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ENGAGING DISADVANTAGED OLDER PEOPLE
IN THEIR HEALTH AND HEALTH CARE:

LIBRARY-COMMUNITY PARTNERSHIPS

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Summary

The aim of this initiative is to improve the health and quality of life for older Americans by making resources and support widely available to help them participate positively and productively in their health and health care. Older people who become "engaged" in their health and health care are those who become:

- More active in preserving their own functioning.
- Better educated patients and consumers of health services.
- More active advocates for effective health care.

In this initiative, at-risk and disadvantaged older adult populations are a priority.

One approach to reaching this aim is building the capacity of public libraries to serve as a focal community health resource. Together with community partners, libraries would inform, encourage and assist older people with being engaged in their health and health care.

The mix of health resources available to older people and their caregivers would be unique to each community. A library-community assessment of older residents' needs — using a framework of engagement behaviors — would lead to interventions to assist vulnerable groups in performing three to five behaviors necessary to be positive participants in their health and health care. These interventions, for example, could be the development of a consumer health information center at the library, educational programs at the library and other community sites, development of a patient navigator volunteer program that utilizes reliable medical information, a smoking cessation program for new grandparents and a communications campaign to inform and motivate older people and their caregivers to take advantage of the new resources. In time, older adults and their caregivers will think of and access health information, education, and services via their public library, gradually becoming more engaged health consumers.

In most communities, libraries currently lack capacity to serve as a proactive senior health resource center. But effective consumer health information and services at several libraries demonstrate that with an infusion of technical assistance, training and grants, public libraries can help consumers become more actively engaged in their health and health care. The potential initiative would offer all libraries access to a centralized source for guidance, tools and Web-assisted training. Interested libraries could also compete for grants, individualized technical assistance and advanced training. As a result of these investments, the library, with its community partners, would have the means to conduct community assessments, gather resources, conduct outreach and implement services to support older people in performing target behaviors. Partnerships would extend libraries' services into the community, reaching older residents who do not use libraries.

Why are public libraries the best bet for serving as the go-to health resource center for older adults and their caregivers in communities? Outnumbering McDonald's franchises, public libraries are in nearly every community in the United States. Free services and resources enable people of all means to get information, gain new knowledge and skills and access technology so they can participate in modern society. Older people, in

particular, already turn to libraries to obtain information about financial, retirement, health, Medicare and other personal matters.

The Challenge

Conventional wisdom within the health industry is that cost reductions and improvements in quality of care will occur when patients behave more responsibly by practicing health promotion; getting screened properly at the right time; choosing the right doctors, hospital and treatments; and managing their chronic conditions effectively.

However, this is not happening and cannot happen so long as patients are in the dark about what they are expected to do to participate by staying well and by actively managing their health care when they are ill.

In a recent series of interviews, the Center for the Advancement of Health (the Center) found that people are surprised, not only that they need to learn about the emerging details of a new diagnosis, but also by the tasks they and their families were expected to take on in order to get good care.

Some older people were surprised that they were expected to find and evaluate the qualifications of specialists to give them second opinions. Others were shocked when they realized that their own doctor might not have the expertise to treat their condition.

Some were taken aback by the need to maintain their own medical record as a back-up to ensure that information was not lost among doctors and hospitals. And others believed — until disastrously proven wrong — there was no need to ask questions because the doctor would tell them everything they needed to know.¹

Whatever the level of discourse, health care now uses the language of "personal responsibility" and the notion of individuals as "consumers" as shorthand to describe people who exert "choice" and who are "empowered" patients.

Unfortunately, unless a person has had a lot of experience with illness — and knows what it means to negotiate the health system as a patient these days, it is likely that that patient lacks even a basic understanding about what must be done to get the best possible care. Until illness strikes, many people have limited knowledge about what they can do to be as healthy as possible.

Doctors, labs and hospitals have clear expectations about what patients must do. Some expectations (such as do not smoke, get regular exercise and lose excess weight) are so obvious that few health professionals think to mention them. Sometimes expectations have changed, but the person has not received any messages about the change (such as always check about getting insurance pre-authorization for procedures and tests). Finally, some expectations develop as a side effect of communication gaps among doctors and hospitals (such as obtain test results and send them to all relevant physicians).

The Engagement Framework

What are the behaviors that the health system expects consumers to perform? The Center compiled the Engagement Framework of behaviors that constitute "positive participation" in health and health care (see Appendix A). This list comes from the Center's review of the scientific literature, consultation with experts and extensive interviews with a large sample of individuals.

Recognizing that patient engagement in health and health care is necessary to achieving acceptable outcomes in the current health care climate, health and consumer organizations have developed and tested interventions to help patients adopt healthier behaviors (such as smoking cessation services) and participate in their health care (such as self-care components in disease management programs).

Performance of other behaviors in the Engagement Framework depends on a person's resources or abilities (such as arrive on time for medical appointment). Local non-profits have developed services to support some of these behaviors (such as transportation to medical appointments). Researchers and practitioners have collected considerable information about the characteristics of individuals and groups that are most likely to need support in performing certain behaviors.

In order for older people to become positive participants in their health and health care, they — or their caregivers — need to know what these expectations are and be able to act on them. If they are unable to perform these behaviors, they will need to know of and use support — information, resources and services — that will enable them to do so.

The Approach: Public Libraries as a Focal Community Resource for Health Information, Education and Programs

Public libraries offer many advantages for serving as the main strategy for engaging older people in their health and health care. Libraries already offer free materials and services in health to a wide range of patrons. Past initiatives have shown that when resources are invested in their capacity, public libraries can be a vital link between older adults (and their caregivers) and information needed in order to obtain quality care and improve their health and quality of life. Further, the public is turning to libraries for health information and will use enhanced resources and services.

As focal health resources, public libraries would add a vital new component to the health and aging infrastructure in America's cities and towns. The approach of making libraries a focal point for engaging older adults in their health and health care rests on the assumption that libraries will form partnerships with local organizations. These library-community partnerships will assess the needs of the older people and their caregivers in their community, choose three to five behaviors from the Engagement Framework for which there is a clear need for support that a library and its partners can uniquely provide, and then, with the support of Atlantic Philanthropies for selected projects, implement a

set of strategic interventions to provide such support for the selected behaviors. (See the What Would this Initiative Look Like? section.)

Why Public Libraries?

Public libraries are well suited to becoming community resources that support consumers in engaging in their health and health care.

First, public libraries offer a wide array of services that respond to community needs. Reference services, collections, computers, Internet access, library Web sites and education and training programs enable library patrons to find answers to their questions and gain skills. This broad reach offers libraries the opportunity to engage residents about their health and health care before they become ill or have a disability.

Second, public libraries are trusted sources for free information and services and are proficient in helping patrons obtain information they need for their particular situation. For example, Americans report relying on libraries to provide free services, information, books and programs. Nearly two-thirds (64 percent) think libraries should offer computers and Internet access.²

In fact, because they trust their libraries,^a Americans turn to them as a source of health information, education and programs. Each week public librarians assist with more than 10 health reference questions, and one in three Internet searches on library computers relate to health.³

Third, public libraries have a track record of successful community partnerships to address local needs. In their public meeting rooms and other spaces, libraries host a wide variety of education, training and programs, including Alcoholics Anonymous meetings, blood drives organized by the American Red Cross and health education classes.⁴ Libraries also take their resources out to the community through local fairs, bookmobiles and events organized by other organizations.

