U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON ENERGY AND COMMERCE

September 16, 2015

TO: Members, Subcommittee on Health

FROM: Committee Majority Staff

RE: Hearing: "Improving the Medicaid Program for Beneficiaries."

I. INTRODUCTION

On Friday, September 18, 2015, at 9:00 a.m. in 2123 of the Rayburn House Office Building, the Subcommittee on Health will hold a hearing entitled, "Improving the Medicaid Program for Beneficiaries."

II. WITNESSES

- Michael Boyle, M.D., Vice President of Therapeutics Development, The Cystic Fibrosis Foundation; and,
- Tim Clontz, Senior Vice President for Health Services, Cone Health; and,
- Rick Courtney, President, Special Needs Alliance

III. BACKGROUND

Created in 1965 as a joint Federal-State program to finance health care coverage for low-income Americans, Medicaid is now the world's largest health insurance program. As of June 2015, Medicaid covered nearly 72 million individuals.[1] Eligibility for Medicaid is determined by both Federal and state law, whereby States set individual eligibility criteria within Federal standards. Individuals must meet both categorical (e.g., elderly, individuals with disabilities, children, pregnant women, parents, certain non-elderly childless adults) and financial (i.e., income and sometimes assets limits) criteria. In addition, individuals need to meet Federal and State requirements regarding residency, immigration status, and documentation of U.S. citizenship.

Federal law requires State Medicaid programs to cover a wide array of mandatory services, and permits States to cover additional services at their option. As a result, Medicaid generally covers a wide range of health care services, including services that are not typically covered by private health insurance. Medicaid covered services can be categorized into broad types of coverage, including hospital care; non-hospital acute care, such as physician, dental,

[1] http://www.medicaid.gov/medicaid-chip-program-information/program-information/downloads/june-2015-enrollment-report.pdf

laboratory, and preventive services; prescription drugs; and long term services and supports provided in institutions and in the community

In general, benefits are made available to Medicaid enrollees via two service delivery systems: fee-for-service (FFS) or managed care. Under the FFS delivery system, health care providers are paid by the State Medicaid program for each service provided to a Medicaid enrollee. Under the managed care delivery system, Medicaid enrollees get most or all of their services through an organization under contract with the State. Some States also utilize a primary care case management (PCCM) arrangement, through which the State contracts with primary care providers to provide case management services to Medicaid enrollees. Typically, under PCCM, the primary care provider receives a monthly case management fee per enrollee for coordination of care, but the provider continues to receive fee-for service payments for the medical care services utilized by Medicaid enrollees.

IV. LEGISLATION

At this hearing, the Subcommittee will discuss four bills targeted at improving the Medicaid program, by strengthening vulnerable populations' eligibility for coverage and improving enrollees' access to care.

A. H.R. 209, Ensuring Access to Clinical Trials Act of 2015

There are approximately 7,000 rare diseases afflicting individuals in the United States, according to a recent Institute of Medicine report.[2] A rare disease or condition is defined in the Orphan Drug Act as one which affects less than 200,000 persons in the United States, or which affects more than 200,000 in the United States and for which there is no reasonable expectation that the cost of developing and making available a drug for such disease or condition will be recovered from sales in the United States of such drug. Some diseases are so rare that the number of reported cases is in the single or low double digits, while others afflict hundreds, thousands, or tens of thousands.

Clinical trials help generate the evidence base for decision-making about the use of new treatments. However, because trials are dependent upon voluntary participation from individuals who meet trial-specific criteria, successfully conducting a clinical trial can be challenging if there is a small pool of potential participants, such as individuals with rare diseases. As of March 2014, there were over 4,800 rare disease clinical trials in the United States seeking participants from a relatively small pool of individuals who may each choose to participate or not to participate in these trials for a variety of reasons.[3]

Because advances in medicine depend on clinical trial research, researchers may face challenges enrolling participants in rare disease clinical trials, and offering payment to participants may pose a barrier to enrollment if the payments threaten participants' eligibility for Medicaid or Supplemental Security Income (SSI). In 2010, Congress passed the Improving

