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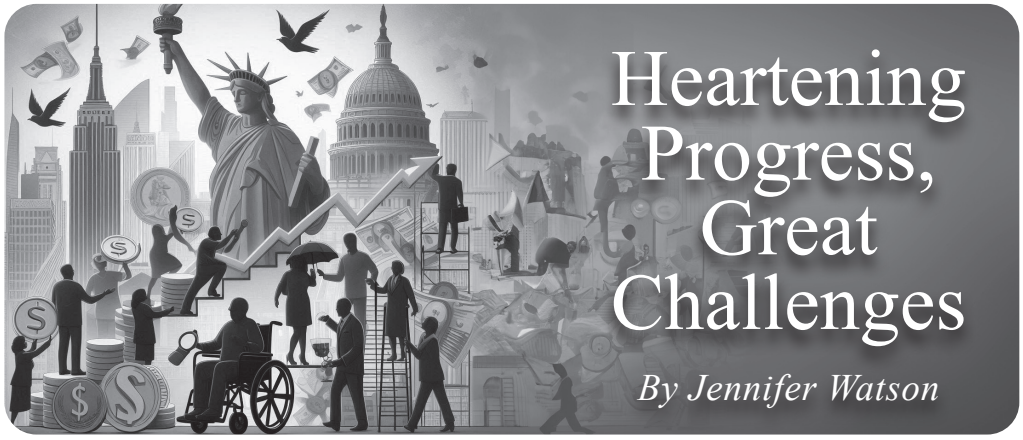
The Voice of Disability Rights in the (Bureaucratic) Empire State since 1984

AccessAbility

Summer 2024
Number 155



Heartening Progress, Great Challenges

By Jennifer Watson

The outcome of the SFY 2024-25 NYS budget presented a mixed bag for New Yorkers with disabilities. In many ways it demonstrated NY's commitment to ensuring that people with disabilities are valued and have access to supports and services, and with equal and opposite force it revealed quite the contrary.

Some positive highlights include heightened attention towards mental health initiatives, increased funding for postsecondary special education, and enhanced resources allocated for Disabled individuals within the justice system. Additionally, funds were committed to develop an Olmstead Plan, which will play a crucial role in ensuring that Disabled New Yorkers have access to services in the most integrated setting possible, promoting autonomy and consumer control. The budget also increased funding for Independent Living Centers, like STIC, as well as the Access to Home program, which provides for accessibility modifications.

In a decidedly different direction, the budget contained a monumental and incredibly harmful change to the Consumer Directed Personal Assistance Program (CDPAP). In the ever-evolving landscape of healthcare in New York, the CDPA Program stands as a beacon of dignity and autonomy for people who need personal care services. CDPA empowers people with disabilities to hire, train, and supervise their personal assistants, fostering a model of care that respects the unique needs, culture and preferences of each person.

A proposal pushed by the Governor and Speaker of the Assembly will force CDPA under a single statewide Fiscal Intermediary (FI). At best this shift undermines the core values that make CDPA a lifeline for so many people, and at worst it will cost thousands of New Yorkers with disabilities their independence or even their lives.

Leading up to the final enacted budget, advocates from across the state spent many long days and even an unprecedented night at the Capitol fighting to keep the CDPA program intact. It was through these efforts that Independent Living Centers, having a dual role as CDPA Fiscal Intermediaries, were included the final budget language, that also called for a statewide FI.

We are immensely grateful to the NYS Senate, who stood strong against efforts to move to a statewide CDPA FI, pushing back until this remained one of the few outstanding items keeping budget discussions open. The Assembly membership also championed our cause asserting that a statewide FI was a bad idea and that ILCs must be included, despite Speaker Heastie's insistence to the contrary.

INSIDE

AccessAbility

June 2024

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Authorship

All articles appearing in this newsletter are written by John McNulty unless otherwise noted. Generally, I get tired of seeing my name on every page, and I'd rather use the space for something more interesting. I do put my name on controversial stuff, though, so you'll know who to blame.

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Though ILCs were spared, the negative impact of this plan is far reaching and will have devastating consequences if enacted.

First and foremost, the essence of CDPAP lies in its flexibility and allowance for consumer choice and control. Despite the inclusion of 11 ILCs, consumer choice would essentially be eliminated.

With no competitors, a statewide FI would have little accountability since consumers have no other options when issues arise.

It's been reported that there are over 200,000 New Yorkers receiving CDPA services across the state and consequently there would be at least as many personal assistants working for them. The logistical complexities of transitioning such a large number of consumers and their caregivers to a single entity cannot be overstated. Even minor disruptions in the process would result in delays or gaps in service delivery, leaving people without essential care, resulting in hospitalizations, institutionalizations, or deaths.

This would have a devasting impact on a workforce that is already in crisis. Many consumers have established long-standing relationships with their personal assistants, built on trust, familiarity, and mutual understanding of their specific needs. Disrupting these relationships by mandating a switch to a new employer of record will likely result in personal assistants leaving this workforce due to changes in pay or benefits. Without the support their personal assistants, individuals with disabilities will be forced into nursing homes or other institutional settings, depriving them of their autonomy, independence, and quality of life.

Despite the inclusion of a single statewide Consumer Directed Personal Assistance (CDPA) Fiscal Intermediary (FI) in the budget, slated for implementation by April 1, 2025, our advocacy efforts must persist to prevent its full execution. It is imperative that any changes to the CDPA program undergo thorough and thoughtful deliberation, prioritizing the preservation of the rights and dignity of people with disabilities. We must advocate for policies that uphold the autonomy, choice, and well-being of individuals with disabilities, ensuring that their voices are heard and respected throughout any decision-making process that affects them.

In another blow to the independence of people with disabilities, a bill that would have repealed eligibility changes made to CDPA, Personal Care, and MLTC enrollment was ultimately not included in the final budget. The eligibility changes were initially passed in the 2021 NYS budget, so they have not been implemented due to Maintenance of Effort (MOE) requirements of the American Rescue Plan Act (ARPA). Even though the Public Health Emergency was declared over as of May 2023, NY cannot make changes to eligibility until after they spend their federal ARPA funds that were provided during the pandemic, or March 31, 2025, whichever comes first. Given that NY has spent most of its ARPA funds, these eligibility changes could happen as early as this summer.

