

This issue is part of a series of periodic reports from the National Health Law Program's Washington office, reporting briefly on recent and forthcoming developments in federal policy of interest to NHeLP advocates and friends. We always appreciate your feedback and comments. Please send them to Deborah Reid at [reid@healthlaw.org](mailto:reid@healthlaw.org). For updates and information on NHeLP publications, go to <http://www.healthlaw.org>.

## **SUBJECTS COVERED**

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## **CMS CLARIFICATION OF SCHIP DIRECTIVE**

On May 7, the Centers for Medicare & Medicaid Services (CMS) issued a clarification of their August 17, 2007 directive to state health officials on how CMS reviews state requests to expand State Children's Health Insurance Program (SCHIP) eligibility to children in families with incomes above 250 percent of the federal poverty level (FPL).

The August 17 CMS letter imposed certain requirements ostensibly designed to reduce substitution of SCHIP coverage for private insurance ("crowd-out"), such as a one- year period of non- insurance before a child could be covered by SCHIP and a showing that private employer sponsored insurance in the state had not declined by more than two percent over a five year period. The directive also indicated that CMS would no long allow states to cover children with gross incomes above 250 percent of the FPL, unless a state could demonstrate

that it was already covering at least 95 percent of all children eligible for Medicaid and SCHIP with incomes below 200 percent FPL.

Some states viewed the CMS letter as an illegal attack on their SCHIP programs instead of a "clarification" of existing policy and actually sued the Secretary of HHS. That case is currently being considered by a court in New York. The U.S. Government Accountability Office (GAO) and the Congressional Research Service (CRS) also both determined that the August 17 CMS directive is an agency rule subject to the Congressional Review Act, which must be first submitted for review to Congress and the GAO Comptroller General before it can be legally effective.

Against this background, CMS issued the May 7 "Dear State Health Official" letter, which states that while CMS will generally continue to require a one-year period of non-insurance before a child can be covered by SCHIP, the agency will now consider alternative approaches suggested by the states. The May 7 letter also explained that the August 17 crowd-out requirements do not apply to fetuses covered by SCHIP, and that CMS will entertain state requests for exceptions for other population groups. Additionally, CMS explained that states' policies in response to the August 17 letter do not have to be applied to already enrolled SCHIP beneficiaries, as long as those children remain continuously eligible for the program. Crowd-out policies also do not have to be applied to beneficiaries with family incomes at or below 250 of the FPL, although they may be. Finally, CMS said that it would consider state-specific data, including survey results, in determining whether a state has met the obligation to provide at least 95 percent of all eligible children with incomes below 200 percent FPL with health insurance.

Despite the May 7 clarification by CMS, the lawsuit challenging the August 17, 2008 letter continues.

## **NEW LAW - GENETIC INFORMATION NONDISCRIMINATION ACT**

On May 21, President Bush signed the "Genetic Information Nondiscrimination Act of 2008" (H.R. 493) into law. The Act includes several Congressional findings, including: the existence

of workplace genetic discrimination in the form of pre-employment genetic screening; the history of now repealed state laws that required the sterilization of persons having presumed genetic “defects”, such as mental retardation, blindness, hearing loss, and epilepsy; and the existence of discriminatory testing of certain racial and ethnic groups and genders because of their presumed predisposition to certain medical conditions and disorders.

Among other provisions, the law amends the Employee Retirement Income Security Act of 1974 (ERISA), the Public Health Service Act (PHSA), and the Internal Revenue Code to prevent group health plans from changing premiums or contribution amounts for a group on the basis of genetic information. The Act also prohibits unlawful employment practices, such as discharging an employee, or failing to hire the individual based on his or her genetic information, as well as otherwise discriminating against the individual with respect to terms, compensation, or privileges of employment.

## **BILLS OF INTEREST**

Health Information Technology (HIT) Bills:

Several HIT bills are currently pending before the House and Senate. They include:

### *HIT Draft Discussion Bill*

*On May 22, Representatives John Dingell (D-MI), Chairman of the House Committee on Energy and Commerce; Joe Barton (R-TX), Ranking Member of the Committee on Energy and Commerce; Frank Pallone, Jr., (D-NJ), Chairman of the Subcommittee on Health, and Nathan Deal (R-GA), Ranking Member of the Subcommittee on Health released draft legislation for discussion to integrate the role of the federal government in health information technology (HIT), and strengthen privacy protections in the use of electronic information. The draft bill would require the permanent establishment of the Office of the National Coordinator of Health Information (ONCHIT), which was created in an April 2004 executive order by President Bush. Among other provisions, the discussion draft establishes two federal advisory committees for expert stakeholders to offer input and assist ONCHIT in the development and implementation of a nationwide HIT system; and provides patients with greater ability to know where and when*

*their protected health information is released to other parties. Providers would also be required to remove identifying information from their patients' records, such as names and Social Security numbers, before the records could be shared with other providers.*

#### *Wired for Health Care Quality Act*

Although the Senate Health, Education, Labor and Pensions Committee approved the "Wired for Health Care Quality Act," (S. 1693) in August 2007, the legislation has not moved further due to concerns over privacy issues. Senators Edward Kennedy (D-MA) and Michael Enzi (R-WY) originally introduced the bill. S. 1693 authorizes annual allocations for two years for matching grants and loans to providers, in order to assist them in purchasing qualified health information technology. The bill also creates a public-private Partnership for Health Care Improvement that would advise the Secretary of Health and Human Services (HHS) on how to obtain a nationwide interoperable HIT infrastructure; recommends standards and criteria for exchanging electronic information; and develop a corresponding schedule for assessing standards and implementation details. In addition, the legislation requires operators of health information electronic databases to adhere to privacy regulations, although it relies upon the inadequate protections found in the Health Insurance Portability and Accountability Act (HIPAA) in order to address improper disclosures of health information. Lastly, the bill would allow individuals the right to review and obtain a copy of their electronically formatted protected health information.

