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New York State's Reckless CDPA Transition Endangers Lives

By Jennifer Watson and John McNulty

New York State continues to play politics with the lives of people with disabilities, this time through an abrupt and arbitrary transition to a single fiscal intermediary (FI) for the Consumer Directed Personal Assistance (CDPA) program. This reckless move threatens to disrupt care for hundreds of thousands of individuals who rely on it. For years, the CDPA program has empowered people with disabilities and seniors to direct their own care by hiring and managing their own personal assistants. Fiscal intermediaries (FIs) have been a crucial part of this system, providing payroll, consumer support, and regulatory compliance. Yet, despite the program's success, New York State has decided to overhaul it—without a plan, on an impossible timeline, and with complete disregard for the lives of the people it serves.

The decision to move CDPA services to a single FI by April 2025 was enacted in last year's state budget. However, the state did not announce the winner of the Request for Proposals (RFP) until September 30, 2024, and the contract with the single FI wasn't signed until January 2025. Despite this, the state somehow expects over 250,000 consumers and more than 400,000 personal assistants to transition to the new system in less than three months. This timeline isn't just unrealistic—it's impossible. For the past year, STIC and other disability advocates have been warning that the CDPA transition is a disaster in the making. Meanwhile, the Department of Health (DOH) insists that everything is fine, moving according to plan, and will result in the smoothest transition ever. Health Commissioner Dr. James McDonald has even described it as a "beautiful transition,"



dismissing concerns as baseless lies. However, reality tells a different story.

NYS has proudly announced that approximately 75,000 consumers and 75,000

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personal assistants have "either started or completed" the registration process. This deceptive statistic combines those who have merely begun the transition with those who have actually completed it. That means 175,000 consumers and 325,000 personal assistants have not even started the process. With just 35 days remaining before the arbitrary April 1 deadline, it is completely unrealistic to expect the transition to be successful. What happens when the system fails? Tens of thousands of per-

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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.

sonal assistants will show up to work only to find that they don't get paid. They will then be forced to choose between continuing to work for free indefinitely while waiting for this mess to be fixed or abandoning their consumers, leaving them completely without care.

For many CDPA consumers, particularly those with significant disabilities, the consequences will be dire. Some will be confined to their beds, unable to eat, drink, bathe, or take necessary medications. While some may have family or friends who can step in, that will result in lost wages for those individuals, potential job losses, and a localized recession in New York's home care sector. Others without a support system will face even worse outcomes—some will die, while many will end up in hospitals, overwhelming emergency departments. Many more will be forced into nursing homes, violating their rights under the Americans with Disabilities Act (ADA) and the Supreme Court's *Olmstead* ruling. Advocates have repeatedly warned Governor Hochul about these dangers for over a year. She has dismissed them as lies. If she's wrong, this governor will have a policy-related body count to rival her predecessor—except he at least had a global pandemic as an excuse.

Who benefits from this transition? SEIU 1199, the state's most powerful healthcare union, stands to gain immensely. Eventually, surviving CDPA consumers will get new or continuing personal assistants who can work under a single FI. This means 400,000 workers will be required to pay union dues, funneling millions into SEIU 1199, which in turn will provide generous campaign contributions and political support to Governor Hochul and her party. If a million of New York's most vulnerable must suffer and some must die to make this happen, well—

gotta break some eggs to make an omelet, right?

Even more troubling, the Health Department has announced that any consumer who cannot successfully navigate the technology used to transition to the single FI will be deemed “not self-directing.” This conveniently allows DOH to claim that every self-directing consumer has transitioned successfully, while quietly stripping others of their independence. Those unable to complete the process—many of whom have cognitive disabilities or language barriers, will be removed from the program altogether. Meanwhile, DOH will pat themselves on the back for a “successful” transition, ignoring the suffering they have left in their wake.

This is not just a bureaucratic failure; it is a deliberate and cynical effort to balance the state budget on the backs of people with disabilities, all to benefit unions and wealthy donors in the nursing home industry. It is going to be a disaster. And when the inevitable suffering, tears, and bloodshed occur, no one will find solace in saying, “We told you so.”

Governor Hochul must immediately take action to prevent catastrophe. The transition timeline must be extended to at least two years, following the example of other states that have implemented similar but significantly smaller transitions. A continuity-of-care policy must be guaranteed to ensure no consumer loses essential services due to bureaucratic incompetence. The state must conduct a thorough readiness review before eliminating existing FIs, and direct, individualized outreach must be provided to assist consumers—especially those with cognitive impairments, disabilities, or language barriers—through the transition.

This isn't just about bad policy—it's about life and death.

Elimination of DEIA Threatens Independent Living Movement

By Jennifer Watson

Back in 1970, Judy Heumann just wanted to teach elementary school, nothing more, and nothing less. She was well-qualified, with a bachelor's and master's degree in speech therapy, and applied for a teaching license in New York State, usually a routine matter. But she was declined because early childhood polio made her a wheelchair user. She sued, alleging discrimination and demanding equal inclusion, and won. Today we would call that an advance in Diversity, Equity, Inclusion, and Accessibility (DEIA).

In our nation's history, every major civil rights movement has fought against systemic efforts to exclude, marginalize, and silence entire communities. We are witnessing a new chapter in this fight—an attack on DEIA initiatives. These attacks are not just policy decisions; they are a direct assault on the civil rights of a wide range of historically marginalized communities, including people with disabilities.