Fourth, libraries make information accessible to all community residents.

- Information in multiple formats, along with assistive technology devices, enables libraries to serve residents with vision problems, deafness and hearing impairments.
- They are also a welcoming place with accessible facilities and professionals who work with persons of all abilities.
- Collections in foreign languages are another key way that libraries meet the needs of underserved populations.
- With evening and weekend hours, libraries enable patrons to access their resources on their own schedule.

^a In a public opinion poll, Americans described libraries as friendly and having highly-skilled librarians (KRC Research & Consulting, n.d.).

- Free services and collections remove financial barriers for persons with limited incomes.

Even patrons with no cognitive or physical limitations may need special help in finding, understanding and applying health information to their situation. This is because much health information is not easily accessible. It tends to be written in technical language, and the body of knowledge is voluminous and can be confusing due to the incremental nature of health research. Further, differentiating trustworthy from questionable information sources can be challenging.

Fifth, libraries are in nearly every community and are a central part of residents' lives. Approximately 16,500 public libraries span the United States, and over half (62 percent) of adults has a library card. The average user visits the library about 13 times each year.⁵

Sixth, libraries have strong potential. Almost every aspect of library capacity can be expanded and enhanced. The experience of health information centers in public libraries (see Appendix I) demonstrates that when libraries make health information and learning opportunities more accessible, older people and other target populations become more educated consumers.

Seventh, libraries offer an excellent return on investment. One study found that each dollar spent on library operations can generate a fourfold return.⁶ One reason for the high return is that libraries are well-used community hubs.⁷ Further, Americans view their public libraries as one of the best-run institutions in their communities; in fact, 63 percent strongly agree that public libraries are essential for maintaining a productive community.⁸

What Are Older Adult's Needs for Health Information and Assistance?

As they age, older adults encounter an increasing array of decisions with the onset of health conditions and disabilities. Research indicates older people generally prefer to obtain health information from physicians, nurses and pharmacists. Family, friends and other professionals (such as ministers) are also favored. In information seeking, television, newspapers and magazines are a second tier for older Americans.^{9,10,11}

Although doctors are their leading source of health information, one in four seniors goes to the Internet for health answers.¹² In time, the share of older adults who go online for information will grow as long-time Internet users reach their 65th birthday. Currently, 54 percent of Americans ages 60-69 years use the Internet, as compared to 28 percent of adults age 70 and older.¹³ Specific medical conditions and specific medical treatments were the top two subjects for which adults 65 years and older conducted an online search. Other topics included medications, diet and nutrition, exercise or fitness, and Medicare or Medicaid. About half (53 percent) of adults reported that the information retrieved online had an impact on their own health care or the health care of someone for whom they care.¹⁴

A factor in the reliance on interpersonal sources for health information may be the need for assistance. Many older people need special supports.

- Eighty percent of adults ages 65 and older have limited literacy proficiency.¹⁵ Because consumer health information materials tend to be written for a tenth grade reading level or higher, instead of the eighth grade reading level recommended for the general public, older people may benefit from help in reading, understanding and applying the health information to their situation.¹⁶
- Twenty-nine percent of older adults report having a long-lasting, substantial physical limitation that interferes with basic activities, including walking and carrying. Over half (53 percent) of adults 85 years and older report such problems.¹⁷
- Fourteen percent of adults 65 and older have one or more sensory disabilities (i.e., vision problems, deafness and hearing impairments). Among adults 85 and older, the prevalence is 35 percent.¹⁸

Why Can Public Libraries Meet Older Adult's Needs for Information and Assistance?

Older adults already turn to public libraries for assistance with personal information needs: 68 percent of adults ages 55-64, and 59 percent of those 65 and older, report having used the library in the previous year.¹⁹ Almost a quarter of library users (22 percent) are adults ages 55 and older.²⁰ Beyond leisure activities, older people use libraries for information and services relating to employment, community services, health, retirement and financial planning.²¹

Public libraries are already assisting older people in accessing health information, education and services (see Appendix I program profiles). For example,

- Through health reference interviews, library professionals help patrons find reliable sources of information in a way that protects health privacy.
- Collections, Internet access and assistive technology devices enable patrons to access information in a variety of formats, languages and literacy levels.
- Libraries also have literacy classes and professionals who are skilled in helping patrons with limited literacy obtain and understand information.
- Services, such as bookmobiles, Web sites and telephone reference assistance, reach older people who are unable to easily come to the library.

Historic Precedents

To explore the feasibility of public libraries becoming focal community health resources for older people, the Center identified and profiled 16 noteworthy programs (presented in Appendix I). Most of these programs sought to increase the number of consumers who received assistance in making health and health care decisions. Individual health information centers at libraries are amongst the profiles. The remaining programs built the capacity of libraries and other community institutions as change agents that enriched information, education or programs to meet consumer needs.

As documented in the program profiles, libraries can successfully provide a range of consumer health information and supports, some of which are from community partners.

- Health materials in a variety of formats, languages and literacy levels
- Computers, Internet connections and subscriptions to online databases
- Consumer training in searching reliable information sources
- Special health reference services from librarians or trained volunteers
- Membership in the National Network of Libraries of Medicine, which enables public library members to obtain scientific publications through interlibrary loan
- Health programs via partnerships with other community groups
- Referrals to community resources
- Support for external community programs by enriching the health information provided to consumers
- Presentations in other community settings about finding reliable consumer health information

In these profiles, the primary librarian role is helping patrons obtain information directly relating to their specific situation. They do so without learning the content themselves or helping patrons interpret it. Librarians also are community conveners, partnering with many organizations because local needs drive the provision of information and education.

The profiles are evidence that public libraries can become focal community resources for health. Specifically, data in the profiles indicate:

- Older adults and other members of the public are turning to libraries for help in finding answers to health-related questions.
- When libraries develop and market consumer health services to meet community needs, local residents — including underserved populations — use the services. Utilization of consumer health information services appear to increase with time.
- With adequate capacity, public libraries and their community partners help consumers acquire and understand health information.
- Public libraries can attract commercial, professional and non-profit partners to support consumer health services. Profiled libraries have used a variety of funding strategies to sustain their expanded consumer health capacity once it had been developed.
- Public libraries want additional capacity to meet the growing demand for consumer health information services.
- Obstacles in providing consumer health services at libraries can be overcome.

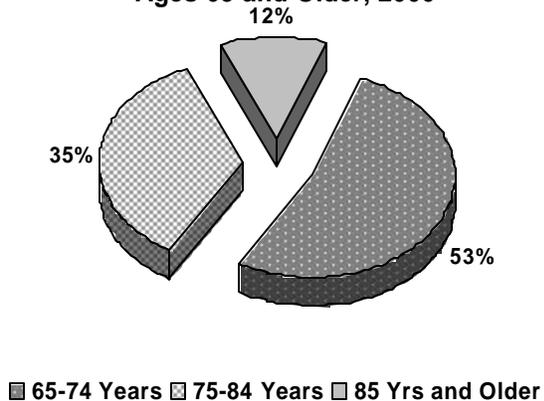
Lessons Learned

In some library program profiles, the number of community members who use services and participate in programs is modest. After all, reaching the underserved and people before they have a medical crisis is challenging, even with good marketing. In these cases, incentives and flexible scheduling structures make a difference. Also, it takes time to build programs so a critical mass of people and organizations know about the available services.

