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**WOMEN'S HEALTH
INFORMATION**

**HHS Lacks an Overall
Strategy**

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SUMMARY OF GAO TESTIMONY BY MARK V. NADEL
ON WOMEN'S HEALTH INFORMATION

GAO's ongoing work indicates that the Department of Health and Human Services (HHS), which is responsible for providing health information to the public, lacks an overall strategy for getting health information to women. In response to a request by the Subcommittee on Housing and Consumer Interests of the Select Committee on Aging, GAO examined (1) how HHS decides what information to produce, (2) how accessible the information is to the public, and (3) whether HHS assesses the usefulness of the information it distributes. At the request of the Subcommittee, GAO focused on the following six conditions that are of vital concern to midlife and elderly women: heart disease, breast cancer, osteoporosis, menopause, hormone replacement therapy, and urinary incontinence. GAO's preliminary results indicate that:

- HHS has no overall strategy to ensure that the most needed and useful information is distributed to the public. Rather, information activities are left to the discretion of HHS's Public Health Service agencies, which plan how they produce and distribute information largely independent of each other and generally based on the availability of sound research results.
- Even when information for the public is produced and distributed, it is not always easily accessible. PHS regional offices and state and county health departments are key links for HHS in providing local communities with health information. But when GAO contacted a sample of such offices and departments, only about half the time was requested information or a referral phone number provided.
- HHS does not routinely evaluate the usefulness of information produced. Therefore, agencies within HHS cannot determine whether their efforts are appropriately targeted to raise women's awareness and increase their knowledge about conditions that confront them.

Madame Chairman:

I am pleased to be here today to testify on how the Department of Health and Human Services (HHS) discharges its health information responsibilities with regard to the needs of women.

As women age, they face a host of special health problems, such as breast cancer and osteoporosis, that if not detected early or treated properly can cause chronic debilitating conditions or in some cases, result in death. One way to control some of these conditions or diseases is to encourage behavioral changes by providing women with health information.

Because of the importance of health promotion activities for midlife and older women, you asked us to determine whether the Department of Health and Human Services, charged as the lead federal agency for providing public information on health promotion, is meeting the health information needs of women, particularly older women. You asked us to determine if HHS has a strategy to assure that women receive health information most critical to their acting to prevent and control diseases that affect them as they age. Specifically, you asked us to assess the following: (1) How does HHS decide what health information to produce? (2) How accessible to the public is the information? and (3) Does HHS assess the usefulness of the information it distributes?

As you requested, we concentrated our work on HHS's activities related to six diseases or conditions that affect women as they age. These are heart disease, breast cancer, osteoporosis, urinary incontinence, menopause, and hormone replacement therapy. Although we focused on these six conditions affecting midlife and elderly women, HHS's responsibility to educate the public on important health issues extends to other groups as well. Accordingly, our findings on the Department's health information activities may be applicable in a broader context. Because our work on women's health information is ongoing, we should emphasize that these results are preliminary.

We interviewed relevant HHS officials in agencies of the Public Health Service (PHS) who are responsible for producing and distributing health information. In addition, we reviewed HHS documents related to health promotion and women's health issues. Finally, to test the ability of consumers to get health information from PHS regional offices and state and local governments, we telephoned these offices in five cities.

RESULTS IN BRIEF

The Department of Health and Human Services does not have an overall strategy to identify what information is needed, whether consumer information is available on important health issues for

women, and the usefulness of that information. Instead, these activities are left almost exclusively to the discretion of the PHS agencies which do their own planning largely independent of each other. We found that even when information is being produced and distributed, it is not always accessible. When we contacted five PHS regional offices and five state or local health departments--HHS' link to local communities in providing health information--we were only successful in receiving information or a referral phone number about half the time.

Finally, except in conjunction with major health campaigns, HHS does not routinely evaluate the usefulness of the information produced. Therefore, it does not always know whether its health information targeted to midlife and elderly women is having any effect in raising their awareness or in influencing behavioral changes to more healthy lifestyles.

BACKGROUND

With the aging of the U.S. population, women's health concerns are dramatically affecting the quality of their lives and impacting the cost of our health care system. Public health has long included information and education activities among its efforts to help people understand the changes they experience as they age, to prevent and control disease, and to reduce premature death. Research shows that the incidence of chronic disease is associated with personal health behavior. Therefore, knowledge about the health risks of diseases that midlife and elderly women face is a first step to improving their health status. For example, according to HHS over 80 percent of cases of urinary incontinence can be improved or cured with early treatment and education. In order to get women to seek treatment, it is first necessary for them to have information about the availability and usefulness of treatment options. Information about health risks and preventive behaviors must be translated into health messages that are easily understood by the women at risk for health problems.

PUBLIC HEALTH SERVICE LACKS INFORMATION STRATEGY FOR WOMEN

The Department of Health and Human Services is responsible for providing health information to the American public.¹ The Public Health Service is the principal component of HHS which is responsible for promoting public health, in part by communicating research results to health professionals and the public.