When enacted, new applicants for services would be required to demonstrate a minimum need for certain assistance with activities of daily living (ADLs). Specifically, individuals with dementia or Alzheimer's must need at least supervision with more than one ADL, and all others must need at least limited assistance with physical maneuvering with more than two ADLs. Activities of daily living (ADLs) include bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating. This change would essentially elimi-

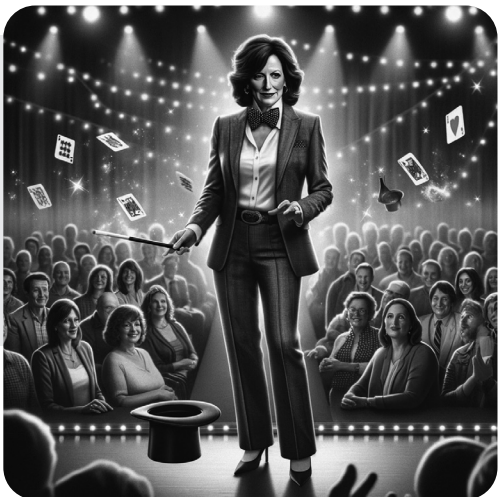
nate stand-alone "Level I" personal care services, which includes meal preparation, grocery shopping, laundry, and running errands like picking up prescriptions--things that are essential for keeping some people in the communities. People already receiving services before the effective date of these changes will be grandfathered in.

Individuals newly seeking services who fail to meet eligibility may be forced into institutions as their only means of support, at an exponentially higher cost, to both them and to Medicaid. Similar situations will arise for people already living in an institution – eligible for Medicaid-covered nursing home care -- who seek to return to the community, only to find that they are not eligible for services due to not meeting heightened eligibility criteria.

Advocates continue to fight back against these changes, as they violate federal rules regarding discrimination on the basis of diagnosis when accessing Community First Choice Option (CFCO) services, which include home care, personal care, and consumer directed personal assistance.

While we achieved notable victories and legislative gains, significant shifts in the budget and those things completely left out threaten to erode the very foundations of essential services for individuals with disabilities. These overarching changes, if left unchecked, will detrimentally impact the accessibility of vital resources and support systems for all New Yorkers with disabilities.

Bad Faith Hochul Performs Sleight-of-Hand with Budget Proposals



In our last newsletter, we alerted our readers to Governor Kathy Hochul's reckless budget proposals, most launched 30 days after the initial proposal in the amendment period, which seemed a bit like a dirty trick. (It was, but as we will see, it was just Step 1).

Her proposals were aimed at cutting spending by eviscerating home and community-based care. To summarize, the cascading, abominable measures included (but are not limited to)

- Cutting the already grossly inadequate pay to caregivers.
- Increasing the thresholds for eligibility for benefits, abandoning to their own devices over half of those relying on services for activities of daily living.
- Making it impossible for those with severe physical, mental, or developmental disabilities to obtain or maintain services by eliminating the role of Designated Representatives, typically unpaid family members who speak for those who can't speak for themselves, such as children and people with dementia, traumatic brain injuries, developmental disabilities, and mental disabilities.

The initial responses to the Governor's budget from the Senate and Assembly were very promising, as both houses overwhelmingly rejected all or most of the Governor's proposed cuts. The rank-and-file revolt, entirely justified by the maliciousness and/or absurdity of the proposals in the Governor's 30-day amendments, for the most part carried the day – nearly all of them were pulled fairly quickly from the final budget under discussion.

But negotiations between "The Three People in the Room," Governor Hochul and the leaders of the two legislative chambers, Senate Majority Leader Stewart-Cousins and Assembly Speaker Heastie, continued under a veil of secrecy. This bizarre and spectacularly anti-democratic means of finalizing the budget negotiations every year eventually revealed what now seems to be what they were going for all along, while preoccupying advocates with the initial, dead-on-arrival proposals.

The reporting was that Governor Hochul and Speaker Heastie were driving this proposal; Senator Stewart-Cousins resisted as best as she could, but to no avail. That is interesting because we have been hearing that new State Budget Director under the governor, Blake Washington, was the source of the single Fiscal Intermediary (FI) idea, which originated from the Assembly – Speaker Heastie – rather than the Governor. In Mr. Washington's previous job, he was Secretary of the Assembly Ways and Means Com-

mittee, which means he was the chief adviser on fiscal and budgetary matters for – wait for it – Speaker Heastie and the Assembly majority. Well…we shall be generous and call it synergy.

The new "plan," vociferously opposed by majorities in both houses but enacted by the all-powerful leadership, was to effect cost control over the Consumer Directed Personal Assistance Program (CDPAP) by eradicating the FI program that was launched and nurtured by non-profit, public interest agencies, including but not limited to Independent Living Centers in New York, as part of the CDPAP program, and then foolishly compromised in the implementation of the ill-advised Managed Care program in 2012, which is when the 1200% increase in CDPAP spending that the governor bemoans took flight.

However, that 1200% figure is fantastically misleading because it does not, for the most part, represent new CDPAP spending that would not have happened otherwise. It represents the movement of people's home and community care from traditional plans to CDPAP. Traditional home care spending has declined by *more* than CDPAP has grown, and that was to be expected – one of the primary benefits of CDPAP is that it is *less* expensive than the traditional models.

If one spends a lot of money on inexpensive domestic widgets because one stopped spending money on pricier imported widgets, one is still acquiring the same volume of widgets, but spending less. That's a good thing! And that is what is happening when CDPAP supplants traditional plans.

To use a metaphor, managed care was a carcinogen on the body of CDPAP that created a cancer of exploding FIs and accompanying costs. The first way one treats a cancer is to cut it out of the body, if possible. Abandoning the failed managed care experiment and exerting direct and vigorous oversight over the FIs, with the goal of thinning the herd of the least effective, would do that.

The unitary FI approach is something different; they're trying to make the carcinogen less toxic by introducing a new agent that both administers the carcinogen efficiently, as intended, with better therapeutic outcomes, and that will be easier for the supervising physicians – the state – to observe and assess.

Problems with this: The carcinogen (managed care) is still there. We don't know if the new therapy (the unitary FI) will be effective, but past results are not promising, and there's a real danger the effect will be the opposite of the intent – like giving steroids to a cancer patient, boosting a tumor's growth. There's not much evidence to support that this new situation will be any easier for the doctors (the state) to control the new situation than the old one.

Most importantly, the parts of the body in most need of protection – the consumers and the caregivers – will definitely suffer in the short-term with switching costs in the transition, and quite probably in the long term as well, as caregivers find different jobs, the labor crisis gets even worse, and the services the consumers receive suffer or disappear completely. We understand that it is a necessity to control spending. But these expenditures are not mere line items on a ledger; each one represents a human being in New York either having a better life or a worse one. The Hippocratic Oath tells physicians "Do no harm." An ineffective treatment does harm because the problem gets worse while we wait for an outcome that won't materialize.