In recent weeks, the federal government's aggressive rollback of DEIA initiatives has sent shockwaves through the disability rights community. This full-scale assault on civil rights threatens to push people with disabilities and other marginalized groups back into the shadows of systemic discrimination.

The disability rights movement in the United States is rooted in the fight for self-determination and equality. In the early 1970s, activists like Ed Roberts pioneered the Independent Living (IL) Movement, advocating for the rights of people with disabilities to live autonomously and participate fully in society. Roberts co-founded the Berkeley Center for Independent Living,

the first organization of its kind run by and for people with disabilities, setting the stage for a nationwide movement to demand accessibility, dignity, and control over their own lives.

The IL movement gained national attention during the 504 Sit-in of 1977, when disability rights activists occupied a federal building in San Francisco for nearly a month. This protest led to the implementation of Section 504 of the Rehabilitation Act of 1973, a landmark regulation that prohibited discrimination based on disability in any program receiving federal financial assistance. The success of this sit-in demonstrated the power of collective action and set the stage for future legislative victories, including the Americans with Disabilities Act (ADA).

The ADA was a historic triumph, but it was never enough on its own. Systemic discrimination persists, and DEIA programs have long played a crucial role in addressing disparities in employment, education, healthcare, and housing. Even with these laws and initiatives in place, people with disabilities regularly face access issues and disparities in education, employment and health outcomes. Imagine how much worse these challenges will become when DEIA initiatives are dismantled.

In January 2025, President Trump issued an executive order titled “Ending Radical and Wasteful Government DEI Programs and Preferencing,” mandating the elimination of DEIA initiatives across federal agencies. This order asserts that such programs promote “illegal and immoral discrimination” and calls for a return to so-called “merit-based” practices—a coded phrase that ignores the systemic barriers marginalized communities face.

The consequences have been immediate and severe. The U.S. Department of Education has begun scrubbing DEIA references from its communications and workforce initiatives, effectively dismantling progress toward inclusive education. The White House has also altered federal contracting rules to eliminate DEI considerations, shutting down efforts to ensure accessibility and equity in federally funded programs.

One of the biggest successes of DEIA initiatives has been the improvement of workplace accessibility and inclusion. These policies encouraged hiring people with disabilities, ensuring reasonable accommodations, and fostering a culture of belonging. Already, statistics show that the unemployment rate for people with disabilities is significantly higher than for non-disabled individuals. With DEIA programs weakened or removed, employers may deprioritize accessibility, making it harder for people to advance and achieve financial independence. For many, this isn't just about employment—it's about the right to contribute to society and support themselves with dignity.

Beyond employment, the dismantling of DEIA policies in government agencies threatens the progress made in ensuring accessibility in public services and policymaking. These programs played a crucial role in amplifying the voices of people with disabilities, ensuring that our needs were considered in policy decisions, public transportation, housing, and social services. Without these frameworks, accessibility becomes more of an afterthought than it already is.

Moreover, the removal of DEIA policies also affects federal contracting and funding priorities. Many government-

funded programs require adherence to inclusive hiring and accessibility standards. Weakening these programs means that fewer companies and organizations will be held accountable for providing equal opportunities for people with disabilities. This is not just a setback; it is an erasure of years of advocacy and progress.

To make matters worse, all of this is happening at a time when the federal government has frozen funding for critical community services and programs, ignoring court orders. There are also discussions about cutting funding for essential services like Medicaid and Medicare, which millions of people, especially older adults and people with disabilities rely on to live in their own homes and control their own lives. The combination of DEIA rollbacks and funding cuts could create a devastating reality where access to necessary services becomes even more limited, forcing many disabled people into poverty, poor health, and isolation.

Perhaps even more insidious than the policy changes themselves is the rhetoric used to justify them. The federal government's move to disable DEIA programs is often framed as a rejection of "identity politics" or an effort to create a "merit-based" system. But in reality, these arguments ignore the systemic discrimination that marginalized groups, including people with disabilities, continue to face every day.

The danger of this rhetoric is that it normalizes exclusion. It emboldens people and organizations to deprioritize accessibility and fosters a cultural shift that devalues diversity and equity. This is not just about funding or policy changes; this is about the signal that the government is sending to the rest of society. When the highest levels of government dismiss the importance of inclusion, it gives permission for others to do the same.

History has shown us that progress is not linear, and while this moment feels like a step backward, it is also an opportunity for renewed advocacy. We must

continue to fight for inclusion at every level—within workplaces, schools, health care and in our communities. We must push for enforcement of protections, demand accountability from our leaders, and support efforts that uplift marginalized communities.

DEIA programs were never just about people with disabilities advocating for themselves; they were about creating a culture where everyone, regardless of ability, race, gender, or background, has a fair chance to succeed. The dismantling of these initiatives should concern all of us because when we allow one group to be marginalized, we open the door for discrimination against all.

Now is the time to raise our voices, mobilize our communities, and hold those in power accountable. DEIA was never about special treatment; it was about leveling the playing field and ensuring that everyone has the opportunity to pursue happiness as they wish.

As Judy Heumann, who after her brief teaching career became a revered disability activist, urged, "We have to continue to fight for our rights. We have to continue to speak up and speak out." We must stand firm in our commitment to a more inclusive and equitable society for all.

Congress Flinches on LRFA

It seemed like a sure thing.

The Latonya Reeves Freedom Act (LRFA) has been a top priority for disability rights activists for years. It would codify the rights granted by the Supreme Court's *Olmstead v. L.C.* decision in 1999 where the Court ruled that the Americans with Disabilities Act of 1990 (ADA) considered the unjustified isolation of a person with a disability capable of living in the community was discriminatory and violated the ADA, and that all such persons were free to live, work, and thrive in the most integrated setting possible.

