

AccessAbility

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Stop Slandering CDPA!

By
Maria
Dibble

A recent report released by the Empire Center asserts that Personal Care, and Consumer-Directed Personal Assistance (CDPA) especially, are too expensive and growing too quickly. The report was very critical of homecare overall. It implies that the programs are out of control, and that the dollars aren't there to support them. Yet in mid-November the New York State Division of the Budget announced higher-than-expected personal income tax collections, and projected a balanced budget for 2023 and a nearly-balanced one in 2024, refuting any arguments that expenditures are unsustainable. Actually, the 2023 fiscal year is expected to have a surplus, which will supplement possible downturns in 2024.

The Empire Center report compares expenditures in NY to other states in the US and presents figures showing that NY spends far more than others on these services. What isn't mentioned is that many other states are only paying their workers the federal minimum wage of \$7.25 an hour, less than half of what is paid in NY. This would obviously make their numbers much lower than ours, so it's like comparing apples to oranges.

It should be no surprise that CDPA has grown so much and so fast in NY; after

all, it is the least expensive personal care service in the state. It is the service that Medicaid managed care organizations (MCOs) try to encourage their customers to choose. One only needs to compare the CDPA rates to those of Certified Home Health Aides and traditional Personal Care Attendant services to see this. Therefore, MCOs steer more people to CDPA than to the more expensive options. This was predictable, and it saves taxpayers money.

The report implies that the rates the state pays to CDPA providers (Fiscal Intermediaries or FIs), whether directly through fee-for-service Medicaid, or indirectly through managed care plans, are too high. The rates we receive barely cover our expenses (mostly salary, fringe and travel) and our administrative rate is under 8%. I challenge the state or most agencies to operate for less. We are efficient and we run a tight ship. I have an idea of the rates the state gives to MCOs to pay us (see page 3), and of course I know the rates we receive, and the MCOs are clearly making money, not us. Perhaps the author of the report should investigate whether Cuomo's transition to Medicaid managed care saved money, or added additional costs. My guess is the latter.

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The report also very strongly implies that there isn't a shortage of workers, because there are already so many. Just because there are a lot of aides, and homecare workers account for a large proportion of jobs in NY, doesn't mean there isn't a shortage. Furthermore, sources all over New York State and the nation have been predicting, and reporting, growing homecare worker shortages for over 20 years. Just about everyone with any real expertise in this issue agrees that there currently is a critical shortage, one that will get worse as time passes if nothing is done about it (such as better wages and benefits).

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Authorship

All articles appearing in this newsletter are written by Ken Dibble 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.

STIC has a program called Open Doors that helps to get people out of nursing facilities. Currently, there are several people who cannot transition to the community because every provider in the area has said they don't have the workers to serve them. People in CDPA may have a slightly better success rate at finding workers, but not everyone is capable of managing their own care, nor are they necessarily appropriate for the CDPA program. There absolutely is a shortage and it isn't just in Binghamton but throughout NY, especially in upstate areas. The shortage is real and isn't going away any time soon.

The report implies that the wages paid to homecare workers are too high, leading me to wonder if the author believes that people who care for our loved ones should make less than fast food workers. That was exactly the case until the rate went to \$15.20 an hour on October 1 in upstate NY. Homecare work is difficult, physically and emotionally draining labor. We *should* place more value on those who care for us than on those who cook our burgers!

Additionally, the report alleges that there is a significant amount of fraud in Personal Care, and likely more in CDPA, but cites only one case. We would be fools if we claimed that fraud doesn't exist, but it is not widespread, and when it is caught by FIs it is quickly dealt with and reported to the NY State Department of Health (DOH) and other entities as required. STIC has had a few cases of crooked personal care workers over the years. and

when discovered the money was paid back to the state, so we suffered the loss, not NY. These cases have been few and far between over the last 23 years we've been serving as an FI. STIC was audited by the Office of the Medicaid Inspector General (OMIG) a few years ago, and we were given a completely clean bill of health. Our audit was part of a statewide effort to audit FIs, and to my knowledge no pattern of fraud and abuse was found. People with significant disabilities rarely commit fraud, because their lives depend on the services they receive—services they will lose when they are caught. CDPA is not a luxury, it is a service that helps people live independently. If people didn't need assistance to bathe, go to the bathroom, get out of bed, etc. they wouldn't choose to have such an intimate intrusion on their lives. If they are allocated the hours of service, they actually need them! The fact that the CDPA program has grown quickly isn't proof that there must be fraud; it's proof that CDPA is cost-effective for MCOs.

CDPA requires fewer regulations to implement than other programs, a cost-saving feature that I'd think the Empire Center would appreciate, yet they decry the fact that there are no nurses supervising the CDPA workers, as if this would prevent fraud. The one case cited in the report concerned a crooked FI agency. If an FI is determined to become a criminal enterprise, it won't matter whether their employees are nurses or not. You can't have it both ways. The cost is lower because the regulations are fewer. Regulate the CDPA program more. and it will cost more.

BAD WEATHER?

If the weather is bad, call 724-2111 (voice/TTY) to make sure we're open. The answering machine will explain why we're closed. Listen to the entire message since we sometimes ask you to call back to check later in the day. If we're going to be closed, the message will say so by 7:30 am. For Deaf consumers, there will be a generic TTY message saying we're closed. This message is always the same no matter why we're closed.

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Finally, humans are fallible and a small proportion of them in every industry are criminals. The fact that a few cases of fraud have occurred, when compared to the overwhelming number of honest transactions in the CDPA program, just means we're normal.

The report also criticizes the slow transition of people from nursing facilities into the community (which of course would again raise the expenditures in CDPA and similar programs), but we know part of that is the shortage of workers. A shortage of accessible housing for people with low incomes is also a big part of it. If the transitions really were going too slowly, that would be troubling. The Open Doors program moves people out of nursing facilities regularly across NY; that is our job, and we have the numbers to prove it. If DOH isn't reporting this information accurately, that must be investigated.

The report says that people are getting allocated too many hours of care. For the record, FIs don't have anything to do with how many hours of CDPA services a person receives. Those decisions are made by the MCOs or county Departments of Social Services. In upstate counties it is almost impossible to get 24-hour care; they just won't fund it except in rare circumstances. Instead, people who need a high number of hours, typically more than six-

teen a day, are deemed to be too disabled to remain in their own homes, and efforts are made to incarcerate them in nursing facilities, almost always more expensive than community care when proper comparisons are made between Medicaid rates received by the specific programs that do, or would, serve them. Comparing the most expensive CDPA rate to the least expensive, or even the statewide average, nursing facility rate, is highly misleading. Every CDPA program and nursing facility gets its own negotiated rates, which also vary depending on level of care. When researchers actually do their homework and compare apples to apples, they don't find many cases where a person's homecare is more expensive than the nursing facility that person would go to. The fact that a handful of such cases exist is really not relevant. The aggregate costs are all that matter to taxpayers, and in the aggregate, the costs of meeting people's long-term service and support needs with homecare is much less than meeting those same people's needs with nursing facilities.