The profiles demonstrate that once libraries expand their capacity, they often encounter challenges to sustaining it. In particular, two lessons learned from the Bill & Melinda

Gates Foundation's U.S. Libraries initiative (included in Appendix I) provide useful insights. First, the initiative enabled three-quarters of the nation's public libraries to offer free computer and Internet access services, yet a portion of libraries struggled in helping patrons use these resources and in maintaining the services over the years. Second, libraries did not fully leverage the technologies to respond to specific community needs; this may have contributed to inadequate local commitment to public access computing, which jeopardizes some libraries' ability to sustain the services.^{22, 23}

Figure 1. U.S. Adult Populations, Ages 65 and Older, 2000



Sustaining capacity means developing local support for the new resources. To do so, library professionals need skills and leadership support to:

- Use the new capacity to meet specific community needs.
- Develop partnerships that pull target populations into the library and bring library services out to the community.
- Build broad-based support for the new capacities by using them to meet high-priority community needs.
- Evaluate the use and impact of libraries' health information, education and programs.
- Educate voters and policy makers about the positive contributions of the new resources.

The profiles also reveal a tandem strategy, that of investing in organizations that support libraries. Program partners included the American Library Association and its affiliates, regional library networks, state libraries, WebJunction^b and others. The National Library of Medicine and National Network of Libraries of Medicine are another existing support offering expertise, tools and training to help medical and public libraries improve access to health information. Appendix B offers a listing of some of the major players supporting libraries.

Additional Perspectives

To further explore the idea of using public libraries to increase assistance for older people, the Center convened two meetings of stakeholders with representatives from the domains of aging, libraries, health care, public health, caregivers and Cooperative Extension. (Appendices D-H have rosters of participants and notes from each discussion.)

^b WebJunction is a cooperative of library staff sharing and using online resources to share ideas, solve problems and take online courses (<http://www.webjunction.org>).

Participants broadly agreed that the potential libraries strategy is feasible and critically needed. They reported that it especially makes sense in rural areas because residents have few options for support and the local library has a major role in community life. They affirmed that older people would benefit if libraries in all communities enriched their health information, education and services.

These stakeholders expressed a willingness to be a partner with libraries or the organizations that would be implementing the potential initiative.

Source: Gist, Y.J., Hetzel, L.I. (2004). *We the people: aging in the United States. Census 2000 special reports, series CENSR-19*. Washington, DC: U.S. Census Bureau.

Two notable commitments came from

the Gates Foundation and Centers for Medicare and Medicaid Services (CMS).

- The Gates Foundation will ensure that libraries have the technology needed to access online health information and programs. The foundation is also helping libraries better communicate their value so public support remains strong.
- CMS, because of the agency's interest in promoting consumer health, may be willing to help sustain libraries as health resources for Medicare beneficiaries in the same way that CMS supports state health insurance programs.

Why This Approach Now?

The graying of the U.S. population represents a growing need for resources and supports to help older people become positive, productive participants in their health and health care.

Older Americans are more numerous than ever before, in part because they are living longer.²⁴ Census data indicate that between 1990 and 2000, the number of adults ages 65 years and older increased by 12 percent to 35 million.²⁵ Figure 1 provides a breakout by age of the current older adult population.

The trend toward an aging population is heightened by the sheer size of the baby boom generation, whose members are now reaching 65 years and older. Figure 2 presents Census projections for older adults that indicate the number of adults ages 80 years and older will *double* between 2000 and 2030.

Figure 2. Number of U.S. Adults Ages 65 and Older, By Age Group, 2000 and 2030
In millions

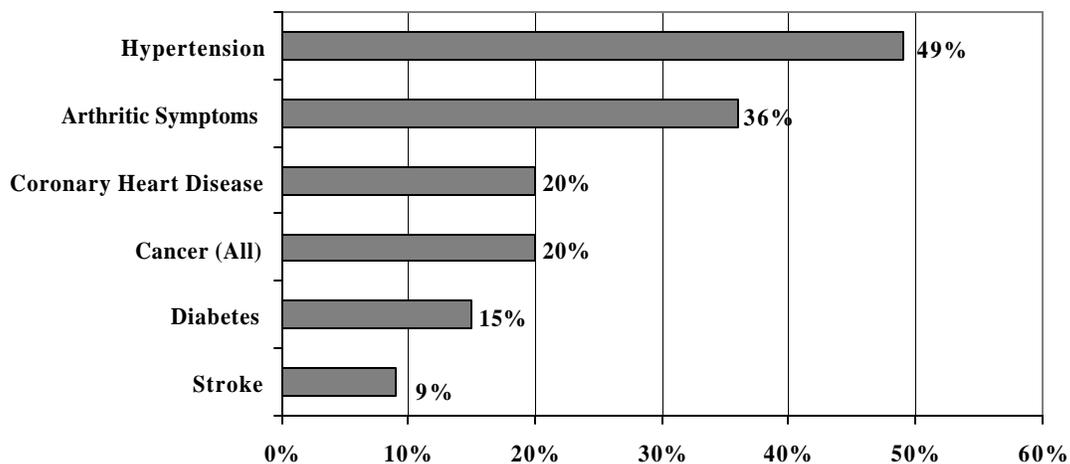
	2000	2030	Percent Change
65 — 74 Years	12.2	37.7	209%
75 — 79 Years	7.4	14.0	89%
80 Years and Older	9.2	18.6	102%
Total	28.8	70.3	144%

Source: Kinsella, K., Velkoff, V.A. (2001). *An aging world: 2001. U.S. Census Bureau, series P95-01-1*. Washington, DC: U.S. Census Bureau.

Although Americans are living longer, not all of the added years are healthy. Figure 3 features a small array of the many chronic conditions afflicting adults 65 years and older. Risk for these and other health conditions rises as people age. In fact, 80 percent of Americans ages 65 and older have at least one chronic disease; half have two chronic diseases or more.²⁶

The years before and during changes in their health are important opportunities for older people to gain knowledge, skills and assistance to move from being passive patients to educated health consumers. To effectively use health services and manage their health, older people need to easily find good information, interpret it in the context of their circumstances and act on it. This means performing the numerous behaviors captured in the Engagement Framework, with support from community organizations to overcome cognitive, physical or other limitations that can impede positive engagement.

Figure 3. Prevalence of Chronic Diseases among U.S. Adults Ages 65 Years and Older



Source: *The state of aging and health in America 2004*. (2004). Centers for Disease Control and Prevention, Merck Institute of Aging & Health. Retrieved September 28, 2006 from http://www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf

Timing Right for Libraries, Too

From a library perspective, the time is right too. Information presented in the program profiles (Appendix I) and from stakeholders (Appendices D-H) indicates libraries are responding to increased demand from patrons wanting reliable health information. Many libraries also are reaching out to and creating new programs for their communities' older residents.²⁷

In recent years, some public libraries have been threatened with closure, most prominently in communities in California, Michigan, New York and Oregon.²⁸ Libraries with relatively stable funding also are concerned that they may face similar fiscal problems in coming years.

