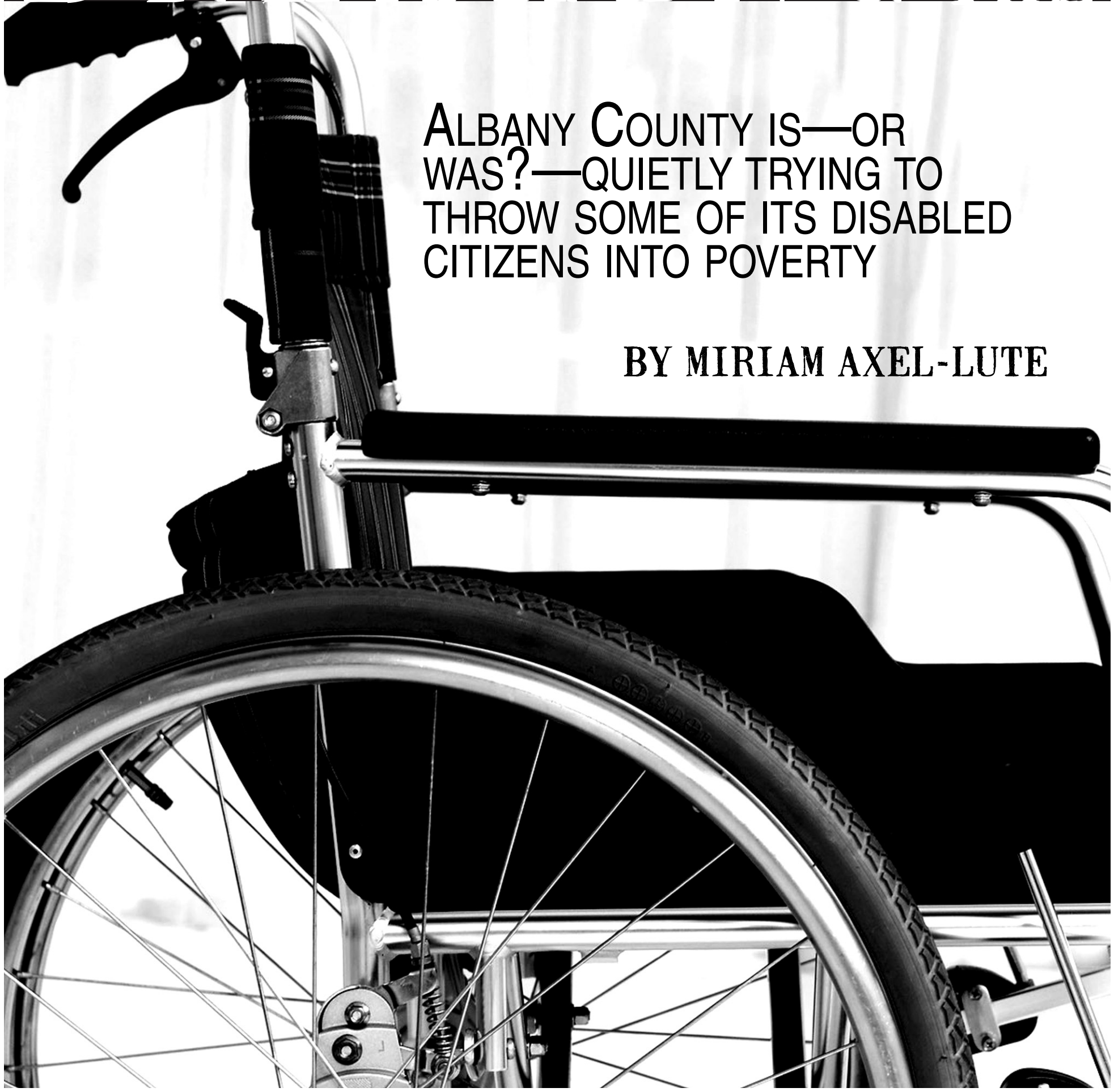


BREAKING THE

ALBANY COUNTY IS—OR
WAS?—QUIETLY TRYING TO
THROW SOME OF ITS DISABLED
CITIZENS INTO POVERTY

BY MIRIAM AXEL-LUTE



TRUST

SOME HAVE TRAUMATIC BRAIN INJURIES FROM ACCIDENTS. Some have multiple sclerosis. Others have had strokes. Across Albany County, dozens of people disabled for various reasons rely on Medicaid to help them get the medical care they need.