People are aging and becoming more disabled, and inevitably costs will rise. We **cannot** cut spending on Medicaid-funded long-term services and supports as long as this demographic trend continues. We can only control its growth by maximizing use of the least expensive types of

services, and those are Personal Care and CDPA. This applies to you and me, and to the writers of the report. We need to examine our priorities as a society and we need to look into ourselves and ask, "If it was me in this situation, where would I want to live, in a nursing facility or my own home? Would I prefer an agency to schedule and choose my aides, or would I want to have more control over the services I receive, as I can in CDPA?" In other words, "Would I rather have a stranger wipe me after using the toilet, or would I feel more comfortable with a friend or family member performing that intimate task?" Disability is inevitable if you live long enough, and it's only an accident away right now, for everybody, so perhaps looking at these services through your own eyes will produce a more compassionate response.

In any case, people with disabilities have a right to receive services in the most integrated settings. This is a legally-enforceable federal and New York State civil right. Any effort to cut homecare services and force people into segregated programs merely to save money has been, and will continue to be, fiercely fought in courts of law. We always win these cases, and we will continue to do so, regardless of whether anti-Medicaid "think tanks" slander us in the media or not.

What Happened to the Personal Care Wage Boost?

Almost as soon as the last state budget passed, granting a \$2 increase in the minimum wage for personal care workers, we began hearing that Medicaid managed care organizations (MCOs) had no intention of raising rates paid to Consumer Directed Personal Assistance (CDPA) providers so we could afford to pay those wages.

The providers brought the issue to the NY State Department of Health (DOH).

DOH responded that the MCOs claimed they were offering us adequate rates and that we were just being greedy.

Well, we aren't. But what needs to go into the CDPA rate?

First, wages. The rate needs to be high enough so that the CDPA providers (Fiscal Intermediaries, or FIs) can pay the new personal care minimum wage. As of

October 1, that wage is \$15.20 in upstate New York. On December 31, it will increase to \$16.20, so that needs to be taken into account. It will increase again on October 1, 2023 to \$17.20, but it's probably too much to ask that this be included in the current round of negotiations.

Second, fringe benefits. By law FIs must pay for standard fringe benefits, such as disability and workers compensation in-

insurance. FIs that want to stand a chance of being able to recruit personal care workers also need to offer at least some paid time off, and if possible, health insurance options. This is calculated as a percentage of the hourly wage.

Third, overtime. It used to be that “domestic workers,” including personal care attendants, didn’t have to be paid higher wages for overtime work, but that has changed. The objections and court battles over this have been settled and it must now happen, if attendants work over 40 hours per week. It’s federal and state law. Some disability advocates hate this because they think it will make it harder to get enough hours of service. But we think it’s a good thing—the right thing. The reason why domestic workers weren’t

included when the feds began mandating overtime pay is racism, plain and simple. At that time most domestic workers (maids and cooks) were black, and southern politicians didn’t want them making extra money. There is no reason to let one disadvantaged minority (disabled people) unfairly exploit another disadvantaged minority (people of color, which is what most personal care attendants are). STIC does not permit attendants to work overtime on a regular basis; consumers need to be able to schedule enough workers to provide all of the hours of service they need without overtime. But if overtime does occur on rare occasions, we have always paid time-and-a-half. In January, DOH may require all FIs to allow overtime. This cost must be included in our rate if we are going to be able to pay it.

Fourth, administration. We have to pay people to carry out all of the work

necessary to gather hours data, process payroll, issue checks, keep records, and comply with a slew of accounting regulations. It’s not cheap or easy, but even so, STIC’s administration rate is under 8%, which is low as these things go, so we aren’t trying to profiteer here.

CDPA FIs have to negotiate separate rates with every MCO that funds those services. At STIC, we work with several of them, and only one has so far offered an adequate rate to cover these new costs, with the exception of anticipated overtime requirements. Meanwhile, the MCOs got an increase of about \$8.00 per hour in upstate NY, well over what they need to compensate us.

This is happening to all CDPA FIs statewide. So they got together to conduct a survey. The questions were simple: What rate(s) were you getting before October 1, 2022? What rate(s) are you being offered by MCOs after that date? For nearly all who responded, for nearly all MCOs, the answers were the same: they were not offered any increases at all, or if they were, it didn’t cover the increase to the minimum wage. (One vendor only offered us an additional five cents.)

FIs can file a formal complaint about this with DOH, but many FIs are afraid of retaliation from the MCOs if they do so, and there is some evidence that such retaliation has occurred.

We heard earlier this fall that DOH convened a meeting of at least some MCO representatives and read them the riot act about all this. After we presented our survey results and evidence of MCO retaliation, DOH’s attitude toward the

FIs seems to have softened a bit, and we are hearing that they are pressuring the MCOs on these points. DOH initially said they thought 17.5% was a fair fringe rate and were telling MCOs they had to provide at least a \$2.35 per hour increase. But that will only cover the bare minimum of mandatory fringe benefits. The FIs have been calling for \$2.66 per hour and have asked DOH to support this.

We hope this situation will be resolved fairly. At press time we had not finalized negotiations with MCOs, but the contracts will be retroactive to October 1, so we aren’t worried about that.

About 30% of the Medicaid recipients our CDPA program serves aren’t in managed care; we get fee-for-service rates from each county for them. Each year’s fee-for-service rate is derived from what the actual costs for the program were two years previously. There is no indication that this methodology will be changed any time soon, but we can report that the rate was increased by \$2.35. We are now receiving fee-for-service rates based on our 2020 costs, plus the additional funds to cover minimum wage, so that is a victory.

We also serve some people who aren’t on Medicaid at all; their services are funded through the New York State Office for Aging (OFA). We negotiated a satisfactory rate so we will be meeting expenses in that program.

You can see that this is a complicated set of factors to balance to maintain a successful CDPA program. We’d love to pay even higher wages, because we highly value the personal assistants and believe their work is worth a lot more, but the rates just won’t allow for it. We are being honest with you, and we hope you understand that we are doing our almighty best to pay people as well as we can and provide the best possible fringe benefits, and that personal assistants will continue to work with us and the people we serve.

It’s not cheap or easy, but even so, STIC’s administration rate is under 8%, which is low as these things go, so we aren’t trying to profiteer here.

What about the Personal Care ADL Minimums?

As part of the NY state budget passed in March 2020, the state restricted eligibility to Medicaid Personal Care services, including Consumer Directed Personal Assistance (CDPA), to people who need hands-on assistance with at least 3 “activities of daily living” (ADLs), such as mobility, bathing, using the toilet, and eating, except for people with dementia, for whom the threshold is at least 2 ADLs.

This change never took effect due to “maintenance of effort” (MOE) requirements in the first major federal COVID relief act, the Trump Families First Coronavirus Relief Act. We previously reported that the new rules would kick in when the federal COVID-19 public health emergency is lifted. That turns out not to be the case, because the Biden American Rescue Plan Act (ARPA) has a different MOE, whereby states must not reduce service eligibility rules until they finish spending the extra ARPA money. That money originally had to be expended by March 31, 2024, but in June the feds extended it to March 31, 2025. At press time, however, the NYS Department of Health (DOH) was saying they still expected to use up that money in 2024. So the ADL minimums won’t take effect until then. They only apply to new

Medicaid recipients; anybody who has Medicaid Personal Care or CDPA now will not be affected.

