State Implementation of the Breast and Cervical Cancer Prevention and Treatment Act of 2000: A Collaborative Effort Among Government Agencies

Cynthia French, MA[a]
Susan True, MEd[a]
Rosemarie McIntyre, RN, MS[a]
Margherita Sciulli, MPA[b]
Kathleen A. Maloy, JD, PhD[c]

SYNOPSIS

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), administered by the Centers for Disease Control and Prevention through grants to states, tribes, and territories, has successfully provided breast and cervical cancer screening and diagnostic services to low-income women since 1990. On October 24, 2000, Congress passed the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) authorizing states, if they chose, to provide Medicaid coverage for treatment services for women screened under the NBCCEDP. Under BCCPTA, uninsured women younger than age 65 who are screened through the NBCCEDP and found to have breast or cervical cancer (or precancerous conditions) may gain access to Medicaid services for and during their cancer treatment. Implementation of the BCCPTA requires collaboration and coordination among many government agencies, including the Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, state Medicaid directors, and directors of state and tribal grant programs. This article describes the implementation of the program and demonstrates to policy makers that coordinating resources among government agencies can facilitate the rapid adoption of public health programs as pathways for specific populations to gain access to publicly funded health insurance coverage.

[a]Program Services Branch, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA

[b]Centers for Medicare & Medicaid Services, Baltimore, MD

[c]Department of Health Policy, School of Public Health and Health Services, The George Washington University, Washington, DC

Address correspondence to: Cynthia French, MA, Program Services Branch, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, 4770 Buford Hwy. NE, MS K-57, Atlanta, GA 30341-3717; tel. 770-488-3156; fax 770-488-3230; e-mail <cyp2@cdc.gov>.

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), administered by the Centers for Disease Control and Prevention (CDC) through grants to states, tribes, and territories, has successfully provided breast and cervical cancer screening and diagnostic services to low-income women since 1990.[1] Although the authorizing language of the NBCCEDP specifically precludes the use of these funds for treatment, grantees are required to assure that clients have access to affordable treatment services. While grantees have been quite successful in obtaining low-cost or pro bono services, identifying and brokering these services is complex and time consuming. Women's treatment choices may be influenced by cost as much as preference. Awareness of these challenges led to action by advocacy groups, and on October 24, 2000, Congress passed the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) authorizing states, if they chose, to provide Medicaid coverage for treatment services for women screened through the NBCCEDP.[2] Researchers from The George Washington University will assess the impact of early access to treatment on the health outcomes and treatment experiences of enrolled women.

Implementing the BCCPTA requires cooperation and coordination among a number of government partners, including the CDC, Centers for Medicare & Medicaid Services (CMS), state Medicaid directors, and directors of state and tribal grant programs. This article outlines the methods used to implement BCCPTA to date and demonstrates the implications for future partnerships among government agencies working toward adoption of public health programs that allow specific populations to gain access to publicly funded health insurance coverage.

METHODS

Implementation of the BCCPTA was coordinated through various communications among CMS, CDC, state Medicaid directors, state screening program directors, service providers, and other stakeholders. These communications ranged from daily telephone and e-mail consultations among CDC and CMS staff members to conference calls, website postings, and a meeting of CDC, CMS, state and tribal screening program directors, and state Medicaid directors in October 2002.

Barriers to the implementation partnership were virtually nonexistent at the federal level, due to constant communication between CDC and CMS personnel. The only major communication barrier experienced during the implementation resulted from the fact that CMS does not typically have routine contact with state Medicaid directors. This provides more opportunities for miscommunications—especially among CMS and state Medicaid directors, and somewhat among state and tribal screening program and Medicaid directors. In efforts to overcome this potential barrier, the stakeholders organized a face-to-face meeting of state and tribal screening program directors, state Medicaid directors, and CDC and CMS staff members to address and help resolve BCCPTA issues and improve communication.

CMS interpretation letter

On January 4, 2001, the CMS issued a letter to state health officials outlining the federal interpretation of BCCPTA.[3] The letter explained that states that wished to choose the BCCPTA option were required to submit an amendment to their existing Medicaid State Plan to CMS for approval. If their plan amendments were approved, states could provide Medicaid coverage for women diagnosed with a breast or cervical cancer or pre-cancerous condition under the state's screening program. If their amendments were not approved, CMS would work with them (i.e., suggesting changes or requesting additional information), and they could resubmit the plan amendment.