But late in 2005, many of them found themselves distracted from the everyday challenge of living with their disabilities. They, or their caretakers, had gotten notices in the mail from the county announcing a major change in a financial tool many of them they rely on to make ends meet.

Thanks to a new way of interpreting the law, the amount of their Social Security Disability checks that they had been setting aside each month in a trust to be used only for their care was now going to be owed to the county before they could continue to qualify for Medicaid. This would mean the effective loss of several hundred dollars a month in income, and would leave them with standard Medicaid eligibility income levels—barely more than half the earnings of a full-time minimum-wage job, about \$100 per month below the official poverty level for a single person—to cover all their living and health-care expenses not paid for by Medicaid.

Those who could afford to appeal the change are doing so. So are some who can't quite afford to. "It's just a great time of the year for this to be happening," says Rob Korotitsch sarcastically, a few days before Christmas. Korotitsch is a service coordinator for people with traumatic brain injuries at the nonprofit Living Resources, and several of his clients are affected. "I've got one man who can't afford Christmas because of this; he had to give all his money to his lawyer."

But the ones who can't afford to appeal are in an even worse limbo. "I've got people who are having breakdowns over this because they simply cannot deal with the stress of this happening to them," says Korotitsch. "I have some people so cognitively overwhelmed that I worry about them hurting themselves."

From the date of the notice, trust beneficiaries have to file an appeal within 10 days if they want their benefits to stay active during the appeals process. For many affected people, that may just not be happening, says Ed Wilcenski, a lawyer who works with the special needs com-

munity and is vice chair of the state bar association's Medicaid committee. "What happens often, something comes in the mail, they read and set it aside because it scares the bejesus out of them, and they don't get these timelines."

It's true a few trusts may have large balances in them, but the majority of the people who have them are "living on fumes," says Wilcenski.

No one's benefits have yet been affected. In fact, the county *may* be backing down on the change, despite its formal change notices. But even if so, it has left many in the disabled community and those who serve them feeling under attack.

"I have people who have been teachers, doctors, paid into the system, they've always done the right things," says Korotitsch. "They paid their taxes, shared all of their information with the county up front. . . . They're not hiding anything. They need Medicaid to live. . . . Now they feel that they are being attacked by Albany County."

THE CHANGE THAT THE LAW DEPARTMENT OF Albany DSS is trying to implement is arcane and technical. It involves new interpretations of a small part of a regulation applying to a special kind of trust that most of us wouldn't have even known existed, let alone how it worked. But there are two reasons to pay attention anyway: First, these kinds of rule changes could have real and devastating effects on vulnerable citizens. Second, it's characteristic of local, state, and federal trends to try to deal with the burgeoning cost of Medicaid through punitive short-term measures that merely set up the country, and its poor and disabled, for further, costlier, crises down the road.

HERE'S THE CRASH COURSE IN ALBANY County's latest sortie into short-term thinking:

Medicaid is generally intended for the completely destitute: To qualify in 2006 in New York state, an individual's income must be no more than \$692 per month. People with somewhat more income than that, but large medical expenses, can qualify for Medicaid if they prove that they have "spent down" the difference between their income and the income limits, on qualifying medical care, prescriptions, etc. This is also called a Medicaid deductible.

However, since 1993, federal and state laws have recognized that the disabled are a special case: They gener-

ally can't work, at least not full time; they often need extensive medical care and specialized therapies, some of which might not even be covered by Medicaid; and they are likely to be institutionalized if they don't receive financial support and targeted services to help them stay living in the community. In addition, younger disabled people who are institutionalized may have more health and social needs than a typical nursing home can accommodate.