LRFA is so important because *Olm-*

stead, while Constitutional law as interpreted by the Court, is judge-made law, and rights that a judge grants are rights that another judge can take away. Justice Clarence Thomas wrote the dissent in 1999 for the minority of the Court; he is now the most senior Associate Justice, and a majority of the Court now seems more likely to adopt Thomas's contrarian view than previous configurations had been.

An absolute majority of members of the House of Representatives, 224 of the 435-person membership not just supported the Latonya Reeves Freedom Act, but had co-sponsored the bill, whose lead author was Rep. Steve Cohen, Democrat from Memphis, Tennessee. Surely the will of Congress could not be foiled this time.

Alas, for a bill to pass, it must come up for a vote. Mike Johnson, the Louisiana Republican serving as Speaker, controls what bills do get to the floor for a vote and what bills do not. Speaker Johnson didn't want the bill to be voted on, for reasons that remain unexplained, so he sat on it.

There is recourse; we still enjoy the vestiges of a democracy. Rep. Cohen filed with the Clerk of the House a Discharge Petition for LRFA. This is a last-ditch device that compels the Speaker to bring the bill up for a vote, but it requires a majority of the members of the House to sign the petition. That's a high bar, but a majority of the House were bill co-sponsors; surely, they would be willing to call for a vote on a bill with their name already on it.

You know where this is going, right?

Only 115 members signed the petition before the 118th Congress adjourned, barely over half of the signatures needed. How did this happen?

Well, let's break the co-sponsors down by party: They were heavily Democratic, 208 versus only 16 Republicans. There were only a handful of Democrats who didn't co-sponsor the bill. Among them were:

- Minority Leader Hakeem Jeffries
- Minority Whip Katherine Clark
- Speaker Emerita Nancy Pelosi
- Majority Leader/Minority Whip Emeritus (i.e., #2 Democrat) Steny Hoyer

So, pretty much every Democrat was for LFRA except for past and present leadership, and thus the behavior of the Democratic cosponsors begins to make sense. It's one thing to co-sponsor a given bill, it's another to outright defy your party leadership, and about half the Democratic caucus either owed leadership, or feared leadership, or made some bargain with leadership to induce them to walk away from the discharge petition.

That leads us to the 16 Republicans. They were already out on a limb co-sponsoring what was perceived as a Democratic bill, and now they were faced with the prospect of directly undermining their own Speaker, in an environment with the MAGA lobby where any perceived betrayal of then-President-elect Trump could be a career ending act. Hence, not a single Republican signed the discharge petition, including those who had promised to do so during the campaign.

In fairness, once half the Democratic caucus caved, any Republican signing the petition would be making an entirely futile gesture – there was no path to 218 signatures without at least most Democrats in the body. No one wants to be the first man out of a fox-hole facing a cannonball in the kisser for mere symbolism.

With the end of the 118th Congress, the bill dies, and a new one must be re-submitted in the 119th. Until such a bill passes both houses, and then is signed by the president or his veto overridden, the freedoms afforded by the ADA and *Olmstead* are on a knife's edge, subject to the wrong court case being considered by nine brilliant and distinguished, yet fallible, justices.

Alas, the 118th appears to have been LRFA's best chance in the foreseeable

future. If it had passed the House, a Democratic Senate would have likely passed it, and a Democratic president would have almost certainly signed it. Now, with unified Republican control of Congress and the executive, prospects appear dim in the near term.

No reason was given by either Democratic (Rep. Pelosi, et al) or Republican (Speaker Johnson) leadership for their implacable opposition. Indeed, through their parliamentary maneuvering, they never even had to go on the record opposing the bill – they just smothered it in the crib. What motivated them to take this course?

One must follow the money to find what seems a likely answer – the institutional nursing home lobby poured money into party leadership coffers to take LRFA

off the table, for hopes of filling their beds to bursting by undermining home- and community-based care. According to OpenSecrets.org, donations from the health care sector were over half a billion dollars last election cycle, with 62% going to Democratic candidates or affiliated groups.

Medicaid and Medicare pay for most of institutional long term health care, and the industry loves them because they always pay the hefty fees that are charged for 24-7 care. They want to keep the gravy train on the tracks and not lose money to home- and community-care just because of a little thing like quality of life. These are the stakes, and they are why we keep fighting.

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The End of Sheltered Workshops?

Part of the mission of the Independent Living Movement is to help people with disabilities live and flourish in the most integrated settings possible, including the realm of employment. We have long been opposed to sheltered workshops where people with disabilities work for sub-minimum wages. Working for under the minimum wage is inherently exploitative. An hour of labor from a person with a disability is as precious and irreplaceable as from a person without one, and if our states and the nation has decided there's a minimum value on that, it should apply to all.

Further, the assumption that people with disabilities or other challenges cannot be sufficiently productive to merit the minimum hourly wage our legislatures have deemed fair is "the soft bigotry of low expectations," as former President Bush memorably coined. Any success involves the risk of something less than success; not to risk is not to be a full member of society.

With that preamble...it seems the Department of Labor agrees! It has solicited public comment on a new policy, essentially a new interpretation of a subsection of the minimum wage law from 1938, specifically 14(c). 14(c) permitted the Secretary to grant certificates allowing firms of various types to offer hourly pay below the minimum wage established by Congress. These were usually termed to be "sheltered workshops," establishments where people with disabilities who were unable to produce at a pace meriting the full minimum wage could have an opportunity to be employed regardless and compensated at a lower rate. The initial target population was disabled World War veterans (there had only been one world war in 1938). Since then, the world has changed dra-

matically, and these workshops have become vestigial anachronisms.