Experience tells us that smaller, regional FIs are most effective in serving their consumers; having a single FI serving consumers in both Brooklyn and Ballston Spa, from Batavia to Broome County to Babylon, just makes no sense. (And that's only a few of the 'B's.) The lawmakers recognized this, belatedly, and so the unitary FI will subcontract with a carefully selected group of regional agencies currently serving their consumers well as FIs, many of which are Independent Living Centers (and one of which is STIC). That is a good thing, but it raises the question: What value is the supervising FI providing, and is it sufficient to justify what it is skimming from the CDPAP budget for expenses and profits?

It is an open secret that the statewide FI is intended to be a firm called PPL. PPL is a massive for-profit healthcare administration provider that spans the nation; notably, they have assumed this unitary FI role in California, where, contrary to Hochul's assertions, the new organizational structure is going poorly. PPL will subcontract with some current FIs delineated by the legislature, including ILCs. STIC will retain its role for the CDPA consumers it serves (perhaps; the details are not yet clear), but most of the for-profit FIs will be cut out of the loop, though they are suing to prevent this.

Of course, all this will take a long time to implement. The current effective date for all this is April 1, 2025, but between inevitable bureaucratic and labor delays and an expected blunderbuss of litigation it will probably exceed this target date by quite a bit. In the meantime, those of us dedicated to the CDPA program will continue on two tracks.

First, we shall try to make the current situation the best it can be, as much as it may feel like putting lipstick on a pig. Second, we shall lobby for true reform to abolish the disastrous managed care experiment and streamline the program to provide excellent service to consumers at a reasonable cost – which is pretty much what was in place before managed care. We will report on this further as events unfold.

STIC Fights to Preserve CDPA

When the governor's budget, with its savage cuts to programs critical to our mission, was unleashed upon us on February 1st, and even more so when her 30-day amendments compounded the threat, STIC did not falter, but got to work fighting these unjust and awful ideas.

We made several pilgrimages to Albany to meet with legislators and staffers for the governor and joined hundreds demonstrating in the Capital Building. The most dramatic--if purposefully anticlimactic--event was, when things seemed most dire, the leadership of several of the groups exercising their First Amendment rights decided to up the ante to civil disobedience.

So, we spoke to the state troopers working security (who were wonderful young men and women, by the way) as to how to go about that; we didn't want to do anything violent or destructive, but we did want to get taken away in handcuffs before news cameras, to alert the wider public of our plight. We determined that if we remained in the Capital after the official closing time of 7pm, we would be trespassing and thus could be lawfully arrested and detained.

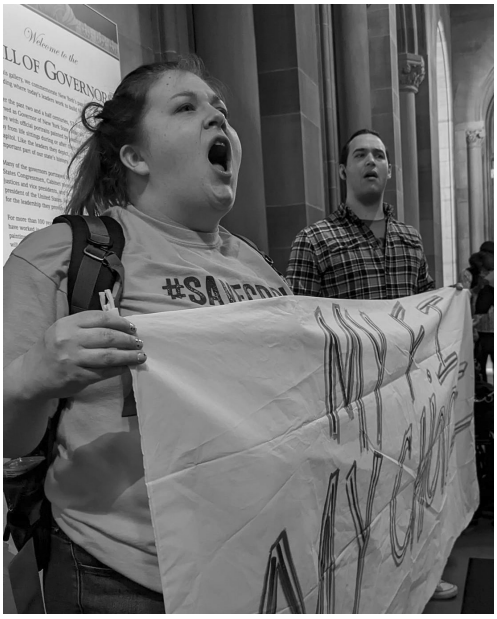
Well, we hung around until the appointed hour, and…nothing happened. We demonstrated more loudly, blocked doors, and did all we could without doing anything *malum in se.*

("*Malum in se*" is a legal term in Latin meaning "bad in itself" – hitting people or breaking things is *malum in se*, trespassing and disturbing the peace is not. The term for that is "*malum prohibitum,*" "bad because it's prohibited").

Alas, word came down at about 8:30 that the governor had instructed that we were not to be arrested for trespassing or anything else non-violent; we were to be permitted to stay in the capital's public spaces for as long as we wished. In plain terms, she would not take the bait. It was a cagey ploy to silence our voices; civil disobedience doesn't work if the disobedience is tolerated.

About a dozen hardy souls volunteered to stay all night, and in fact we had a constant presence through the weekend. But most of us dispersed.

STIC also reached out to its advocates and allies at frequencies that may have been unprecedented – if not, it's been quite a while – to encourage our friends and supporters to reach out to their representatives and leadership with emails and phone calls to urge them to reject these misbegotten plans and/or encourage those supporting us to hold fast. We plan to continue such outreach in the future, albeit not at the same pace.



A Note to Our CDPA consumers

by Lucretia Hesco

The NYS budget has been approved and it includes a bill that brings about changes affecting Consumer Directed Personal Assistance Program (CDPAP) and all current Fiscal Intermediaries (FI). This change includes a plan to transition CDPAP into a single statewide FI, responsible for overseeing services for all consumers in NY State by 4/1/2025. We wanted to reach out to you, as our valued consumers, to clarify what this means for you within our CDPA Program.

Please know long delays should be expected in the implementation of this transition. Additionally, the details and steps required for this transition have not yet been fully established. Importantly, the bill stipulates that the single statewide FI must sub-contract with the 11 current Independent Living Centers (ILC) that oversee CDPAP services. STIC is one of these 11 ILCs, which means that STIC will continue to serve as your FI for your CDPAP services for the foreseeable future.

We want to reassure you that STIC's CDPA Department remains fully committed to you, your program, and your services. We're here to address any questions or concerns you may have.

Other State Budget News

Aside from the assault on Medicaid, there was much of note in the state budget. A lot of the governor's pet projects found funding once she decided to use Medicaid as a piggy bank.

One reason the Medicaid budget has been squeezed is because New York has had to spend a lot of money – more than any other state not on the southern border – on supporting asylum seekers. We do not denounce that support, but we recognize it is a strain on the state budget that was difficult to plan for in advance. The final budget for support of asylum seekers was $2.57 billion, one-sixth higher than the proposals of either house or the governor; the increase presumably reflects an upward adjustment in cost estimates.

Tenants' rights legislation long sought by advocates known as "good cause eviction" was included in the budget. However, the version in the budget differs substantially from the original legislation, with a number of exceptions and exclusions mitigating the impact on smaller landlords, upstate properties, and new construction. Neither landlords nor renters seem entirely happy with this, which we hope means it's fair.

The legislature wanted to increase child care funding, specifically by boosting wages to retain employees and attract new ones, but this was largely blocked by the governor.

A proposal to enact limitations on social media use for minors was strongly supported by "the three people in the room," as well as the state Attorney General, but a burst of vigorous lobbying from well-heeled big tech firms scuttled the proposal.

The governor's initiative to improve mental health funding seemed to go through virtually intact, although oddly the legislature's proposal that largely held was over twice as large as Governor's Hochul's proposal, which seems strange considering she was extolling it as her signature initiative. Anyway, she got what she wanted and then some.