As Korotitsch puts it, federal law wanted to make it so that "people who had a working history, who through no fault of their own became disabled, wouldn't have to become poverty-stricken to get their medical needs taken care of."

And so lawmakers created a special legal provision called a supplemental-needs trust. Resources put into such a trust are exempt when determining Medicaid eligibility. In 1997, New York state clarified explicitly that income could be put into the trust as well. When the assets and income funding the trust belong to the person with the disability, as opposed to a third-party donor, they are called First Person Supplemental Needs Trusts. It is this kind of trust the county's decision is affecting.

First-person supplemental-needs trusts (hereafter SNTs) often are initially funded with a lawsuit settlement, inheritance, or a small amount of savings, and contributed to with pensions or Social Security checks.

Some SNTs are administered by family members, others by nonprofits like NYSARC, Inc. The funds in the trust can be spent by the trustee *only* for the disabled person's needs, support, and comfort, according to a careful set of guidelines. The trustee pays service providers directly—the disabled beneficiary cannot get cash directly.

Trusts are often used for supplemental therapies not covered by Medicaid, a chance for younger institutionalized disabled people to attend programs outside their nursing home, or for basic needs like rent and groceries.

That's how it has worked in New York state since the mid-1990s.

THEN THIS SUMMER, OKLAHOMA'S TENTH Circuit Court ruled that people could not put Social Security income into SNTs. Their arguments were based on a portion of federal law that says Social Security checks cannot be "assigned" to a third party. The law was intended to keep aggressive creditors from involuntarily diverting people's Social Security checks.

The Tenth Circuit court case is being appealed to the Supreme Court as being opposed to the decisions of several other courts, and as being contrary to the intention of federal law. Those appealing the case also say there's nothing involuntary about individuals receiving

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Social Security checks and then depositing them into a trust for their own benefit. New York state has not taken a position on the case, nor brought a similar one.

Nonetheless, this fall, the legal department of Albany County's Department of Social Services decided it agreed with the Tenth Circuit's interpretation. On Oct. 14, 2005, DSS faxed a memorandum to trustees administering SNTs.

The memo is unambiguous and makes no indication that it is presenting a change in policy. Under the heading "Funding," it reads, "Social Security Disability ('SSD') benefits can not be used to fund a SNT. . . . (meaning all SSD income . . . should be spent down in order to receive means tested benefits.)" It says the same about Supplemental Security Income (usually received by a dependent disabled person who was never able to work, or sometimes by those who don't qualify for enough SSD to live on).

The memo concludes with a bolded paragraph titled "Warning," which says that failure to follow the above guidelines will result in the discontinuance of benefits and may also lead to legal action against the trustee in the state's Supreme Court and a referral to the attorney general's office for "possible prosecution of breach of fiduciary responsibility."

Beginning after this memo, and continuing through the end of 2005, individuals with SNTs who were receiving Medicaid (DSS says there are about 90 in the county), began receiving "Notice of Intent to Discontinue/Change Medical Assistance" forms. The handwritten explanation on one such form, sent on Dec. 29, reads, "Your entire Social Security Disability Benefits must be considered available money for purposes of determining Medicaid Eligibility. So you cannot meet your Medicaid excess income Spenddown by depositing your Social Security Disability income into your NYSARC or (SNT) Special Needs Trust."

For those disabled individuals whose only source of income is their SSD checks, this change would mean they would have to "spend down" on medical expenses all but \$692 per month (\$900 for a family of two) in order to continue to qualify for Medicaid.

For those whose trust balances were high enough to afford a lawyer, many trust beneficiaries, or their trustees, are appealing the change notice. Wilcenski says he's filed at least five already.

But, he notes, quite a few more are not going to have the resources to appeal—especially within the 10 days required to keep the benefits in place while the appeal goes forward.