In this context, libraries are pursuing opportunities to be visible, expand partnerships and meet important community needs. The potential initiative provides such an opportunity, especially because its technical and financial supports will enable libraries to build their capacity to help residents access and act on reliable health information. Beyond the immediate incentives of grants and technical assistance from the initiative, libraries may be motivated to participate for intermediate and longer-term benefits. For example, new aging and health partners represent potential library advocates and donors, community partnerships can heighten visibility and new services are likely to increase library statistics (such as circulation, reference inquiries and number of library card holders) that policy makers consider in funding decisions.

Yet, not all libraries would pursue a grant and take advantage of available training and technical assistance. Although the Center has not assessed library interest, the experience in Iowa may be informative. A partnership of state-level non-profits and government agencies asked 50 public libraries across the state to host a training session for Medicare beneficiaries on the new prescription drug coverage benefit. About 40 percent (n=21) agreed to participate. The rest cited either philosophical or capacity concerns. (See Medicare Part D Educational Outreach profile in Appendix I.)

What Would This Initiative Look Like?

(The Center provided the following scenario to stakeholders for discussion.)

To improve the health and quality of life of older people in their communities, public libraries would form partnerships with other community organizations and groups to support and enable behaviors that constitute positive participation in health and health care. Each library would assess the needs of older adults in their community in terms of the behaviors identified in the Engagement Framework. After selecting three to five specific behaviors that are suited to both the library and the community, a partnership with appropriate community organizations would be built, and a work plan developed, using evidence-based strategies. The partnership would reach out to older residents and their caregivers and engage them in the new programs and services to support the target behaviors.

Here is a hypothetical example. A small partnership, convened by a public library, includes the area agency on aging, the chair of geriatrics at the hospital and the directors of two senior centers in a large town. This group receives a small planning grant and uses an online toolbox to identify populations of older people in their community, assess their health needs and relevant health care behaviors, and target three behaviors within the Engagement Framework that the initiative would support older residents in performing.

They decide "making quality choices about health information and care" will be their focus. Using the Engagement Framework, the community partnership would invite new partners to join them, such as the state health insurance counseling and assistance program (SHIP), the medical librarians from all the area hospitals, insurers, local providers and other community groups. This group, in turn makes use of evidence-based strategies that would increase the number of older residents who can locate good health information and use it when making decisions about health care and aging services providers, insurance coverage and treatments. With a second capacity-building grant, training and technical assistance, the library-based partnership coordinated partners' implementation of various strategies, which included the following.

- A consumer health advocacy group works with the nearby state university to develop an annual report card on local providers.
- A local pharmacy and the library conduct a series of educational seminars on selecting a Medicare prescription drug plan, disseminate resources to inform a decision about pharmaceutical treatment options, and offer an educational program about poly-pharmacy that travels to community settings where older adults gather.
- The state senior health insurance information program and regional AARP office provide assistance with insurance plan enrollment at the library and other community sites.
- The library creates and updates a senior health Web site with a section devoted to using the annual report card developed by other partners. The area health education center conducts a semi-annual training session for older adults on using the online information.

Through this process, the library evolves into a focal community resource for health information, education and programming. Older residents and their caregivers use their library and other community resources to obtain information about quality of care, learn about making smart choices and receive assistance in managing their health and health care.

What Will it Take to Implement This Strategy with Public Libraries?

(The Center provided the following scenario to stakeholders for discussion.)

The Appendix I program profiles show how other organizations have structured initiatives to build library capacity to better serve their communities. Based on these

profiles, the initiative at the national level would include the six major components, which are summarized in Figure 4. Appendix C presents additional details.

Figure 4. National-Level Components

Component	Purpose
Advisory council	Obtain guidance on the national initiative; members would have expertise in consumer health information services, library and information science, public education campaigns, community health and evaluation
Coordinating council	Ensure national partners align their individual efforts to maximize impact, provide seamless services and minimize duplication
Centralized technical resources	Provide all interested libraries with a range of supports including training, technical assistance, tools such as planning guides
Grants	Provide public libraries with financial resources to support the development of local capacity-building plans and the capacity-building process itself
Public education campaign	<p>Make public libraries a top-of-mind resource for health information among older adults and their caregivers</p> <p>Support local community outreach efforts to motivate older people to use libraries for health information and learning centers</p> <p>Engage policy makers in supporting and advising on policy implications and providing public recognition for the campaign</p>
Evaluation	Measure changes in capacity at the local and national levels, identify best practices and model programs, and document impact on older people and communities

Given the scope and nature of the initiative, multiple national partners would be necessary. Among the national partners would be organizations that have:

- Networks of medical and public libraries.
- Expertise in consumer health information and services, library development, community engagement, public education campaigns and evaluation.
- Established track records of providing effective technical assistance, tools and grant programs.
- Visionary leadership to position libraries as vibrant hubs of civic life.

APPENDIX A

The Engagement Framework

A growing consensus within the health care industry holds that cost escalation will be restrained and quality of care and outcomes improved if people become more actively engaged in protecting their health and managing their health care. This is particularly true for older people, who are more likely to have at least one chronic condition and thus use more health care. However, there is little consensus about exactly what engagement means. While the idea is appealing, it frequently lacks the precision necessary to achieve its potential. Embedded in the rhetoric about consumer engagement is a set of expectations that place substantial new demands on Americans seeking and using health care. The purpose of this framework is to explicitly lay out what actions are required of competent patients in an era of Consumer Engagement.

If health care delivery predicated on the notion of responsible individual behavior is to become a reality, our nation will require a dramatic change in the awareness, willingness and capacity of most older people to assume the wide range of personal responsibilities expected of them.

The following behaviors constitute engagement in health and health care and set the conditions under which – based on the best available evidence – individuals are more likely to receive the optimal benefits of medical science and practice.

I. Active Engagement in Managing Health

A. Healthy behaviors

Individuals and their caregivers will continuously

1. Acquire and use information to:

- a. Assess their risks for poor health, disease and injury
- b. Set priorities for changing behavior to prevent disease and maintain health
- c. Identify and locate services to support changing behavior and maintaining those changes over a lifetime

2. Take action to:

1. Exercise regularly
2. Eat a balanced diet
3. Maintain recommended body weight
4. Not use tobacco products and not abuse alcohol or other substances
5. Act to prevent injuries at work, home, play and in transit

B. Chronic disease self-management behaviors

Individuals and their caregivers will

1. Acquire and use information to:

- a. Understand their disease and what can be gained by medication use and behavior change
- b. Evaluate their treatment options
- c. Identify and locate services to support changes in their behavior and maintaining those behaviors over time

2. Take action to:

1. Follow treatment regimens, including diet, exercise, and substance use agreed upon by them and their provider
2. Monitor symptoms/condition (for diabetes – regular glucose monitoring, checking feet; for depression – medication and/or counseling and monitoring symptoms; for hypertension – regular measurement of blood pressure; blood pressure diary)
3. Manage symptoms
4. Know what their targets and danger signs are (what one's blood pressure should be) and act to meet those targets

II. Active Engagement in Managing Health Care

A. Medical encounter behaviors

Individuals and their caregivers will

1. Acquire and use information to:

1. Prepare a list of questions/issues for discussion in visit
2. Learn about the possible side effects or complications of new prescription medications

