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MEDICAID

Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States





Highlights of [GAO-09-384](#), a report to congressional requesters

Why GAO Did This Study

Tens of thousands of women die each year from breast or cervical cancer. While screening and early detection through mammograms and Pap tests—followed by treatment—can improve survival, low-income, uninsured women are often not screened. In 1990, Congress authorized the Centers for Disease Control and Prevention (CDC) to fund screening and diagnostic services for such women, which led CDC to establish the National Breast and Cervical Cancer Early Detection Program. The Breast and Cervical Cancer Prevention and Treatment Act of 2000 was also enacted to allow states to extend Medicaid eligibility to women screened under the Early Detection Program and who need breast or cervical cancer treatment. Screened under the program is defined, at a minimum, as screening paid for with CDC funds.

GAO examined the Early Detection Program's screening of eligible women, states' implementation of the Treatment Act, Medicaid enrollment and spending under the Treatment Act, and alternatives available to women ineligible for Medicaid under the Treatment Act.

To do this, GAO compared CDC data on women screened by the Early Detection Program from 2002 to 2006 with federal estimates of the eligible population, surveyed program directors on the 51 states' (including the District of Columbia) implementation of the Treatment Act, analyzed Medicaid enrollment and spending data, and conducted case studies in selected states.

To view the full product, including the scope and methodology, click on [GAO-09-384](#). For more information, contact James Cosgrove at (202) 512-7114 or cosgrovej@gao.gov.

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Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States

What GAO Found

The CDC's Early Detection Program providers screen more than half a million low-income, uninsured women a year for breast and cervical cancer, but many eligible women are screened by other providers or not screened at all. Comparing CDC screening data with federal estimates of low-income, uninsured women, GAO estimated that from 2005 through 2006, 15 percent of eligible women received a mammogram from the Early Detection Program, while 26 percent were screened by other providers and 60 percent were not screened. For Pap tests, GAO estimated that from 2004 through 2006, 9 percent were screened by the program, 59 percent by other providers, and 33 percent were not screened.

Most states extend Medicaid eligibility under the Treatment Act to more women than is minimally required. As of October 2008, 17 states met the minimum requirement to offer Medicaid eligibility to women whose screening or diagnostic services were paid for with CDC funds; 15 extended eligibility to women screened or diagnosed by a CDC-funded provider, whether CDC funds paid specifically for these services or not; and 19 states further extended eligibility to women who were screened or diagnosed by a non-CDC-funded provider. In most of the states that offer Medicaid eligibility only to women served with CDC funds or by a CDC-funded provider, if a woman is screened and diagnosed with cancer outside the Early Detection Program, she cannot access Medicaid coverage under the Treatment Act.

Medicaid enrollment and average spending under the Treatment Act vary across states. In 2006, state enrollment ranged from fewer than 100 women to more than 9,300. Median enrollment was 395 among the 39 states reporting data, with most experiencing enrollment growth from 2004 to 2006. Among the 39 states, average monthly spending per enrollee was \$1,067, ranging from \$584 to \$2,304. Spending may vary due to several factors, including differences in state eligibility policies and practices and Medicaid benefit plan design.

Few statewide alternatives to Medicaid coverage are available to low-income, uninsured women who need breast or cervical cancer treatment but are ineligible for Medicaid under the Treatment Act. Early Detection Program directors in only four of the states with more limited eligibility standards reported having a statewide program that pays for cancer treatment or provides broader health insurance or free or reduced-fee care. And while several sources identified possible local resources as alternatives—donated care, funding from local charity organizations, and county assistance—the availability and applicability of these resources varies by area. For example, an Early Detection Program official in Indiana told us that densely populated areas of the state had multiple treatment resources, but women living in rural areas had limited access to them.

Commenting on a draft of this report, the Department of Health and Human Services concurred with GAO's findings.

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Abbreviations

CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
FPL	federal poverty level
HHS	Department of Health and Human Services
MDE	Minimum Data Elements
MEPS	Medical Expenditure Panel Survey
MSIS	Medicaid Statistical Information System

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United States Government Accountability Office
Washington, DC 20548

May 22, 2009

The Honorable Max Baucus
Chairman
Committee on Finance
United States Senate

The Honorable Barbara A. Mikulski
United States Senate

The Honorable Debbie Stabenow
United States Senate

In 2008, an estimated 182,000 women were diagnosed with breast cancer and 40,000 women died from the disease. In addition, an estimated 11,000 women were diagnosed with and 4,000 women died from cervical cancer. Screening and early detection through mammography and Pap tests to detect breast and cervical cancer—followed by treatment—can improve survival. But among low-income, uninsured women, such screening is underused and access to treatment is sometimes difficult. To improve access to screening, in 1990 Congress authorized the Centers for Disease Control and Prevention (CDC) to make grants to states¹ for breast and cervical cancer screening services, which led the CDC to establish the National Breast and Cervical Cancer Early Detection Program (the Early Detection Program).^{2,3}

¹CDC may make grants to states, which is defined under federal law as the 50 states, the District of Columbia, and U.S. territories. In this report however, the term states only refers to the 50 states and the District of Columbia.

²Breast and Cervical Cancer Mortality Prevention Act of 1990, Pub. L. No. 101-354, 104 Stat. 409 (1990) (codified, as amended, at 42 U.S.C. § 300k, et seq.). In 1993, Congress also expressly authorized the CDC to make grants to tribes and tribal organizations for breast and cervical cancer screening services. Preventive Health Amendments of 1993, Pub. L. No. 103-183, § 101, 107 Stat. 2226, 2228 (1993) (codified, as amended, at 42 U.S.C. § 300n(c)(3)).

³CDC defines eligibility for the Early Detection Program as women who are low income and uninsured or underinsured, such as those who have limited insurance coverage or a high deductible.

Subsequently, the Breast and Cervical Cancer Prevention and Treatment Act of 2000 (the Treatment Act) was enacted, which allowed states to offer Medicaid coverage to uninsured women under the age of 65 who were screened under the Early Detection Program and who need treatment for breast or cervical cancer.⁴ The CDC and the Centers for Medicare & Medicaid Services (CMS), which administers the Medicaid program, define what it means to be screened under the Early Detection Program. States electing to provide Medicaid coverage under the Treatment Act must, at a minimum, offer eligibility to women who received screening services paid for, at least in part, with CDC funds. But states have additional flexibility. For example, a state may extend eligibility to women screened by providers such as community health centers or family planning clinics, regardless of whether the providers receive CDC funds.

Because of concerns that low-income, uninsured women living in certain states may still have difficulty accessing and paying for treatment services, you asked us to report on the impact of the Early Detection Program and the implementation of the Treatment Act. In this report, we examine (1) how many eligible women have been screened by the Early Detection Program; (2) how states have implemented the Treatment Act; (3) how many women have enrolled in Medicaid under the Treatment Act and the average spending by state for this coverage; and (4) alternatives available to low-income, uninsured women who need treatment for breast or cervical cancer, but are not covered under the Treatment Act.

To determine how many eligible women have been screened by the Early Detection Program,⁵ we analyzed information from the CDC's Minimum Data Elements (MDE)⁶ on the number of women screened by the program from 2002 through 2006. We then compared this information with estimates from the Medical Expenditure Panel Survey (MEPS)⁷ on the

⁴Pub. L. No. 106-354, 114 Stat. 1381 (2000) (codified, as amended, at 42 U.S.C. §§ 1396a, 1396b, 1396d, 1396r-1b). U.S. territories also have the option of extending this Medicaid coverage to eligible women.

⁵In this report "screened by the Early Detection Program" means screened by providers who receive CDC funding from grantees of the Early Detection Program.

⁶MDE are data reported by Early Detection Program grantees to CDC. The MDE include data for women whose services were paid for in part or in full with CDC funding.

⁷MEPS, a survey administered by the Agency for Healthcare Research and Quality, is a set of large-scale surveys of families and individuals, their medical providers (doctors, hospitals, pharmacies, etc.), and employers across the United States. The survey collects information including individuals' demographics, health status, and insurance status.

number of low-income, uninsured women⁸ who would likely be eligible for screening by the Early Detection Program, and with the overall number of women who received a mammogram or a Pap test within the recommended screening interval (2 years for a mammogram, 3 years for a Pap test).

To determine how states have implemented the Treatment Act, we conducted a Web-based survey of Early Detection Program directors in the 51 states. We determined that the Early Detection Program directors were knowledgeable about their states' Medicaid eligibility policies and practices regarding the Treatment Act based on preliminary interviews and discussions with the CDC.

To determine how many women have enrolled in Medicaid under the Treatment Act, we analyzed data from CMS's Medicaid Statistical Information System (MSIS).⁹ Data on Treatment Act enrollment were not available for all states and all years. Data are presented for 2004 (38 states) and 2006 (39 states). To determine the average spending by state for providing coverage under the Treatment Act, we analyzed CMS's MSIS data on Medicaid spending for women under the Treatment Act. As with enrollment data, these data were not available for all states and all years. Spending data are presented for 39 states reporting data for 2006.

To identify alternatives available to low-income, uninsured women who need treatment for breast or cervical cancer, but who are not covered under the Treatment Act, we obtained general information from our Web-based survey of Early Detection Program directors. For a more in-depth understanding of these alternatives, we conducted case studies of three states: Florida, Indiana, and Virginia. These states were selected because they are among the states that do not extend Medicaid eligibility under the Treatment Act beyond the minimum, women whose screening services were paid for with CDC funds. These states also have low rates of low-

⁸We defined low income as at or below 250 percent of the federal poverty level (FPL) because federal guidelines allow the Early Detection Program to pay for services for women whose income is at or below this level. Since some grantees set their income eligibility criteria below 250 percent of the FPL, our estimate of potentially eligible low-income women may be a slight overestimate. However, this may be offset by the fact that we were unable to estimate the number of women who were underinsured and thus potentially eligible for the Early Detection Program, as MEPS does not include information on whether women were underinsured.

⁹The MSIS contains state-submitted Medicaid enrollment and claims data.

income, uninsured women screened for breast and cervical cancer by the Early Detection Program when compared to the national average. In each state, we interviewed Early Detection Program directors and other officials,¹⁰ representatives of cancer advocacy groups such as the American Cancer Society and Susan G. Komen for the Cure (Komen for the Cure),¹¹ and other relevant organizations and providers. For more information on our methodology, see appendix I.