Reached on Tuesday, Albany DSS Commissioner Elizabeth Berlin insisted that the matter was actually still under review. "It's a matter we will continue to be looking at over the next several months," she said. "We will continue to be working with other legal counsel in other districts, to understand their interpretation [of the Tenth Circuit case] . . . as well as seek clarity from the governance bodies over us, the state health department, the federal government."

Berlin said the policy in the October memo was still the interpretation that her legal department stood by, but that despite the formal change notices, they "are not going to be taking any action at this point in time. . . . The matter is still under review."

Asked if the department usually sends formal notices about questions still under review, she said, "Certainly it's our desire to have the review completed before we issue anything that would come out of the department. In this situation the matter was still under review and the notices got out. I think that did cause some confusion as to the direction the department was taking." Berlin said the department will follow up with clarifications.

Responding to this assertion on Wednesday, Korotitsch said that the county certainly *seems* to be acting on the notices, given that his organization has already been called to represent

clients in "fair hearings" (i.e., appeals). Wilcenski concurred, saying the county had made no move to settle or withdraw the notices in response to his filing for appeals.

EVEN ASIDE FROM THE EFFECT ON THOSE IN THESE trusts, Albany County's actions, and their motivations, seem questionable on a couple of fronts.

First, both Albany County Comptroller Mike Connors and Greg Olson, a staffer for Steve Englebright (D-Suffolk County), chairman of the Assembly Aging Committee, told *Metroland* that the county doesn't have the authority to change Medicaid eligibility policy—that's up to the state. "I would be concerned what the state Department of Health is doing to ensure that every county is following the same standards and rules," says Olson. (Connors, Olson and other Medicaid experts who didn't immediately have affected clients all had been unaware of the change when contacted by *Metroland*.) Repeated calls to DOH were not returned.

Preventing people from setting aside SSD income is also not likely to save the county much, if any, money. The average amount of Social Security income being deposited into these trusts per person is a couple hundred dollars per month, say various advocates. Making those individuals turn that over to the county before they become eligible for Medicaid will amount to a small short-term savings.

But, say those working with these clients, for many of the people affected, that couple hundred could mean the difference between being able to maintain a home and live in the community and going into an institution, which is much more expensive. The room rate at the public Albany County Nursing Home, for example, is \$230 *per day*. Even those who manage to stay in the community will do so only by drawing on other types of county assistance, such as food stamps or rental subsidies.

"The endgame for this, which nobody wants to acknowledge, [is] then there'll be a new crisis because the hospitals are flooded with people with no payment source and everyone will start pointing fingers, saying 'How did this all happen?'" says Louis Pierro of Pierro and Associates LLC. "They're hoisting themselves on their own petard, because the people they are chasing out of the community, who they're paying a couple hundred dollars a month for now in foregone income, they're chasing them into a setting that's going to cost them 50 times as much. . . . The people making these decisions have no clue what's going to happen on the back end of this. Nor do they want to. They don't want to know."

Not only that, but the balance of these trusts goes back to the county when the beneficiary dies, to recoup some of what was spent for that person's medical care. Since anyone with a trust who can afford a lawyer is appealing this change, often spending most of the balance of the trust on legal fees, the action is directly cutting away at balances that eventually could have returned to the Medicaid program.

Besides, in 2005, the state finally capped the amount counties have to pay for Medicaid, reducing their unpredictable double-digit growth in costs to a small, fixed percentage, which would seem to reduce the immediate pressure for the county to scramble to cut its Medicaid costs by any means necessary.

COMMISSIONER BERLIN EVEN SAYS THAT THIS decision didn't have to do with trying to cut costs; in fact, she claims she hasn't even *done* a cost analysis of what the change would mean for the county. Rather, she says, "This has really been about ensuring integrity of the program, fairness of the program, and the appropriateness of adhering to the parameters that exist," as well as "making sure we are abiding by the direction given at the federal and state level."