[2] Institute of Medicine, Rare Diseases and Orphan Products, Accelerating Research and Development (Washington, D.C.: National Academies Press, 2010).
[3] http://www.gao.gov/assets/670/665629.pdf

Access to Clinical Trials Act of 2009. The law, which is scheduled to expire on October 5, 2015, created a $2,000 exclusion for rare disease clinical trial compensation when determining an individual's income eligibility for Medicaid and SSI. According to the U.S. Government Accountability Office (GAO), since this law was enacted, compensation for participation in clinical trials has been excluded for 36 SSI recipients when determining their eligibility and benefit amounts.[4] The amount of compensation excluded for each recipient generally ranged from $50 to $2,000 each year.

The Ensuring Access to Clinical Trials Act of 2015, which was introduced by Rep. Doggett, Rep. Marino and Rep. McGovern, would make the Improving Access to Clinical Trials Act permanent by removing the sunset provision. As a result, patients with rare diseases would continue to be able to receive up to $2,000 in compensation for participating in clinical trials without that compensation counting towards their income eligibility limits for SSI or Medicaid. This bill would enable individuals with rare diseases to get the benefit of new treatments, while also generating the evidence base for determining the efficacy of the treatments being tested.

B. H.R. 3243, to amend title XI of the Social Security Act to clarify waiver authority regarding programs of all-inclusive care for the elderly (PACE programs).

The Program of All-Inclusive Care for the Elderly (PACE) is an integrated care program that provides comprehensive long-term services and supports to individuals aged 55 and older who require an institutional level of care — many of whom are dually eligible for both Medicare and Medicaid. In 2014, 31 States had a PACE program, which is an optional program under Medicaid. PACE providers receive capitated payments from both Medicaid and Medicare to cover the entire continuum of medical care and long-term services and supports for enrollees. In many cases, the PACE program enables enrollees to remain in the community rather than receiving services in an institution such as a nursing facility.

Currently, the PACE model is limited to those aged 55 and older who meet State-specified criteria for needing a nursing home level of care. However, many populations — including younger individuals, people with multiple chronic conditions and disabilities, seniors who do not yet meet the nursing home level of care standard, and others — could benefit from the comprehensive nature of the PACE model.

H.R. 3243 — introduced by Rep. Smith, Rep. Kennedy, Rep. Lance, Rep. Bilirakis, and other Members — authorizes the Secretary of the Department of Health and Human Services to waive applicable general and Medicaid requirements in order to conduct demonstration projects through the Center for Medicare and Medicaid Innovations that involve PACE. For example, the bill would allow the Secretary to waive eligibility requirements in order to allow States to develop pilots using the PACE model to serve those under 55 years of age and those at risk of needing a nursing home. However, the Secretary cannot waive either the requirement to offer items and services under Medicare and Medicaid without limitation to PACE program enrollees or certain requirements regarding enrollment in and disenrollment from PACE programs.

[4] http://www.gao.gov/assets/670/665629.pdf

C. H.R. 670, Special Needs Trust Fairness Act of 2015

Under Federal law, most trusts are counted as an asset in determining Medicaid eligibility for aged and disabled individuals and are subject to asset transfer rules. However, certain types of trusts are exempt and not counted as an asset for Medicaid eligibility determination. Specifically, Medicaid does not count certain special-needs trusts and pooled trusts as assets. Asset transfer rules do not apply to these trust types. This exception is commonly referred to as the "special needs trust exception."

In order for a trust to qualify under the special needs trust exception, a trust must contain the assets of an individual under age 65 (i.e., non-elderly individual) who meets the statutory definition of disability. Federal Medicaid law permits only parents, grandparents, legal guardians, or a court to establish a special needs trust on behalf of a non-elderly disabled individual. Such trusts must contain assets of the disabled individual, and the trust must be used to provide funding for certain expenditures that supplement Medicaid benefits, subject to certain limitations. Special needs trusts allow non-elderly individuals with disabilities to maintain their eligibility for Medicaid. When the beneficiary dies, the State receives the remaining proceeds of the trust equal to any amounts paid for medical assistance provided under the State Medicaid program.