There was substantial funding to keep struggling hospitals open, most prominently SUNY Downstate University Hospital in Brooklyn.

New York has some unique policies on Work Leave. It is the only state with paid Covid leave still in effect, and the budget extends it through the end of July of 2025. New York is also the first state to guarantee twenty hours for paid prenatal leave, meaning time off for the pregnant to receive medical care from health professionals.

Hochul has made fighting crime a priority, with an annual initiative focusing on one type of crime prominent in the news at the time. Last year it was gun violence; this year it is retail theft. Amusingly, much of the new policy on retail theft mirrors last year's proposal on gun crimes, with just the type of crime altered. Other initiatives in law enforcement and areas related to it fund fighting opioid addiction, new laws to enable better prosecution of illegal cannabis dispensaries, accelerated closures of underutilized prisons, and augmentation of the existing menu of "hate crime" offenses.

On climate and energy issues, most of the noteworthy news is what was *not* funded. The proposal for a Climate Change Superfund, imposing a fee on fossil fuel companies for past carbon emissions, was declined. A law designed to resolve previous, contradictory laws and phase out natural gas in New York State failed. An initiative by Hochul to cut funding for water infrastructure was defeated.

A tax credit supporting the hiring of journalists at local or regional press outlets passed, in an effort to support struggling small newspapers, the only source of local news for many parts of the state and which have declined by 40% since 2000. The governor's Artificial Intelligence initiative was launched by funding a research

consortium to be headquartered at the University at Buffalo.

Measures were implemented to stiffen penalties for fare and toll evasion, though they were scaled back from the crackdown first offered by Governor Hochul. Also, a 20 mph speed limit was approved for all of Manhattan and much of the outer boroughs; an exception was created for three or more lane highways outside of Manhattan.

Lastly, having trouble coping with all this? The Covid-era law allowing to-go alcohol from bars and restaurants was extended by five years. We encourage the use of a designated driver; cheers!

Introducing STIC's New Splash Page QR Code: Your Gateway to Support and Information

By Lucretia Hesco

We are excited to introduce a new and convenient way for you to connect with the Southern Tier Independence Center (STIC) -- our brand new splash page QR code! This innovative feature provides quick and easy access to all the essential information and resources STIC offers, right from your smartphone or device.

What is the STIC Splash Page QR Code?

The STIC splash page QR code is a scannable code that directs you to a comprehensive landing page. This page serves as a hub for all things STIC, giving you instant access to our website, social media channels, advocacy tools, and more. By simply scanning the code with your phone's camera, you'll be able to stay connected and informed with just a few taps.

How to Use the QR Code

1. Open the camera app on your smartphone.
2. Point the camera at the QR code.

3. Tap the notification that appears to open the splash page.

What You'll Find on our Splash Page

STIC's Splash Page is designed to be your one-stop shop for everything STIC-related. Here's what you can access:

- **STIC Website**: Visit our main website to learn more about our mission, services, and programs. Explore the comprehensive resources we provide to support independent living.
- **STIC Facebook Page**: Follow us on Facebook to stay updated on our latest news, events, and community activities. Join our online community to connect with others and share your experiences.
- **STIC Twitter (X) Page**: Keep up with our real-time updates, advocacy efforts, and important announcements by following us on Twitter (now X).
- **STIC Voter Voice**: Make your voice heard! Use our Voter Voice tool to engage in advocacy and contact your legislators about issues that matter to you.
- **STIC Instagram Page**: Follow us on Instagram to see our latest photos, stories, and events in our community and view likes, comments, and shares.
- **STIC Xscapes**: Discover our unique fundraiser, Xscapes, offering five (5) interactive escape room experiences.
- **STIC Merch Store**: Show your support for STIC by visiting our merch store! Browse our selection of apparel, accessories, and more, with all proceeds reinvested in supporting our programs and initiatives.

Why Use the QR Code?

The splash page QR code is more than just a quick link – it's a tool to enhance your connection with STIC. Whether you're looking for support, want to stay informed about our latest initiatives, or are eager to get involved in advocacy, the splash page has everything you need in one convenient place.

We invite you to scan the QR code today and explore the many ways STIC is here to support you. Stay connected, stay informed, and stay engaged with STIC – your partner in promoting independence and empowerment.

Thank you for being a part of our community. Together, we can continue to make a positive impact!

New Service ALERT! New Service ALERT!

By Hannah Hickox

The Supported Employment department has been busy this past year developing the newest program to be offered to STIC consumers with OPWDD eligibility. We are excited to announce that in July 2024, STIC will launch its Community Based Prevocational Services Program (CBPV).

The CBPV program is designed to help support individuals who want

to work someday by preparing them to enter the competitive workforce. Participants will have the opportunity to explore their interests and develop the necessary skills in a combination of classroom-style learning and hands on work experiences in the community. Participants will learn skills like taking direction, taking initiative, effective communication, professionalism, and time management. Participants will also learn about their rights, learn to advocate for themselves, and learn to identify early on what, if any, accommodations they may require in the workplace. The CBPV program is perfect for people who have a little to no actual work experience but want to try new things and focus on building a solid foundation of healthy work habits before settling on a specific field. The program could also be fantastic for someone who is currently working but is considering a career change in the future.

STIC is now accepting new referrals for its Community Based Prevocational Services Program. Interested participants with current OPWDD eligibility should contact their Care Manager to complete a referral. Those who are not yet OPWDD eligible or who have questions about eligibility can contact STIC's Employment Director, Hannah Hickox, by phone at 607-742-2111 ext. 228 or by email at hannahh@stic-cil.org.

STIC is also accepting referrals in all of its employment programs. To learn more, visit our website at www.stic-cil.org or contact the Employment Director.

STIC is hiring! If you are a human services professional looking for a career in providing employment services, check out our posting on Indeed or visit our website for more details. Send your resume to apply@stic-cil.org.

STIC Fiscal Intermediary (FI) Services

By Lisa Gavazzi

The Southern Tier Independence Center (STIC) is an OPWDD Fiscal Intermediary (FI). We are now accepting referrals for people who are interested in directing their own lives and deciding on what services to utilize.

In addition, STIC is open to building new relationships with brokers. Interested brokers should contact our FI Specialist, Lisa Gavazzi, at sds@stic-cil.org.

FI Services offered: Community Habilitation, Respite, Paid Neighbor…..

Highlighted Service for this Quarter

Paid Neighbor:

The Paid Neighbor stipend is paid to a neighbor to serve as an "on-call" support. This is someone who should be available to respond when needed. Paid Neighbors cannot live with the participant, live more than 30 minutes away from the participant, or be a "family member" of the Self-Direction participant.