We should add that both MOEs also forbade states to cut anybody off from Medicaid who already had it when the pandemic started, until the public health emergency ends. So NY could begin terminating Medicaid for people who would have lost eligibility during the pandemic long before the ADL minimums take effect.

When might that be, you ask? At press time the emergency had been extended until at least the end of January 2023. It might run longer.

Meanwhile, as we’ve reported (*AccessAbility* Summer 2022), the ADL minimums likely violate the ADA because they are a form of discrimination on the basis of disability, and the state would probably lose a lawsuit on that basis. More help on this may be coming, though not, perhaps, soon. The Affordable Care Act (ACA, “Obamacare”) contains a provision that makes it illegal for health programs to discriminate on the basis of sex or disability. The Trump Administration issued a rule that narrowed the applica-

tion of that rule to only cover health programs created by the ACA itself, such as the private insurance plans available on the state or federal “exchanges.” Recently the feds announced that they believe this doesn’t meet the requirements of the law, and they are planning to revoke that rule and make the nondiscrimination language apply to all forms of health insurance, both public and private. Medicaid is public health insurance, and the feds also asked for input on how they can ensure that state Medicaid programs don’t discriminate on the basis of disability, including by causing people to be segregated or institutionalized unnecessarily. If this rule change goes into effect, we would have much more ammunition to argue that the ADL minimums are discriminatory and illegal.

Unfortunately, the feds can take years to finalize a rule after they ask for public comments. We sent ours in, to be sure. Fortunately, we now have at least until sometime in 2024 before things hit the fan.

Unfortunately, yet again, we’ve heard that the politicians in New York State also feel they have breathing room before taking up the question of repealing the ADL minimums. We think they should be made to change their minds. So we repeat: If we only get one thing out of Governor Hochul in the 2023 budget cycle, it has to be repeal. We urge advocates to make that their top priority, ahead of everything else, including pushing for more homecare wage increases.

courts watch

Health & Hospital Corp. v Talevski: An unprecedented threat

This case has been widely reported as a serious threat to the ability of individual Medicaid recipients to sue to enforce Medicaid and other federal laws that provide services for people with disabilities. That’s very important, as it

would affect two ongoing cases in New York State on which we’ve previously reported (*T.C. v DOH*, *AccessAbility* Fall 2022; and *C.K. v Bassett*, *AccessAbility* Summer 2022), both of which rely on the ability to sue over the state’s failure to provide Medicaid-funded services with reasonable promptness. The outcome will depend on the views of the

most recently appointed US Supreme Court justices.

The issues in the case are fiendishly complicated, providing opportunities for the Supremes to take right or wrong turns. We would need half of this newsletter to fully explain the situation, and even I—your faithful Supreme Court nerd—can’t

justify that. So I'll just hit the highlights.

Talevski is an elderly man with dementia who lived in a county-owned nursing facility in Indiana. Like some 20% of nursing facility residents nationwide, he was over-medicated in order to keep him quiet and docile. When his family complained, the facility transferred him against his (actually their) will to a facility much farther away. A law enacted in 1987, the Federal Nursing Home Reform Act (FNHRA), specifically says that nursing facilities must protect residents' rights "to be free from chemical restraints imposed for purposes of discipline or convenience rather than treatment," and "not to be transferred or discharged unless certain criteria are met."

The FNHRA is an amendment to the federal Medicaid law. It provides a set of "administrative remedies" that residents can use if they feel their rights are violated by nursing facilities. Talevski's lawyer says they exhausted those remedies without getting appropriate relief. They filed complaints and appealed decisions and the state told the county to order the nursing facility to stop overmedicating the man. The facility did not comply; it just transferred him to get him and his troublesome family out of its hair. The family had to hire their own doctor at their own expense to work with the new nursing facility to get him weaned off the drugs. The original facility was also ordered to readmit him, but the family felt the facility would retaliate against him, so they refused to have him moved. The family sued the facility and the county in federal court, seeking costs (for the doctor and the legal services).

The FNHRA, like other portions of federal Medicaid law, does not include a specific statement that individuals can sue for money damages when the law is violated. However, beginning in 1964, the Supreme Court has provided a workaround for that problem, known as Section 1983.

Section 1983 is part of the federal Ku Klux Klan Act of 1871. It was originally passed to protect freed people from abuse and terrorism by southern state governments, which began routinely ignoring post-civ-

il-war federal civil rights laws as soon as they were passed. It says, "Every person who under color of any statute, ordinance, regulation, custom, or usage, of any State or Territory or the District of Columbia, subjects, or causes to be subjected, any citizen of the United States or other person within the jurisdiction thereof to the deprivation of any rights, privileges, or immunities secured by the Constitution and laws, shall be liable to the party injured in an action at law, suit in equity, or other proper proceeding for redress." In other words, if a state—or a person acting under the authority of the state—violates your federal rights, you can sue the state for money damages even if the law that grants those rights doesn't say you can.

Since 1964 the Supremes have been narrowing the circumstances under which people can file such suits under federal Medicaid law. We've covered this concept recently (see *Cummings v Premier Rehab Keller*, *AccessAbility* Summer 2022). Importantly, the Medicaid Act is a so-called "spending clause" law, which enables the federal government to direct states to do specific things that it ordinarily could not do under our Constitution, only because states can choose whether to participate; if they participate, they get federal funds but must follow federal rules. Since 2000 or so, the Supremes have been saying that this is a type of "contract" between two parties—the feds and the state—and that ordinarily third parties (in this case Medicaid recipients) can't sue for damages to enforce a contract unless the law explicitly says they can.

As it stands now, you can sue in such cases only if the relevant portion of the law pretty clearly confers a right or benefit directly to you, *and* the law does not contain clear and specific ways, other than suing, that are likely to be effective for you to gain redress.

Medicaid law has a requirement that states must set Medicaid rates for providers high enough to ensure that Medicaid recipients will be able to obtain needed services. Many years ago the Supremes ruled that ordinary Medicaid recipients can't sue to enforce that requirement because it's only about rate-setting by state governments;



it doesn't confer a benefit on individuals. However, the Supremes have agreed that where the law specifically establishes "rights," or requires states to provide specific services to individuals, or to provide them "with reasonable promptness," individuals can sue the state for damages in federal court under Section 1983.

Talevski lost in the federal district court in Indiana, which found he didn't have the right to sue for damages. He appealed to the Seventh US Circuit Court of Appeals, which found in his favor. So the facility took it to the Supreme Court. Oral arguments were made there on November 8.

The lawyers for the nursing facility asked the Supremes to discard over forty years of its own precedents and declare that there is no private right of action in spending clause cases unless the law explicitly says, in so many words, that individuals can sue. Their argument mostly hinges on the notion that the court must consider what Congress would have expected concerning lawsuits over contracts in 1871 when Section 1983 came into being. They claim that at that time "common law" mostly prohibited third parties from suing to enforce government contracts.