We conducted our work from May 2008 to May 2009 in accordance with all sections of GAO's Quality Assurance Framework that are relevant to our objectives. The framework requires that we plan and perform the engagement to obtain sufficient and appropriate evidence to meet our stated objectives and to discuss any limitations in our work. We believe that the information and data obtained, and the analysis conducted, provide a reasonable basis for any findings and conclusions.

Background

The Early Detection Program is implemented through cooperative agreements between the CDC and 68 grantees—health departments in the 50 states, the District of Columbia, and the 5 U.S. territories, as well as 12 American Indian/Alaska Native tribal organizations. The program funds breast and cervical cancer screening services for women who are uninsured or underinsured, have an income equal to or less than 250 percent of the federal poverty level (FPL),¹² and are aged 40 through 64 for breast cancer screenings or aged 18 through 64 for cervical cancer screenings. Within these eligibility criteria, CDC prioritizes certain groups for screening and individual program grantees may target certain groups

¹⁰Other officials included regional coordinators, a quality assurance coordinator, and a case manager.

¹¹Komen for the Cure is a nonprofit organization that supports education, research, and treatment for breast cancer.

¹²Under federal law, grantees must prioritize services to low-income women. 42 U.S.C. § 300n(a). Under its guidance, CDC has defined low income as at or below 250 percent of the FPL. Forty-two grantees set their income criteria at 250 percent of the FPL; 17 at 200 percent; 2 at 225 percent; and 1 at 185 percent. The income criteria for the remaining 6 grantees was not available. Under federal law, grantees must also provide services free of charge to women with income of less than 100 percent of the FPL. 42 U.S.C. § 300n(b).

or broaden eligibility.¹³ Breast cancer screening consists of clinical breast exams and mammograms. Cervical cancer screening consists of pelvic exams and the Pap test.^{14,15} While screening services represent the core of the Early Detection Program, program providers must also provide diagnostic testing and follow-up services for women whose screening tests are abnormal. The CDC funds cannot be used to pay for treatment; however, for women diagnosed with breast or cervical cancer, program providers must provide referrals for appropriate treatment services and case management services, if determined necessary.

The Early Detection Program, which was reauthorized by Congress in 2007, is funded through annual appropriations to the CDC. According to CDC officials, in fiscal year 2008, total funding for the program was approximately \$182 million. To implement the program, the CDC solicits applications to select Early Detection Program grantees every 5 years. All grantees must submit an annual request for funding to CDC. According to CDC officials, annual budgets are awarded based on performance and other factors. By law, grantees must match every \$3 in federal contribution with at least \$1 in non-federal contribution.¹⁶ Grantee matching funds may support the screening or non-screening components of the program. At least 60 percent of the awarded funds must be used for direct clinical services;¹⁷ the remainder may be used for other program functions including program management, education, outreach, quality assurance,

¹³CDC prioritizes screening of women aged 50 to 64 for breast cancer and women aged 40 to 64 who have not been screened in the past 5 years for cervical cancer. Some grantees screen women younger than 18 if they are symptomatic, or 65 and older if they lack the resources to obtain a screening elsewhere. Although women who are enrolled in Medicare Part B are not eligible for the Early Detection Program, the program can serve women 65 and older who cannot afford the premium to enroll in Medicare Part B or are ineligible for Medicare Part B.

¹⁴In the Pap test, cells are collected from the cervix to detect cancer or abnormal cells that may lead to cancer.

¹⁵The U.S. Preventive Services Task Force recommends screening mammography, with or without clinical breast examinations, every 1 to 2 years for women aged 40 and older and Pap tests for women every 3 years, beginning about 3 years after onset of sexual activity, but no later than age 21.

¹⁶42 U.S.C. § 300l(a). The average size of CDC's grant in 2008 was \$2.3 million. The range was from about \$75,000 to \$8.8 million.

¹⁷Under federal law, at least 60 percent of the CDC grant must be expended to provide breast and cervical cancer screenings, to provide appropriate referral for treatment for women screened, and to ensure that the women receive—to the extent practicable—appropriate follow-up services and support services. U.S.C. § 300m(a).

surveillance, data management, and evaluation. Some grantees have also acquired additional state or local resources for their programs. Early Detection Program grantees typically have a network of local providers such as community health centers and private providers that deliver the screening and diagnostic services to women.

Under the Treatment Act states may extend Medicaid eligibility to women who are under age 65, uninsured,¹⁸ otherwise not eligible for Medicaid, and who have been (1) screened under the CDC-funded Early Detection Program and (2) found to be in need of treatment for breast or cervical cancer including precancerous conditions.¹⁹ All 51 states chose to implement this optional Medicaid eligibility category.²⁰ In doing so they were required to provide full Medicaid coverage to eligible women screened under the Early Detection Program and found in need of treatment for breast or cervical cancer. States must provide Medicaid coverage for the period when the woman needs treatment for breast or cervical cancer.²¹ In guidance provided to states, CMS and CDC define “screened under the program” as, at a minimum, offering Medicaid eligibility to women whose clinical services under the Early Detection Program were provided all or in part with CDC funds. Accordingly, CDC officials stated that any state offering Medicaid coverage under the Treatment Act would be required, at a minimum, to offer coverage to

¹⁸A woman must not otherwise have “creditable coverage,” which includes a group health plan, Medicare, Medicaid, Armed Forces insurance, or a state high-risk health insurance pool. However, there are limited circumstances when a woman has creditable coverage but is not actually covered for breast or cervical cancer treatment, which allows her to qualify for Medicaid. For example, if a woman has coverage but is in a period of exclusion for treatment of breast or cervical cancer or has exhausted her lifetime limit on benefits under her health insurance plan, she would not be considered covered for breast or cervical cancer treatment.

¹⁹In 2001, the Native American Breast and Cervical Cancer Treatment Technical Amendment Act was enacted, providing states with the option to extend this Medicaid coverage to American Indians and Alaska Natives who are eligible for health services provided by the Indian Health Service or by a tribal organization. Pub. L. No. 107-121, 115 Stat. 2384 (2002) (codified, as amended, at 42 U.S.C. § 1396a(aa)).

²⁰States seeking to implement the Treatment Act were required to submit an amendment to their existing Medicaid state plan to CMS for approval. State plan amendments were approved for 50 states. Massachusetts amended its existing section 1115 Medicaid demonstration project to include coverage of women with breast or cervical cancer.

²¹Once a woman has completed treatment and is no longer enrolled in Medicaid, those who continue to meet Early Detection Program eligibility requirements may reenter the program for rescreening consistent with the recommendations of the U.S. Preventive Services Task Force for breast and cervical cancer screening.

CDC's Early Detection Program Screens More Than Half a Million Women Annually, but Many Eligible Women Are Not Screened

women screened with CDC funds, provided the women met all other eligibility requirements. The guidance also allows states to use a broader definition of "screened under the program," which includes extending Medicaid eligibility to (1) women screened by a CDC-funded provider within the scope of the state's Early Detection Program, even if CDC funds did not pay for the particular service, or (2) women screened by a non-CDC-funded provider whom the state has elected to include as part of its Early Detection Program.²²

The CDC's Early Detection Program screened about half a million or more women for breast and cervical cancer annually from 2002 through 2006.²³ In 2006, the program screened 579,665 women. There were 331,672 women screened with mammography and 4,026 breast cancers detected. There were 350,202 women screened with a Pap test and 5,110 cervical cancers and precursor lesions detected. Almost half of all women screened by the Early Detection Program in 2006 were screened by grantees in 10 states.²⁴ (See app. II for information by grantee.) A number of factors determined how many women were screened by a grantee, including the CDC funding awarded, the availability of other resources, and clinical costs (for example, the use of more costly screening technologies such as digital mammography).

Over the 5-year period from 2002 through 2006, the Early Detection Program screened 1.8 million low-income, uninsured women. About 1.1 million women were screened for breast cancer, and 18,937 breast cancers were detected. Similarly, about 1.1 million women were screened for cervical cancer, and 22,377 cervical cancers and precursor lesions were detected. The age and race of women screened reflect the Early Detection Program's policies that prioritize breast cancer screening for

²²Regardless of which definition a state chooses, women must meet the income and uninsured status requirements of the Early Detection Program in order to be eligible for Medicaid.

²³The number of women screened is an unduplicated count of women who received a CDC-funded screening procedure (that is, a mammogram, clinical breast exam, or Pap test). A woman might receive more than one procedure in a given year, but she would only be counted once.

²⁴The states were California, Colorado, Florida, Illinois, Michigan, New Jersey, New York, Texas, Washington, and West Virginia.