The STIC Fiscal Intermediary is currently providing this service to qualifying individuals. STIC is open to new consumers, without a waiting list.

For any interest or questions contact Lisa Gavazzi, FI Specialist at sds@stic-cil.org

Vestal Town Square Mall Improves Accessibility

By Susan Hoyt

The Accessibility Committee at STIC would like to acknowledge the Town Square Mall in Vestal for installing ramps to allow better access to sidewalks and stores. The ramps look beautiful and will allow people of all abilities to enjoy shopping at the mall. Thank You!

In Memoriam: R.J. Barham

Our dear friend and colleague Richard Joseph Barham, called Joe by some and (more commonly at STIC) R.J. by others, passed away unexpectedly on May 6.

R.J. volunteered at STIC and was of great help any way he could be – organizing files, shredding confidential documents, and just being available to do anything that needed to be done. Despite confronting health struggles that would deter many, R.J. continued his volunteer work and never complained because he was passionate about advocating for people with disabilities and advancing their fight for equal rights.

Many of us at STIC enjoyed getting to know R.J., with his good cheer, quick wit, and deep reservoir of knowledge and experience in many arenas garnered during his rich and varied life, working both as a research scientist at IBM and driving an 18-wheeler. He could speak with experience about Italian food, disability rights, upstate New York history, and much more. The author of this remembrance had a fascinating discussion of string theory by the coffee machine; R.J. enthusiastically explained how he made the math work for a sixteen-dimensional Grand Unified Theory of cosmology and particle physics. I tried to keep up; fortunately it was my second cup.

As a man of both science and faith, R.J. can probably now sense all sixteen dimensions on the higher plane newly enriched by his addition, as we mourn him on this mortal coil. Our deepest sympathies go towards the large brood of family and friends R.J. leaves behind. RIP.

Dis*COVEN* Our Newest Xscapes Adventure!

By Todd Fedyshyn

Xscapes @ STIC is thrilled to introduce the latest addition to our mobile escape room tent rentals: "COVEN." This innovative escape room experience features state-of-the-art projection mapping inside the tent, creating an immersive and magical atmosphere. Players will interact with a captivating witch video, enhancing the gameplay and adding an extra layer of excitement and challenge.

"COVEN" is the perfect rental for fall parties, Halloween events, or any occasion that needs a unique and memorable attraction. Whether you're hosting a corporate event, a birthday party, or a community gathering, our escape room tent will provide an unforgettable experience for all participants.

Visit www.Xscapes-STIC.com to book your escape room, or rent a tent today and bring the thrill of "COVEN" to your next event.

Van Operators Needed!

By Ronald G. Hirst

BC Transit is actively recruiting qualified Van Operators. In this position, you will be driving a 16-passenger van that will be used to safely transport passengers at scheduled times.

- P/T positions are Monday-Sunday, typically 3 to 4 days per week.
- Must have the ability and patience to effectively communicate and interact with all people, especially senior citizens, and persons with disabilities.
- CDL C license preferred, but BC Transit will train the right person for the job.
- Paid comprehensive training, with great wages.
- Starting pay is $17.99 per hour.
- Mandatory NYSDMV 19A physical.
- Mandatory pre-employment drug test.
- Apply at BC Transit, 413 Old Mill Rd, Vestal NY.
- EEO/AA females and minorities encouraged to apply.

XSCAPES

courts watch

U.S. Food and Drug Administration, et al v. Alliance for Hippocratic Medicine, et al: More standing around

As promised last newsletter, we're going to keep a close eye on the standing issue in these pages, and there was another major case in which standing was in question in March. Many people missed the real question before the Court because the standing that was in question is the right to sue the Food and Drug Administration for their various approvals of a drug called mifepristone, commonly known to most of America not by that name but as the "abortion pill."

That of course, introduces the "abortion distortion," as Justice Scalia termed it, where whenever abortion is a part of any larger, adjacent, or even tangential question, the legal gravity of abortion bends everything else involved like a black hole bends light. This is because in terms of constitutional law, we deal with abortion differently than just about any other issue, largely because both the politics and the legal reasoning behind *Roe v.*

Wade were…let's say unique. Whether and to what degree *Dobbs*'s reversal of *Roe* and *Casey* will ameliorate that remains to be seen, but it's safe to say that for now abortion remains the legal equivalent of Whoopi Goldberg in a choir of nuns.

We shall not address the merits of the abortion pill question here – not with a ten-foot pole. Rather, we want to pull Whoopi from the choir (hiding her safely from the racketeers, of course) and just discuss whether the original plaintiffs, now the respondents on appeal, had standing to file a legal challenge against the FDA about some unnamed drug XYZ.

This is a textbook example of "judge shopping."

The Alliance for Hippocratic Medicine (AHM) is an association of medical professionals that espouse and follow a code of ethics that is for the most part distinguished by conscience objections to euthanasia and abortion at any stage and for any reason (with the usual accommodations for extremely rare circumstances where the life of the mother is in imminent peril). They were established in 2022, coincidentally when the *Dobbs* decision came down, and incorporated in Amarillo, Texas, ironically the location of a division of the U.S. Northern District of Texas where only one judge is seated, Matthew Kacsmaryk, a Trump appointee who rather reliably rules favorably towards social conservatives that come before him. This is a textbook example of "judge shopping," and Judge Kacsmaryk himself has expressed some discomfort about his court in out-of-the-way Amarillo being a gateway for all manner of Republican lawfare, but if the cases are filed there, there's not much he can do about it. It should be noted that several other similar anti-abortion organizations are part of this litigation; AMH is just the lead named respondent.

So, AMH sued the Food and Drug Administration (FDA) claiming their approval of the drug in 2000 and subsequent amendments to the approval loosening reporting requirements, expanding the pool of those eligible to prescribe, and most recently (2021), being authorized to be deliverable by mail. Now, the plaintiff physicians do not prescribe mifepristone, or perform any other function in service of a termination, and they certainly don't take the drug themselves. Their claim is that they may be forced, against their conscience objections, to treat patients in emergency situations that experience relatively but not exceedingly rare complications from the use of mifepristone, primarily severe bleeding from where you would expect, and in some cases where this happens, the unborn human survives alive, if almost never viable for full-term gestation and live birth.

The FDA argued that these AMH physicians lack standing, because the circumstances they envision that might threaten their conscience objections involve a series of events – someone pregnant taking the medication, then experiencing a rare complication, and then finding herself in a situation in which the only medical professional available to treat them happens to be one of these who object to any treatment that might tend to terminate life -- each of which are sufficiently unlikely as to make the whole sequence too improbable for a valid standing claim. FDA is joined in this appeal by the pharmaceutical company that manufactures brand-named mifepristone, Danco Laboratories.