The market is recognizing this; while people with all sorts of disabilities once toiled in sheltered workshops, today virtually all of them are comprised of people with intellectual or developmental disabilities. Moreover, sheltered workshops hardly exist anymore in the private sector; the overwhelming number of these still extant (93%) are community rehabilitation programs, whose purpose is not primarily to make a profit or provide the market with a good or service, but rather to serve the population that they "employ" and underpay, keeping them occupied in a supervised environment. This employment is an offensive pretense. Productive employees are wasting their time and talents in these enterprises, and unproductive employees are engaged in a Potemkin exercise that demeans all those involved.

In one sense, the elimination of the subminimum wage certificates is simply following the law as written. The regulation stipulates that 14(c) certificates may only be issued if the Labor Secretary determines that a subminimum wage is necessary to prevent the curtailment of employment opportunities.

Since the last major regulatory review of these laws in 1989, the expansion of opportunities and resources for people with disabilities has been so great, in no small part because of the Americans with Disabilities Act enacted the following year, as well as the Supreme Court's *Olmstead v. L.C.* decision in 1999, that the subminimum wage is never necessary. The twenty-odd states that have already banned or limited subminimum wage sheltered workshops provide empirical proof of that fact. No statutory authority is required beyond what the Secretary has already been granted by the Congress.

The Individuals with Disabilities Education Act, passed in 1990 in a retitling of the Education for All Handicapped Children Act, extended the protections of the ADA to the edu-

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cational realm, insuring that children with disabilities can receive early intervention services and a free, appropriate education, with the goal of maximizing the opportunity for students to lead productive and independent lives, including transitional plans to help entry into post-secondary life, notably competitive employment. The Departments of Health and Human Services and of Education have both adopted a policy of maximum inclusiveness of children with disabilities, reaffirming this as recently as 2023, and they have issued a cornucopia of rules supporting the independence and self-determination of people with disabilities. Executive orders in 2014 and 2021 direct that federal agencies may not contract with any entity not willing to pay minimum wage.

Simply put, the continued existence of sheltered workshops is entirely inconsistent with the federal government's disability policy and has been for thirty-five years. Further, the existence of sheltered workshops is, justly, approaching extinction as they are both unacceptable to most potential partners and customers, and they no longer make any economic sense.

Greater justification seems gratuitous, but we should note that the U.S. Commission on Civil Rights has recommended a phaseout of sheltered workshops, providing time for adjustment for both employers and the employed, very much along the lines of this proposal. The National Council on Disability also has issued multiple reports recommending the cessation of subminimum wages, and notes that as far back as 2001 the Government Accountability Office (Congress's investigator and auditor) observed that it is a rarity (about five percent, or one in twenty) for sheltered workshop employees to advance to employment in an integrated setting, which would be the most desired outcome.

It strikes us that this observation is subject to a substantial selection ef-

fect. By 2001, over a decade after the ADA, people who could work in integrated environments with reasonable accommodation would have no reason to start working in a sheltered workshop in the first place, so those who did choose to work there would be highly unlikely to transition away. Of course, the slow disappearance of sheltered workshops implies fewer and fewer people are making that choice.

Over half of U.S. states have passed laws eliminating or severely constraining subminimum wage employment. This new rule, while necessary and useful, would affirm on the federal level what the states and the market are doing anyway. The time has come for this rule, to establish once and for all that in the United States of America the minimum wage is truly the minimum wage.

The Labor Department is setting an initial three-year phaseout timeline and allowing for the possibility of extensions if warranted. It is hard for us to conceive of a good reason to extend the timeline further, other than perhaps a trivial extension numbered in days such as making the end date the last day of the month, or a Friday, the conclusion of a pay period, etc. Three years is more than fair to employers and employees who might struggle to transition, few as we envision there being.

The Secretary will always have the authority to grant waivers and exceptions, and there may surely be justifications we cannot foresee, but we suggest it would be most practical to shutter sheltered workshops with finality, without any loose ends to tie up down the line. "Grandfathered" entities sometimes have a way of staying grandfathered; it's best to make a clean break. Extensions that are granted, if any, should be finite, non-renewable, and as short as possible. After all, if a sheltered workshop must stay open for business, all that necessarily must be done is to grant its laborers a raise

to the minimum wage. That seems not too much to ask.

We do not mean to suggest there is no downside here; there are always externalities. Families of adults employed in 14(c) sheltered workshops appreciate them as a structured environment that is safe for the employed, allowing other family members to go to work or enjoy some respite. While the stated goal here is to transition workers into competitive integrated workplaces, some fraction of these workers are likely to land in facility-based, non-work programs such as day habilitation centers, while others may slip out of the system altogether. There must be a concerted effort to make such outcomes, arguably the opposite of the desired one, as rare as possible.

To facilitate this, we must support further legislation such as (but not limited to) the Transformation to Competitive Integrated Employment Act currently before Congress, which will create funding and support for transition from sheltered workshops to more typical environments. One rule and/or one bill by itself cannot remedy a situation that has obtained for nearly one hundred years; we must monitor the success and the failures of each initiative and amend as we must. Here the potential negative outcome is readily apparent, so affirmative measures must be taken to minimize and ameliorate the negative effects which are unfortunately inevitable for at least an unlucky few.