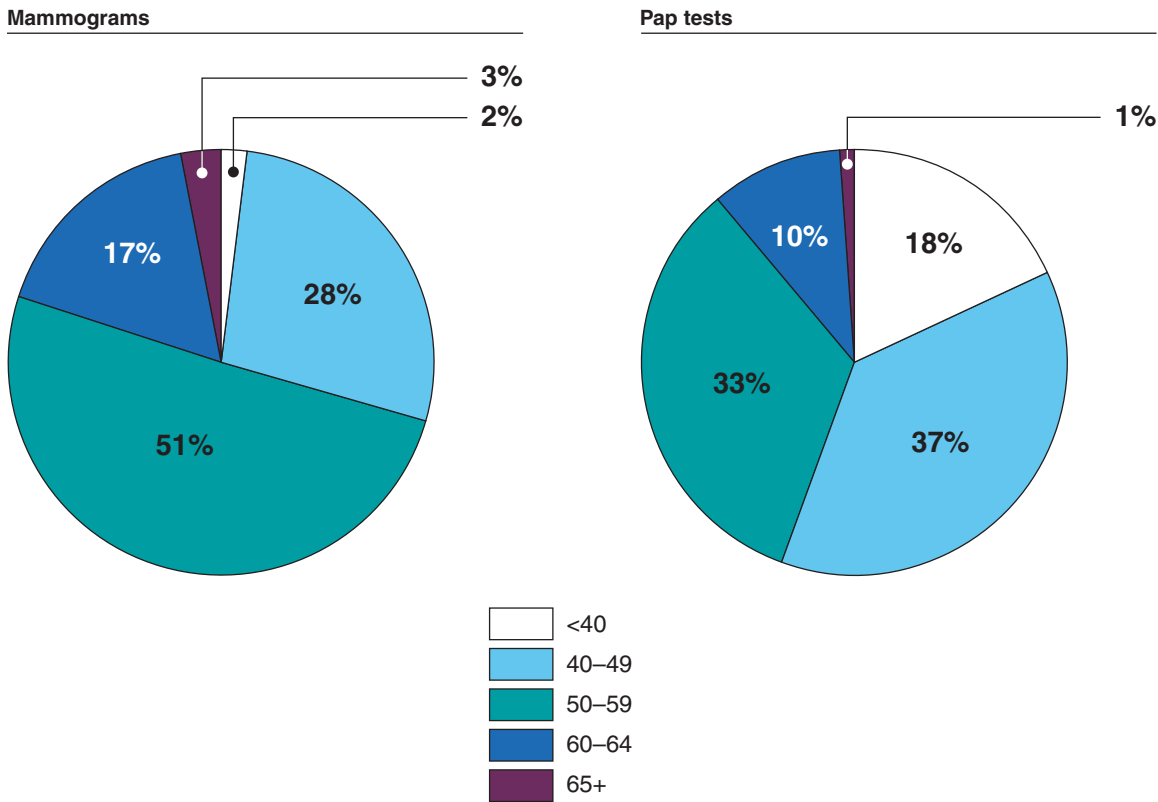
women 50 to 64 years old²⁵ and cervical cancer screening for women 40 to 64 years old.²⁶ Thus, women who received a mammogram tended to be older, with 71 percent age 50 or older. Women who received a Pap test tended to be younger, with 55 percent under age 50. (See fig. 1.) The program also targets racial and ethnic minorities, who tend to have lower screening rates for breast and cervical cancer, so more than half the women screened were racial or ethnic minorities. (See fig. 2.)²⁷

²⁵Twenty-five grantees set the minimum age for mammograms at age 50. However, some of these grantees will cover clinical breast exams at an earlier age or will provide mammograms to a younger woman if she is symptomatic.

²⁶Thirty-three grantees set the minimum age for cervical cancer screening at age 40 or older. However, some of these grantees will screen younger women, if symptomatic, for diagnostic purposes or for other specific reasons.

²⁷Race and ethnicity are self-reported by participants.

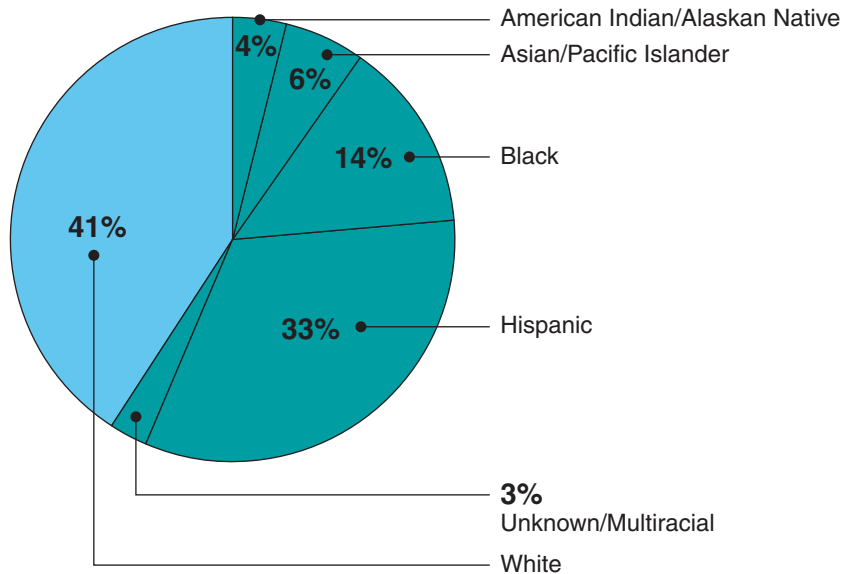
Figure 1: Age of Women Receiving Mammograms or Pap Tests from the Early Detection Program, 2002 through 2006



Source: GAO analysis of CDC MDE data.

Notes: Women aged 40-64 are eligible for breast cancer screening and women aged 18-64 are eligible for cervical cancer screening by the Early Detection Program. Some grantees screened women under age 18 years if they were symptomatic or women aged 65 or older if they lacked resources to obtain a screening elsewhere. Percentages do not add to 100 due to rounding.

Figure 2: Race and Ethnicity of Women Receiving a Screening from the Early Detection Program, 2002 through 2006



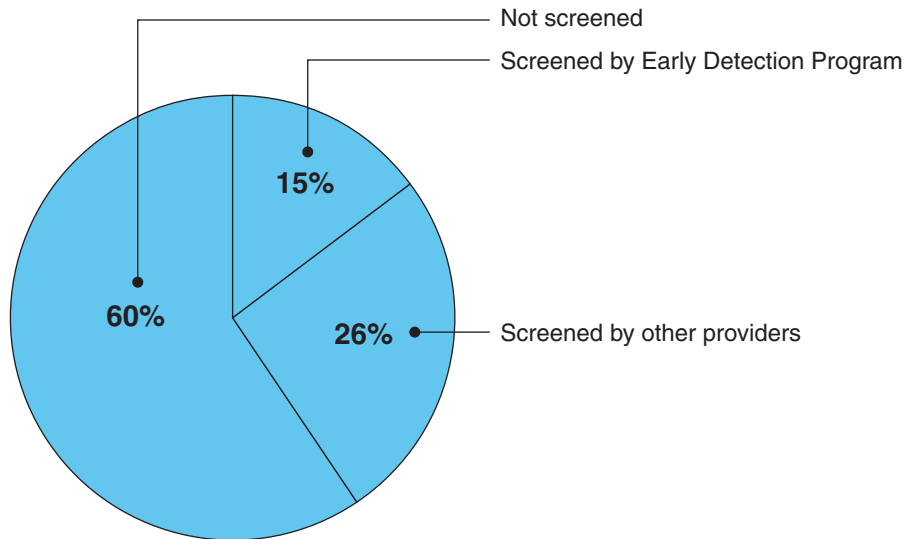
Source: GAO analysis of CDC MDE data.

Notes: Race and ethnicity are self-reported by participants. Percentages do not add to 100 due to rounding.

The Early Detection Program screened a small share of all eligible, low-income, uninsured women, but some eligible women sought screenings from other providers and many were not screened at all.²⁸ From 2005 through 2006, we estimated that the Early Detection Program provided mammograms to about 15 percent of eligible women 40 to 64 years old in the recommended 2-year period. About 26 percent received a mammogram from other providers, such as free clinics and mobile vans. The remaining 60 percent of eligible women did not receive a mammogram from any provider. (See fig. 3.) According to CDC officials, women do not receive mammograms for a variety of reasons, including a lack of insurance, high personal costs such as deductibles and co-pays, fear of painful procedure, fear of having cancer, lack of knowledge about need for screening or recommended screening intervals, inadequate provider capacity, and a lack of accessibility to services in geographically isolated areas.

²⁸We estimated the number of low-income, uninsured women potentially eligible for screening through the Early Detection Program by identifying women whose income was at or below 250 percent of the FPL and who were uninsured.

Figure 3: Percentage of Eligible Women 40 to 64 Years Old Who Received a Mammogram, 2005 through 2006

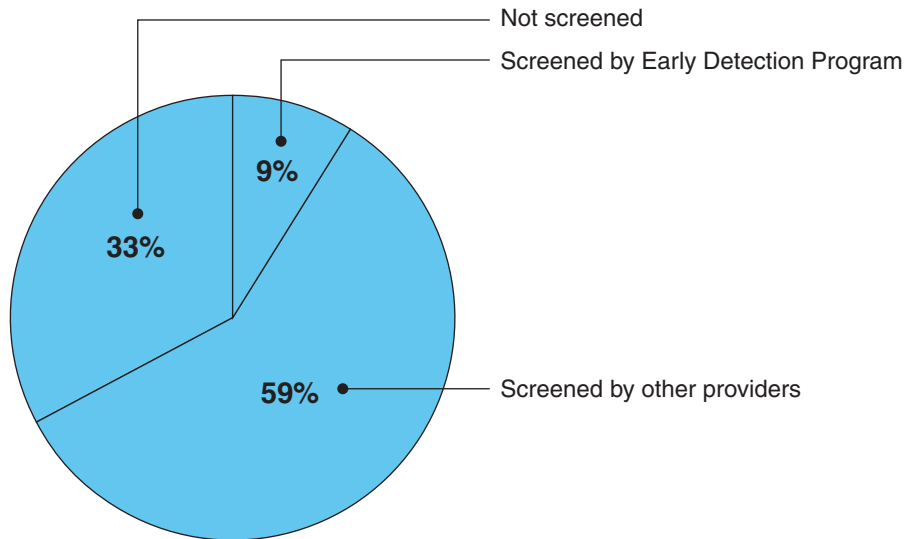


Source: GAO analysis of MEPS and CDC MDE data.

Notes: Eligible is defined as low income (at or below 250 percent of the FPL) and uninsured. Since MEPS does not include women living in the tribes or territories, the percentage of women screened with a mammogram by the Early Detection Program represents those women screened by the 51 state program grantees. Percentages do not add to 100 due to rounding.

From 2004 through 2006, we estimated that the Early Detection Program provided Pap tests to about 9 percent of eligible low-income, uninsured women 18 to 64 years old in the recommended 3-year period. About 59 percent were screened by other providers, such as family planning clinics. (See fig. 4.) The remaining 33 percent of eligible women did not receive a Pap test from any provider. Women do not receive Pap tests for reasons similar to those for not receiving a mammogram.

Figure 4: Percentage of Eligible Women 18 to 64 Years Old Who Received a Pap Test, 2004 through 2006



Source: GAO analysis of MEPS and CDC MDE data.

Notes: Eligible is defined as low income (at or below 250 percent of the FPL) and uninsured. Since MEPS does not include women living in the tribes or territories, the percentage of women screened with a Pap test by the Early Detection Program represents those women screened by the 51 state program grantees. Percentages do not add to 100 due to rounding.

