents must interact with and coordinate benefits from a variety of disjointed public and private institutions. This represents a challenge under the best of circumstances, but can be particularly onerous while also caring for a disabled child. The availability and generosity of assistance can vary greatly from one locale to another and over time. There is no single source of information on the resources available for disabled children, who represent a heterogeneous group—with different ages, conditions, and degrees of impairment. Families of children without definitive diagnoses may need the most help negotiating the system, since it is rarely clear that their children qualify for particular programs and the burden of proof often falls upon them. For each program or service, parents need to be aware of its existence, go through a program-specific application process, sometimes re-apply for services or benefits annually, and often have to wait months or years to be offered services, at which time their children may be too old to receive the services. Programs are not always implemented as intended. Family support services are generally available on an ad hoc basis.

Successfully navigating the idiosyncratic and shifting landscape of disability benefits requires parents to be proactive and enterprising or to have the means and awareness to hire a child disability lawyer or consultant. Anecdotes of families' difficulties abound. A poignant example is that of a professional couple who assumed care for the wife's adult disabled brother after the siblings' mother died. These two highly

(Impact continued from previous column)

educated individuals, both in health-related professions, describe the administrative hurdles, redundancies, inconsistencies, and frustrations they experienced when relocating the brother from one state to another and trying to secure needed services.

Three recent legislative changes may have created additional obstacles for families with disabled children, particularly those who are poor: The Personal Responsibility and Work Opportunity Reconciliation Act of 1996, which dramatically restricted eligibility for cash assistance by establishing time limits on the receipt of welfare, expanding work requirements for those receiving welfare, and allowing states to impose stricter sanctions for non-compliance with work requirements or other guidelines; the No Child Left Behind (NCLB) legislation of 2001, which requires states to implement statewide standards in reading and mathematics, annual testing for students in grades 3–8, and accountability systems to ensure that students reach proficiency within 12 years; and the Deficit Reduction Act of 2006, which makes US-born children of illegal immigrants no longer automatically entitled to health insurance through Medicaid. NCLB, while well-intentioned, may result in a shift in focus from children's individualized goals (under IDEA) to preparing for the standardized test, a shift in resources away from the most cognitively impaired children (school districts are penalized for poor test performance of non- and moderately-disabled children, but not those who are severely cognitively impaired), or divert resources from preschool and outreach programs in order to achieve test score goals.

Moving Forward

More attention to the plight of families with disabled children is clearly warranted—in clinical practice, in research, and in the policy arena. The general message for clinicians is to be aware of the complex needs of families with disabled children, which start from the moment they receive a diagnosis or impairment is suspected. Skotko offers specific recommendations on how to deliver the diagnosis of Down Syndrome in a sensitive and balanced fashion that may apply to disabilities more generally. Another recent study found that children with special health care needs have lower access to health services because their parents do not recognize the need for those services.[18] Clinicians should inform parents that their children will need a range of services and that the system may be extremely difficult to navigate. Whenever possible, they should provide referrals to local support and advocacy groups, national organizations focusing on specific conditions, and websites such as those of the National Dissemination Center for Children with Disabilities[19] and the Parent Advocacy Coalition for Educational Rights that provide comprehensive listings of services.

In terms of research, a consensus needs to be reached on how to label, define, and measure child disability, and better data are needed to study the effects of child disability on health, economic, and demographic outcomes of parents, siblings, and grandparents. The ideal would be a national longitudinal multigenerational health database with detailed economic and demographic data, ample sibling information, and rich data on service use. Additional high quality studies using existing data are needed as well.

The implication for public policy is that the only way to equitably and efficiently provide services to disabled children and their families may be through a national coordinating system. The Social Security Advisory Board, in a recent report focusing primarily on education and employment, acknowledges the glaring deficiencies of the current patchwork system of supports for disabled children and urges for a coordinated and purposeful approach, with case managers and “life progression plans”.■

(Design continued from pg14)

The team is now working on the next steps to make the concept a reality. “We’re going through the testing and development and certification for the chair that is going to make that chair viable to go on an aircraft – we’re projecting within 18 months,” said Anderson-Lennert.

