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New York Medicaid Spend-down Consumer Workgroup

Issue Brief on New York Excess Income Program

SUMMARY

We applaud the New York Health Foundation and Manatt Health Solutions for their informative and thought-provoking report, Streamlining New York's Medicaid Excess Income Program.[1] The report presents a clear picture of the daunting complexity of the Excess Income or "spend-down" program. This program makes Medicaid available to 150,000 New Yorkers with disabilities and chronic health conditions, by requiring them to contribute their so-called "excess income" toward the cost of medical care. While the system works well for about 60 percent of these individuals, the Report shows that for the other 40 percent, it fails. These most vulnerable people are forced to jump through huge bureaucratic hoops each and every month in order to obtain Medicaid. Local districts are burdened by immense administrative costs, disproportionate to the small number of people in the excess income program.

According to this Report, there are possible solutions. While the Report shows there are some gaps in available data, there is enough information to explore creative solutions. Because the number of Medicaid recipients stymied by the excess income bureaucracy is relatively small, the cost of improving the system to help them would not be huge. But the stakes are high. These are people with disabilities and chronic health conditions living in the community who need vital medical care, but too often cannot negotiate the barriers imposed by this program.

We call upon the New York State Department of Health (DOH), the NYC Human Resources Administration (HRA), and the other local districts to use the Report as an opportunity to implement improvements in the program. Such changes are not only desirable but are required by the Americans with Disabilities Act in order to provide reasonable accommodations to people with disabilities.

- The State Department of Health should establish a work group to focus on the Medicaid Excess Income Program that includes consumer, provider, and local district representatives from throughout New York State.

- HRA must collect and make public better data about who uses spend-down programs.

- Enact legislation to use the federal option to reconfigure financial eligibility, allowing deduction of rent and other expenses from income. This will eliminate the spend-down for many low-income people, and thus reduce the administrative burden to counties as well as the barriers to health care for vulnerable New Yorkers.

- Explore options to simplify the spend-down program through a "Buy-In" or "Plan of Care" option that will allow people to qualify for extended periods instead of month to month.

- Improve communication with consumers to explain the rules of the program by improving the written application, application procedures, consumer notices, training of local district workers, and manuals.

- Improve procedures when people transition from other Medicaid programs to the Spend-Down program, and for when people leave the Spend-down program for other Medicaid programs.

[1] The report is available at http://www.nyshealthfoundation.org/userfiles/file/EIP%20Report%205_2009_v4.pdf .

THE PROBLEM

The Excess-Income program as it is now is simply unworkable for a core group of vulnerable consumers who must navigate the program themselves, without the help of a home care agency, a hospital, or the Pay-In program. Of the 61,003 Medicaid recipients in the community who participate in the Excess Income program, it is likely that more than half have help navigating the system through the "pay-in" program (8,000 without NYC), a VNS NY pilot (1000), inpatient hospital care, the New York City Home Attendant program, and other home health agencies. The remainder -- perhaps 30,000 -- must navigate spend-down on their own each month. Shockingly, the Report finds that as many as 16,554 of people enrolled in spend-down do not activate Medicaid coverage in any month. While some may have failed to activate coverage because they did not incur bills that meet their spend-down, we suspect that many had medical bills, but were simply unable to navigate the complex system, and lacked providers able or willing to help them. The Report succeeds in identifying this core group of vulnerable people -- a group small enough that manageable and affordable solutions are possible.

An Excess Income Work Group Should be Established

We call on DOH and HRA to establish a work group to focus on the Medicaid Excess Income Program that includes consumer and provider representatives from throughout New York State.

New York City Must Collect Better Data on the Program

We were dismayed to learn that HRA and other districts have so little concrete data on the Excess Income program. We call upon HRA and DOH to begin tracking and compiling the data on the number of participants in the program, the spend-down amounts for participants, and other data on the extent of participation in the program.