Most States Extend Medicaid Eligibility to More Women Than the Minimum Required, but Some Women Are Still Excluded Based on Screening Source

Most states extend Medicaid eligibility under the Treatment Act to more women than is minimally required—those whose screening or diagnostic services were paid for with CDC funds. As of October 2008, 17 states reported applying only this minimum definition in determining Medicaid eligibility under the Treatment Act. Of the states that extend eligibility, 15 states extend Medicaid eligibility to women served by a CDC-funded provider, whether or not CDC funds were used to pay for services. The remaining 19 states further extend eligibility to women who were screened and diagnosed by non-CDC-funded providers. (See fig. 5.)



Source: Copyright © Corel Corp. All rights reserved (map); GAO survey of state Early Detection Program directors, October 2008.

- **Seventeen states offer Medicaid eligibility only to women screened or diagnosed with CDC funds.** Fifteen of these states require a woman to have received at least one CDC-funded screening or diagnostic service to be considered “screened under the program.” Two states, Florida and the District of Columbia, require that both the screening and diagnostic services be paid for with CDC funds for women to be eligible for Medicaid.

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- **Fifteen states extend Medicaid eligibility to women screened or diagnosed by a CDC-funded provider.** In these states, women whose services were paid for with state or other funds, but delivered by a provider receiving some CDC grant funds, are considered eligible for Medicaid if they need treatment. This allows states that fund their Early Detection Programs above the contribution required to receive the CDC grant to extend eligibility to women screened by a program provider but with other funds.²⁹
 - **Nineteen states further extend Medicaid eligibility to women screened or diagnosed by a non-CDC-funded provider.** Some of these states designate specific providers. For example, Iowa extends eligibility to women whose services were provided by Komen-funded providers. Other states consider women eligible for Medicaid under the Treatment Act if they were screened by any qualified provider.

Among the states that limit Medicaid eligibility to women served only with CDC funds (17 states) or that extend eligibility to women served by a CDC-funded provider (15 states), some have alternate pathways to Medicaid eligibility for women initially screened or screened and diagnosed outside the Early Detection Program. In most of these states, women initially screened outside the program can qualify for Medicaid if they later receive their diagnostic services with CDC funds. Only four states reported they do not allow women who have been screened outside the program to receive diagnostic services under the program to qualify for Medicaid.³⁰

In most of the states that limit Medicaid eligibility to women served with CDC funds or that extend eligibility to women served by a CDC-funded provider, once a woman who received her screening and diagnostic services outside the Early Detection Program is diagnosed with cancer, she cannot access Medicaid coverage under the Treatment Act. However, Early Detection Program directors in 6 of these states reported that women diagnosed outside the program can be rescreened under the program to qualify for Medicaid, and in 11 states women can qualify for Medicaid by receiving additional diagnostic services from a program provider. Although rescreening or providing additional diagnostic services is inefficient and may be medically unnecessary, program rules in some

²⁹Early Detection Program directors in 32 states reported receiving additional state or other funds in 2008 over and above the CDC grant.

³⁰These states are Colorado, Florida, Indiana, and North Carolina.

states require a woman to have received at least one CDC-funded service to qualify for Medicaid. Whether a woman can access Medicaid through one of these alternate pathways depends on her obtaining a referral and on the availability of funds and providers to deliver the additional screening and diagnostic services.³¹

In implementing the Treatment Act, most states reported they require a confirmed diagnosis of breast cancer, cervical cancer, or precancerous lesions to meet the requirement that women be in need of cancer treatment services.³² Two states, Missouri and New Hampshire, indicated that a woman may be enrolled in Medicaid in order to receive certain diagnostic procedures, such as a biopsy or magnetic resonance imaging. A third state, Oklahoma, indicated that an abnormal screening test alone met the standard of needing treatment and qualified a woman for Medicaid coverage. In Oklahoma, women with an abnormal mammogram or Pap test are enrolled in Medicaid for their diagnostic services, and Medicaid coverage ends if they are found to not have a cancer diagnosis.

As of October 2008, 20 states had adopted presumptive eligibility—an option allowed by the Treatment Act—to help women get treatment sooner by provisionally enrolling them in Medicaid while their full application is being processed.³³ Among the states that do not have presumptive eligibility, Early Detection Program directors reported that the average length of time it takes a woman to be enrolled once their application has been submitted did not exceed 30 days, with an overall state average of 9 days.³⁴ In most states, whether or not they have adopted

³¹Early Detection Program providers are not available in all areas of all states. Some Early Detection Program providers have waiting lists for screening and diagnostic services and some exhaust their available funds before the end of the year. One-third of state programs reported having to suspend or limit screening services to eligible women in at least 1 of the 3 previous years after expending their CDC funds before the end of the program year.

³²According to CMS guidance, cancer treatment services can include diagnostic services to determine the extent and proper course of treatment, as well as definitive cancer treatment.

³³Presumptive eligibility allows states to enroll Medicaid applicants for a limited period of time before full Medicaid applications are filed and processed, based on a determination by a Medicaid provider of likely Medicaid eligibility.

³⁴With the exception of unusual circumstances, states have up to 45 days from the submission of a Medicaid application by a nondisabled applicant to determine the applicant's eligibility and notify the applicant. 42 C.F.R. § 435.911(a).

presumptive eligibility, a separate visit to the Medicaid office is not required for a woman to be enrolled in Medicaid under the Treatment Act. Early Detection Program staff receive application materials and then forward applications to the Medicaid agency for approval.

Medicaid Enrollment and Spending under the Treatment Act Vary across States

Medicaid enrollment under the Treatment Act varied widely in 2006, ranging from fewer than 100 women in each of South Dakota, Delaware, and Hawaii to more than 9,300 women in California. (See table 1.) Enrollment was concentrated in a few states, with California, Oklahoma, and Georgia accounting for more than half of all Treatment Act enrollees in 2006. However, Treatment Act enrollees are a small share of Medicaid enrollees overall—less than 0.5 percent—with a median enrollment of 395 across 39 states reporting data for 2006.

Table 1: Medicaid Enrollment under the Treatment Act by State, Ranked by 2006 Enrollment

State	2006 Enrollment	Enrollment per 100,000 women ages 40-64
California	9,333	169
Oklahoma	6,550	1,233
Georgia	4,142	290
Tennessee	2,903	289
Texas	1,580	47
Pennsylvania	1,521	73
Michigan	1,345	80
Louisiana	1,078	156
New York	897	28
Illinois	639	32
South Carolina	614	88
Missouri	606	65
Arkansas	580	127
Minnesota	477	54
Washington	466	44
Virginia	442	34
Maryland	432	45
Rhode Island	409	217
Alabama	398	50
Wisconsin	395	43

State	2006 Enrollment	Enrollment per 100,000 women ages 40-64
Oregon	394	65
Nebraska	356	125
New Mexico	319	102
New Jersey	318	21
Florida	292	10
Utah	277	88
Indiana	269	25
Connecticut	260	41
Colorado	248	33
West Virginia	247	77
Mississippi	226	48
Montana	197	119
Wyoming	188	215
Kansas	188	44
Alaska	169	156
Vermont	125	109
South Dakota	67	56
Delaware	66	45
Hawaii	42	20

Source: GAO analysis of CMS MSIS data and U.S. Census Bureau Population Estimates.

Note: Enrollment data from the following states were not available: Arizona, District of Columbia, Idaho, Iowa, Kentucky, Maine, Massachusetts, North Carolina, North Dakota, Nevada, New Hampshire, and Ohio.

Enrollment may be affected by state policies and practices for initial and ongoing eligibility under the Treatment Act. In general, states with the highest enrollment and highest enrollment as a share of population adopted the broadest definition of “screened under the program” by extending Medicaid eligibility to women served by non-CDC funded providers. In 2006, median enrollment was 639 in these states, or an average of 124 enrollees per 100,000 women 40 to 64 years old. In contrast, median enrollment was 265 in states that limit eligibility to women served with CDC funds or by a CDC-funded provider. In these states an average of 44 women were enrolled for every 100,000 women 40 to 64 years old.

Medicaid enrollment of women covered under the Treatment Act has grown in most states. Seven states experienced growth greater than 70 percent, while one state reported a significant decline from 2004 to 2006. (See app. III.) From 2004 to 2006, the median rate of enrollment growth was 40 percent among the 35 states reporting data for both years. States that shifted to broader definitions of “screened under the program” generally experienced higher than average growth.³⁵ Among states that initially applied the minimum definition of screened under the program, but later broadened eligibility to include women screened by non-CDC-funded providers, enrollment growth averaged 67 percent from 2004 to 2006.³⁶ For example, in 2004 South Carolina limited Medicaid eligibility to women served with CDC funds, but in July 2005 it extended coverage to women served by any qualified provider in the state. Its enrollment grew from 162 women in 2004 to 614 women in 2006.³⁷

Enrollment in Medicaid under the Treatment Act can also be affected by state policies and practices for periodic redetermination of Medicaid eligibility.³⁸ Practices for redetermining eligibility can range from a statement by the beneficiary that she continues to need treatment to a verbal or signed statement by the health provider of the beneficiary’s treatment status. For example, in West Virginia, Medicaid enrollment declined from 709 in 2004 to 247 in 2006 after the state imposed stricter redetermination requirements in 2004.

As with enrollment, average per capita Medicaid spending under the Treatment Act also varies widely across states (see fig. 6). Among the 39 states reporting Medicaid enrollment and spending data for 2006, total monthly spending per Treatment Act enrollee averaged \$1,067, ranging

³⁵Several states that initially offered coverage under the Treatment Act to women served with CDC funds subsequently adopted broader eligibility policies. Kansas, Ohio, and Vermont extended coverage to women served by any CDC-funded provider—with or without CDC funds. South Carolina, Texas, Illinois, Wisconsin, Pennsylvania, and Massachusetts extended coverage to women served by non-CDC-funded providers.