All decisions made by government involve tradeoffs, but that does not mean the government should not take steps to improve the common good. Of course it must. Rather, it must do so while cognizant of the downsides, and while taking additional measures to offer remedies for those downsides. With those caveats in mind, we at STIC are ecstatic about the end of the sheltered workshop in the United States.

The MBI-WPD Demonstration Program

Medicaid is a critical government program for people unable to work or are indigent for any reason, including but not limited to people with disabilities. Created during the Great Society era, Medicaid is a program managed primarily by the states but heavily subsidized by the federal government, which sets baseline standards for the states. State participation is voluntary, but all fifty states have participated since 1982 and any state dropping out seems exceedingly unlikely.

Medicaid benefits are generally good ones, accepted by most medical providers, and requiring very low co-payments and deductibles. Indeed, it has been observed that, along with other benefits like SNAP, they are so good that it could create a disincentive to going back to work.

To palliate that unintended consequence, Medicaid & New York State have created a Demonstration Buy-In Program for Working People with Disabilities (MBI-WPD). STIC applauds this program; it is a critical lifeline for the independent living of people contributing to their community that may need extra services and supports, common among this population, that the private insurance market may not provide at a feasible cost.

The program, initially only offered to those people 65 and under, is being expanded, eliminating the age restriction. Additionally, adjustments have been made to the income and asset limits that exclude relatives' resources and retirement accounts from the eligibility calculation. Also, the resource limit has increased nearly tenfold to \$300,000. Our ideal would be for no upper limit at all, but this moves a great distance in the preferred direction, so it is welcomed.

MBI-WPD enables people with dis-

abilities to keep Medicaid coverage while engaged in the pursuit of happiness and dignity that comes with working. This population confronts challenges that are reflected in a higher-than-average unemployment rate. Without this coverage maintaining their services and supports, many would be unable to work and would be forced to stay home, or worse, enter an institution.

Further, should a person reach age 65 and want to continue working, this should be enabled – people's life expectancy and general health have both elongated over the near-century since Social Security made 65 the retirement age. At that time, life expectancy was about...65. So roughly half of the retirees wouldn't make it to retirement age and would never collect on what they'd paid in all their working lives. This is obviously not the case anymore; a person still working at age 65 can expect to live into their eighties, on average, and our laws and rules should reflect that new, happy reality.

The increase in the income and resource limits are also an excellent alteration. The previous numbers, \$31,175 for an individual and \$42,312 for a household of two, are absurdly low. One could be near or over the limit just by owning a car and keeping it in good condition. While we shall once again aver that there should be no limit at all, a limit of \$300,000 excluding retirement accounts and relatives' money can let more affluent people with disabilities continue to live in a manner to which they have become accustomed.

Truly, the only source of dismay here is that participation in this demonstration program is capped at 30,000. We appreciate the need for pilot programs, but we believe this improved MBI-WPD will be embraced by benefit navigators and eligible workers,

and expect the program to expand rapidly, which will necessitate revisiting and revising this cap. And that's not even considering that with the elimination of the age ceiling, attrition will decrease precipitously as people will just maintain their current coverage as they pass age 65. We look forward to this option being offered to everybody soon.

Thoughts as We Approach National Siblings' Day on April 10th, 2025

By Cathy McNulty

Siblings – the definition that comprises love, strife, competition and forever friends. – Byron Pulsifer

When you have one child with a developmental disability and another who is neurotypical, you often hold your kids to different standards and expectations. It doesn't seem fair, but it's just the reality, at least in my house. Lulu is eighteen and is still working on the very basics of life – writing her name and address, getting dressed, answering yes and no questions, learning scaled down chores, following two step directions, asking for desired objects. She is involved in very scaled down versions of activities that meet her capabilities, like pressing the “popcorn” button on the microwave. Annie, who prefers they/them/their pronouns, is twenty-one. Over the years, Annie has been involved in theater, Girl Scouts, softball, and a variety of clubs, and currently works for BOCES in their Oak Tree Program. At home there is an expectation that they will help with their little sister, and Annie, very much to their credit, has not ever complained. There is not that same expectation for Lulu.

Because there is such a large discrepancy in abilities between Annie and Lulu, I often thought that Annie was much

more mature than they really were. Even though efforts were (and are being) made for Annie to be a typical kid (even at 21!), they still grew up too fast. Annie has their own social issues that they are working through, but serving as the big sibling and role model for Lulu has helped Annie make terrific gains.

I often find myself walking a tightrope in the fairness game. It's really not fair to Annie to always have to do the same

things as Lulu, and the same applies to Lulu with Annie's activities. Often for Annie's events we have a sitter because Lulu does not have the patience level to sit through some things. However, when it comes to Lulu's events and activities, we often drag Annie along for the ride, sometimes for the sole purpose of having someone else there to support Lulu. Luckily, I think Annie actually enjoys it because they

are Lulu's biggest cheerleader.

I often say that Annie is the best big sibling to Lulu. I mean that with all my heart. But Lulu is the best little sister for Annie. Lulu brings out levels of kindness, compassion, and patience in Annie that are rare in siblings.

If you want to know how you should treat someone with special needs, just look to their siblings. They will show you. – Dr. Pamela A. Hauser

Medicaid in the MAGA-DOGE Crosshairs

President Trump's aggressive push to cut federal spending, despite promises made to shield entitlements from cuts, has Medicaid funding to states under grave threat. The U.S. House has passed a budget resolution, with the support of the White House, by one vote, 217-215, that mandates \$1.5 trillion (that's with a T) in cuts to federal spending over a ten-year period, with details to be determined by the relevant House committees. That will, in part, pay for \$4.5 trillion in tax cuts; the rest will be borrowed with a \$4 trillion increase in the federal debt limit.