Reasonable Accommodations Must Be Provided to Individuals with Disabilities

Improvements in the Excess Income program are not just a good idea; they are required by laws that guarantee equal access to people with disabilities. Given that the Excess Income program serves those with large, ongoing medical expenses, it should come as no surprise that many who are eligible for the program have disabilities. One likely reason that some individuals do not activate coverage, and why many others who could qualify for the program never even enroll, is that some individuals have disabilities that make it even more difficult to navigate the program. Some individuals with disabilities cannot travel to Medicaid offices and wait in waiting rooms each month to submit bills; others have difficulty understanding complex program rules. Individuals who do not receive nursing home or home health care do not have service providers to assist them in establishing eligibility. As a result, some people with disabilities cannot obtain or activate coverage. If the program is simplified for everyone, people with disabilities will undoubtedly benefit. But even if that occurs, there will still be people with disabilities who cannot navigate the program without additional help or other accommodations.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (Section 504) require DOH and local Medicaid programs to provide meaningful access to the Excess Income program to people with disabilities, and prohibit DOH and localities from administering the program in a manner that has a discriminatory effect on people with disabilities. Most significantly, these laws require the Excess Income program to provide reasonable accommodations to individuals with disabilities. In the Excess Income program, the reasonable accommodations that must be provided include assistance with paperwork; allowing individuals to fax monthly bills to the program if it is difficult for the individual to difficult to travel to and/or wait at a Medicaid office; and seeing the consumer on a priority basis if s/he cannot sit, stand, or wait for extended periods at a Medicaid office. The ADA and Section 504 also require

the program to inform individuals of their rights under the ADA and Section 504, including the right to reasonable accommodations in the program.

To date, districts have not provided reasonable accommodations to individuals with disabilities in the Excess Income program and have not informed individuals of the right to such accommodations. Districts permit consumers to mail in their bills, but many consumers do not use this option, out of an understandable fear that the documents will be lost, and concern about added delay in activating coverage if documents are submitted by mail. Our experience with mailing documents to HRA offices is poor -- often documents are never received or are lost. Moreover, offering a single alternative to program procedures is not sufficient under the ADA and Section 504 because some individuals need other types of accommodations (such as assistance with paperwork) or cannot use the single alternative offered. HRA has recently begun to allow spenddown consumers to fax in their bills. We applaud this development, and call on other districts to do the same, if not for all spend down consumers, then at a minimum, as a reasonable accommodation for individuals with disabilities who need this accommodation. More generally, DOH and localities must adopt procedures for accommodating individuals with disabilities in the program and must inform consumers of their right to accommodations.

Legislative Solutions:

1. The Administrative Cost Savings of Eliminating the Spend-down by Reconfiguring Eligibility Outweigh the Costs

The Report's vivid description of the overly complex and burdensome system set up to extract a financial contribution from a small group of medically needy individuals -- only 2 percent of all Medicaid recipients -- compels serious consideration of the proposal to eliminate the spend-down requirement for many people, by reconfiguring eligibility to deduct shelter expenses such as rent, and more income.

The savings from eliminating the high administrative burden of managing the Excess Income program would substantially offset the cost of expanding eligibility. Any expansion accomplished by deducting housing expenses -- a change allowed by federal Medicaid law -- would not apply to those living in institutions, which are now 60 percent of all those with excess income.

Moreover, the cost of expanding eligibility to eliminate the spend-down for a significant number of people would not be significant. The Report estimates that the majority of Excess Income recipients have excess incomes of $200 or less in New York City, while the median excess income amount in the pay-in program outside New York State is only $85. If income disregards or expense deductions were adopted that disregarded only $85 per month, half of all current recipients outside of New York City would no longer have a spend-down. If $200 in housing expenses were deducted monthly, then half of all current recipients in New York City would no longer have a spend-down.

The Report acknowledges the unavailability of detailed data needed to accurately assess these costs. The State, with a Work Group representing all stakeholders, must carefully look at the potential costs and benefits of this option, given the very significant administrative costs that would be saved.