2. Take action to:

1. Report accurately on the history and current status of physical and mental symptoms
2. Ask about the evidence for the efficacy of different treatments (risks and benefits)
3. Evaluate options in discussion with health care provider
4. Negotiate the treatment plan and follow-through.
5. Ask questions when explanations are not clear
6. Bring a list of medications when visiting a health care provider
7. Check if insurance covers the medications and tests the provider ordered
8. Bring another person to assist them if they are frail, confused, unable to move around or unable to remember the conversation with the provider
9. Bring a summary of medical history, current health status and recent tests to all visits

10. Obtain all test results and appointment records and maintain personal health record at home

B. Consumer Behaviors

Individuals and their caregivers will

1. Acquire and use information to:

1. Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment
2. Compare coverage options when selecting health plans, and match to their own values, needs and preferences and select affordable quality care
3. Use comparative performance data to select high performing providers and facilities
4. Learn what services and programs they qualify for

2. Take action to:

1. Establish a relationship with a trusted health care professional or group
2. Pay all bills in a timely manner or arrange an alternate plan

C. Interact with healthcare institutions (primary care provider, specialist, nursing home, assisted living, hospital, ER).

Individuals and their caregivers will

1. Acquire and use information to:

1. Self-triage to the appropriate setting when a problem requires professional attention

2. Take action to:

1. Obtain referrals and then get recommended screenings (e.g. breast cancer, prostate cancer, colon cancer, cervical cancer)
2. Get an annual flu shot and other vaccines as recommended
3. Make appointments; inquire about no-show policies; arrive on time; stay until the encounter is completed
4. Physically navigate the health facility or obtain assistance to do so
5. Inquire about pre-authorization / pre-certification for all out-of-office tests
6. Maintain all receipts for drugs, devices and services
7. Complete advance directives and medical power of attorney, file with appropriate physicians and produce them for medical authorities when appropriate.
8. Talk with medical providers to ensure that relevant medical information is conveyed between providers and institutions (e.g., discharge plans).

APPENDIX B

Key Library Organizations

American Library Association

<http://www.ala.org>

The American Library Association (ALA) represents more than 66,075 members, including librarians, library trustees, publishers and other interested people. The association serves public, state, school and academic libraries, plus special libraries for people working in government, commerce and industry, the arts and other institutions. Its mission is to provide leadership for the development, promotion and improvement of library and information services and the profession of librarianship in order to enhance learning and ensure access to information for all.

Americans for Libraries Council

<http://www.lff.org>

Americans for Libraries Council is a national nonprofit that advocates for libraries at the national level and develops and promotes programs aimed at realizing the potential of libraries in the 21st century. As the parent organization of *Libraries for the Future*, a leader in library development, the council has substantial expertise in developing and disseminating successful models for programming and advocacy. The council works to generate broader and deeper participation in supporting libraries from all sectors of society.

Institute of Museum and Library Services

<http://www.imls.gov/>

The Institute of Museum and Library Services is the primary source of federal support for the nation's 122,000 libraries and 17,500 museums. The institute's mission is to create strong libraries and museums that connect people to information and ideas. The institute works at the national level and in coordination with state and local organizations to sustain heritage, culture and knowledge; enhance learning and innovation; and support professional development.

Medical Library Association

<http://www.mlanet.org>

MLA is a nonprofit, educational organization of more than 1,100 institutions and 3,600 individual members in the health sciences information field, committed to educating health information professionals, supporting health information research, promoting

access to the world's health sciences information and working to ensure that the best health information is available to all.

National Library of Medicine

<http://www.nlm.nih.gov>

The National Library of Medicine, part of the National Institutes of Health, is the world's largest medical library. Its mission to acquire, organize and disseminate health-related information. The National Network of Libraries of Medicine (NN/LM) is the core component of the National Library of Medicine's extensive outreach program and its efforts to reduce health disparities and improve health literacy. The growing network includes more than 5,800 full and affiliate members.

National Commission on Library and Information Sciences

<http://www.nclis.gov>

The U.S. National Commission on Libraries and Information Science (NCLIS) is a permanent, independent agency of the federal government charged with advising the President and Congress on national and international library and information policies, appraising and assessing the adequacies and deficiencies of library and information resources and services and developing overall plans for meeting national library and information needs. Broadly speaking, the commission is responsible for addressing the information and learning needs of the American people.

Online Computer Library Center

<http://www.oclc.org>

OCLC Online Computer Library Center is a nonprofit, membership, computer library service and research organization dedicated to the public purposes of furthering access to the world's information and reducing information costs. More than 41,555 libraries in 112 countries and territories around the world use OCLC services to locate, acquire, catalog, lend and preserve library materials. OCLC and its member libraries cooperatively produce and maintain WorldCat — the OCLC Online Union Catalog.

Public Library Association

<http://www.pla.org>

The Public Library Association (PLA), with more than 11,000 members, is one of the fastest growing divisions of the American Library Association (ALA). PLA's core purpose is to strengthen public libraries and their contribution to the communities they serve. The association provides a diverse program of communication, publication, advocacy, continuing education and programming for its members and others interested in the advancement of public library service.

APPENDIX C

Program Elements

(The Center provided this scenario to stakeholders for discussion.)

Public libraries require a multi-year investment to build their capacity to serve as focal community resources for improving the health and quality of life for older people. Building this capacity necessitates a partnership of national organizations to deliver needed financial and technical supports. Public libraries would self-select to participate in the capacity-building programs. All libraries would have access to technical resources, and all could apply for grants.

The national partner organizations would have a coordinating council to align their efforts. Some national organizations may be responsible for building awareness of the initiative among libraries and encouraging their participation. Another partner may be the main provider of technical resources, but outsource the development of some supports to other national partners. One of the partners would have the primary responsibility for the grants program.

Technical Resources for All Public Libraries

Through a centralized source, all public libraries would have access to technical resources to help them plan and develop effective health information and learning centers. These technical resources would correspond with a list of expected consumer behaviors (such as seek out health information from reliable sources, prepare questions in advance of health care visit). The resources would promote the use of evidence-based interventions (such as information prescriptions from providers and education programs for persons with newly diagnosed chronic diseases) to develop older people's ability to perform the expected consumer behaviors.

With the other national partners, the centralized source of technical assistance would develop, disseminate and promote the use of:

- Educational resource materials for librarians, local policy makers and library supporters.
- Toolkits and training programs to develop library staff skills in delivering evidence-based educational and training programs (both at conferences and via the Internet). Topics could include needs assessments, effective interventions, partnerships, evaluation, policy maker education and more.
- Directories of medical and health sciences libraries and other organizations that could be partners or resources.
- Recommendations for consumer health collections.
- Performance benchmarks.

- Communications materials that library systems could brand to encourage older adults and caregivers to use libraries as a resource in their health and health care. Also, public education campaign materials would support libraries in outreach to increase older people's use of library health resources.
- Forums for participating libraries to exchange practices and find solutions.
- An initiative-wide evaluation, with standardized forms for participating libraries to use.

Because health information is constantly changing, some of these resources would need periodic updating.

Many of these technical resources would be available online. Others, such as trainings, would use national conferences and Web-based systems as delivery modes.