The oral arguments about this case are revealing. That claim about common law can be disputed on the facts. It can also be argued that Section 1983 was never about contracts; it's about damage suits (or "torts"), so the contract analogy is irrelevant. That ship sailed over 20 years ago, but if somebody wants the Supremes to drop old precedents, they could equally well drop that one.

It boils down to the personal opinions of the Supreme Court justices, especially the newer right-wingers Brett Kavanaugh, Neil Gorsuch, and Amy Coney Barrett. They essentially endorsed those precedents as recently as April 2022 in *Keller*. But then they dramatically reversed almost 50 years of precedents in *Dobbs v Jackson Women's Health Organization*, the case that revoked women's federal abortion rights. In that case, Justice Clarence Thomas recommended that a 1965 decision that established the right to use birth control should also be reversed. People began to ask, how far can this court be pushed? The nursing facility's brief, which argues that all of the relevant precedents about spending clause laws were wrongly decided, is aimed at these judges.

But they might have missed. In the oral arguments, Kavanaugh was the most vocal, and he spent most of his allotted time tearing apart the nursing facility lawyers' sweeping arguments for full reversal. Barrett seemed interested in issuing a much narrower ruling that leaves the precedents intact and states that FNHRA's extensive administrative remedies provide an adequate means of getting relief, an option that the US Department of Justice's "friend of the court" brief endorses. Chief Justice Roberts, who relied heavily on the contract analogy in his 2010 opinion that blocked the Affordable Care Act attempt to force states to expand their Medicaid programs, was also pretty tough on the nursing facility lawyers.

The final word was had by Talevski's lawyer, who pointed out that the administrative remedies had simply not worked in his case.

At this point it's a toss-up. We may not know the outcome until next June. Hold on tight.

Carey v WI Elections Commission: See? We told ya so!

As we predicted last time, a federal judge squarely ruled that states can't enact laws prohibiting people with disabilities from having someone mail or deliver a ballot for them.

The judge had to do this because of a confusing series of events that followed a WI state supreme court decision that upheld a challenge to that state's use of drop-boxes for voting in the 2020 election. In addition to declaring the drop-boxes illegal, a lower court had held that in WI, only voters can mail or return their own absentee ballots. The Wisconsin Supreme Court said that was incorrect and sent the case back to the lower court. A few days later the state's Elections Commissioner said that as far as she knew, only voters can mail their own ballots, but that each local election official—municipal clerks—would have to decide who can and can't vote based on their own interpretation of the law. Nobody made an effort to issue guidance to those clerks on how they should handle disabled voters who choose to have someone else mail their ballots.

In reality, nothing had changed about what was legal in WI for disabled voters. There was no law prohibiting them from having family members or attendants mail or deliver their ballots, and there never had been. But, also in reality, disabled voters now faced grave uncertainty as to whether they would be able to have their ballots mailed; if they tried, some clerk could reject the ballot and refer the matter to the local district attorney for possible prosecution. If they didn't try, then they were deprived of their right to vote.

So some disabled voters sued in federal district court. The suit was filed on July 22. The judge issued his decision on August 31.

There are numerous federal laws guaranteeing the right of disabled voters to have other people help them vote, including mailing or delivering ballots. The judge focused on the earliest of those laws that specifically grants that right: the federal Voting Rights Act (VRA), as amended in 1982, which says, "Any voter who requires assistance to vote by reason of blindness, disability, or inability to read or write may be given assistance by a person of the voter's choice, other than the voter's employer or agent of that employer or officer or agent of the voter's union." Thus the judge didn't need to consider those other laws. He did make the point

that the "Supremacy Clause" of the US Constitution means that federal laws overrule state laws.

He also clarified that a "person of the voter's choice" can be anybody, so long as s/he is not the voter's boss or the boss's agent, or an officer or agent of the voter's union. That means it doesn't have to be a family member; it can be a paid attendant. He also mentioned a 2020 North Carolina decision, which threw out a state law that forbade the same person from assisting more than six people to vote, because it limited the voter's choice of helpers more than the VRA does.

This judge's ruling is not binding on Florida, but it does make it clear that Florida's recent restrictions on assisted voting—which allow only up to two family members to assist a disabled voter—would also be illegal. We don't know if anyone challenged the FL rules in court prior to the November 2022 election.

As for that alleged wave of new laws that would restrict voting by people with disabilities: there doesn't seem to have been one. A *New York Times* article covered difficulties faced by disabled voters on November 8, but the only situation involving specific restrictions of disabled citizens' voting rights that it mentioned was the one in WI. In Texas, new restrictions on absentee ballots resulted in about 23,000 such ballots being rejected during the March primary, mostly because voters either didn't obey the new requirement to put their driver's license number or the last four digits of their Social Security number on the ballot, or because what they wrote didn't match what the state had on record for them—in some cases because voters didn't remember which number they had given the state previously. Probably most of the people in TX who use absentee ballots have disabilities, but if your disability doesn't prevent you—or someone assisting you—from filling out other parts of the ballot, then it can't prevent you from getting the correct numbers on it. Anyway, that's Texas for you; there haven't been reports of similar fiascos in other states with similar laws, and the number of rejected ballots during the November election in TX was 10,000, or 4%, much

lower than in the primary. Yes, other laws were passed to make it harder—in some respects—to vote, but few of them were aimed directly at disabled voters. “Drive-up” voting was outlawed in some places, and some people with disabilities find that more convenient than having to get out of a vehicle and into a building to vote, but drive-up voting wouldn’t have worked for the plaintiffs in the WI case because, due to their disabilities, none of them could drive. Voters who can drive have a lot more options for getting their ballots counted than people with more significant disabilities. Yes, voter ID requirements were strengthened, but most people with disabilities have good ID cards because they receive multiple government benefits. Some states reduced the number of drop-boxes and polling places and shortened voting hours (though many states that tightened ID and mail-voting rules also expanded early voting), but none of that affected people’s ability to file absentee ballots. There were lots of complaints about inaccessible voting machines, but that’s been a perennial problem for decades now. The issue of how internet-based voting would be easier for disabled people came up—but the *Times* also correctly reported that there are legitimate security concerns with that methodology.

Finally, the numbers speak for themselves: Voter turnout for 2022 was very high—perhaps the highest ever for a mid-term election. And although it is not unusual for the party that holds the presidency to lose big-time in such elections, that didn’t happen in 2022, which means that efforts by right-wing extremists to suppress the votes of people who don’t agree with them largely failed. American voters, including those with disabilities, can be justifiably proud of their refusal to be intimidated or deterred from making their voices heard in November.

Perez v Sturgis Public Schools: IDEA v ADA

Miguel Perez, who is deaf, attended public school in Sturgis, Michigan from the time he was 9 years old in 2004, until he graduated from high school at

the age of 20 in June 2016. The school gave him a classroom aide who wasn’t trained to work with deaf people and didn’t know sign language. Nevertheless, Perez did well in school, often getting As and Bs and appearing on the Honor Roll every semester. He and his parents thus assumed he was doing fine and would graduate with a high school diploma. However, when the time came, the school told him he was only getting a “certificate of completion.”