2. Consider "Buy-In" and "Plan of Care" Options

We support options for eliminating the burden of navigating spend-down for many consumers as well as counties and providers. The "buy in" option, which would allow purchase of a flat premium calibrated to be lower than the spend-down amount, merits investigation. The "Plan of Care" option would allow activation of coverage prospectively for longer periods of time. Though these approaches require federal approval, they are worth further investigation, as they would make a tremendous difference in access to Medicaid by this medically vulnerable population.

3. Managed Care is Not a Solution

We do not agree that increasing enrollment in Medicaid Advantage programs is an effective way to address the problems in the excess Income program. Our experience is that people with complex medical needs and chronic disabilities do not get adequate care from Medicare Advantage, Medicaid Managed Care, or managed care in the private insurance market. In our experience, managed care does not provide true coordination of care, but rather, limits and denies care

Administrative Simplification and Streamlining that can be Implemented Now:

We support some of the other approaches discussed in the Report for simplifying the spend-down program, and suggest simplifications that are needed now to remedy serious problems in the current program. The disproportionate administrative burden imposed on this small group of needy consumers, their providers, and the counties compels consideration of the legislative change described above -- reconfiguration of eligibility so as to eliminate the spend-down. Barring a systemic change in eligibility, the procedures must be simplified and improved.

The New York Health Foundation report notes that providers can find out online only whether Medicaid is or is not active, but not whether a patient has Medicaid with a spend-down, how much the spend-down is, and whether any part of the spend-down has yet been met for the month. The report notes that to obtain additional information, providers must telephone the local district, which is time consuming, and sometimes unsuccessful.

Although it was not the focus of the report, the Excess Income program also provides inadequate information to consumers, which adds to confusion and undoubtedly results in the exclusion of some eligible individuals from the program. Some of the problems are described below.

- Tell Applicants They Can Use Past Medical Bills, as well as expenses paid by EPIC and ADAP, to Meet the Spend-down. Individuals first applying for the program are not told that they can submit past unpaid medical bills, or recent paid medical bills, or proof of expenses paid by ADAP or EPIC. All of these bills can be used to meet the spend-down prospectively, sometimes for months or even years. We recently helped a 40-year-old woman struggling with multiple sclerosis to use a past unpaid $15,000 hospital bill to meet her spend-down for the next 30 months -- but it required a fair hearing and six months of advocacy.

    - The Medicaid application incorrectly asks only whether the applicant "has paid or unpaid medical bills within 3 months before the month of application" (LDSS-2921 p. 10, line 10 of 20). In fact, unpaid bills that are older than 3 months can be used to meet the spend-down. Nowhere is it explained why submission of these bills could be helpful to meet the spend-down and activate coverage.

    - EPIC and ADAP expenses can meet spend-down. As noted in the New York Health Foundation report, the federal right to use expenses paid by state-funded programs such as EPIC or ADAP is not well known and not fully utilized. We applaud the recommendation in the report that systems for giving spend-down credit for bills paid by these programs be centralized and automated. However, we question the assertion in the Report that HRA has a centralized process for communicating with the public programs regarding spend down bills. This may be true for ADAP, but we know of no such process for EPIC. In addition, part of the failure stems from the Medicaid application, which cryptically asks only "Has any government agency (public program) besides Medical Assistance or Medicare paid any of your medical bills?" (LDSS-2921 p.

10, line 20 of 20). Without further explanation in the application and by the Medicaid workers, applicants do not know that this question was asking whether s/he used EPIC or ADAP in the past three months.

- Improve Notices Used in the Spend-Down Program and Explanations Given by Local District Workers to Consumers. It is undoubtedly difficult to explain the abstract and complex concepts of the program. Surely the notion of having Medicaid provisionally granted, but not activated, is confusing even to lawyers, let alone to people trying to navigate the system. A Work Group is needed to improve these notices and local district protocols for explaining the rules to recipients in spend-down cases.