Grants and Tailored Technical Assistance for Public Libraries

Public libraries would apply for multi-year grants to build and sustain their capacity to serve as focal community health resource centers that target three to five specific behaviors in the Engagement Framework (Appendix A). Public libraries would self-select to participate in the capacity-building program. Those that are awarded grants would receive technical assistance beyond what would be available to libraries without grants.

A national organization would administer this grant program, with support from an advisory task force comprised of other national partners and select experts. The task force would advise on the grantmaking policies and procedures, guide the development of the tailored technical assistance program and give final approval of grant awards. The task force would monitor the grant program.

Tier 1 — Small Planning Grants (Non-Competitive). Because libraries in small and rural communities have tiny budgets, many would not be able to do a needs assessment and develop a plan without grant support. The small planning grants — available to all public library systems, but perhaps with preference to those in small and rural communities — would be accessible with short applications, simple reporting requirements and no local match. Although non-competitive, the application process might require a letter of support from city or county officials.

The availability of these planning grants would improve opportunities for low-resource public libraries to participate in the competitive tiers of the initiative. Grants could be available on a first-come, first-served basis until the dedicated funding for the year is disbursed. A process would be in place to assure low-resource libraries know about the opportunity and perhaps even receive some limited assistance in applying. A defined threshold of low-resource could increase participation.

Grantees would use the planning grants to organize new or adapt existing library-community partnerships that would develop an "epidemiology of need" for older adults in their community. This assessment, for which a toolkit would be available, would identify

first which groups need consumer health information and services; second, what supports would help these groups adopt behaviors related to positive, productive participation in health and health care; and third, what existing community assets could be leveraged to expand consumer supports. The planning partnerships would then use a directory of effective interventions and obtain public input. The primary deliverable would be an action plan for building library capacity and partnerships to expand the use of reliable health information and education services. This plan would provide a framework for applying for Tier 2 grants.

Tier 2 — Capacity-Building Grants and Technical Assistance (Competitive). To apply for competitive capacity-building grants, public library systems would form partnerships in their communities — if they have not already done so — with whatever local groups they choose: nursing and medical associations, medical and nursing schools, health plans and providers, local health departments, area agencies on aging, community colleges, community colleges or universities, AARP, or Cooperative Extension offices. The partnerships would select three to five program areas (i.e., consumer behaviors) based on a community needs assessment. They would also submit a plan for building capacity to better serve the health information and education needs of older people in their community. Library systems would use their multi-year grants to build and sustain the capacity to engage older adults and their caregivers in meeting specific expectations of the health care system by acquiring the requisite knowledge and skills. Figure 5 offers an example of a capacity-building plan for a library.

Figure 5. Sample Capacity-Building Plan Submitted by a Public Library Grantee

Target Consumer Behavior	Interventions	Capacity Building
Maintain recommended body weight	<ul style="list-style-type: none"> • Weekly Weight Watchers meeting in library facilities • Walking groups starting from library, with participation incentives • Web site with linkages to reliable information about weight loss 	<ul style="list-style-type: none"> • Develop partnership with Weight Watchers • Organize structure of walking groups with community partner and recruit members • Expand library's resource pages for online users • Obtain training in health reference skills and community outreach
Get pre-authorization from Medicare or health plan prior to procedure	<ul style="list-style-type: none"> • Workshops in libraries and other places frequented by Medicare beneficiaries or their caregivers • Educational pamphlets that local health care providers can give to patients 	<ul style="list-style-type: none"> • Develop partnership with Cooperative Extension to develop curriculum and educational materials and conduct workshops • Create a program so trained volunteers can help older adults obtain pre-authorization

Target Consumer Behavior	Interventions	Capacity Building
Arrive at appointment on time	<ul style="list-style-type: none"> • Library referrals to community resources • Medi-port transportation services 	<ul style="list-style-type: none"> • Strengthen referral systems for available transportation supports in community
Bring a list of current medications to each doctor's visit	<ul style="list-style-type: none"> • Media campaigns • Wallet cards for patients to maintain a list of current medications 	<ul style="list-style-type: none"> • Develop partnerships with pharmacies to provide customers with medication lists on wallet-size cards • Adapt sample media campaign materials for community circumstances

The national organization would fund some number of proposals and organize technical assistance for grantees. In addition to meeting milestones and fulfilling reporting and evaluation requirements, grantees would provide a local match, the percentage of which to the total program budget would increase each year to encourage community commitment.

Tier 3 — Challenge Grants. Some libraries that were not chosen during the first round of awards would receive challenge grants, or seed money, to develop their programs with the goal of submitting a winning proposal during subsequent rounds.

Other National-Level Leadership: Public Education and Evaluation

One national partner would develop materials and strategies for a public education campaign to position libraries as focal community health resource centers in the minds of older people. This campaign could follow the model used by the American Library Association in its Campaign for America's Libraries — "@ your library" — that enabled libraries to use templates and fact sheets along with drop-in graphics, copy and scripts to design high-quality local media campaigns (<https://cs.ala.org/@yourlibrary/index.html>). Periodic Web-based training seminars would provide technical support. The campaign would also offer materials and professional development opportunities to support the development of community outreach efforts that promote the use of health information and learning centers at the libraries.

The initiative would have a centralized evaluation system. This evaluation might build on the existing evaluation resources available from the National Network of Libraries of Medicine, the Medical Library Association, the Americans for Libraries Council and state libraries, among others. Evaluation components would include:

- Standardized evaluation forms for libraries to collect information from users and partners.
- Software or other tools to help libraries track usage.

- Independent surveys or interviews of older adults in grantee communities to capture impact on health and health care behaviors.
- Evaluations completed by library staff participating in training sessions and technical assistance.
- Instruments to monitor changes in local sustainability.

The evaluator would develop specific measures to assess changes in national and local capacity, consumer usage of services and programs, and community commitment to consumer health services as a proxy for sustainability. The evaluation would generate periodic reports that the advisory and coordinating councils would use to make mid-course improvements.

Other Systems to Engage as Partners

In their role as focal community resources for improving health and quality of life for older people, public libraries would work with many community partners. Some of the core sectors are illustrated in Figure 6.

Figure 6. Community Sectors to Engage as Partners

Aging Sector	Health Sector	Other Community Partners
Aging services providers	Area health education centers	Businesses serving and employing older people
Aging and disability resource centers	Health care providers, especially federally qualified community health centers	Cooperative Extension offices
Area agencies on aging	Insurers	Faith-based communities
Consumer organizations representing older people	Public health agencies	Local governments
Senior centers	Voluntary health organizations, including those supporting caregivers	Volunteer centers

These partners would assist libraries in identifying and responding to community health needs. The choice of partners would reflect local assets, opportunities and goals.

APPENDIX D

February 13, 2007, Meeting Participants and Notes

On February 13, the Center convened stakeholders to discuss this potential national strategy that would make public libraries a focal community resource for improving the health and quality of life for older people.