In Amarillo, the carefully chosen Judge Kacsmaryk rejected the standing objection as expected, allowing the case to proceed. The FDA appealed to the Fifth Circuit Court of Appeals, headquartered in New Orleans and serving the states of Louisiana, Mississippi, and Texas; this circuit, also well-stocked with Trump appointees, affirmed the District Court decision, at which point the FDA appealed again to the Supreme Court.

There was separate litigation staying the original District Court judgment to limit distribution of mifepristone by telemedicine and by mail, and to abbreviate the interval of gestation where the pill may be administered; this played out similarly along partisan lines. The judgment was eventually stayed by the Supreme Court until the question is settled.

The Supreme Court heard arguments on this on March 26 of this year from plaintiff's attorney, respondent's attorney, and the U.S. Solicitor General; a ruling is expected sometime in the next several weeks. Indeed, it's quite possible the ruling will be released between the time of this writing and the final delivery of this newsletter in mid-June, although it's more likely it will be one of the last cases released in late June or even July. The Court's usual strategy is to release the most controversial choices last; the Justices then can promptly skip town for summer vacation before the protests launch.

Because of the "abortion distortion" discussed above, it may be difficult to generalize this standing question with others, and if the Court rules inconsistently with other questions outside the event horizon of the abortion controversy, it wouldn't be the first time. However, this standing ques-

tion can be lumped in with *Laufer* and *AR NAACP* from last month in the sense that this is another case where citizens claiming federal law is being violated file suit to redress their grievances, and the application of standing doctrine will determine whether they have the right to do so. To a degree, this indicates "standing" is a double-edged sword. I would speculate that the Venn diagrams of those who favor Ms. Laufer's right to enforce the Americans with Disabilities Act and those who concur with AHS that the abortion pill is being unjustly or irresponsibly prescribed have very little if any overlap, but the outcomes of their cases may ride on the same procedural question. We shall stay on this, because a radical redefinition of standing doctrine could herald a *sotto voce* revolution in case law which touches virtually all arenas of American life. We will certainly tell you how this turns out in our Autumn issue and put our two cents in about it.

Pitta v. Medeiros. "Smile, you're on Candid Camera!" "Oh, no, I'm NOT!"

This is a peculiar case that seems to be fueled, reading between the lines, on a fair bit of personal pique and/or animus between the parties. Scott Pitta is the parent of a child that had an Individualized Education Plan (IEP) in the public school he attended in Bridgewater, Massachusetts, and the child's IEP team would meet from time to time to assess student progress and adjust the IEP as necessary. The committee met twice in February and March of 2022 (so during the Covid pandemic). A dispute arose; it's a little unclear, but it seems that Mr. Pitta wanted to withdraw his child from the special education program and mainstream him, and the school district was resisting that, claiming it didn't really have evidence to support such a move.

When minutes of the meeting were later distributed, Mr. Pitta believed that there were "omissions and inaccuracies." Whatever the dispute was, it doesn't affect the merits of the case, but it may explain why the case was pursued to a U.S. Circuit Court of Appeals. Additionally, Mr. Pitta is an attorney, and could represent himself *pro se*, saving thousands of dollars in legal fees.

At a subsequent meeting in September 2022, also virtual, Mr. Pitta announced that he intended to video-record the meeting, which is simple to do with a virtual meeting (it was via Google Meet). The school district, led by the Director of Special Education, Ms. Medeiros, objected to the video recording, stating is was against district policy. She countered that audio-recording was permitted, and she said the district would do that.

Mr. Pitta didn't back down; the meeting was ended when Mr. Pitta would not cease video-recording, after which he filed suit with dispatch against the school district in federal court, making a First Amendment claim that his rights were violated because he was not allowed to create a video record of public officials performing their official duties. After the filing, the school district proposed a compromise where participants would be on camera represented by black boxes; the boxes' borders would light up when that participant was speaking, so it was sufficient to create a complete record of who said what. Mr. Pitta acceded to that, and the committee reconvened in October 2022.

However, the suit continued, and Mr. Pitta made a public records request for all materials related to policies and procedures for the IEP process, as well as communications between members of the committee and other relevant Special Education personnel from 2022 and 2023 up until that point (July). He received a manual with extensive guidelines; there however was no written policy about prohibiting video-recording--or allowing it for that matter. It was unaddressed.

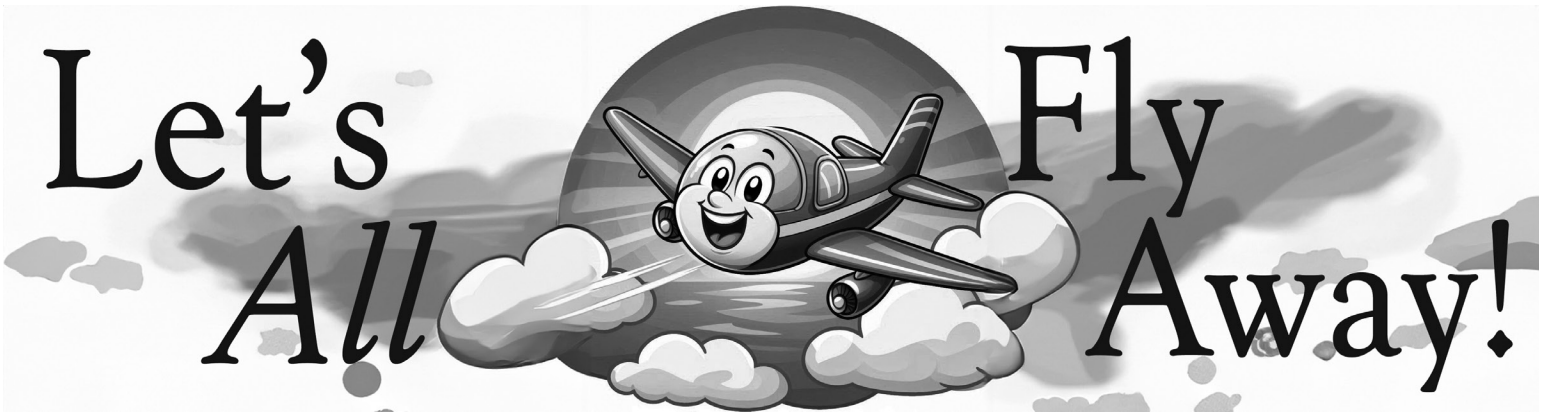
The school district filed a motion in U.S. District Court for Massachusetts for the suit to be dismissed. For one thing, the matter had been resolved so there was a mootness claim. But the more substantive claim was that there was a First Amendment right to video-record public officials performing their duties in a public space, but an IEP meeting, virtual or actual, wasn't a public space – it was a meeting with particular school personnel and parent/guardians closed to the public where information about the student, all confidential, would be discussed. The District Court agreed and vacated the case in May 2023. Mr. Pitta appealed to the First Circuit Court of Appeals, headquartered in Boston and responsible for Maine, Massachusetts, New Hampshire, Rhode Island, and the Commonwealth of Puerto Rico; they affirmed the District Court's de-

cision this past January 4th. After the District Court decision, the school district withdrew the audio-only offer and issued a formal policy banning any recording, audio or video.