The Special Needs Trust Fairness Act of 2015, introduced by Rep. Thompson and Rep. Pallone, would extend the special needs trust exception to allow non-elderly individuals with disabilities to establish a special needs trust on their own behalf. If enacted, special needs trusts established by a non-elderly, disabled individual would no longer be considered an asset in determining that individual's eligibility for Medicaid.

D. H.R. ___, Medicaid Directory of Caregivers Act

While more individuals are enrolled in Medicaid than ever before, the provision of a Medicaid card is of diminished practical value if enrollees have difficulty finding a physician who accepts Medicaid reimbursements and is available to treat them. In a recent report and testimony before the Committee on Energy and Commerce, GAO identified access to care as one of the key issues facing the Medicaid program.[5] GAO noted that "maintaining and improving access to care is critical to ensuring that the program is effective for the individuals who rely on it." Unfortunately, GAO has found that Medicaid enrollees face particular challenges in accessing certain types of care, such as obtaining specialty care or dental care. Additionally, GAO has previously reported that 38 States experienced challenges ensuring enough participating providers.[6]

In a separate report, the Centers for Disease Control (CDC) found that physician acceptance of new Medicaid patients has shown to be lower than acceptance of new Medicare patients or new privately insured patients.[7] On average, one of out three physicians in 2013 did not accept new Medicaid patients. However, the acceptance rate varied significantly by State.

---

[5] http://www.gao.gov/assets/680/671761.pdf and http://www.gao.gov/assets/680/671238.pdf
[6] http://www.gao.gov/assets/650/649788.pdf
[7] http://www.cdc.gov/nchs/data/databriefs/db195.pdf

For example, in 2013, the percentage of physicians who accepted new Medicaid patients ranged from 38.7% in New Jersey to 96.5% in Nebraska.[8]

Medicaid enrollees served by managed care organizations have the benefit of a health plan and its provider directory to assist in the identification of providers participating in their plan and available to serve Medicaid clients. CMS's recent proposed rule for managed care strengthens the requirements related to health plan provider directories, including requiring that online directories be updated within 3 business days of a change in a provider's status and that paper directories be updated monthly.[9]

However, half of States use delivery systems other than risk-based managed care, FFS, or PCCM to serve at least a portion of their Medicaid population. In many cases, those served under FFS and PCCM arrangements include the most vulnerable Medicaid enrollees, such as the elderly and disabled children. These enrollees may have limited assistance in identifying physicians who participate in the Medicaid program. The logistical and practical barriers for enrollees in Medicaid FFS can be so great that Matt Salo, Executive Director of the National Association of the Medicaid Directors, testified at a recent hearing that fee-for-service too often effectively means "fend for self."[10]

The Medicaid Directory of Caregivers Act (or "Medicaid DOC Act"), which will be introduced by Rep. Collins, would build on the requirements for provider directories in CMS's proposed managed care rule. The bill would require State Medicaid programs that operate FFS or PCCM programs to publish an electronic listing of physicians who have billed Medicaid in the prior six months — an indication that the physician accepts Medicaid patients. The listing would include the physician's name, specialty, address, and telephone number. Additional information would be required for physicians participating in PCCM programs since they serve as patient case managers. The availability of an electronic provider directory would provide Medicaid enrollees in FFS and PCCM with an additional tool to assist them in identifying Medicaid providers.

V. STAFF CONTACTS

If you have any questions regarding this hearing, please contact Josh Trent or Michelle Rosenberg of the Committee staff at (202) 225-2927.

[8] http://www.cdc.gov/nchs/data/databriefs/db195.pdf
[9] http://www.gpo.gov/fdsys/pkg/FR-2015-06-01/pdf/2015-12965.pdf
[10] http://docs.house.gov/meetings/IF/IF14/20150624/103670/HHRG-114-IF14-20150624-SD007.pdf