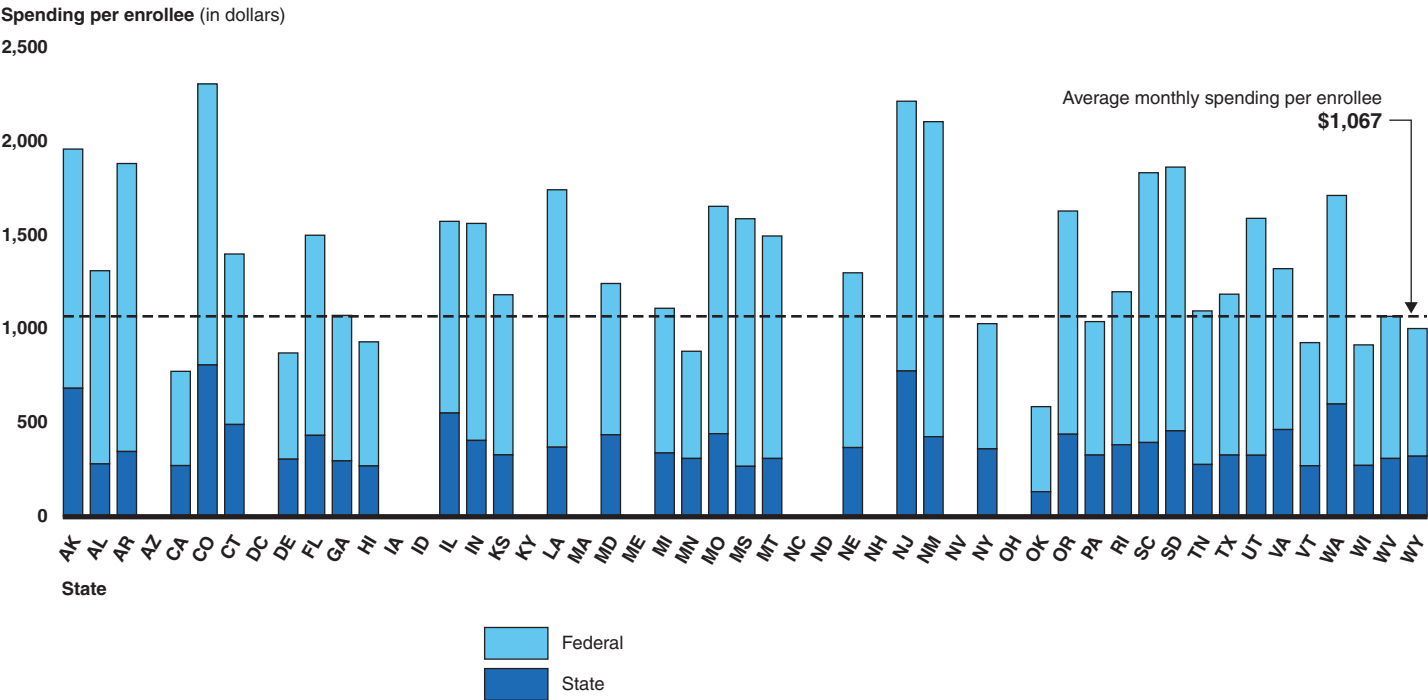
³⁶This includes data from 5 of the 6 states listed above. Data were not available for Massachusetts.

³⁷To address recent state budget challenges, the South Carolina Medicaid agency revised its eligibility policy for the Treatment Act. As of January 1, 2009, coverage under the Treatment Act was available only to women whose screening services were paid for with CDC funds.

³⁸Under federal regulations, states must redetermine the eligibility of Medicaid beneficiaries at least once every 12 months. 42 C.F.R. § 435.916(a).

from \$584 in Oklahoma to \$2,304 in Colorado.³⁹ Federal funds accounted for more than two-thirds of this spending. The average monthly state share per enrollee was \$307, ranging from \$131 in Oklahoma to \$806 in Colorado.⁴⁰

Figure 6: Average Monthly Medicaid Spending per Treatment Act Enrollee by State, 2006



Source: GAO analysis of CMS MSIS data.

Notes: Enrollment and spending data for the following states were not available: Arizona, District of Columbia, Idaho, Iowa, Kentucky, Maine, Massachusetts, North Carolina, North Dakota, Nevada, New Hampshire, and Ohio. Spending may vary across states due to several factors such as differences in Medicaid benefit plan design and reimbursement and differences in eligibility policies and practices.

³⁹Median average monthly spending across the 39 states was \$1,309 in 2006.

⁴⁰States receive an enhanced federal matching assistance percentage, which is the amount the federal government reimburses states for expenditures incurred in providing services to women enrolled in Medicaid under the Treatment Act. In 2006, these percentages, for expenditures for women enrolled in Medicaid under the Treatment Act, ranged from 65 percent to 83 percent.

Some of the variation in average total spending per Treatment Act enrollee may be accounted for by differences in state Medicaid reimbursement rates and variation in states' Medicaid benefit packages.⁴¹ It may also be affected by the relative proportion of breast and cervical cancer patients. For example, a 2007 study using state Medicaid claims data from 2003 in Georgia found that spending for breast cancer patients averaged more than twice that for cervical cancer patients. In 2003, annual Medicaid spending was \$20,285 for each woman with breast cancer, but \$9,845 for each woman with cervical cancer.⁴²

State eligibility policies and practices can also affect average spending. For example, Oklahoma, the state with the lowest monthly per person spending under the Treatment Act, enrolls women in Medicaid based on the results of an abnormal screening test alone. Thus, according to an Oklahoma official, many women in Oklahoma are enrolled in Medicaid only for diagnostic services and do not subsequently incur costs for cancer treatment. At \$584 per month in 2006, average Medicaid spending per Treatment Act enrollee in Oklahoma is the lowest of the 39 states for which we have data. West Virginia has reduced its overall enrollment from 709 in 2004 to 247 in 2006 by taking a proactive approach to disenrolling women if they have completed their cancer treatment, and cannot otherwise qualify for Medicaid. The state requires more than just a woman's self-certification of her continued need for treatment; case managers actively follow women receiving treatment, and a registered nurse evaluation is required to certify their continued need for treatment and Medicaid eligibility. While total spending in West Virginia declined 50 percent in 2006, average monthly per enrollee spending increased by 19 percent, from \$894 to \$1,064.

⁴¹Women enrolled in Medicaid under the Treatment Act qualify for the full range of Medicaid benefits offered in a state, and states differ in the range of services included in their Medicaid benefit package.

⁴²E. Kathleen Adams et al., "The Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) in Georgia: Women Covered and Medicaid Costs in 2003," *Journal of the Georgia Public Health Association*, vol. 1, no. 1 (2007). The researchers identified 1,655 women with breast or cervical cancer who were enrolled in Medicaid under the Treatment Act at the time of their first claim. Of these women, 1,093 had claims for breast cancer and 595 had claims for cervical cancer. The study excluded women who only had claims for treatment of a precancerous cervical condition.

Few Statewide Alternatives to Medicaid Coverage for Treatment Are Available to Low-Income, Uninsured Women; Local Resources Offer Assistance in Some Areas

Among states that limit Medicaid eligibility under the Treatment Act to women screened with CDC funds or that extend Medicaid eligibility to women screened by a CDC-funded provider, few statewide alternatives to Medicaid coverage for treatment are available to low-income, uninsured women who are screened and diagnosed outside of the Early Detection Program.⁴³ Early Detection Program directors in four states⁴⁴ reported having state-funded programs as an alternative to Medicaid. These programs pay specifically for breast or cervical cancer treatment or more broadly provide health insurance coverage or free or reduced-fee health care.

- The Maryland Breast and Cervical Cancer Diagnosis and Treatment Program pays specifically for breast and cervical cancer diagnosis and treatment services, according to our survey. Maryland residents who are within 250 percent of the FPL, are uninsured or meet other health insurance criteria, and were screened for breast or cervical cancer by any medical provider, may be eligible for this program.
- The Delaware Cancer Treatment Program can pay for treatment of breast or cervical cancer, according to our survey. Delaware residents who have been diagnosed with cancer on or after July 1, 2004, have no comprehensive health insurance coverage, and have household incomes less than 650 percent of the FPL may be eligible for free cancer treatment for up to 2 years under this program.
- The state charity hospital system in Louisiana—which provides free health care services for low-income, uninsured residents below 200 percent of the FPL—can provide free breast and cervical cancer treatment, according to our survey. The hospital system also provides reduced-fee care to individuals with incomes above 200 percent of the FPL.
- The Healthy Indiana Plan provides health insurance coverage for state residents who are 19 to 64 years old, earn less than 200 percent of the FPL, have been uninsured for the past 6 months, and do not have access to

⁴³Low-income, uninsured women who are screened outside of the Early Detection Program and ineligible for Medicaid under the Treatment Act may be eligible to enroll in their state Medicaid program through other eligibility categories; for example, women who are pregnant, have children under the age of 18, or are disabled.

⁴⁴State-funded programs reported here reflect Early Detection Program directors' responses to our survey question about statewide programs targeted to breast and cervical cancer diagnosis and treatment and may not necessarily account for all available statewide or state-funded programs.

employer-sponsored health insurance coverage, according to our case study. A program official stated that the benefit package was similar to that of Medicaid and included the same provider network. Since the program's implementation in January 2008, enrollment has been higher than expected, and needed treatment could be delayed because the enrollment process may take 60 to 90 days.

Early Detection Program directors, advocacy groups, and providers reported in our survey and case studies that some local resources were available as alternatives to Medicaid to pay for treatment of breast or cervical cancer.⁴⁵ These include donated care, funding from local charity organizations, and county assistance.

- Physicians may donate free health care services to low-income, uninsured individuals. Fourteen states reported through our survey having donated care available as a resource for breast or cervical cancer treatment. For example, Project Access has networks of physicians in Virginia that provide donated care to eligible residents in local areas.⁴⁶
- Local charity organizations can provide resources to pay for breast or cervical cancer treatment, and 20 states reported through our survey having charity funds available. For example, Anthem Blue Cross Blue Shield and Komen for the Cure affiliates in Indiana provide funding for breast or cervical cancer treatment services for low-income, uninsured women.
- County indigent funds, public assistance programs, and county hospitals can cover some health care costs for low-income, uninsured individuals in some areas. Eleven states reported having some county indigent funds or other public assistance programs available, according to our survey. In Florida, county hospitals provide breast and cervical cancer screening and diagnostic services, as well as funding for treatment costs, for low-income, uninsured women.