We chose to focus on this case because the laws involving IEPs are important to the disability community. However, as this turned out, it seems it raises more questions than provides answers. I tend to think the courts' rulings are correct and there isn't a First Amendment right to record IEP meetings. But, what really is the difference between an audio recording and a video recording, especially for a virtual meeting? If Mr. Pitta was going to be a crank about it, why didn't they just let him make his little movie? What did they have to fear, if they were doing their jobs correctly? But were they? If they weren't, and they feared Mr. Pitta could expose them somehow, it would explain a lot. Perhaps Mr. Pitta was such a crank that they feared he would do something with the recording, such as sue them about something else, but again, pretty much anything he might do with a video recording he can do with an audio recording. I tend to believe they decided to ultimately ban both video and audio because trying to justify one and not the other would prove legally challenging. Not wanting to be recorded is a very understandable impulse, to be sure, but to resist it to this point? How much did the school district end up spending on legal fees?

As for Mr. Pitta, it seems there are much easier remedies to pursue than thinly justified federal lawsuits. Even representing himself, he must have spent thousands of dollars on this effort; wouldn't it have been better spent sending his son to a private school that could educate him precisely as he wanted? And for both parties – how was this allowed to escalate to a federal court of appeals? There's just more to this story we don't know, because the facts we have don't entirely explain the choices everyone made. I feel confident that at least one party was behaving very badly in some form or fashion, and my best guess is that it was more than one. And bad facts make bad law.

But it's over. Even if Mr. Pitta appeals to the Supreme Court, the odds that this would be granted *certiorari* are close to nil. The person we truly feel for is the younger Mr. Pitta, an innocent pulled into this brouhaha, no doubt against his will. I'd bet a week's salary that Mr. Pitta *fils*, should he pursue higher education, will choose a college at least a thousand miles from home.



Commercial airlines have long been stubbornly resistant to making accessibility for all a priority. In part, this is for understandable reasons – there just isn't a lot of space on those jet planes, and the profit margin in competitive commercial air travel is exceedingly thin. The "transportation and warehousing" business sector has the highest rate of business failure in the economy (tied with mining). The only thing on an airplane that makes the airline money is the people occupying seats, so they squeeze as many seats on the great silver beasts as possible, at the expense of all manner of comforts – as frequent flyers can excruciatingly attest.

But just because equal access for all is difficult does not exempt an industry from providing it. The absence of equal access has been found to be illegal, according to the Americans with Disabilities Act and a plethora of subsequent legislation. The challenge they face has resulted in a fair bit of latitude for air carriers from regulators, but eventually the challenge has to be met. The public sector is preparing to force compliance, and the private sector is rapidly producing innovations to make what once seemed impossible seem now to be easy.

The U.S. Department of Transportation is soliciting input on how to improve their implementation

of the Air Carrier Access Act (ACAA) to ensure safe and dignified air travel for wheelchair users. The disability community, and specifically in this instance people reliant on wheelchairs for locomotion, should play a significant role in defining the issues which are critical to this population and how those issues might be best addressed. As one of the disability movement's popular slogans goes, "Nothing about us, without us."

The DOT's Notice of Proposed Rule-Making (NPRM) is comprehensive and detailed when identifying areas to which attention must be paid, but they boil down to four discrete sets of concerns:

1. Clarification and definition of what is required by the ACAA; operational definitions of the statutory language of "safe," "adequate," "prompt," etc., and specification of when assistance must be offered and, if accepted, provided, and how this must be done to comply with the ACAA mandates.
2. Improvement of accommodations for transport of wheelchairs and their users. Proposed measures here include prompt notification to the passenger requiring a wheelchair of any problems in transit, such as damage, misplacement, pilfering, or an inability to transport the device in a given aircraft. Additionally, deadlines are established for the return of a wheelchair delayed in transit, and a series of options are proposed for indemnifying the traveler when problems occur.
3. Requiring annual training for airline personnel in providing physical assistance to people with disabilities and in the handling and stowing of wheelchairs and other assistive devices.
4. Establishing performance standards for on-board wheelchairs (OBWs) used to transport people up and down the narrow aisles of most commercial air carriers, with special attention paid to OBWs on twin-aisle aircraft. Lavatory access is also addressed here, with a requirement that at least one lavatory be large enough for both a user of the lavatory and an attendant. Lastly, it is proposed that if a favored point-to-point airline route proves inaccessible for a non-ambulatory person, or for his/her wheelchair, then the passenger should be reimbursed for the difference between the flight(s) used and the preferred flight inaccessible to him/her.

We have a series of thoughts to contribute to all of these.

For part 1, we would first acknowledge the challenge in operationalizing imprecise adverbs such as "safe," "dignified," and "timely," but as well we note that the degree of subjectivity is variable here. While people have different degrees of risk aversion, an objective definition of a minimized risk of bodily injury, or "safety," seems clear enough. Defining "dignity" is quite a bit more subjective, and "timeliness" is somewhere in-between, with the definition probably quite contingent on circumstances such as missed connecting flights or tardiness to major events that are the reasons for travel in the first place. The *Chevron* standard established by the Supreme Court would therefore prevail here: An executive branch agency's reasonable interpretation of statutory language and mandates will be given deference by the courts. So it is up to DOT to provide reasonable definitions. (There is much speculation that the Court may revisit the *Chevron* deference principle relatively soon; I suppose we shall cross that bridge if it comes.)

We would never argue that air travel should be less miserable for us than it is for everyone else!

There is discussion of passengers with disabilities feeling anxious and frustrated when they experience delays or difficulties. That should be avoided, to be sure, but it seems to us that a state of anxiety and frustration during 21st century air travel is far from unique to people with disabilities. The Independent Living philosophy is that people with disabilities should be treated equally, not specially, so we would never argue that air travel should be less miserable for us than it is for everyone else!

Mischievous observations aside, this is to say that we believe the "totality of circumstances" standard in measuring whether a person has received service sufficient for compliance with the ACAA is satisfactory. Airline personnel should strive to provide *everyone* with the best customer service they can provide, including any reasonable accommodations needed for people with ambulatory difficulties, but we do not suggest such passengers should receive better treatment than other travelers, which is what the other posited standard of "people available at all times" would seem to require.