He followed proper procedures under the Individuals with Disabilities Education Act (IDEA), and filed a formal complaint with the state Department of Education, claiming that the school provided an inadequate education in violation of IDEA; he also alleged violation of the ADA, the federal Rehabilitation Act, and a couple of Michigan laws. He got a hearing before an administrative law judge (ALJ), who threw out the ADA, Rehab Act, and one of the state law complaints due to lack of jurisdiction. He then scheduled a hearing on the IDEA claim.

Before the hearing the family and school district settled. The district agreed to pay to send Perez to the Michigan School for the Deaf, for any “post-secondary compensatory education,” for sign language classes for Perez and his family, and for attorney fees. The ALJ then dismissed Perez’s case “with prejudice,” meaning he is not allowed to bring it up again under the IDEA complaint resolution process.

Perez later sued the school district in federal court, alleging illegal discrimination by the district under the ADA, and asked for declaratory relief and cash compensation for emotional distress.

The federal district court ruled that IDEA requires people to exhaust the complaint and appeals process written into that law before they can seek any other form of legal redress. Because he settled before the IDEA hearing, he didn’t meet that requirement, so he can’t sue under any other law. Perez appealed to the Sixth Circuit Court of Appeals and lost there as well. From there he took his case to

the US Supreme Court, which agreed to consider it, because the Sixth Circuit is at odds with several other—perhaps all other—federal circuit courts on this point.

The case turns on the meaning of the phrase “available relief.” Under IDEA, people must exhaust that law’s procedures to obtain all available relief before turning to other venues. When the ALJ dismissed the case with prejudice, the process was exhausted even though there was no ruling on the case, because Perez could not return and resume it. The appeals court judge ignored this point, apparently presuming that Perez should have gone back to the ALJ to be told, “Hey, I said ‘with prejudice’! You can’t come back here!” Also, compensatory damages are not available under IDEA; if the ALJ had let Perez back in the door he would have said, “Sorry, you can’t get there from here.” However, the appeals court found that since Perez’s IDEA claim was failure to provide a free and appropriate public education (FAPE), and since IDEA does have some forms of relief “available” for that, then Perez had to exhaust IDEA’s capability to deliver its own particular forms of relief before going on to sue for damages under the ADA or some other law. This is a classic case of requiring a person to engage in a “futile gesture” in order to pursue a lawsuit. In most cases courts will say that’s improper, but the Sixth Circuit is different.

Before we go further, some may be inclined to question Perez’s sincerity. He is now 26 years old, and he and his family did receive a great deal of relief from the settlement—enough relief to put him firmly on the path of a good education and a decent career. But let’s think about what actually happened to him. The school district refused to educate him, but it continuously lied to him and his parents about it. It gave him fake good grades that he could not have earned, and it put him on the honor roll under false pretenses every semester. This filled him with the expectation that he was a great student, that he was learning everything he needed to know, and that

he was working toward a diploma that would give him a shot at making a good living. Then, a few months before he was ready to graduate, the district took all of that away from him. This certainly could be a huge psychological and emotional blow, inducing long-lasting traumatic effects, and worthy of compensatory, if not punitive, damages.

The case is interesting because the Sixth Circuit's opinion claims that other circuit courts agree with it, whereas Perez's lawyers say that none of them do, and that even the Supreme Court has already ruled that IDEA does not require futile gestures in order to exhaust its complaint process. However, in a previous case the Supremes had an opportunity to consider whether

IDEA requires exhaustion before someone can seek relief that IDEA does not offer, but chose to leave that "for another day." Perhaps they've now decided that day has come.

The Supremes agreed to take the case in October; we should have a result in the spring of 2023.

Housing, Crime and Mental Disabilities: the Elephants in the Room

In October Governor Hochul and New York City Mayor Eric Adams announced a joint project to open unused units in two state psychiatric centers to provide temporary housing, termed "Transitional Housing Units," to homeless people. About \$10 million is earmarked for this project, which was scheduled to begin on November 1 at Manhattan Psychiatric Center, with a second downstate location to open early in 2023. Another \$7.3 million will be used for a step-down housing program for people coming out of those units; this is temporary housing with training in how to be a responsible tenant and maintain stable housing, prior to being referred to permanent supportive housing.

Some advocates have objected to the first part of this plan on the grounds that it might be a step toward re-opening psychiatric hospitals and using them for long-term housing for people with mental health issues. The advocates generally support the second part of the plan, the step-down program. In the wake of those objections, *Crain's Health Pulse* published an article which, while a well-intentioned effort to give voice to concerned advocates, misrepresented some of the facts.

Although this story is about New York City and surrounding suburbs, the issues involved are relevant to people in other parts of the state.

Advocates called for the \$10 million to go to:

- "'low threshold' housing that can accept people experiencing major mental health

and addiction related challenges, including Housing First and Safe Haven programs

- new crisis stabilization centers
- peer engagement and crisis support"

According to United Way Connect and the Corporation for Supportive Housing, "low threshold" housing is permanent supportive housing that is aimed at people who are currently experiencing a crisis and are not necessarily in treatment and/or are currently using addictive substances. The low threshold refers to qualifications for admission; not all supportive housing programs accept people who are not in treatment or "sober." Further, the only support that everybody gets in this type of housing is rental assistance or subsidies; they aren't required to accept any other services, though they are available. Low-threshold housing is certainly a good thing.

We've reported previously on crisis stabilization centers, a "new" idea initiated by the Cuomo Administration a couple of years ago. They are supposed to offer "walk-in" housing with both peer and professional support services.

Peer engagement and crisis support are of course highly effective; they are the basis of the Independent Living service model. There should always be more of that available.

But let's be clear on what we're talking about here. "Housing First" is an excellent idea; research shows that homeless people make better progress on their



other issues if they first have permanent stable housing. But homelessness is a dangerously acute crisis for individuals; today people are living out on the street, in subway tunnels, on riverbanks, under bridges, or in predator-infested "shelters." Permanent housing for people with low or very low incomes, including permanent supportive housing, is in scarce supply and we need a lot more of it, but it cannot be developed quickly. Getting large numbers of homeless people into safe housing as soon as possible can't happen if all of the available money goes to developing permanent supportive housing. There has to be some temporary housing if we want to move quickly. Also, the plan for crisis stabilization centers has always involved using empty psych center beds. We don't see much difference between Hochul's \$10 million plan and those centers.

So what are the issues homeless people face? Advocates have been understandably upset by portrayals of people with mental health disabilities as causing an alleged major violent crime wave. Politi-

cians like Mayor Adams and some members of the state legislature have been feeding this stuff to the media over the last year or so. In fact, most people with mental health disabilities are neither violent nor criminals, and there is no major crime wave.

But if we really want to influence public policy in a good way, we have to go beyond those bullet points and describe the details in the real world. So let's do that.

Is there a crime wave in New York?