Advocate support

As state Medicaid directors evaluated the interpretation letter and considered administrative costs, implementation issues, and appropriations needed for this new provision, the American Cancer Society (ACS) worked with national and local media to communicate the importance of the BCCPTA to the general public. The ACS also met with state Medicaid directors, governors, and state legislators to educate and galvanize support, and worked with state screening program directors to ensure provider participation in the program and to address implementation-related issues. CDC staff members collaborated with ACS and other stakeholders by providing evidence-based cancer information to support public education efforts.

Daily coordination between CDC and CMS

Key staff members from CDC and CMS discussed implementation issues via telephone and e-mail nearly daily. Decisions about issues in question were made based on a mutual understanding of which agency had responsibility to answer the specific question. When issues arose that involved a particular state, conference calls were scheduled to include the CDC and CMS staff members as well as the appropriate state screening program and Medicaid directors.

Conference calls

As states began submitting plan amendments, numerous questions arose from screening program and Medicaid directors regarding the federal interpretation of the Act and the need to collect data related to its implementation. Dialogue between CDC and CMS staff led to the coordination of conference calls tailored to address unique questions from the states. Calls usually involved at a minimum the BCCPTA contact persons for CDC and CMS, state Medicaid and screening program directors (usually to address a question one of them had asked), and the CDC program consultant assigned to work with each screening program. If the question was not resolved during the call, the CDC and CMS contact persons sought higher authorities within their agencies to answer the question, and communicated the resolution to interested parties via e-mail.

One unintended consequence of the interpretation of the Act was confusion among state screening program and Medicaid directors about determining which women would be eligible to receive services under the Act. This confusion often became apparent during conference calls. If a state chose to enroll women under the BCCPTA, the CMS policy stated that eligible women were those screened under the NBCCEDP. In addition, the states could choose to screen women who: (*1*) ". . . are screened under a state Breast and Cervical Cancer Early Detection Program in which their particular clinical service was not paid for by CDC Title XV funds, but the service was rendered by a provider and/or an entity funded at least in part by CDC Title XV funds, and the service was within the scope of a grant, sub-grant or contract under that state program . . ." and/or (*2*) ". . . are screened by any other provider and/or entity and the CDC Title XV grantee has elected to include screening activities by that provider as screening activities pursuant to Title XV." As state screening program directors decided which categories of screened women with positive findings could be referred to Medicaid for treatment, it sometimes became apparent that the screening program's interpretation of appropriate referrals differed from that of the Medicaid directors. For example, some state screening program and Medicaid directors simply did not agree on which categories of women should be referred to Medicaid. One state chose to refer only selected subcategories of women partially funded with CDC funds.

CMS and CDC websites

CMS and CDC both posted information about the BCCPTA on their websites, including a summary of actions, a state activity map illustrating the status of approved state plan amendments, a sample model agreement that could be used as a guide for state Medicaid and screening program directors to designate responsibilities, an opportunity to e-mail questions about the Act, and an extensive list of technical and policy questions and answers developed as a result of the many inquiries received by CDC and CMS.[4–6]

Legislative amendments

When advocates such as the ACS and the National Breast Cancer Coalition recognized that the BCCPTA extended coverage only to eligible women who had no "creditable coverage" as defined by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), they sought a legislative remedy. Because the HIPAA definition includes a reference to the medical care program of the Indian Health Services, the law effectively excluded Indian women from eligibility for Medicaid under the BCCPTA. Advocates quickly addressed this issue, and on January 15, 2002, the Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001 was signed into law.[7] The Technical Amendment establishes eligibility for Medicaid treatment of American Indian and Alaska Native women screened through the federally funded screening programs and found to need treatment. This eligibility applies even if they are also eligible for medical care provided by the Indian Health Services.