For part 2, it seems to us that secure stowage of wheelchairs and other such devices is really an engineering problem; since we have no special

expertise in that arena, we reached out to an expert who earns seven figures annually doing luxury import/export (also goods that must be handled with care). In his opinion, there are no special skills necessary, just a great deal of care. Ensuring a heavy, large, irregularly-shaped object remains still and secure during transport, and making sure other cargo does not collide with it, is an empirical problem with any number of feasible solutions. Securing fragile cargo in place during flight involves strapping the object in place – there is typically strong but lightweight netting drawn tight along the walls for this purpose – and distancing it from other cargo that might shift during flight and damage the fragile cargo. When necessary, temporary walls/dividers can be put in place to separate fragile cargo from the general allotment of suitcases and duffel bags with contents mostly invulnerable to damage.

Basic management theory teaches us that if no one is in charge of a problem, it never gets addressed.

Again, these measures need not and should not be confined to mobility devices. Any item that is fragile ought to be handled with similar care; equal, not special. If someone is flying with a precious work of art, or a rare and priceless antique, or a wheelchair bespoke for the needs of its user, or really anything that merits the label "Fragile – Handle with Care," all should be transported with the same caution and deference.

Similarly, damage resulting from mishandling between terminal and airplane and back, and from one airplane to another if not a direct connection, can be minimized through some combination of training and best practices. We acknowledge that any item that is large, heavy, unevenly weighted, and irregularly shaped, such as a wheelchair, will sustain damage in handling at a higher rate than a standard-size suitcase of modest weight, for reasons clear to anyone who has had to move a recliner, but we can and must do better than we are now.

Management will need to make the security of high-value, high-fragility items a priority concern, along with other obvious ones like speed and proper routing. Perhaps assigning a few people – perhaps just one per airport, maybe more at a high traffic hub – to have special responsibility for high-risk checked freight, some sort of quality-control role, would make a difference. And maybe assigning someone in corporate to track the overall performance. Basic management theory teaches us that if no one is in charge of a problem, it never gets addressed. We are hopeful that adjustments in the practice of handling mobility devices will prove beneficial for all manner of frangible freight. Such are the rewards for doing the right thing.

In terms of timely notification to the consumer about where and what the status is of their wheelchair, the technology to do so is already widespread; we encounter it most when dealing with parcel delivery services. Attach a bar code or some similar identifier to the device and scan it into the system at each discrete step of its journey. If it gets misdirected, we know where we saw it last. I have no personal knowledge, but I would be surprised if some air carriers did not already have a system like this in place for high-value freight. It's common practice for letters and packages being sent via the USPS, UPS, or Federal Express to "hitch a ride" on a commercial carrier with excess capacity. Perhaps some kind of a partnership could be worked out between the parcel carriers and the airlines?

For indemnifying the traveler for a lost or damaged wheelchair, it seems logical to treat it like an insurance policy; indemnification is what insurance does. Further, it seems suboptimal for each airline to self-insure; an airline-subsidized (at least for the start-up phase) specialty insurance trust serving all commercial carriers would work best here. Insurance professionals could work there, setting fair premiums and adjusting them for better or worse performance periodically, and most importantly a staff of claims professionals with a strong proficiency in wheelchair & other medical assistive devices that could expertly and rapidly assess the needs of the passenger requiring redress and deliver a replacement or repaired product with minimal delay. In fact, it seems logical that the staff would include a significant percentage of people who use mobility devices themselves, which is of course of great importance to the disability community. Who would know better what a wheelchair user needs than a fellow wheelchair user?

The economy of scale will be beneficial here: each airline will not need its own staff of professionals in disability technology (likely a scarce resource), the premium structure will offer clear incentives to minimize losses, the efficiency of settling claims should be maximized, and it would create a profitable new company and some to-be-determined number of

new jobs, likely disproportionately including people with disabilities. This could in theory be a public-private partnership run through DOT, but better to have the DOT exert oversight on the new entity and keep the new firm's attention where it's needed--on the airlines' performance in safe transport and on the customers who depend on such.

We have already addressed half of part 3 in part 2 above with our discussion of handling mobility devices from drop-off to pick-up. The other half, training in providing physical assistance to people with disabilities, is even more important. Nothing has higher value than people. People with mobility challenges need extra accommodation negotiating the passenger cabin as well, which will be further addressed in part 4 in terms of structural issues.

This part is just about training – properly training personnel to assist such passengers to and from their seats both safely and in a dignified fashion is of obvious importance. How frequently this training need be refreshed is an open question, but annually seems a reasonable place to start. We would not object to changing the frequency in the future as experience indicates whether it should be more frequent or less frequent; our guess is less frequent, actually, because as airline personnel receive the training multiple times, expertise will diffuse through the workforce, and newer employees will be better able to pick up the necessary skills and knowledge while "on the job." But we shouldn't pre-judge, and any changes should be data-driven by future performance.

We would also encourage the inclusion of people who use wheelchairs in the design, execution, and evaluation of the training program. Inclusion is always important, but especially in this case, the perspective of the people who actually get the assistance, good and bad, can't really come from anywhere else with the same specificity. There is no substitute for firsthand experience.

Moving on to part 4, we are again in the realm of engineering challenges, which we are disinclined to opine about in great detail. But obviously, it is of great importance for a passenger to get to and from her seat, and to be able to use the lavatory with a modicum of dignity, and these problems are solvable. The challenge is that every cubic inch is valuable on an aircraft, and we appreciate that, but at the same time the amount of weight on an aircraft is equally critical – making a roomier lavatory might take up some extra space, but it will also shave some poundage off, saving a little bit of increasingly expensive jet fuel. Where exactly the breakeven point is between weight and volume, we'll leave to the actuaries and accountants, but we feel confident it is nonzero.

We have become aware of some novel solutions coming from designers seeking to serve this market from an article in *Paraplegia News*, November 2023 issue, titled "Now Boarding." The Air4All consortium from the UK has a product where a chair that seems like all the others can convert into a space where a wheelchair can be transported to and securely anchored in the main cabin with its user seated in it. The ACCESS lavatory, coming from a collaboration between Singapore- and UK-based firms, is a brilliant innovation where a lavatory would basically be able to be expanded like an accordion to permit universal access for people of all abilities (and sizes). We are delighted that the free market is generating solutions, and we look forward to more to come.

The last point, remunerating a flyer for her preferred route being inaccessible and being forced to fly a more expensive route, is basically simply a mandate of the ADA law, and we trust it will be applied fairly. The presence of this law will be a spur to the airlines – and the airplane manufacturers that supply them with their aeronautical vehicles – to make as many planes accessible to people with disabilities as possible, which is indeed part of the intent of the law.

None of the above should be interpreted as negative feedback. The disability community applauds this effort and wishes to participate as partners in the common goal of improving the experience of commercial air travel for everyone. This is how progress is made.

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