In short, no. There have been some recent, brief, spikes in violent crime in New York City. The murder rate there was about 45 per month in 2010, and since then had been hovering around 30 per month or so, with some higher fluctuations during the worst of the pandemic. More generally, the crime rate always increases some during economic downturns. Over the long term, across most places in the United States, including New York, violent crime remains at record lows compared to the 1980s and 1990s, when New York City's murder rate averaged 187 per month in 1990. A few violent attacks occurred in the city's subways in the spring of 2022 and shocked and frightened a lot of people. At least one of the attackers had a mental health disability, and the others may have been homeless. These are statistical anomalies, not evidence of a crime wave among homeless people. The belief harbored by many New Yorkers that crime is on the rise is driven by politicians using high-profile single events as a campaign issue, with the backing of police unions, and it has no actual basis in fact.

What's a "mental health disability"?

In independent-living-movement/disability rights terms, this is a broad category. It includes "serious mental illness"—the "big four" of schizophrenia, schizo-affective disorder, bipolar disorder, and chronic major depression. But it also includes trauma-induced conditions such as post-traumatic stress syndrome, including that resulting from sexual or physical abuse or bullying, acute depression, and "severe emotional disturbance" in children. And it

also includes substance abuse. The media and general public also sometimes confuse this category with certain developmental disabilities that can affect behavior, such as intellectual disability or autism.

What is the prevalence of violence among people with mental health disabilities?

You'll get different answers depending on how you define that disability category. According to the American Psychological Association, as of July 2022 ("Mental illness and violence: Debunking myths, addressing realities" at <https://www.apa.org/monitor/2021/04/ce-mental-illness>), in a study of 34,653 people, about 2.9% of people with serious mental illness committed violent acts within a two- to four-year period. That figure rose to 10% for people with both serious mental illness and substance abuse disorder. According to the federal Substance Abuse and Mental Health Services Administration (SAMHSA), co-occurring serious mental illness and substance abuse disorder is "common" among those who receive psychiatric medications.

Autism and intellectual disability are not mental health disorders, but for clarity we'll address those as well. Autism, by itself, is not a significant risk factor for violent behavior, but autism combined with certain types of trauma-based or serious mental illnesses may pose a risk. According to a 2019 study in the *Journal of Autism and Developmental Disorders* (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6669096/>), 91% of autistic children or adolescents, and 31% of autistic young adults have a co-occurring psychiatric disorder. People with intellectual disabilities (ID) have a low incidence of violent behavior; that incidence increases if they also have attention deficit hyperactive disorder (ADHD), but those numbers are still very low. Only about 5% of people with ID abuse drugs or alcohol, but when they do, they have a greater risk of violent behavior as well.

Are "politically motivated" mass shootings and mental health disabilities related?

Yes. Although it's been reported that the incidence of "mental disorders" among violent extremists only ranges between 10% and 17%, and that members of terrorist organizations don't differ from the general population in terms of mental health, there is evidence that "lone wolf" terrorists—who engage in mass shootings on their own and justify their actions with extremist political rhetoric—have a high incidence of depression, anxiety, and/or personality disorders.

What is the prevalence of mental health disabilities among homeless people?

We first have to point out that the pandemic itself led to a nationwide rise in homelessness among people with disabilities, many of whom are elderly. This was due to the closure of several nursing and assisted living facilities, which were unable to maintain adequate staffing and/or were so ridden with disease that they were deemed unsafe. Another cause was sudden loss of income among people who never made much money and now were laid off due to the economic shutdown. Although measures were quickly taken to stop evictions, in the early months some people lost their homes. New York City already had a severe shortage of low-income housing, made worse by Hurricane Sandy. Many people with disabilities lost their apartments in that storm and were sent to nursing facilities and other temporary forms of housing.

We also need to say that certain areas of the country have extremely high housing costs overall coupled with severe shortages of low-income housing ("affordable" housing is not "low income" housing; it means housing that people at or near the local median income level can afford). These areas have high chronic homelessness rates, including people who have jobs and are making decent money while living in their cars. This is a structural problem that can only be solved when people accept that not everybody can afford to live in or near the same half-dozen or so big cities, and start moving to less expensive places. This is already starting to happen in California.

Crain's reported that "A small fraction of unhoused New Yorkers live with serious mental illness, and research indicates that homeless people are likelier to be the victim of a violent crime than commit one." The first part of that sentence is misleading. The incidence of serious mental illness among the general population is under 5% according to various studies, but in 2010 SAMHSA reported that "26.2% of all sheltered persons who were homeless had a severe mental illness" and "34.7% of all sheltered adults who were homeless had chronic substance use issues." First, "sheltered persons" as a group doesn't fairly represent all homeless people; it only includes those who seek shelter, and they are less likely to have mental health issues. Second, "severe mental illness" as defined here, is far from the only mental health disability that leads to homelessness. In short, the claim that most homeless people don't have mental health disabilities is false most of the time. The modern "homelessness problem" began in the 1970s, and it grew as disability rights activists succeeded in getting psychiatric hospitals closed and their residents released—but without ensuring adequate levels of community-based supports.

These are uncomfortable facts for mental health advocates, but they *are* facts, and there is no use in burying our heads in the sand about them if we want to succeed in fixing the problem.

The fact that most people with mental health issues aren't dangerous to others is a very good reason to avoid a services approach that merely involves putting people into institutional settings.

The fact that a significant number of people with mental health issues are dangerous to themselves, and are living miserable lives, hasn't been enough to stimulate a compassionate and effective response. That response must provide a massive increase in permanent housing for people with low or very low incomes, and a massive increase in ongoing community-based support services, including peer support, truly intensive case management, crisis-response teams, and employment assistance. The current ap-

proach of medication plus periodic bouts of inpatient services separated by periods of no support is not working. Medication and short-term therapy work well for some people, but for many others they do not. They instead need to be offered high levels of ongoing community-based support services indefinitely. We accept this need for many people with developmental disabilities, and we willingly pay for those services. But we are so afraid of reinforcing stigma about mental illness that we are obscuring the permanently disabling nature of these conditions for many, if not most, of the people who have them.

We also have to deliver the message that substance abuse, in virtually all cases, is a symptom of a mental health disability. People who use recreational drugs or alcohol but don't have underlying mental health issues don't get addicted. Addicts are self-medicating because they are suffering physically (severe depression causes physical pain) and emotionally.

So what's left in our bag of advocacy tricks? Only the fact that violent behavior scares people into taking action, and that gives us an opportunity to steer that action in a better direction. Getting homeless people into safe housing is an essential first step, even if that housing is temporary. The fact that a building that is used to house homeless people was formerly a psychiatric hospital doesn't make it one now. Is it possible that the effort will stop there? Perhaps—but there's no evidence that will happen in this situation. There is a plan to move people out of those locations and along the path to permanent housing, with real money behind it. There is a simultaneous plan, announced in September, to build 1400 more supportive housing units, which can include low-threshold and/or simply rent-subsidized housing, across the state. Taken as a whole, this is the right approach: provide services to homeless people in safe environments right now, start building more permanent low-income housing right now, and get people into that housing when it's ready. Let's support it, and ask for more.