Joint CDC/CMS meeting

As CDC and CMS continued to communicate state-by-state and to identify categories of similar questions and common concerns, the need to conduct a face-to-face meeting among CDC and CMS staff and their state directors became apparent. Preparation for the meeting brought to light major differences in the organizational, administrative, and operational methods used within these agencies. For example, CDC funds its programs using a cooperative agreement process in which there is a continual, almost daily, information exchange between CDC and the state screening program directors. These communications are intensely focused on the management and implementation of specific policies, program components, or special initiatives. In contrast, although state Medicaid plans are approved by CMS, state Medicaid is primarily a financial system rather than a program focused on specific disease processes. Because CMS does not have routine contact with the state Medicaid offices at an operational level, even identifying the appropriate state Medicaid representatives to attend the meeting was a challenge. The October 2002 meeting in Atlanta pro-

vided opportunities for the agencies to learn how each operated, to solve problems jointly and identify continuing challenges, and to learn how resources could be shared to maximize the benefits of implementing BCCPTA activities. Roundtable discussions held among state screening program and Medicaid directors led to opportunities for future problem solving among all concerned. The information learned by CDC and CMS representatives is being used to develop guidance and additional policies related to the BCCPTA.

The BCCPTA implementation study

In February 2002, CDC and CMS engaged The George Washington University (GWU) Center for Health Services Research and Policy to conduct a 20-month study to identify the states' initial efforts to implement the BCCPTA. This research uses a case study approach in selected states to identify: (*1*) how states are taking advantage of this new Medicaid option; (*2*) how state Medicaid and screening program directors are collaborating on implementation; (*3*) whether and how the BCCPTA implementation is affecting the operation of state screening programs; (*4*) what procedures are being developed for enrolling women in Medicaid; and (*5*) the states' experiences to date in implementing the BCCPTA.

The study's primary method of data collection involves interviews with a range of state stakeholders, including state Medicaid and screening program directors and representatives from provider and community organizations. Several key issues guide the interviews and analysis: (*1*) the women chosen to be screened by the states; (*2*) the key challenges encountered in implementation; (*3*) the factors facilitating collaboration between the state Medicaid and screening program directors; (*4*) whether existing state screening programs and staff have been affected; (*5*) how BCCPTA Medicaid eligibility is determined; and (*6*) whether access to treatment through Medicaid has been expanded for uninsured women.

RESULTS

As of January 1, 2003, 49 states and the District of Columbia had elected to cover women eligible for treatment under the BCCPTA (see the Table). Anecdotally, screening program directors have shared that more women are willing to be screened, and more physicians are willing to conduct screening, now that treatment through the BCCPTA has become a reality for those for whom it was not previously a viable option. Data regarding the number of women referred to Medicaid by each screening program are collected annually as part of states' funding applications to CDC.

The GWU implementation study provides early information and insights regarding how states can and are implementing the BCCPTA. The study examines three questions that must be addressed before assessing the impact of the BCCPTA: (*1*) can the BCCPTA be implemented, (*2*) how is implementation working, and *(6)* is the BCCPTA being implemented as intended. Impact research will assess the effect of the BCCPTA on the timeliness and appropriateness of treatment for uninsured women diagnosed with breast or cervical cancer and will assess whether using a public health screening program as a pathway to publicly funded health insurance coverage can improve access to care and health outcomes.

Findings from the GWU study indicate relatively smooth BCCPTA implementation and easy inter/intra-agency collaboration in the states. Despite confusion about particular operational elements of the BCCPTA (e.g., states had difficulty understanding the screening options created by federal guidance that allowed states to consider expanding access to BCCPTA Medicaid to women who haven't received a CDC-funded service), states were able to establish the new Medicaid coverage. Because state screening programs vary widely, state approaches to BCCPTA varied as well, but this variability did not appear to affect the enrollment of eligible women, which proceeded smoothly. It is noteworthy that the states made BCCPTA Medicaid eligibility procedures very simple and women do not have to go to the Medicaid/Welfare offices to enroll. State experiences with estimated and actual Medicaid expenditures also varied, although due to the early stage of implementation, these findings are limited.