\$880 billion of those \$1.5 trillion spending cuts are earmarked to come from Health and Human Services and will be proposed by the House Energy and Commerce Committee. It's at least implausible, and likely impossible, that those reductions can be achieved without cutting Medicaid, particularly if the promise to protect Medicare from cuts is kept.

Medicaid is administered by the states, but states are reimbursed by the federal government for at least fifty percent of expenditures (poorer states get a lot more than 50%). These Medicaid reimbursements comprise more than a quarter of state budgets, on average. Should those appropriations be cut drastically, states would have to cut services, abruptly raise taxes, borrow money (in states where unbalanced

budgets are constitutionally permitted), or most likely some combination of all of these. Some states may choose not to participate in Medicaid at all anymore – it's not mandatory that they do, although all fifty have opted in for over forty years.

Originally established as a program for the poor and/or disabled, Medicaid has expanded to be a benefit enjoyed by much of the middle class. Nearly twenty percent of health care expenditures in the United States are paid for by Medicaid. Nursing homes are mainly paid for by Medicaid; after they expend all of a resident's personal wealth (which happens rapidly, with residency rates in or approaching six figures annually), they are poor enough to qualify for Medicaid for the rest of their lives. Medicaid pays for over sixty percent of long-term care overall, and in many rural regions of the country, Medicaid is the primary insurer of the population because private health insurers don't find the region lucrative enough to cover providers there.

Advocates for the disabled warn that the scale of cuts called for in the House plan would represent an imminent threat to home and community-based services, which are currently considered optional Medicaid offerings under federal law.

"If cuts of this magnitude are allowed to become law, it is not hyperbole to say that the results would be catastrophic for people with disabilities, family caregivers, direct support professionals," said Nicole Jorwic, chief of advocacy and campaigns at Caring Across Generations, an organization advocating for caregivers and people who rely on them. "Service providers will have to close, the workforce crisis that already exists will get exponentially worse, and waiting lists around the country will grow."

Nevertheless, the relevant committees will search for ways to achieve the spending cuts in the budget resolution. The House Ways and Means Committee, which oversees government revenue, has put out a document proposing several possibilities. These are some of the means, far from an exhaustive list, by which they suggest they can save the money. Judge for yourself whom these proposals will benefit and whom they will harm. I'll add commentary here and there to be helpful.

- Restructure the Earned Income Tax Credit to reduce improper payments (savings unknown).
- Various reductions to the Temporary Assistance for Needy Families program (a.k.a. Welfare) totaling \$41 billion over ten years.

- Cap state-directed payments in Medicaid, raising up to \$25 billion over ten years.
- Cap federal Medicaid reimbursements to states per capita, raising up to \$900 billion over a decade.
- Reduce 50% floor in federal medical assistance percentage, i.e., the percentage of Medicaid reimbursed to the states by the federal government. This would primarily impact high-income states like New York.
- Repeal Biden Administration Rule expanding access to Home and Community Based Services (HCBS) in both fee for service and managed care plans, raising \$121 billion over ten years.

The dismantling of the welfare state and health care entitlements; specifically, these measures are the most direct threats to people with disabilities.

- A series of tax reductions that nonetheless are estimated to raise revenue over ten years.
 - Eliminate tax on tips, raising \$106 billion.
 - Eliminate tax on overtime pay, raising \$750 billion.
 - Exempt Americans abroad from income tax on foreign income, raising \$100 billion.
 - Create an Auto Loan Interest Deduction, raising \$61 billion.
 - Repeal IRA's Corporate Alternative Minimum Tax, raising \$222 billion.
 - Eliminate the Estate Tax, raising \$370 billion.
 - Cancel mandatory amortization of Research & Development Expenses, permitting these costs to be immediately expensed, raising \$169 billion.
 - Lower the Corporate Income Tax to 20% (raising \$73 billion) or 15% (raising \$522 billion). The current rate is 21%.

These will reduce revenue, not raise it, but they keep campaign promises to both segments of the working poor and to the 1%.

- Tariffs
 - Raise \$100 billion from increased tariffs on China.
 - Raise \$1.9 trillion from a 10% tariff on all imports.
- Establish a Border Adjustment Tax on goods where they are consumed, not produced, shifting from an origin-based tax to a destination-based tax, raising at least \$1.2 trillion. (This reduces incentive to manufacture outside of the U.S.)

An all-out assault on the free trade policies that fueled a forty-year economic boom.

- Eliminate the State and Local Tax (SALT) Deduction altogether, for both individuals and businesses. It is currently extant but capped at \$10,000. This would raise one trillion dollars over ten years.
 - Other options preserving parts of SALT are proposed also, raising less money.
- Eliminate the Home Mortgage Interest (HMI) Deduction, raising about a trillion dollars.
 - Other options reducing but not eliminating the HMI deduction are proposed also, raising less money.
- Eliminate tax credits for child and dependent care, raising \$55 billion over ten years.
- Eliminate Head of Household filing status, raising \$192 billion over ten years.
- Eliminate the American Opportunity Tax Credit (AOTC), which permits deductions up to \$2500 for eligible students' first four years of education. This would raise \$59 billion over a decade.