Salanitiri said DFP has also started informal discussions with the US Federal Aviation Administration, as well as the UK Civil Aviation Authority.

Although DFP is a subsidiary of Delta, Salanitiri said he cannot confirm whether or not Delta will be the first airline to implement the seat design.

The ultimate goal, added Wood, is getting the seat on every airline.

The team hopes implementing the concept would be straightforward for airlines to install, though they currently don’t know what costs could look like.

“Here’s the perfect world,” said Salanitiri. “I pick up the front row of all domestic airplane seats and I drop these in, no other changes, I’d have to integrate a little bit of IFE [in-flight entertainment] into it, there’ll be some regulatory certification that goes into it, but it’s a very low time, low cost modification in the perfect world.”

In terms of ticket fare, Salanitiri said the wheelchair version of the seat will likely be within “the price point of a standard domestic first class seat.”

Key step

Flying Disabled’s Wood said he’s thrilled his team’s found a potential way to improve what he calls the biggest barrier to accessible air travel, but he acknowledges that there are other unresolved issues and more to be done.

Wheelchair traveler Lee agrees, pinpointing aircraft restrooms as the next problem that should be addressed.

“Currently, they are so small that it’s impossible for a caregiver and I to go in for me to use the restroom,” he said. “Currently, I have to severely limit my food and liquid intake in the days leading up to a flight, so that I won’t need to use a restroom onboard the plane.”

Still, Lee said he’s thrilled that “an airline has finally acknowledged that there needs to be a wheelchair spot on planes, and is trying to make it happen.” He adds that he’s “immensely looking forward” to a time when he can stay in his own wheelchair on a flight.”

“On a daily basis, I receive messages from other wheelchair users saying that they want to travel, but they’re terrified that their wheelchair will get damaged, so they choose to just do road trips,” Lee said. “In 2023, they shouldn’t be saying that. Until air travel is inclusive for everyone, including wheelchair users, it isn’t inclusive at all. ■

Developmental Disability Professional Day July 15, 2023

Sources: [Professional Day](#)

This day is all about recognizing the work done by developmental disability professionals, who often go unnoticed despite providing services to some of the most vulnerable people in the country. ■

National Disability Independence Day July 26, 2023

Sources: [National Day](#)

National Disability Independence Day is celebrated every year on July 26.

It commemorates the signing of the Americans with Disability Act (A.D.A.) in 1990. This civil rights law criminalizes any kind of discrimination against individuals with disabilities and assures them full participation in the community, independent living, and economic self-sufficiency. The Americans with Disability Act covers the following areas: public accommodation, employment, transportation, and state and local government services. A.D.A. is a life-changing act for many people. Today, one in four Americans with a disability can access and participate better in their workplaces and general communities.

History Of National Disability Independence Day

The American disability movement started in the 1960s, aiming to resist the age-old notion that people with disabilities are defective, and as such, need to be segregated from civic life. The movement was inspired by the broader civil rights struggles of the time. It rejected cruel attitudes and advocated for full access to opportunities in education, public life, and employment.

The passage of Section 504 of the Rehabilitation Act of 1973 was a major step for the betterment of people with disabilities. This section prohibited recipients of federal funds from discriminating against people with disabilities. Section 508 of the same act, which was later updated in 1998, included that federal information, which was distributed electronically, should be made accessible to those with disabilities. This section was updated again in 2017, to make all digital information accessible to the disabled.

The A.D.A. was first introduced in 1988, designed to build on the progress of the Rehabilitation Act and expand the rights of the disabled community into a single law to ensure their freedom from discrimination in employment, transportation, communication, and government and public establishments. ■

UPCOMING EVENTS

WV STATEWIDE INDEPENDENT LIVING COUNCIL MEETING SCHEDULE

August 2, 2023 - Full Council Meeting
9:00 AM - 4:00 PM
WV Division of Rehab Services and Hybrid/zoom

September 6, 2023 - Executive Committee
1:00 PM
SILC Office - Hybrid/Zoom

October 4, 2023 - Full Council Meeting
9:00 AM - 4:00 PM
WV Division of Rehab Services and Hybrid/zoom

November 1, 2023 - Executive Committee
1:00 PM
SILC Office - Hybrid/Zoom



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