    - Many consumers do not receive a notice informing them that their Medicaid is active for the month, or informing them how long it has been active. Others receive a notice but too late to use Medicaid coverage for the month(s) authorized. Like providers, they must call the local district (or in New York City, the Medicaid helpline). Often consumers have a very difficult time getting through to anyone that can answer their questions about their coverage. As a result, some individuals may assume Medicaid has not been activated and may forego needed care.

- Local Agency Staff Must Receive Better Information and Training on the Program, Including Clearer Explanations in the State Medical Assistance Reference Guide
  When advocates submit past paid or unpaid medical bills for a consumer, it is often necessary for advocates to submit detailed written explanations of how the bills should be used to meet the spend-down, and for what "budgeting period" they should be used for, because many Medicaid staff do not know the rules of the program. Consumers who lack the assistance of an advocate often are stymied in obtaining prospective coverage with past bills.

  Though the state's desk reference for Medicaid workers, the Medical Assistance Reference Guide, has a short section on spend-down, it lacks clear practical instructions for Medicaid workers. For example, although the right to apply payments by public programs such as EPIC and ADAP toward the spend-down has been in effect since 1991, the sole reference in the Guide, states only: "Bills paid by a public program of the State or its political subdivisions may be used to meet an A/R's excess income liability."[3] This is too bare-bones to provide sufficient guidance to staff. Few Medicaid workers would understand this is a reference to ADAP and EPIC, much less know how to implement this rule. Procedures are only in a 1991 Administrative Directive (91-ADM-11). As a result, staff are not sufficiently familiar with the program, which causes confusion and leads to low program participation. Similarly the notion that applicants have the right to choose a budgeting period of between one and six months is virtually unknown to Medicaid workers (96-ADM-15).

  We recommend improved staff training, and implementation of procedures to ensure that applicants, and those recipients who are new to the spend-down program, have the opportunity to submit these bills, and receive clear explanations of these rules in improved notices. In addition, the Medical Assistance Reference Guide should be revised to provide detailed and clear instructions to staff on the program.

- Help People who Transition from Medicaid with no Spend-down to the Spend-Down program. Individuals receiving Medicaid because they receive public assistance or SSI have no spend-down obligation. When they begin receiving Social Security Disability or Retirement benefits and first have a spend-down obligation, the local district workers do not explain the rules, and the standard form notices are confusing. No one tells them that they can use old unpaid bills, recent paid bills, or ADAP or EPIC bills paid in the past three months.

- Give clear notices. Notices now confusingly state either that Medicaid is "discontinued" because they have excess income, or that their Medicaid case is "accepted," without explaining that Medicaid was, in effect, being reduced by imposing a spend-down for the first time..

- Help People who Transition From the Spend-down Program to other Special Programs, who Now Suffer Interruptions in Coverage Because they Mistakenly Stay Coded as Having a Spend-down. Individuals with disabilities who eliminate their spend-downs by placing excess income in supplemental needs trusts (SNT) or by participating in the Medicaid Buy-in Program for Working People with Disabilities (MBI-WPD) must be ensured continuity of coverage pending their annual renewals. Under the current computer system, individuals with SNTS lose coverage each year at renewal, while they must again prove that they are placing their excess income into an SNT. Similar gaps in coverage are experienced by those who are mistakenly recertified into the Excess Income Program, rather than MBI-WPD. Critical losses of health care services and unnecessary administrative hurdles could be eliminated by simply assigning a computer code to individuals recertified as SNT or MBI-WPD.

Conclusion

The New York Heath Foundation report creates a long-needed opportunity to address some of the longstanding problems with the Excess Income program. We hope the Department of Health, New York City Human Resources Administration, and other local districts will seize this opportunity to address some of these problems**.** We are available to work with you on these efforts.

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