- Eliminate the Lifetime Learning Credit, raising \$26 billion over a decade.
- Eliminate student loan interest tax exemption, raising \$30 billion over ten years.
- End tax-exemption for meal and lodging reimbursements from employers, raising \$87 billion over ten years.
- Eliminate tax deductions for charitable contributions to health organizations, raising \$83 billion over ten years.

The fundamental annihilation of every major tax deduction commonly used by middle-class taxpayers.

- Undocumented non-citizens in the United States are eligible for Medicaid and other health-related tax credits; that eligibility would be revoked, with an estimated savings of \$35 billion.
- Require both parents and children to have a Social Security number to be eligible for the Child Tax Credit. This would save \$27.7 billion over ten years.
- Establish a penalty reducing federal Medicaid payments to states that use state money to cover undocumented non-citizens under Medicaid (savings unknown).
- Secure the Border Act, a comprehensive border security plan saving \$26 billion over 10 years.
- Increase in Immigration Fees, saving between \$5-20 billion over 10 years.
- Extend and increase Custom User Fees, saving \$25 billion over 10 years.
- Eliminate Diversity Visa Program, saving \$3.2 billion over 10 years.
- Reinstate Public Charge rules, reducing the number of people eligible for green cards or visas, saving \$15 billion over 10 years.

- Reclaim funding from the following offices and programs.
 - U.S. Refugee Admissions Program
 - United Nations Refugee Agency
 - International Organization for Migration
 - Safe Mobility
 - Executive Office for Immigration Review (EOIR)
 - EOIR Language Access Plan
 - Stab-Serv and Case Management Pilot Program
 - Welcome Corps
 - Housing Programs for illegal migrants
 - Non-governmental Organizations participating in aiding illegal migration.
- Increase Visa Overstay Fee and make them non-waivable.
- Impose Ongoing Immigration Fees for Parole, Asylum, Work Authorization, and Work Application.
- Increase penalties for employing illegal immigrants.
- Rescind DOJ Asset Forfeiture Account, saving \$1 billion over 10 years.
- Bonuses to Law Enforcement Agencies that honor ICE detainees.
- Border Wall Funding Appropriation.
- State reimbursement for Border Security Initiatives
 - Mainly intended for Texas.
- Hire (and retain) thousands more Border Agents, at estimated cost of \$12.7 billion.
- Improve Technology at the Border.
- Destroy Invasive Plant Species along the Southwest Border. (*Illegal vegetation?*)
- Extend and Increase TSA Security Fees, raising up to \$25 billion over ten years.

Just relentless, frothing hostility aimed at undocumented aliens, or anyone that might be mistaken as such.

- Tax scholarship and fellowship income as ordinary income, raising \$54 billion over a decade.
- Eliminate tax exemption of credit union income, raising \$30 billion (and basically eliminating credit unions, which would either close or convert to conventional banks).
- Tax 501(c)(3) nonprofit hospitals at ordinary for-profit business rates, raising \$260 billion over ten years.

Attacks on the non-profit sector:

- Repealing “green” provisions of the Inflation Reduction Act, raising \$12.69 billion.
- Repeal “green” energy tax credits, saving up to \$796 billion over ten years.
- Expand Energy Leasing and Permitting Provisions, saving \$7.5 billion over ten years.
- Repeal EPA Tailpipe Emissions Rule and DOT CAFÉ Standards Rule, saving \$111.3 billion over ten years.
- Sell Oil from the Strategic Petroleum Reserve (based on need for hard currency).
- Repeal spending programs, saving up to \$232 million over a decade, relating to
 - Alternative Fuel and Low-Emission Aviation Technology Program
 - Oceanic and Atmospheric Research and Forecasting for Weather and Climate Budget Authority
 - Computing Capacity and Research for Weather, Oceans, and Climate
 - Acquisition of Hurricane Forecasting Aircraft
- Auction of available frequencies

on the Electromagnetic spectrum, generating \$70 billion over a ten-year period.

- Modify eligibility for Infrastructure Investment and Jobs Act funding, restricting or limiting spending on “green” measures.
- Redirect Oil Spill Liability Trust Fund to deficit reduction, saving \$5 billion over ten years.

The rollback of the “green” agenda.

- Various procedural rule changes and benefit cuts that raise \$375 billion from the USDA SNAP program over ten years.

Closing loopholes and tightening standards related to Food Stamp benefits.

- Various procedural rule changes and benefit cuts that raise \$334 billion from the ED student aid program over ten years.

Closing loopholes and tightening standards related to Student Loan repayments.

- Restructuring of rules controlling health care practices and coverages, and enabling alternative health coverages, to raise a minimum of \$3 billion over ten years.

Closing loopholes and tightening standards related to federal health care coverage.

- Increasing school eligibility thresholds and requiring income verification for families of students relating to School Breakfast & Lunch programs, saving \$12 billion over ten years.

Constricting free breakfast and lunch programs for impoverished school-age students.

- Shrinking or eliminating financial regulation agencies outside of the Treasury Department, saving \$58 billion over ten years.

- Eliminate Office of Financial Research
- Eliminate Securities and Exchange Commission Reserve Fund; also forbid carrying over unspent monies from one fiscal year to next.
- Create option to de-fund through appropriations process:
 - Office of Comptroller of the Currency
 - National Credit Administration
 - Federal Deposit Insurance Corporation
 - Consumer Financial Protection Bureau
- Repeal Orderly Liquidation Authority, end big bank bailouts.
- Reduce Federal Reserve Dividend Payments to big banks.
- Restructure Federal Reserve pay and benefits scale to align with the rest of the executive branch.