Unrestrained Mistreatment

In October and November 2022, the Albany *Times-Union* ran a series of stories about the Hearst newspaper chain's year-long investigation of the use of restraint and seclusion in public schools.

"Restraint" means restricting a person's bodily movements by means of straps, confining furniture, or by staff physically holding the person down. There is also "chemical restraint," meaning drugs that produce sedation or unconsciousness. "Seclusion" means confining a person to a small room such as a closet, bathroom, or padded cell. Those places are usually locked; there is a distinction between seclusion and "time-out," in which the location may not be a separate room, and if it is, it must not be locked, allowing the person to leave of their own free will.

We should note that although these practices have been used on white students without diagnosed or "classified" disabilities, they are predominantly used on disabled students, and especially those who are black or Hispanic. In New York, for example, where 17% of all students are black, 27% of students who are restrained or secluded are black.

This happens "thousands of times per day" across the US. Students, and school employees, are frequently injured, and sometimes the students die. In a surprising number of cases, the students' families are not informed until much later, if at all.

Some states have no laws restricting the use of restraint and seclusion in schools, or requiring parental notification. Others do, though how strict the rules are varies. You may be surprised to learn that New York is not very strict.

For example, prone restraint, in which a student lies face-down with staff holding her down, frequently by lying on top of her, is dangerous; it can cause breathing or heart stoppages, and death. For this reason, the US Department of Education says it should never be used. The NY State Office of People with Developmental Disabilities (OPWDD) defines prone restraint as abuse and forbids its use. The

New York State Education Department (NYSED) allows it.

NYSED forbids the use of restraints as punishment and says that they should only be used “in emergency situations in which alternative procedures and methods not involving the use of physical force cannot reasonably be employed.” However, unlike some other states, and OPWDD, it allows restraints to be used for reasons other than protecting people from physical harm. New York schools can therefore use it as a last resort to control a student “whose behavior is interfering with the orderly exercise and performance of school or school district functions, powers and duties.” That rule frequently gets ignored. NY students have been restrained for throwing a glass of water at a pair of shoes, or for refusing to carry out an assignment.

NYSED prohibits use of seclusion and defines allowable time-out as confinement in a location only by means of physical action by an employee (such as holding an unlocked door closed by the handle), and with continuous observation of the confined person (such as, through a window in the door). There must be time limits on how long a student can be confined. Unless needed to protect a person’s physical safety, time-out can only be used if it’s prescribed in the student’s individual behavioral intervention plan. Yet in New York, students have been continuously kept in time-out rooms with no bathroom breaks for several hours, locked in the rooms without an observer present, and kept in the rooms even while screaming,

banging their heads against the wall, or trying to climb out through a ceiling vent.

NYC public schools have a disturbing habit of having police arrest students for misbehavior. 56% of restraint incidents involved an arrest, and Velcro or metal handcuffs are often used.

Sadly, nearly all of these incidents involved younger students in elementary or primary school, not teenagers.

New York public schools are not required to report incidents of restraint or seclusion to the state. They have been required to notify parents if their child has been subjected to restraint or time-out since at least 2009, but prior to August 2022 there was no time-frame for doing so. Some New York parents said they didn’t find out about these incidents until weeks or months later. NY schools must now notify parents on the day on which the incident occurred.

There are many reasons why these things happen, and they can’t all be chalked up to bad attitudes among school employees, though those certainly do exist. Nationally, “interviews suggested that overwhelmed teachers in under-resourced classrooms with high student-to-staff ratios, frequent staff turnover, lack of access to specialists or zero-tolerance school climates may perform restraints and seclusions more often when unable to identify or meet students’ educational or emotional needs.” Teachers frequently report that they receive little or no training on how to handle students’ behavioral issues. They are also frequently injured by students, perhaps more often than the students themselves are hurt.

As we’ve often said, proper use of positive behavioral supports—giving people meaningful and interesting things to do that are incompatible with acting out and rewarding them for doing them—is highly effective in reducing or eliminating problem behaviors. These techniques are generally required under federal education law for students who have behavioral intervention plans. But even when the law is followed (and it often is not), doing this right requires a lot of training and a clear commitment from school authorities, and it often requires extra support in the classroom, things that schools frequently don’t provide, in large part because they aren’t adequately funded.

It’s also true that many school districts would rather spend funds on athletic programs or programs for “gifted” students—voluntary activities not mandated by regulations—and use that as an excuse for refusing to beef up their special education programs.

None of these problems are new; *Accessibility* reported on this back in the 1990s. What is new is a high-profile, embarrassing, series of articles on the subject in an Albany newspaper.

After those articles appeared, and just prior to election day, several state politicians expressed support for doing something about the situation, such as outlawing prone restraints, requiring schools to report incidents to NYSED, and providing more funding to schools for special education. It remains to be seen whether anything comes of this sudden interest.



In the year 2020, COVID-19 was the number-one cause of death among people with developmental disabilities (DD) in the United States; it was only number 3 for people without those disabilities, accord-

ing to a study conducted by Syracuse University researchers and published in October 2022 (<https://www.sciencedirect.com/science/article/pii/S1936657422001261>). Further, the people with DD who died

were considerably younger, overall, than other COVID victims.

The usual COVID-19 “co-morbidities” (things like being elderly or obese or diabetic) were roughly the same among both groups, though incidence of hypothyroidism and seizure disorders were higher among those with DD. Respiratory problems, which are risk factors for COVID-19 death, and are more prevalent among people with some types of DD, such as Down syndrome or cerebral palsy, were not found to have contributed to this situation.

The study also noted that in many cases intellectual or developmental disability is wrongly stated as an underlying cause of death on death certificates. People who have developmental disabilities don't die from them; they die from heart attacks, pulmonary embolisms, liver or kidney failure, or strokes, like everybody else, and like everybody else, they may have contributing causes of death such as atherosclerosis or cancer or COPD or uncontrolled diabetes. During the height of the pandemic, COVID-19 was more likely to be listed as the primary or contributory cause of death due to greater awareness among physicians, but now that things are getting back to normal, these doctors have returned to form. This makes it difficult to determine whether COVID-19 continues

to kill more people with developmental disabilities than others.

The big question is, why? The study shows that DD, by itself, is not a big enough risk factor to account for this.

Here's what the study's authors said: "While the available data do not allow an in-depth look at risks outside of medical conditions, it is important to note that other social determinants of health have been implicated in severe outcomes during this pandemic. In this death certificate data, people with IDD were noted to be living in a nursing home at the time of death at a higher percentage than those without, especially those with intellectual disability (1.6 times higher). Congregate living settings, especially when high levels of

close-contact personal care support over multiple shift direct care workers are provided, are associated with poor outcomes from COVID-19, for people with and without IDD. For people with IDD, with estimates of around 13–20% of adults with IDD residing in congregate care settings, this risk cannot be overstated."