⁴⁵Our analysis was based on our review of states that limit Medicaid eligibility under the Treatment Act to women screened with CDC funds or that extend Medicaid eligibility to women screened by a CDC-funded provider.

⁴⁶Project Access is a community partnership of health care providers that provide donated primary care and specialty care to low-income, uninsured individuals in the regions they serve. Other states have created networks of community organizations modeled after Project Access.

However, the availability of these resources varied by locality, and 21 Early Detection Program directors reported as much in our survey. Furthermore, in our case studies, several officials and providers cited concerns over the availability of treatment resources on a local level. For example, an Early Detection Program official in Indiana told us that densely populated areas of the state, such as North Central Indiana and South Bend, had multiple treatment resources, but women living in rural areas had limited access to them. A Komen for the Cure official in Indiana stated there was only 1 county hospital to serve low-income, uninsured residents in a 21-county region. We also spoke with the executive director of a Komen affiliate in Florida who said that some areas of the state, such as West Palm Beach and Tallahassee, had limited treatment resources, while southern areas had more accessible resources. Furthermore, physicians we spoke to in Virginia stated that treatment alternatives vary by location in the state, and some areas have problems with access to care.

Although not required, some Early Detection Program staff help women screened outside the program and ineligible for Medicaid under the Treatment Act find local treatment resources, as reported in two of our case study states. Officials said they encouraged these women to contact local or county hospitals or referred them to available local programs. In addition, three Early Detection Program directors surveyed reported having programs that track the treatment process for women screened outside the Early Detection Program.

Furthermore, in some states, charity organizations have programs to provide referrals to low-income, uninsured women for local treatment resources. We learned from advocacy group representatives in our case study states that Komen for the Cure and the American Cancer Society operate cancer resource hotlines and health insurance information hotlines women can call for information about local cancer treatment resources. They also fund patient navigators who provide counseling and support services, which include finding local programs for women ineligible for Medicaid under the Treatment Act.

Agency Comments

The Department of Health and Human Services (HHS) reviewed a draft of this report and provided comments on our findings, which are reprinted in appendix IV. Overall, HHS concurred with our description of the Early Detection Program. HHS indicated that the data we provided on states' implementation of the Treatment Act, including eligibility options, Medicaid enrollment, and treatment cost data were useful. Finally, HHS

noted that the information contained in our report will be used to make improvements to better serve low-income women.

HHS also provided technical comments, which we incorporated as appropriate.

As we agreed with your offices, unless you publicly announce the contents of this report earlier, we plan no further distribution of it until 30 days from the date of this letter. At that time, we will send copies of this report to the Secretary of Health and Human Services, the Director of CDC, the Administrator of CMS, appropriate congressional committees, and other interested parties. The report also is available at no charge on GAO's Web site at <http://www.gao.gov>.

If you or your staff have any questions regarding this report, please contact me at (202) 512-7114 or cosgrovej@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in appendix V.

A handwritten signature in black ink, appearing to read 'James C. Cosgrove', with a large, stylized initial 'J'.

James C. Cosgrove
Director, Health Care

Appendix I: Scope and Methodology

To determine how many eligible women have been screened by the Early Detection Program,¹ we compared the number of women screened by the Early Detection Program with the number of low-income, uninsured women eligible to be screened, including those who were screened by another provider or were not screened by any provider. We analyzed data from the Centers for Disease Control and Prevention's (CDC) Minimum Data Elements (MDE) to determine the number of women screened by the Early Detection Program. Program grantees report these data to the CDC twice a fiscal year (October and April).² MDE data include data for some women whose services were paid for in part with state or other nonfederal funding. We analyzed MDE data for calendar years 2002 through 2006, including information in total and by grantee on the number of women screened by the Early Detection Program—those who had mammograms and Pap tests—and the number of breast cancers and cervical cancers or precursor lesions detected. We also analyzed the age, race, and ethnicity distributions of the women screened. The Early Detection Program has policies and procedures for standardizing and assessing the quality of the MDE data submitted by grantees. We found the data to be sufficiently reliable for our purposes by reviewing these policies and procedures and the results of an MDE data validation study.

We then compared the number of women screened by the Early Detection Program to the number of women potentially eligible for screening, which we determined with data collected from the Medical Expenditure Panel Survey (MEPS), administered by the Agency for Healthcare Research and Quality.³ For our analysis of women receiving mammograms, we pooled MEPS data for 2005 and 2006 because the U.S. Preventive Services Task Force recommends that women receive a mammogram every 1 to 2 years. We identified how many women were 40 to 64 years old—the age group

¹In this appendix, “screened by the Early Detection Program” means screened by providers who receive CDC funding from grantees of the Early Detection Program. Within the period 2002 through 2006, funding was provided to health departments in the 50 states, the District of Columbia, 6 U.S. Territories, and 15 American Indian/Alaska Native tribal organizations. The time period crossed over two funding cycles of the CDC's Early Detection Program.

²The MDE are a set of standardized data elements considered to be minimally necessary for grantees and CDC to monitor client demographics and clinical outcomes of women screened by the program.

³As part of its household component, MEPS collects the following information from individuals: demographic characteristics, health conditions, health status, use of medical services, charges and source of payments, access to care, satisfaction with care, health insurance coverage, income, and employment.

generally eligible for a mammogram by the Early Detection Program—as well as low income and uninsured. We defined low income as at or below 250 percent of the federal poverty level (FPL) because federal guidelines allow the Early Detection Program to pay for services to women whose income is at or below this level. According to MEPS, women are considered uninsured if they indicated for each of the 12 months of the year that they were not covered under any type of health insurance for the entire month. Although underinsured women are eligible for screenings provided by the Early Detection Program, we were not able to identify this population in MEPS.⁴ Next, we determined how many of these potentially eligible low-income, uninsured women 40 to 64 years old received a mammogram in 2005 to 2006. We then compared this number with the number of women that the Early Detection Program screened with a mammogram in 2005 to 2006.⁵

For our analysis of women receiving Pap tests, we pooled MEPS data for 2004, 2005, and 2006 because the U.S. Preventive Services Task Force recommends that women receive a Pap test at least every 3 years. We identified how many women were 18 to 64 years old—the age group generally eligible for a Pap test by the Early Detection Program—as well as low-income and uninsured, using the above criteria. We determined how many women meeting these criteria received a Pap test in 2004 to 2006. We compared this number with the number of women that the Early Detection Program screened with a Pap test in 2004 to 2006.⁶ In our analyses of women receiving mammograms and Pap tests, we did not examine why women did not receive either of these screening tests, because it was beyond the scope of this report.

⁴Our estimate of low-income women may be a slight overestimate because 20 grantees set their income eligibility criteria below 250 percent of the FPL. However, this may be offset by the fact that we were not able to estimate the number of women who were underinsured, who were potentially eligible for the Early Detection Program.

⁵Since MEPS does not include women living in the tribes or territories, the number of women screened with a mammogram by the Early Detection Program represents those women screened by the 51 state program grantees.

⁶Since MEPS does not include women living in the tribes or territories, the number of women screened with a Pap test by the Early Detection Program represents those women screened by the 51 state program grantees.

We determined that the MEPS data were sufficiently reliable for our purposes by speaking with knowledgeable agency officials at the Agency for Healthcare Research and Quality, reviewing related documentation, and comparing our results with CDC and U.S. Census data.

To determine how states have implemented the Treatment Act, we conducted a Web-based survey of Early Detection Program directors in the 51 states. We reviewed federal guidelines for implementing the Treatment Act, and interviewed Early Detection Program directors and other officials in selected states to gather information to design the survey questions. We reviewed previous studies of the Treatment Act conducted by George Washington University in 2004 under contract with the CDC and by Susan G. Komen for the Cure (Komen for the Cure) in 2007. We determined that the Early Detection Program directors were knowledgeable about their states' Medicaid eligibility policies and practices for the Treatment Act based on this review and discussions with CDC and Centers for Medicare and Medicaid Services (CMS) officials.

The survey included both closed-ended and open-ended questions on characteristics of the Early Detection Program, implementation of the Treatment Act, Medicaid eligibility criteria, and the Medicaid enrollment process. We pretested the survey at CDC's national meeting of Early Detection Program directors in Atlanta, Georgia, on September 9, 2008. The survey was fielded during October 2008, and we obtained a 100 percent response rate from all 50 states and the District of Columbia. Survey responses were edited for logic and appropriate skip patterns. We reviewed survey responses for outliers and followed up with officials in selected states to verify the accuracy of responses.

To determine the number of women enrolled in state Medicaid programs under the Treatment Act and average state spending for this coverage, we analyzed enrollment and spending data from CMS's Medicaid Statistical Information System (MSIS) as presented in the MSIS State Summary Datamart.⁷ The MSIS contains state-submitted Medicaid enrollment and claims data, including each person's basis of eligibility, use of services, basic demographic characteristics, and payments made to providers. We used MSIS data on the number of women enrolled in Medicaid with the Treatment Act as their basis of eligibility by state for fiscal years 2004 and

⁷The MSIS State Summary Datamart was accessed from <http://msis.cms.hhs.gov> (downloaded January 28, 2009).

2006. We then calculated the average per person monthly spending by state for fiscal year 2006 using MSIS data on total spending for Medicaid enrollees under the Treatment Act and the total number of months of eligibility accounted for by all enrollees during the year. Our analysis was limited to 38 states for 2004 and 39 states for 2006 because MSIS data on enrollment and spending were not available for all states or for all years. According to CMS, data from the remaining states either were not reported separately for Treatment Act eligibility or had not yet passed CMS's data quality control process. In addition, we could not separately determine both the number of women enrolled in Medicaid and Medicaid costs for women by diagnosis (breast cancer, cervical cancer, or precancerous conditions) because enrollment data reported in the MSIS State Summary Datamart are not broken down by diagnostic category.

We worked with CMS officials to establish the reliability of the data used in our analysis. States submit their MSIS data quarterly to CMS. The data are submitted to a system of quality control edit checks. Data files that exceed prescribed error tolerance limits are rejected and must be resubmitted by states until they are determined acceptable by CMS. Following the quality review process, data are then posted to CMS's public Web site.⁸ We also reviewed MSIS documentation including user manuals, design specifications, a data dictionary, and known MSIS data anomalies. We also interviewed knowledgeable CMS officials and followed up with states whose reported enrollment and per capita spending data appeared as outliers when we arrayed the data for all states. We determined that the data were sufficiently reliable for our purposes based on our review.