Findings also suggest that the impact on nearly half of the state screening programs was greater than expected due to two new duties: (*1*) tracking women for initial Medicaid eligibility and (*2*) managing women's ongoing Medicaid eligibility. While screening programs were traditionally concerned about assuring that women could initiate treatment, the extent to which they took on new responsibilities related to the BCCPTA varied depending on several factors, including: (*1*) the extent of the program's existing/customary activities; (*2*) whether the state Medicaid agency requested the new duties; and (*3*) whether the state screening programs could voluntarily assume new duties. A few state screening programs reported decreased workloads because previously uninsured women diagnosed with cancer and needing treatment now have

Table. Submission, approval, and implementation dates for the Breast and Cervical Cancer Prevention and Treatment Act of 2000

State	*Received*[b]	*Approved*[b]	*Date*[c]	*State*	*Received*[b]	*Approved*[b]	*Date*[a]
Alabama	06/22/01	08/27/01	10/01/01	Montana	05/24/01	06/01/01	07/01/01
Alaska	09/19/01	10/19/01	07/01/01	Nebraska	09/07/01	10/19/01	07/01/01
Arizona	09/24/01	10/18/01	01/01/02	Nevada	06/10/02	08/14/02	07/01/02
Arkansas	09/21/01	10/19/01	12/01/01	New Hampshire	03/06/01	03/23/01	03/01/01
California	09/12/01	10/18/01	01/01/02	New Jersey	09/28/01	12/06/01	07/27/01
Colorado	05/08/02	07/26/02	07/01/02	New Mexico	08/20/02	10/29/02	07/01/02
Connecticut	08/13/01	10/19/01	07/02/01	New York	06/24/02	09/20/02	10/01/02
Delaware	10/04/01	01/08/02	10/01/01	North Carolina	02/08/02	03/12/02	01/01/02
District of Columbia	09/30/02	12/27/02	07/01/02	North Dakota	07/13/01	08/27/01	07/01/01
Florida	08/30/01	10/19/01	07/01/01	Ohio	04/01/02	05/10/02	07/01/02
Georgia	06/20/01	08/27/01	04/01/01	Oklahoma			
Hawaii	07/29/01	10/18/01	07/01/01	Oregon	01/02/02	02/08/02	04/01/02
Idaho	05/21/01	06/01/01	07/01/01	Pennsylvania	12/31/01	02/15/02	01/01/02
Illinois	05/23/01	06/01/01	07/01/01	Rhode Island	03/24/01	05/14/01	01/01/01
Indiana	05/23/01	06/01/01	07/01/01	South Carolina	07/26/01	08/27/01	07/01/01
Iowa	07/17/01	08/27/01	07/01/01	South Dakota	05/18/01	06/01/01	04/01/01
Kansas	08/15/01	10/19/01	10/01/01	Tennessee	04/24/02	05/31/02	07/01/02
Kentucky	09/20/02	11/13/02	10/01/02	Texas	08/12/02	10/15/02	12/01/02
Louisiana	03/27/02	04/18/02	01/01/02	Utah	05/04/01	06/01/01	04/01/01
Maine	09/14/01	10/19/01	10/01/01	Vermont	09/28/01	10/19/01	07/01/01
Maryland	12/28/00	03/23/01	04/01/02	Virginia	06/19/01	08/27/01	07/01/01
Massachusetts[a]	07/16/02	12/04/02		Washington	07/07/01	08/27/01	07/01/01
Michigan	09/28/01	10/19/01	07/01/01	West Virginia	03/01/01	03/23/01	04/02/01
Minnesota	05/14/02	07/02/02	07/01/02	Wisconsin	03/26/02	04/17/02	01/01/02
Mississippi	07/13/01	08/27/01	07/01/01	Wyoming	08/28/01	10/19/01	10/01/01
Missouri	07/27/01	08/27/01	08/28/01				

[a]BCCPTA eligibility group added via amendment to existing section 1115 demonstration project rather than via state plan amendment (not yet implemented).

[b]By the Centers for Medicare & Medicaid Services.

[c]The implementation date may be retroactive to the first day of the quarter in which the State Plan Amendment was submitted (January 1, 2003).

BCCPTA Medicaid. Other programs reported increased workloads associated with Medicaid eligibility and redetermination procedures.

GWU's evaluation found early success in enrolling women in BCCPTA Medicaid based on effective collaboration between state Medicaid and screening programs that had substantial state political support for the adoption of the BCCPTA. Uncertainty about costs and utilization may present longer-term challenges to ongoing implementation. Study findings suggest that public health screening/prevention programs may be an effective way for uninsured women facing a costly disease like breast cancer to acquire publicly funded insurance (e.g., Medicaid). Impact evaluation research will assess whether the BCCPTA has improved access to treatment for breast and cervical cancer to uninsured women, and whether women experienced improved health outcomes as a result. Final results of the implementation evaluation are expected in 2004 and will be available on the CDC and CMS websites.