This is clear confirmation that nursing and group "homes" are dangerous to people's health whenever serious infectious disease is on the loose. COVID-19 is the most dramatic example of this, but we're potentially looking at a bad flu season this year, and we can expect more deaths in those places. We need to ask ourselves why we continue to expose our loved ones to this danger.

Can We Get Rid of the Marriage Penalty?

There are a couple of situations where, if a person with a disability gets married, they can lose important federal benefits that provide cash income and/or make them eligible for life-sustaining long-term services and supports.

The first involves the "Disabled Adult Child" (DAC) benefit under Social Security. The second concerns Medicaid eligibility conferred by receipt of SSI (Supplemental Security Income).

When a parent begins receiving their Social Security benefit, if their child has a disability that was acquired before the age of 22, even if that child is now an adult, s/he may be eligible for a monthly cash Social Security benefit. Importantly, the disability must fit the strict Social Security definition, and the child's income must be below the eligibility threshold for a working-age person. Currently, if that child marries a person who does not qualify for the DAC benefit, s/he will lose their benefit. Receipt of Social Security typically confers eligibility for Medicare, so such people may also lose their Medicare insurance coverage.



SSI is a Social Security benefit that people who are over age 65 and/or disabled, and who also have low incomes, may receive. Getting married may increase such a person's total income over the eligibility limit, and they will then lose SSI, which may make them ineligible for Medicaid.

Both of these benefits are only important to people who have very low incomes. A working-age person may have a low-paying part-time job and keep SSI or a Social Security benefit. A cash benefit is not necessary for a person who is working and making a decent living. In states that offer the Medicaid Buy-In (see page 15), including New York, people with disabilities aged 65 or younger can qualify for Medicaid even with a pretty good middle-class income.

But there are some people whose disabilities likely will preclude ever having an income above poverty level, so they will always need a cash benefit, and right now, the rules prevent them from getting married—at least to a nondisabled person as defined by Social Security. In some cases, the rules will also kick in if you're in a

"common law" marriage and live with your partner.

In January 2022, Congressman Jimmy Panetta (D-CA) introduced the "Marriage Equality for Disabled Adults Act." This bill will remove the rule that only unmarried adult disabled children can receive the DAC Social Security benefit. It will also eliminate consideration of the spouse's income when determining whether that adult disabled individual qualifies for the benefit. The bill ensures that, at least in some circumstances, a common-law marriage will be considered to be an actual marriage for purposes of these benefits. Finally, it establishes that an unmarried person who is eligible for Medicaid by virtue of receiving SSI can continue to receive Medicaid after they get married—under some circumstances. Unfortunately, the relevant passages of this part of the Social Security law are so convoluted that we weren't able to fully understand what those circumstances are. (If anybody can explain what Section 1902(f) of the Social Security Act actually means, please contact me at kend@stic-cil.org.)

A new Congress begins in January and this bill will need to be reintroduced. A similar bill had been brought forward in the Senate by Sherrod Brown (D-OH); that will also have to be redone. Prospects for passage are unknown. Stay tuned.



Disability rights advocates really thought they had the Rotenberg Center's electric-shock torture program on the ropes this summer. Action on the federal level seemed certain. Both the House and Senate were working on Food and Drug Administration (FDA) reauthorization bills that would have banned the practice, and the House had already passed theirs. The Senate version was a little better, and the fact that the two were different would have required a joint conference committee to reconcile the differences before a final bill could be signed. Nobody thought this was going to be a problem.

So everybody was ... er ... shocked when House and Senate leaders announced near the end of September that they were going to pass a "clean" version of the reauthorization bill, one that omitted several things, including the shock ban. The reason given for this was that the FDA bill was going to be added to a larger appropriations bill and they didn't want issues requiring reconciliation to slow things down. Likely they were anxious to get out of Washington and on the campaign trail prior to the election.

At press time advocates were pointing out that another opportunity was avail-

able as Congress rushed to pass another raft of bills before adjourning at the end of the year. We didn't know how realistic it was to expect action on this issue; likely this will have to be taken up again in 2023.

Meanwhile, anti-shock activists gained another ally in their fight. Applied Behavioral Analysis International (ABAI), an association of people who provide behavioral support services to people with disabilities, finally agreed to issue a formal statement opposing the use of skin shocks "under any condition."



STIC NEWS



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Buy It for Free!

By Chad Eldred

Wouldn't it be great if there was a way for a person for a person with a disability to participate in employment without having to sacrifice their Medicaid benefits? What if I was to tell you that a way does exist and countless people who are eligible for such a benefit don't even know that they are? If that sounds interesting, then please keep reading.

The Medicaid Buy-In for Working People with Disabilities (MBIWPD) allows those with incomes much higher than the usual limit for Medicaid to have Medicaid coverage if they are employed. This allows someone with a disability to pursue employment without fear of losing benefits that they may be counting on to live a healthy and supported life. Employment is an important part of life and purpose for many. Providing a pathway for those

who count on Medicaid benefits to participate in the work world can have numerous positive benefits for the individual receiving benefits and for society as a whole.

Before going any further, let's talk about how awful the name of this program is. The "buy-in" branding doesn't make a lot of sense. There is no purchase that takes place. The Medicaid Buy-In simply entitles an applicant with a disability to higher income and asset limits when determining Medicaid eligibility. That's it. No purchase required.

The limits are relatively generous when considering what the normal limits would be. As of this writing, a single person who makes more than \$934 dollars per month (\$11,200 annually) is not Medicaid eligible. That's not a lot of income. Working

just a few hours a week at a minimum wage job will cause a person to exceed that limit. Given that part time employees are often not eligible for or can't afford employer health insurance, there is a profound disincentive for people with disabilities to take on employment. However, with the Medicaid Buy-In, a person can make up to \$5,749 per month (\$68,988 annually) and have Medicaid coverage.

Income is not the sole financial criterion for Medicaid eligibility. There is also an asset test. Currently there is a \$16,400 resource limit for a single individual. This figure increases to \$20,000 for someone eligible for the Medicaid Buy-In. A less impressive boost than the income figure, but every little bit helps. I won't go into a great deal of detail as to what counts as an asset and what doesn't. That is a much more complex conversation, but one worth having for a person who thinks that they may qualify for the Buy-In.

Both the income and resource limits are higher depending on household size, and there are other stipulations for the Medicaid Buy-In. Medicaid eligibility is not simple and that has always been problematic for the public and those attempting to apply. More information regarding eligibility can be found at https://www.health.ny.gov/health_care/medicaid/program/buy_in/. STIC also has facilitated enrollers who assist with applying for Medicaid. Call STIC (607) 724-2111 (voice/TTY) to find out more and for Medicaid enrollment assistance.



STIC's Offices will be
**CLOSED FOR
THE HOLIDAYS**

December 26, 2022
through

January 2, 2023

We will reopen as usual
on Tuesday,
January 3, 2023.

Happy Holidays to All!



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All donations are tax-deductible. Contributions ensure that STIC can continue to promote and support the needs, abilities, and concerns of people with disabilities. Your gift will be appropriately acknowledged. Please make checks payable to Southern Tier Independence Center, Inc.

THANK YOU!

Southern Tier Independence Center

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