Just this month, Senator Olympia Snowe (R-ME) offered an amendment to the bill that would provide added privacy protections for patient health records. Among other provisions, the Snowe Amendment imposes fines on entities that improperly disclose patient health information, if they do not provide notice to the affected individual within 30 days. However, the Amendment does not address penalties for improperly disclosing information in those instances where the provider does provide notice to the affected person(s). Additionally, the amendment increases the number of consumer representatives to HIT advisory boards.

#### *Personalized Health Information Act of 2007*

The "Personalized Health Information Act of 2007," (H.R. 1368) is currently pending before the House Energy and Commerce Committee's Subcommittee on Health. Representative Patrick Kennedy (D-RI) introduced the bill in March 2007. The bill would require the Secretary of HHS to establish a program to provide financial incentives for Medicare patients and their providers to use personal health records and to give patients and their representatives access to personal health data and information. The legislation also creates a patient-controlled web-based personal health record, and sets minimum security, data use, and privacy standards for these records.

## Medicaid Moratoria:

On May 22, the Senate passed a moratorium on implementation of certain Medicaid provisions by a vote of 75-22. The moratorium provisions were included as an amendment in the "Supplemental Appropriations Act, 2008" (H.R. 2642, "Military Construction and Veterans Affairs and Related Agencies Appropriations Act"). The legislation imposes a moratorium until April 1, 2009 on seven CMS regulations that impact federal Medicaid policy and payments concerning state revenue formulas; reimbursements for services in public hospitals and teaching hospitals; the scope of Medicaid coverage for school-based administrative and transportation costs; and services related to rehabilitation, case management, and hospital care. Previously, on April 23, the House approved the Medicaid moratorium provisions, as detailed in the "Medicaid Safety Net Act of 2008 (H.R. 5613) by a vote of 349-62. The vote margins are important because they are sufficiently large to override a possible veto should a final bill get to the President's desk.

## LITIGATION UPDATE

### *The Disappearing Medicaid Act?*

In *Newton-Nations v. Leavitt*, a case in federal district court in Arizona, the Secretary of HHS is arguing that a state does not have to follow the Medicaid Act at all for anyone receiving Medicaid, except for those people in mandatory eligibility categories. In other words, the Secretary says that every person who falls into any of the optional categories of coverage listed in the Medicaid Act can be denied any or all of the protections that the Act appears to afford them.

How is this possible? The argument goes as follows: One federal appeals court has determined that the Medicaid Act protections do not apply to "expansion populations", i.e., individuals who are receiving Medicaid under a demonstration project (a so-called "waiver" program) and who could not qualify for Medicaid if there were no waiver. (This group is limited to childless adults.) The Secretary is now claiming, however, that the Medicaid Act also does not protect people that the state could cover under the Medicaid Act, but has chosen to cover instead under a waiver. This group of people includes all of the optional categories in Medicaid, and if the Secretary were right, a state could treat them in any way it wished as long as the

conduct did not violate the Constitution or some federal law other than the Medicaid Act.

NHeLP has filed a brief with the court pointing out all of the legal and policy problems with the Secretary's position, and expects a decision sometime later this year.

## **FEDERAL FACTOID**

Lest one miss the enormous potential impact of what the Secretary is arguing in Newton-Nations (above), it should be noted that approximately 29 percent of all Medicaid recipients (13 to 15 million people nationwide) qualify for Medicaid because they fall into an optional coverage group. More than half of elderly people (56 percent) and about a quarter of individuals with disabilities (22 percent) on Medicaid qualify through an optional coverage group. See Kaiser Family Foundation, Medicaid's Optional Population Groups: Coverage and Benefit (Feb. 2005), available at <http://www.kff.org/medicaid/upload/Medicaid-s-Optional-Populations-Coverage-and-Benefits-Issue-Brief.pdf>.

## **RESOURCES**

The National Health Law Program has released two new publications, "Q & A: Non-Emergency Medical Transportation for Pregnant Women," (located at: <http://www.healthlaw.org/library/item.193488>), and "Q & A: HIPAA, Remuneration, and Medicaid Share of Cost," (found at: <http://www.healthlaw.org/library/item.194919>).

The Kaiser Family Foundation and the Asian & Pacific Islander American Health Forum recently released a fact sheet, entitled, "Health Coverage and Access to Care Among Asian

Americans, Native Hawaiians and Pacific Islanders,” that determined certain subgroups of those populations in the U.S. are doing much worse than other subgroups in terms of health insurance coverage and access to health care. The study is located at:  
<http://www.kff.org/minorityhealth/upload/7745.pdf>.

The National Economic and Social Rights Initiative (NESRI) has published an analysis of the violation of the human rights of Hurricane Katrina survivors, entitled, “Betraying an American Tradition: The Killing of Charity Hospital.” Although certain floors of Charity Hospital (that housed its outpatient clinics, Level 1 Trauma Center and inpatient psychiatric Crisis Intervention Unit) were prepared to reopen within a month of Hurricane Katrina, the hospital remained closed, which impacted predominately African American, low income, and uninsured residents who relied on the facility for their primary source of health care. For further details, see [http://www.nesri.org/Killing\\_Charity\\_Hospital.pdf](http://www.nesri.org/Killing_Charity_Hospital.pdf).