What does this mean? Berlin, who is careful to note that the Medicaid program is "wonderful" and that the county has been doing added outreach over the past year in senior centers and hospitals to make sure everyone who qualifies applies, has two specific concerns regarding the trusts: "Dollars that are used in a manner outside of the fundamental purpose of putting in place a supplemental-needs trust," and, "Is there a population that is not having to meet certain eligibility criteria because they have a special-needs trust, but that is inconsistent with those individuals who are in similar situations but just do

not have a special-needs trust?"

"Those trusts have sometimes millions of dollars in them," she notes, though she admits she does not know the average balance of the trusts in the county.

A DSS employee told a trust beneficiary who called in late December that an example of the sorts of problems they were concerned about was a trust paying for a beneficiary to bring his whole family, rather than just one traveling companion (allowed under trust rules), with him on a trip to Florida.

Although this decision would go against established state practice, it seems that Berlin is concerned with showing the state that the Medicaid cap is not going to make the county relax its vigilance. "Even though the funding growth may not be limited, we still have a responsibility as the administrative agent to be ensuring that the program maintains the integrity of the eligibility determination," she says. "I think what we've done in Albany County is we've really embraced that. I think there is concern at state level that some counties will walk away from that responsibility. That is not something we are going to do here in Albany County."

"It's not cost cutting" is not everyone's story, however. DSS lawyer Marshall Day, reached last week, said he couldn't comment on the specifics of the interpretation and policy change as it was still under review, but responded to the observation that there were many people who had received these notices who were panicking about the possible effects by saying, "I'm sure there are, and some should be, but we're trying to control spending on Medicaid, that's why we're looking at these issues."

That rings more true for those who have been following Medicaid trends over the years. "My sense is they're trying to recoup any finances they can," says Korotitsch.

Disallowing Social Security income in the trusts "is very much a result of a much broader effort by states and localities to cut Medicaid expenditures," says Wilcenski.

"They're saying it's about program integrity, but it's about money," says Olson. "I'd really love to see their fiscals on this."

EVEN FAIRNESS AND PROGRAM INTEGRITY WOULD seem to be questionably served by preventing Social Security income from going into these trusts. One of the reasons the Tenth Circuit case is being appealed is that it's discriminatory against people who rely on public disability, still letting disabled people who have lawsuit settlements, inheritances or private pensions shield that income from Medicaid means testing, while singling out those relying on SSD and SSI.

As for problems with misuse of funds already in the trusts, they may well be happening. Wilcenski notes that sometimes individual trustees are not well-equipped to understand and follow the details of the legal requirements. But how is that related to what sort of income is funding the trust? It could be addressed separately, whether through better education or the October memo's threatened legal actions. (Berlin refused to address this question directly, only saying there are concerns when you "introduce another government program into that dynamic.")

WILL THE COUNTY END UP BACKING AWAY FROM this rule change? Will the state weigh in and either tell them to knock it off or change their own rules to support the county? "I think until they're sued, nobody will react," says Pierro. "The unfortunate part of this is they're playing a game of chicken. If people don't do anything, if they simply take the rules and try to live by them, the rules will fly."

Either way, says Pierro, this one case is merely a representative example of a larger disturbing trend. "It's really just one little pinprick, but when you look at the other things that are happening at the federal level and state level. . ." He mentions the federal government's recent budget, which cuts \$10 billion from Medicaid, tightens eligibility, and increases Medicaid co-payments and deductibles, and also several rule changes that he expects Gov. George Pataki to propose again this year including one that would no longer allow people to keep their own income when their spouse becomes disabled and needs Medicaid.

And yet, he says, "On the other side, you have local government telling people that they can't utilize this tool [SNTs] that the federal government created to help keep people at home. Where do people go?"

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**THE PEOPLE MAKING
THESE DECISIONS HAVE
NO CLUE WHAT'S
GOING TO HAPPEN ON THE
BACK END OF THIS.**