To identify alternatives available to low-income, uninsured women who need treatment for breast or cervical cancer, but who are not covered under the Treatment Act, we obtained general information from our Web-based survey of Early Detection Program directors (described above). We targeted the relevant survey questions to states that limited Medicaid eligibility under the Treatment Act to women screened or diagnosed with CDC funds or that extend Medicaid eligibility to women screened by a CDC-funded provider. Our findings were limited by responses to a narrowly-worded survey question on statewide programs for breast and

⁸CMS's MSIS data contractor has not followed up with states failing to report data in the Treatment Act enrollment category, citing the small number of enrollees compared to the overall Medicaid program.

cervical cancer diagnosis and treatment and may not necessarily account for all available statewide or state-funded programs.

We also conducted case studies of three states that limited Medicaid eligibility under the Treatment Act to women screened or diagnosed with CDC funds only: Florida, Indiana, and Virginia. We chose these states because their rate of screening eligible women was lower than the national average. In each state, we interviewed: Early Detection Program directors and other officials;⁹ representatives from Komen for the Cure,¹⁰ American Cancer Society local chapters, and other state or local organizations; and health care providers. We developed a protocol for each interview with semistructured interview questions and obtained detailed examples of available alternatives to Medicaid under the Treatment Act. Our findings are illustrative examples and thus are not generalizable, because the officials we surveyed and interviewed may not have had complete knowledge of all available local resources, and because available resources may vary by state.

We conducted our work from May 2008 to May 2009 in accordance with all sections of GAO's Quality Assurance Framework that are relevant to our objectives. The framework requires that we plan and perform the engagement to obtain sufficient and appropriate evidence to meet our stated objectives and to discuss any limitations in our work. We believe that the information and data obtained, and the analysis conducted, provide a reasonable basis for any findings and conclusions.

⁹Other officials included regional coordinators, a quality assurance coordinator, and a case manager.

¹⁰We interviewed representatives from Komen state affiliates and a Komen-funded patient navigator. Komen patient navigators are health care workers who provide counseling and support services to breast cancer patients to help them navigate through the health care system and receive quality care.

Appendix II: Number of Women Screened by National Breast and Cervical Cancer Early Detection Program Grantees, 2002–2006

Program	Women screened ^a	Women screened with mammogram	Breast cancers detected	Women screened with Pap Test	Cervical cancers and precursor lesions detected (CIN2 ^b or worse)
Alabama	37,987	19,928	481	21,526	245
Alaska	21,979	4,538	85	19,812	435
Arizona	17,521	11,502	267	9,021	96
Arkansas	17,889	15,879	288	8,516	65
California	394,564	322,523	2,454	112,471	498
Colorado	35,674	20,465	410	23,975	157
Connecticut	12,330	10,784	137	6,946	35
Delaware	9,360	2,112	52	8,190	220
District of Columbia	5,832	3,831	32	3,653	12
Florida	36,989	33,082	606	21,606	107
Georgia	37,937	34,074	577	19,124	456
Hawaii	3,277	2,924	81	2,717	24
Idaho	8,888	7,551	187	5,183	159
Illinois	44,013	30,029	689	27,038	1,017
Indiana	25,685	10,365	292	20,087	249
Iowa	18,870	12,955	285	13,476	171
Kansas	16,243	9,490	164	12,284	344
Kentucky	34,928	18,136	207	31,301	146
Louisiana	18,967	12,532	181	10,429	60
Maine	10,845	9,305	122	8,181	64
Maryland	27,059	19,267	294	21,852	174
Massachusetts	33,652	19,578	275	21,598	684
Michigan	66,507	26,263	355	53,993	1,450
Minnesota	29,107	18,412	292	21,964	1,056
Mississippi	16,496	8,454	245	10,362	181
Missouri	22,102	13,875	552	16,621	503
Montana	9,112	8,110	238	6,423	220
Nebraska	25,142	13,609	276	20,503	852
Nevada	20,702	9,366	217	18,220	167
New Hampshire	10,748	4,894	99	8,932	335
New Jersey	40,525	18,444	324	35,023	327
New Mexico	32,434	19,910	355	24,237	517
New York	160,282	57,236	1,288	103,105	3,477

**Appendix II: Number of Women Screened by
National Breast and Cervical Cancer Early
Detection Program Grantees, 2002–2006**

Program	Women screened^a	Women screened with mammogram	Breast cancers detected	Women screened with Pap Test	Cervical cancers and precursor lesions detected (CIN2^b or worse)
North Carolina	43,340	32,189	511	29,159	426
North Dakota	6,489	3,831	83	5,639	121
Ohio	28,512	20,815	532	20,260	189
Oklahoma	31,708	10,343	248	26,214	141
Oregon	20,935	11,236	334	15,248	278
Pennsylvania	23,897	18,754	383	14,539	308
Rhode Island	10,873	5,011	107	8,224	280
South Carolina	22,954	20,545	276	19,353	93
South Dakota	9,024	3,191	65	7,258	144
Tennessee	20,951	12,220	333	12,400	514
Texas	65,923	45,178	1,304	35,036	2,498
Utah	14,517	12,206	198	8,839	63
Vermont	6,660	3,200	65	5,014	167
Virginia	15,418	14,412	392	10,719	78
Washington	39,480	19,470	547	30,712	238
West Virginia	43,789	24,897	392	34,714	1,337
Wisconsin	28,716	22,331	397	21,416	220
Wyoming	3,011	2,277	83	2,277	223
American Samoa	2,055	742	23	1,682	7
Guam	1,019	847	7	876	8
Commonwealth of Northern Mariana Islands	833	155	<5	774	5
Republic of Palau	3,416	1,228	6	3,183	57
Puerto Rico	296	206	<5	262	0
Virgin Islands	712	386	<5	581	<5
Mississippi Band of Choctaw Indians	180	71	0	180	0
Kaw Nation	1,554	851	6	1,079	44
Yukon-Kuskokwim Health Corporation	2,163	784	<5	1,995	25
Consolidated Tribal Health Project	121	47	0	97	<5
Southeast Alaska Regional Health Consortium	5,472	2,795	41	4,648	35
Hopi Tribe	1,747	1,358	13	1,025	6
Native American Community Health Center	25	21	0	<5	0

**Appendix II: Number of Women Screened by
National Breast and Cervical Cancer Early
Detection Program Grantees, 2002–2006**

Program	Women screened^a	Women screened with mammogram	Breast cancers detected	Women screened with Pap Test	Cervical cancers and precursor lesions detected (CIN2^b or worse)
Navajo Nation	8,707	4,141	21	7,915	7
Native American Rehabilitation Association of the Northwest	1,635	686	12	1,398	24
Arctic Slope Native Association Limited	1,367	615	<5	1,175	7
Southcentral Foundation	15,249	4,763	73	14,412	170
Poarch Band of Creek Indians	263	120	<5	190	<5
Cherokee Nation	11,575	5,899	48	9,318	128
Cheyenne River Sioux	1,248	819	10	734	9
South Puget Intertribal Planning Agency	1,496	848	<5	1,088	19
National Aggregate	1,800,976	1,138,911	18,937	1,108,006	22,377

Source: CDC's Minimum Data Elements reported by Early Detection Program grantees.

Notes: This table reports the number of women screened by all Early Detection Program grantees from 2002 through 2006. During this time period, 50 states, the District of Columbia, 15 American Indian/Alaskan Native tribes, and 6 U.S. territories received funding from CDC's Early Detection Program. A few of the tribe and territorial grantees were funded only for a portion of the years, 2002 through 2006. They include the Commonwealth of Northern Mariana Islands, Virgin Islands, Consolidated Tribal Health Project, and Native American Community Health Center. The time period crossed over two funding cycles of the Early Detection Program.

^aThis is an unduplicated count of women who received a CDC-funded screening procedure (that is, a mammogram, clinical breast exam, or Pap test).

^bCIN2 is an abbreviation for cervical squamous intraepithelial neoplasia, a condition that can lead to cervical cancer.

Appendix III: Medicaid Breast and Cervical Cancer Prevention and Treatment Act Enrollment and Spending, 2006

State	Enrollment		Total annual spending	Monthly spending per capita		
	2004	2006	2006	Total	Federal	State
Alabama	390	398	\$4,733,139	\$1,309	\$1,029	\$279
Alaska	124	169	\$2,173,209	\$1,956	\$1,274	\$682
Arizona	—	—	—	—	—	—
Arkansas	405	580	\$8,570,636	\$1,879	\$1,534	\$345
California	6,719	9,333	\$69,657,527	\$772	\$502	\$270
Colorado	145	248	\$4,858,792	\$2,304	\$1,497	\$806
Connecticut	176	260	\$3,861,573	\$1,397	\$908	\$489
Delaware	47	66	\$356,648	\$870	\$566	\$304
District of Columbia	—	—	—	—	—	—
Florida	209	292	\$3,719,093	\$1,497	\$1,066	\$431
Georgia	2,768	4,142	\$43,601,079	\$1,071	\$775	\$295
Hawaii	33	42	\$371,361	\$928	\$661	\$268
Idaho	—	—	—	—	—	—
Illinois	479	639	\$8,138,906	\$1,570	\$1,021	\$550
Indiana	275	269	\$3,547,444	\$1,561	\$1,156	\$404
Iowa	—	—	—	—	—	—
Kansas	107	188	\$1,819,427	\$1,180	\$853	\$327
Kentucky	362	—	—	—	—	—
Louisiana	659	1,078	\$16,248,144	\$1,738	\$1,371	\$368
Maine	143	—	—	—	—	—
Maryland	—	432	\$5,365,543	\$1,240	\$806	\$434
Massachusetts	—	—	—	—	—	—
Michigan	—	1,345	\$13,344,682	\$1,108	\$771	\$337
Minnesota	354	477	\$2,971,940	\$879	\$571	\$308
Mississippi	156	226	\$2,407,028	\$1,586	\$1,319	\$266
Missouri	516	606	\$8,611,334	\$1,650	\$1,211	\$440
Montana	151	197	\$2,253,399	\$1,492	\$1,185	\$308
Nebraska	323	356	\$3,247,296	\$1,297	\$931	\$366
Nevada	165	—	—	—	—	—
New Hampshire	—	—	—	—	—	—
New Jersey	198	318	\$7,018,332	\$2,210	\$1,437	\$774
New Mexico	309	319	\$6,022,159	\$2,102	\$1,678	\$424
New York	717	897	\$7,095,939	\$1,027	\$667	\$359
North Carolina	—	—	—	—	—	—