¹The Public Health Service Act, 42 U.S.C. §300u(a)(1), requires the Secretary of HHS to formulate national goals, and a strategy to achieve them, with respect to health information and health promotion, preventive health services, and education in the appropriate use of health care.

During the 1980s, the Public Health Service began to assess how this responsibility applied to the area of women's health. In 1985, the Assistant Secretary for Health commissioned the Task Force on Women's Health Issues to identify the most important issues affecting women and lay out a blueprint for meshing those issues with PHS priorities. In its report, the Task Force concluded that the PHS needed to be more focused in its efforts on women's health issues. The task force report noted that "in the area of women's health . . . efforts aimed at education and dissemination of information have been somewhat sporadic and often have suffered from fragmentation."

Today this situation still exists, despite the task force conclusion that an "urgent need exists for a comprehensive, unified and consistent approach to educating and informing women about all aspects of their health." We believe that such an approach would identify areas where information would be most useful, identify the most efficient communication channels, and provide guidance for evaluating the impact of the information. Moreover, we agree with the task force recommendation that the PHS should provide leadership and that such efforts be unified and comprehensive.

HHS does not have such a unified and comprehensive strategy. Responsibility for producing and distributing health information is decentralized at the agency, institute, or office level, rather than focused at any central point within PHS. When we attempted to find out about the efforts of Public Health Service agencies to distribute information related to the six health conditions or diseases in our study, we could obtain information on the specific activities of each agency but not the Department's overall information strategy for addressing a particular condition or disease. This situation is particularly true in the Department's approach to producing consumer information about conditions such as menopause, hormone replacement therapy and urinary incontinence, which do not fit neatly into one institute.

Most health information that HHS produces and distributes on our six conditions comes from the National Institutes of Health, along with other PHS agencies such as the Food and Drug Administration, and the Centers for Disease Control. These agencies produce a variety of information for the public including publications, videos, and public service announcements.

The decision about whether to produce information for the public is based on various factors. The major factor is the availability of scientifically sound research results. Once a scientific basis is established, the individual agencies or institutes decide whether there is a need to produce information on the topic. Other factors include the extent of consumer inquiry about the subject, staff judgment, existing information on the topic from other sources, and the goals stated in documents such as Healthy People 2000 and The Action Plan for Women's Health. The

Congress, Administration, or the media can also influence what information is produced. However, because HHS information is science-based, the availability of research results on a subject is a prerequisite to providing health information on it. Therefore, what may appear as a gap in public information may be due to a gap in available research.

Just as there is no centralized plan for producing health information, decisions on distribution are also highly decentralized. Generally, each agency develops its own plans and conducts its own distribution activities independent of other PHS agencies. Whenever a publication is approved for printing, the required clearance form indicates a distribution plan but there is not an overall PHS distribution strategy.

PUBLIC OFTEN HAS DIFFICULTY IN GETTING INFORMATION

PHS regional offices are designated as the focal point for providing information to consumers. Because the regional offices represent HHS at the local level, we telephoned five of them and requested health information on the six conditions or diseases in our study. As PHS officials told us they also work with state or local health departments to distribute information, we contacted five of them as well.

We were often unsuccessful in obtaining either information about the six health conditions or appropriate referrals to other federal or local information sources. When we contacted PHS regional offices and state health departments in Boston, Chicago, Denver, Los Angeles, and Seattle, we asked for information on breast cancer, heart disease, osteoporosis, menopause, hormone replacement therapy, and urinary incontinence. We judged a call successful if we were sent information or referred to another information source that could provide us the requested information.

Of the 30 calls made to PHS regional offices, 16 callers were able to obtain health information. Unsuccessful callers either (1) had difficulty in obtaining a PHS or HHS phone number, (2) were unable to speak with an HHS employee, (3) were told that no information was available, or (4) were provided a referral phone number that ultimately could not supply information. For three of the unsuccessful calls, our callers were told to obtain information from their local bookstores or hospitals.

Of the 30 calls made to state or local health departments, 14 were successful. Twelve of our unsuccessful callers were told that the health department did not have information or referral phone numbers. One state health department employee asked one caller, "What is osteoporosis?"

HHS RARELY EVALUATES THE EFFECTIVENESS OF ITS HEALTH INFORMATION

An important step in producing and distributing information is determining whether or not it effectively reaches a given audience. Normally, this is done by evaluating the effectiveness of distribution efforts and assessing the impact on the target population. Most of the HHS agencies we talked with said they pretest messages by conducting focus groups and gather data on the number of requests they receive for information. However, officials also told us that although evaluations are sometimes conducted on the impact of major health campaigns, for the information routinely disseminated on women's health issues, agencies do not usually evaluate its usefulness for the public.

Without evaluations, key agency officials agreed, the agencies cannot determine whether their efforts are appropriately targeted to raise women's awareness and increase their knowledge about conditions that confront them. Officials concurred that this type of evaluation would be of substantial help in designing more effective health information.

CONCLUSION

In conclusion, while HHS puts out much information and its component units do their own planning, there is no overall strategy to direct the various agency activities.

As we continue our work, we will develop more information on the health information activities of the component units and will examine whether the current approach of HHS satisfies its health information mandate in the Public Health Act.