Centralizing all financial policymaking into the Treasury Department under direct control of the Secretary.

- Rescind funds transferred from the Home Affordable Modification Program (HAMP) to the Hardest Hit Fund (HHF).
- Reform Fannie Mae and Freddie Mac to increase revenues and extract government from bad portfolio of debt, netting at least \$20 billion.
- Halt subsidies to the National Flood Insurance Program, saving \$11 billion.

Beginning the extraction of the federal government from the subsidization of home ownership.

- Natural Resources – about \$5 billion total revenue projected over ten years.

- Restore noncompetitive leasing.
- Offshore Oil and Natural Gas leasing.
- Onshore Oil and Natural Gas leasing.
- Reopen Alaskan National Wildlife Reserve and require new lease sales.
- Increased Geothermal Leasing.
- Increased Coal Leasing.
- Permit Processing Reform for Geothermal.
- Increase Timber Sales.
- Increase sales of federally held land.
- End restriction on oil and gas leases in Chaco Canyon.
 - Location of a US National Historical Park in northwestern New Mexico holding a large concentration of pre-Columbian indigenous ruins of pueblos.

Drill baby, drill!

- Rescind Inflation Reduction Act (IRA) funds, saving over \$2 billion over ten years.
 - Defund Investing in Coastal Communities and Climate Resilience.
 - Defund National Parks and Public Lands Conservation and Resilience.
 - Defund US Geological Survey 3D Evaluation Program.
 - Defund Bureau of Reclamation Domestic Water Supply Projects.
 - Defund Department of Interior Oversight.
 - Defund National Parks Service Employees.
 - Defund Endangered Species Act Recovery Plans.
 - Defund Funding for US Fish and Wildlife Service to Address

Weather Events.

- Defund Tribal Climate Resilience.
- Defund Native Hawaiian Climate Resilience.
- Defund Emergency Drought Relief for Tribes.

Almost seems like they just used a keyword search to identify “green” programs in the IRA. That couldn’t be it...could it?

- Rescind Presidio money from IRA, saving \$200 million.

The Presidio is a dormant military base in northwest San Francisco. A slap at Nancy Pelosi?

- Various reforms to federal employee health, pension, and civil service protection plans to save \$50-\$100 billion through a combination of reduction-in-force and poorer compensation packages to those who remain.
- Federal Building Occupancy at Minimum of 80 Percent.
 - Surplus properties to be disposed of.
- Budgeting reform to restrict new, unfunded regulatory costs.
- Permitting reform to streamline the process and eliminate individual permit review.

Measures to lower costs of capital and labor in the federal government.

It is safe to say that there may be political pushback on many of these proposals, and no doubt this only represents an opening bid with an idealized wish list. Nonetheless, this represents almost a wholesale revision of the executive branch’s remit, the likes of which we haven’t seen since the Great Society reforms of the 1960s. Interesting times are ahead.

STIC Does Advocacy in Albany RE: NYS Budget & CDPA

By Matthew Requa and John McNulty

On Tuesday, February 11th, staff and management from Southern Tier Independence Center attended NYAIL Budget Advocacy Day at the Capitol Building in Albany, NY. Some of our staff attended the Joint Health and Medicaid Budget hearings before or after visiting with legislators.

We would like to thank the following legislators and their representatives for their time, compassion and expertise: Assemblyman Andrew Molitor, Assemblyman Jeff Gallahan, Assemblymember Anna Kelles, Assemblymember Donna Lupardo, Senator Peter Oberacker and Senator Lea Webb. Additionally, we want to thank Assemblyman Joe Angelino, who was unavailable in Albany on Tuesday but who graciously made time for us to meet with him in his district office on the preceding Friday. Our exchanges with all of the above were constructive and encouraging.

In our discussions we focused on encouraging a pause (at the least) in the implementation of a single Fiscal Intermediary (FI). We also encouraged the restoration of funding for Centers of Independent Living, opposed a cap on enrollment in the Nursing Home Transition and Diversion (NHTD) Medicaid Waiver, urged the repealing of eligibility cuts for community-based long-term supports and services, urged that last year's Access to Home funding increase stayed in place, opposed efforts to expand involuntary commitment, and more.

We returned to Albany on Wednesday March 5 to join Independence Centers around the state, together calling

even more urgently for a pause in the implementation of the single state-wide FI currently scheduled for April 1; the rollover of consumer and care worker information is nowhere near completed, and an April 1 launch would be catastrophic.

Several legislators joined us at our demonstration, including the chairs of both the Senate and Assembly's Health Committees, Gustavo Rivera and Amy Paulin, and STIC's own Senator Lea Webb. Leaders of several Independence Centers around the state spoke as well, including STIC's own Jennifer Watson.

We will continue our crusade for the rights of the disability community, and the unalienable right for people to remain in their own homes with proper care, comfort, dignity, and access to a world we all share...a world where we are all one!



STIC Celebrates the Holiday Season

On December 13th of last year, the STIC family all came together to celebrate the winter holidays and a successful year of helping our friends and neighbors reach their fullest potential. We enjoyed seasonal treats and each other's company.



We are Hiring at STIC!

At Southern Tier Independence Center (STIC), we're growing and looking for passionate individuals to join our team! This isn't just a job—it's an opportunity to build a meaningful career and be part of the Disability Rights Movement.

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nization. We offer 5 different games where our themes immerse players in exciting worlds while encouraging communication, collaboration, and creative thinking.

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Benefiting people with disabilities

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IN NOVEMBER



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