Participants

- Yanira Cruz, DrPH, President and CEO, National Hispanic Council on Aging
- Catherine Gordon, RN, MBA, Senior Public Health Analyst, Office of the Director, Centers for Disease Control and Prevention
- Gail Hunt, President and CEO, National Alliance for Caregiving
- Chris Johnson, National Director of Access Programs, Libraries for the Future
- Judith Miller Jones, Director, National Health Policy Forum
- Douglas Kamerow, MD, MPH, U.S. Editor, British Medical Journal, RTI International
- Sue Lachenmayr, MPH, CHES, Office of Community Education and Wellness, Division of Aging and Community Services, New Jersey Department of Health and Senior Services; Past President, Society for Public Health Education
- Christopher Langston, PhD, Senior Program Officer, The Atlantic Philanthropies
- Pauline Lapin, MHS, Office of Research, Development, and Information, Centers for Medicare and Medicaid Services
- Molly Mettler, MSW, Senior Vice President of Mission, Healthwise
- Jill Nishi, U.S. Library Program, Bill and Melinda Gates Foundation
- Mitzi Perdue, Commissioner, U.S. National Commission on Libraries and Information Science
- Donna Thurmond, National Director of Senior Services, Volunteers of America

CAH Participants

- Jessie Gruman, PhD, President, Center for the Advancement of Health (Chair)
- Molly French, Consultant
- Margaret Holmes-Rovner, PhD, Visiting Professor, Center for the Advancement of Health

Main Points

- Broad agreement among participants that the potential strategy of investing in libraries is feasible and would benefit older people.
- Gates Foundation committed to ensuring the technology infrastructure is in place and helping libraries better articulate their value. This means Atlantic Philanthropies can focus on content. Both foundations seek to reach low-income and other disadvantaged populations, although Atlantic will have an additional focus of older people.

- The Centers for Medicare and Medicaid Services (CMS) is interested in promoting consumer health and may be willing to help sustain libraries as health resources for Medicare beneficiaries in a way similar to how CMS supports state health insurance programs.
- Some data about older people's information-seeking behaviors and preferences could be useful. For example, Hispanic older adults do not go to a library. Instead, they turn to the news media or want one-on-one help from someone they trust. Thus, libraries may need to target family caregivers.
 - Gates-funded research indicates about 71% of computer users in libraries have searched for health information.
 - A generational shift is coming in how older adults seek information.
 - Patient activation typology could be useful in describing information seeking. It uses four combinations of motivated/unmotivated and skilled/unskilled.
 - Potential data sources: National Alliance for Caregiving, AARP, CMS and the leading information schools at Syracuse University, University of North Carolina at Chapel Hill and University of Washington.
- The initiative needs to not over-reach for the typical library, yet still cultivate industry leaders so that the new capacity can accommodate future technology advances and changes in the information-seeking behaviors of baby boomers. Once early adopters are fired up, the initiative can lead mainstream libraries in "skating to the puck."
- A pilot phase for local library capacity building (such as a pilot phase in one region of the country) would enable the implementing organizations to refine supports before taking it to scale.

Other Suggestions

- Ensure that disadvantaged, underserved older people are the target.
- Would the typical library be interested in seeking a grant and participating in training and technical assistance to expand consumer health information and services? The Institute of Museum and Library Services could help inform this question.
- Professional development must include skills for health reference, partnerships and outreach to underserved communities. Librarians will need to know how to structure services so they protect health privacy.
- Local partnerships will need to think about transportation and strategies to reach the home-bound and those living in institutional settings.
- Acknowledge the current context libraries in which libraries are operating. Many libraries are experiencing reduced or level-funding. Libraries are pursuing opportunities to stay relevant. Paper might also describe some of the differences

between small/medium and large library systems vis-à-vis their need for technical assistance, funding, and other supports.

- Providing high quality, accessible information is not enough. How does this translate into the desired changes in behaviors?
- Libraries need flexibility in their programmatic focus and implementation strategies.
- Meeting participants want updates on how the project proceeds and the final recommendations.
- More libraries want to meet community needs because the bulk of their funding is local. Requests for assistance with health information have been increasing.
- *What Does It Look Like* section:
 - Libraries should use existing community assessments, such as those conducted by public health agencies, area agencies on aging, United Ways and community foundations.
 - Outreach is essential so people know about library resources.
 - To keep costs down, library partnerships would tap into existing community resources (such as 2-1-1, aging and disability resource centers, National Network of Libraries of Medicine and area agencies on aging).
 - Evaluation measures should correspond with what local policy makers think is important, yet protect health privacy of individual library users. Because of local flexibility in program design, intermediate measures could help with cross-site comparisons.
- *Program Elements* section:
 - National economies of scale include:
 - ? Developing new or identifying good existing health bibliographies (such as from the Medical Library Association).
 - ? Transferring ideas and models among libraries.
 - ? Establishing national partnerships to stimulate local support or partners. Possible partners include Institute of Museum and Library Services; AARP; National Council on Aging for its network and BenefitsCheckUp; Elder Care America; Administration on Aging for its services and programs, especially the chronic disease self-management program funded by Atlantic Philanthropies; CMS for state health insurance programs; National Institutes of Health and National Institute on Aging; Centers for Disease Control and Prevention; Corporation for National and Community Service, Senior Corps and various other volunteer service corps; Department of Housing and Urban Development for service coordinators in senior housing facilities; relevant congressional caucuses; American

Academy of Family Physicians, American Geriatrics Society, National Medical Association, American Nurses Association and other associations of health professionals, including discharge planners and geriatric case managers; nationwide or large regional disease management companies; Kaiser Permanente and other large health plans investing in patient self-care; Alliance of Community Health Plans; National Council of La Raza; Univision; the Lutheran church and other denominations with a national structure; Catholic Charities; American Red Cross; Meals on Wheels Association of America; major hospital chains; National Governors Association, National League of Cities and other public interest groups; National Association of City and County Health Officials; Ad Council; and journalists covering a health or aging beat.

- ? Encouraging library and information sciences schools to incorporate components into curriculum. For example, Libraries for the Future has done this with LifelongAccess. Medical Library Association and National Network of Libraries of Medicine training ought to be integrated into workforce development.
- Grants should be structured so libraries have sufficient time to build strong partnerships. Often it takes a couple of years to get a coalition on firm footing, especially when the partners have disparate levels of power and resources. Also, some libraries may need to use community intermediaries so the grant does not appear to be in their core budget.
- Technical resources should include a variety of models for how libraries can staff the project. Current library professionals can develop specialized skills, or libraries could use service coordinators (as done in federally funded senior housing), circuit riders and volunteers.
- Regarding local library efforts with their partners:
 - ? Community assessments would identify and understand target users, existing health infrastructure and best opportunities for sustaining the consumer health information, education and programs after Atlantic Philanthropies funding ends. Assessment should segment audience and recognize that intermediaries, both organizations and individuals like caregivers, may be needed to connect with hard-to-reach populations. The epidemiology of need must link to the Engagement Framework. Finally, selection of community partners and intervention strategies must be tightly related to three to five behaviors that the library partnership pursues.
 - ? Developing partnerships and building relationships takes time and skill. This task is never "done." Community partnerships need four types of partners in their tent: those with cache and convening power, those whose approval is needed for success, those who can provide funding or important in-kind support and those needed for program elements. Local champions are essential.