DISCUSSION

Implementation of the BCCPTA has provided a model for the coordination of resources and partnerships to impact morbidity and mortality among a defined group of people at risk for a specific disease or condition. A key factor in the success of this effort was to have single points of contact from the lead agencies (CDC and CMS) who communicated daily to address the volume of questions posed by state screening programs and Medicaid directors and to ensure answers were consistent. Questions posed by the general public were also discussed by the lead agencies, responded to consistently, and shared with state screening programs and Medicaid directors. These actions added a foundation of clear and consistent communications to the agencies' common goal.

The true test of the success of the BCCPTA will be to determine whether this type of legislation will ultimately decrease breast and cervical cancer morbidity and mortality among women enrolled in Medicaid under its provision. Specifically, we must be able to determine if, as a result of implementation of the BCCPTA: (*1*) more women are being screened for breast and cervical cancer; (*2*) more women are being diagnosed with breast or cervical cancer or pre-cancerous conditions; (*3*) more women are being diagnosed with breast and cervical cancer at an earlier stage; (*4*) all women who are eligible under the BCCPTA are referred to and enrolled in Medicaid; (*5*) women are receiving treatment more quickly; and (*6*) women are receiving appropriate, complete treatment. Each of these questions is complex and interrelated. For example, if an increase in screening is apparent, is that related primarily to the comfort women feel knowing treatment is available if they are diagnosed, or the result of an increase in providers willing to screen with the availability of treatment support more widely guaranteed, or an expansion in providers recognized under the screening program? To answer these questions, GWU researchers will work with CDC and CMS staff members to identify relevant data elements already collected by the NBCCEDP or CMS, explore potential relevant data linkages that can be used to enhance existing data sets (e.g., cancer registry data), and determine additional data to be collected. Researchers will consider whether and how an impact evaluation can focus on the expenditure trends of BCCPTA women, including utilizations/expense of cancer-related services vs. non-cancer related services and the BCCPTA impact on state Medicaid budgets.

CONCLUSION

Government agencies at all levels, despite their differences in responsibility, structure, management, and function, can develop methods to coordinate resources in ways that ultimately benefit the general public. Identifying the needs of a specific population is the cornerstone around which federal, state, and local programs can pool their resources to meet those needs. Implementation of the BCCPTA is one example of how this can be accomplished. Though most states have readily chosen to provide Medicaid coverage for women screened through the NBCCEDP, implementation of BCCPTA activities continues to evolve. How best to protect client confidentiality, whether needed data will be readily available in a useable format, how to separate cancer treatment expenses from those related to other Medicaid-reimbursed services, and the lag between local cancer reporting and the presence of data in statewide databases are among the challenges that have been identified. Through continued collaboration, such challenges will be addressed and an assessment of the impact of the BCCPTA on women throughout the United States will be produced.

REFERENCES

1. Public Health Services Act Amendment of 1990, Pub. L. No. 101-354, 104 Stat. 409 (Aug. 10, 1990).
2. Social Security Act Amendment of 2000, Pub. L. No. 106-354, 114 Stat. 1381 (Oct. 24, 2000).
3. Centers for Medicare & Medicaid Services (US). Letter to state health officials outlining federal interpretation

of BCCPTA [cited 2003 Jul 20]. Available from: URL: http://www.cms.hhs.gov/states/letters/SHO01041.asp
4. Centers for Disease Control and Prevention (US). Guidance and summary of actions on the BCCPTA of 2000 [cited 2003 Jul 20]. Available from: URL: http://www.cdc.gov/cancer/nbccedp/law106-354.htm
5. Centers for Medicare & Medicaid (US). Breast and cervical cancer prevention and treatment activity map [cited 2003 Jul 20]. Available from: URL: www.cms.hhs.gov/bccpt/bccptmap.asp
6. Centers for Medicare & Medicaid (US). Model agreement for provision of breast and cervical cancer screening, prevention, and treatment services [cited 2003 Jul 20]. Available from: URL: http://www.cms.hhs.gov/bccpt/modelagr.pdf
7. Social Security Act Technical Amendment of 2001, Pub. L. No. 107-121 (Jan. 15, 2002).