**Appendix III: Medicaid Breast and Cervical
Cancer Prevention and Treatment Act
Enrollment and Spending, 2006**

State	Enrollment		Total annual spending	Monthly spending per capita		
	2004	2006	2006	Total	Federal	State
North Dakota	—	—	—	—	—	—
Ohio	—	—	—	—	—	—
Oklahoma	—	6,550	\$23,226,705	\$584	\$453	\$131
Oregon	217	394	\$5,695,840	\$1,626	\$1,189	\$437
Pennsylvania	1,090	1,521	\$12,225,505	\$1,038	\$711	\$326
Rhode Island	303	409	\$4,039,385	\$1,197	\$815	\$381
South Carolina	162	614	\$10,491,019	\$1,830	\$1,437	\$393
South Dakota	44	67	\$1,259,064	\$1,860	\$1,405	\$455
Tennessee	712	2,903	\$25,158,691	\$1,094	\$818	\$276
Texas	846	1,580	\$18,901,552	\$1,183	\$857	\$326
Utah	282	277	\$3,852,413	\$1,587	\$1,262	\$325
Vermont	73	125	\$938,930	\$924	\$656	\$269
Virginia	336	442	\$5,371,603	\$1,319	\$857	\$462
Washington	—	466	\$7,244,698	\$1,709	\$1,111	\$598
West Virginia	709	247	\$2,692,830	\$1,064	\$863	\$201
Wisconsin	269	395	\$3,313,859	\$913	\$642	\$271
Wyoming	134	188	\$1,601,317	\$1,000	\$680	\$320

Source: GAO analysis of CMS MSIS data.

Note: Total annual spending includes both the federal and state share.

Appendix IV: Comments from the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

APR 24 2009

James Cosgrove
Director, Health Care
U.S. Government Accountability Office
441 G Street N.W.
Washington, DC 20548

Dear Mr. Cosgrove:

Enclosed are comments on the U.S. Government Accountability Office's (GAO) report entitled: "MEDICAID: Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States (GAO-09-384).

The Department appreciates the opportunity to review this report before its publication.

Sincerely,

A handwritten signature in cursive script that reads "Barbara Pisaro Clark".

Barbara Pisaro Clark.
Acting Assistant Secretary for Legislation

Attachment

**GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
(HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT
ENTITLED: MEDICAID -- SOURCE OF SCREENING AFFECTS WOMEN'S ELIGIBILITY
FOR COVERAGE OF BREAST AND CERVICAL CANCER TREATMENT IN SOME STATES
(GAO-09-384)**

The U.S. Department of Health and Human Services, including the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS), wishes to thank the GAO for the opportunity to review and comment on this draft report. HHS concurs with the GAO's overall description of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and respectfully offers the following general comments to add clarification in describing this complex national screening program. Technical comments and edits for the draft GAO report are provided in a separate document.

The CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is built on a public health model and presently funds 68 programs across the country including all 50 states and the District of Columbia plus the 5 U.S. territories and 12 American Indian and Alaska Native (AI/AN) tribes and tribal organizations. Whereas only the states and DC are included in this study of treatment for women diagnosed with breast or cervical cancer, we appreciate that the summary of the NBCCEDP (pages 10-13) and Appendix II (pages 40-43), using CDC's Minimum Data Elements (MDE), reflects all NBCCEDP grantee programs within years 2002-2006.

The MDEs (NBCCEDP surveillance and tracking system) contain patient-level demographic, screening, diagnostic, and treatment initiation data on every woman receiving an NBCCEDP-funded breast or cervical cancer screening since the program's inception in 1991. The MDE data are routinely used for program management and evaluation by CDC and individual grantee programs.

On page 10, the report briefly discusses the factors that determine how many women are screened by a state. The number of women screened by a NBCCEDP-funded program varies depending on many factors such as the amount of CDC and non-Federal funds available (e.g., state appropriations, Komen for the Cure, or the American Cancer Society) for breast and cervical cancer screening, state Medicare reimbursement rate for approved breast and cervical cancer screening and diagnostic procedures, proportion of breast (more expensive) versus cervical (less expensive) cancer screening, number of diagnostic procedures (more expensive) completed, and other factors. Likewise, screening and treatment availability in a state varies depending on factors such as geographic isolation where medical providers and clinical services are scarce compared to a population dense area such as large cities. CDC is presently conducting an economic cost analysis study of the 68 NBCCEDP-funded programs; a pilot cost analysis study¹ in nine states was published in December, 2007.

On pages 13-15 and 34-35, the report described their analysis of MEPS (Medical Expenditure Panel Survey) data to obtain an estimated eligible population and calculate a screening rate for breast and cervical cancer by the NBCCEDP. The CDC and US Census Bureau have collaborated in analyzing official Census data to determine the estimated eligible population for the NBCCEDP and the program's screening rates. CDC notes that the estimated screening rates for both cancers using MEPS are entirely consistent with the screening rates calculated using official US Census data -- 15% versus 14.7 for breast

¹ Ekwueme DU, Gardner JG, Subramanian S, Tangka FK, Bapat B, Richardson LC. (2008) Cost analysis of the National Breast and Cervical Cancer Early Detection Program; selected states, 2003 to 2004. Cancer 112:626-35

**GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
(HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT
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(GAO-09-384)**

cancer screening² and 9% versus 8.7% percent for cervical cancer screening³. We are very pleased and grateful to have independent validation of our screening rates by GAO. However, CMS notes that the report is silent as to why so many women fail to access the system and receive the screening benefit.

Moreover, a new dataset, "Health Insurance Coverage Status by Age, Race, Hispanic Origin, Sex and Income for Counties and States: 2005," was jointly released by CDC and the US Census Bureau online in October, 2008 (<http://www.census.gov/hhes/www/sahie/data/index.html>). This dataset is available for the first time and allows users to generate state-specific and county-specific estimates of eligible population for the NBCCEDP. Such small area analyses will enable better targeting and resource allocation to reach eligible women for screening. Through ongoing collaboration, we plan to continuously update the estimated eligible population and screening rates as new Census population estimates become available.

On pages 18-19, the report describes the alternative pathways to Medicaid eligibility for women initially screened or screened and diagnosed outside the Early Detection Program. Within the national program guidelines for eligibility, each grantee program implements policies and strategies to reach underserved women. The CDC national program guidelines allow diagnostic referrals for women with an abnormal screening test whose initial screening was not paid for with NBCCEDP funds. If these women meet the NBCCEDP eligibility criteria, program funds may be used to pay for their diagnostic work-up. As for the 11 states the report described who rescreen or provide additional diagnostic tests for women already screened and diagnosed with cancer by a non-program provider, CDC has no data or evidence that this is a highly prevalent practice.

On pages 27-31, the report addresses 'Alternatives to Medicaid Coverage for Treatment...' and describes the challenges and some examples of treatment options other than through the Treatment Act. In accepting CDC funding, NBCCEDP grantees are required to identify alternative sources of treatment for women who are diagnosed with breast and/or cervical cancer if they do not qualify to receive treatment through the Medicaid Program. CDC's grantee staff know that women may die from cancer if they do not have access to treatment. They passionately care, know their communities, and exercise creativity and determination in identifying alternative sources of treatment for these women.

We would like to add that once a woman's cancer treatment is completed through Medicaid or an alternative source, those who continue to meet the NBCCEDP eligibility requirements may re-enter the program for rescreening consistent with recommendations of the US Preventive Services Task Force for breast and cervical cancer screening. Regular re-screening is critically important for women who have had cancer and been successfully treated.

² Tangka FK, Dalaker J, Chattopadhyay SK, Gardner JG, Royalty J, Hall IJ, DeGroff A, Blackman DK, Coates RJ. (2006) Meeting the mammography screening needs of underserved women: the performance of the National Breast and Cervical Cancer Early Detection Program in 2002-2003 (United States). *Cancer Causes Control* 17(9):1145-54

³ Tangka FL, O'Hara B, Gardner JC, Turner J, Royalty J, Shaw K, Sabatino S, Ingrid J.E. Hall, Coates RJ. Meeting the Cervical Cancer Screening Needs of Underserved Women: The Performance of the National Breast and Cervical Cancer Early Detection Program in 2003-2005. This manuscript is presently under review by a peer-review journal for publication consideration.

**GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
(HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT REPORT
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(GAO-09-384)**

On pages 15-18, 21-26, 36-38, and 44-45, the report describes implementation of the Treatment Act through state Medicaid Programs. CDC appreciates having access to current information on the Medicaid (Treatment Act) eligibility options used in states, Medicaid enrollment, and treatment cost data.

Finally, on page 36, the report notes, 'the Early Detection Program Directors were knowledgeable about their states' Medicaid eligibility policies and practices for the Treatment Act...' The CDC values its partnership with the Medicaid Program and we would particularly like to acknowledge the excellent and effective partnership between the NBCCEDP grantees and their state Medicaid Programs. All across the country, staff from both programs closely collaborates to facilitate timely access to treatment for eligible women diagnosed with breast or cervical cancer.

HHS was pleased to cooperate with the GAO on their study of the NBCCEDP and Medicaid Program's implementation of the Treatment Act. The information contained in this report will certainly be used to make improvements to better serve low income women in need of breast and cervical cancer screening across the country.

Appendix V: GAO Contact and Staff Acknowledgments

GAO Contact

James C. Cosgrove, (202) 512-7114 or cosgrovej@gao.gov

Acknowledgments

In addition to the contact named above, Jennifer Grover, Assistant Director; Anne Dievler; Eric Anderson; Seta Hovagimian; Dan Ries; Hemi Tewarson; Timothy J. Walker; and Suzanne Worth made key contributions to this report.

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