- ? Beyond the three to five engagement behaviors, libraries can be opportunistic by pursuing shorter-term projects that respond to the needs of older residents, such as obtaining grants from a pharmaceutical company or retail drug chain to organize workshops on medication safety.
 - ? Simply pulling together high-quality health information to make it accessible and navigable for older residents would be a benefit. Libraries could train people to use personal health records.
 - ? Libraries will need multiple strategies because audiences have different styles of information-seeking. Some are self-directed, while others want human interaction. One-on-one assistance may be better to assist them with confidential issues. Because of differences in abilities, multiple languages and formats are necessary.
- Sustainability needs a definition, and the Program Elements section must sufficiently outline the overall sustainability strategy. Key components can be providing libraries with feasible business models, helping libraries and partners to articulate the value proposition to get local funding, branding the library as a top gateway to consumer health information, engaging a variety of funding partners, and using volunteers as a way to address staff shortages.
- Figure 6 (Community Partners): Additional partners could include news media, community centers, community-based organizations that underserved populations trust, community health workers, medical and hospital libraries, universities, transportation providers and programs, aging and disability resource centers, state health insurance program offices, local Senior Corps programs and United Ways.

Miscellaneous Resources Suggested by Participants

- One Economy provides content at sixth-grade reading level (via Beehive)
- National Council on Aging database on behavior change
- Medicare Part D (cautionary tale)
- WebMD
- Healthwise Knowledgebase portal via Yahoo (creating sticky information)
- Robert Wood Johnson Foundation's end-of-life and faith-in-action coalitions
- Initiatives like Family Place (Libraries for the Future) to transform libraries into places where families want to spend time.

APPENDIX E

March 20, 2007, Meeting Participants and Notes

On March 20, the Center convened another group of stakeholders to discuss this potential national strategy that would make public libraries a focal community resource for improving the health and quality of life for older people.

Participants

- Lynda A. Anderson, PhD, Director of Healthy Aging Program, Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention
- Gwendolyn T. Bronson, SHINE/SHIP Counselor, Massachusetts SHINE Program
- Mary L. Chute, Deputy Director for Libraries, Institute of Museum and Library Service,
- Noreen M. Clark, PhD, Center for Managing Chronic Disease, University of Michigan
- Caroline E. Crocoll, PhD, National Program Leader-Family Science and Human Development, Families, 4-H and Nutrition, USDA Cooperative State Research, Education and Extension Service
- Lynne G. Johnson, Health Insurance Specialist, Division of Partnership Development, Center for Beneficiary Choices, Centers for Medicare & Medicaid Services
- Susan Lutz, Coordinator, Health and Supportive Services, AARP
- Monica Sanchez, Deputy Director, Medicare Rights Center
- Jean Pugh Shipman, Director, Tompkins-McCaw Library, Virginia Commonwealth University; President, Medical Library Association
- Nancy Whitelaw, PhD, Senior Vice President and Director, Center for Healthy Aging, National Council on Aging
- Betty Anne Wilson, Assistant Director for Library Advancement. Memphis Public Library & Information Center

CAH Participants

- Jessie Gruman, PhD, President, Center for the Advancement of Health (Chair)
- Molly French, Consultant
- Margaret Holmes-Rovner, PhD, Visiting Professor, Center for the Advancement of Health
- Jim Jaffe, Vice President for Public Affairs, Center for the Advancement of Health

Main Points

- Participants broadly agreed that the potential libraries strategy is feasible and critically needed. It especially makes sense in rural areas where consumers have few options for support, and the local library has a major role in community life.
- The outcome, or intended behavior change, is older adults knowing libraries are a source for health information.

- The Engagement Framework is the principal value added and needs to anchor each part of the initiative. The underlying change needed is a shift in social norms.
- Sustainability is having a lasting effect on the community and the population. Sustainability is not necessarily that libraries continue to provide consumer health information and services after the supports from Atlantic Philanthropies end.

Other Suggestions

- *The Challenge* section: One challenge is how difficult it is to engage people before they have a crisis. However, libraries can overcome this obstacle by engaging their patrons even if they have come to the library for something else. This outreach would target not only older people, but also other adults who may be helping their elders with health and health care issues.
- *Why Public Libraries* section:
 - A core library function and librarian role is helping patrons get the information needed for their particular question so people can make their own decisions. The greatest impact occurs when the individual patron obtains information that directly relates to his or her specific situation. Also, librarians help by making referrals without asking why.
 - Librarians really want to meet community needs, so another key library function is serving as a community convener.
 - It is also important to note what functions libraries do *not* have. Librarians do not want or need to know the content they are helping patrons access; further, their role is not to help patrons interpret information. Also, public libraries cannot directly advocate for funding, but they can educate and provide information to groups that lobby policy makers.
 - Libraries can and do work with community coalitions to get the information needed to meet community needs. In a potential libraries initiative, this outreach would help change community norms.
 - The section needs to explain why libraries will want to participate in the initiative. Incentives could include heightened visibility, higher utilization, improved community image and meeting community needs for improved access to reliable health information.
- *What Would this Initiative Look Like* section:
 - Ideally, the initiative would be both broad and deep. For breadth, the initiative could have a toolkit that all public libraries could use and develop regional resource centers that provide expertise and assistance. Not all libraries would need to receive grants to do something. For depth, one option is to have libraries apply for technical assistance and training and require recipients to do something in consumer health information and services so the investment in their technical capacity will actually benefit older people. Another option is

to require librarians to attain a certificate in consumer health information specialization, from the Medical Library Association, before their libraries can receive free technical assistance.

- Marketing is necessary for not only getting people into libraries but also engaging patrons once they walk in the door (such as merchandising) or enter the library Web site.
 - Librarians want toolkits, basic training and other resources so they can direct people to the best sources without learning the content themselves. They also will need models because the Engagement Framework is a new approach and most public libraries do not view themselves as a change agent in health behaviors. These models should address as many areas as possible of the Engagement Framework and feature a variety of communities and library capacities.
 - Public libraries are the best place for reaching older people with health information, but most will benefit from partnerships with medical libraries for accessing additional expertise and journals. Often facing a threat of closure or significant cuts, medical libraries would be willing to be partners.
 - Because of the needed change in social norms, libraries would also work with community groups promoting broader scale change.
- *Engagement Framework* in Appendix A: Decision-making and powers of attorney could be placed in the chronic disease management section.
 - *Program Elements* in Appendix C:
 - Libraries have different capacities; thus, the initiative should offer a variety of supports because a cookie-cutter approach will not be effective. Low-resource libraries need the most support.
 - To assure that the initiative reaches out-of-the-way places, it could build the capacity of larger organizations to engage smaller libraries and minority-serving institutions. These intermediaries must have a plan to sustain their assistance. Alternatively, initiative leaders could map areas of greatest needs and develop pilots, then capture and share lessons. Either strategy offers the benefit of diversifying risk and generating a variety models and approaches.
 - National economies of scale include:
 - ? Developing a guide for strategic planning and a toolkit. The latter should suggest criteria or core values for credible partnerships and recognize they are challenging to form and sustain and so require an ongoing process. As possible, technical supports should tap existing resources that would be helpful to librarians, including the Medical Library Association's MedSpeak brochures, criteria for evaluating the quality of health websites and consumer health information specialist certification program.

- ? Fiduciary: Public agencies take longer than private agencies to get money out the door. Trade associations may divert program funding to support member services. Problems are inevitable when the implementing organization is different from the fiduciary organization because it separates program and budget oversight. Another model is a single fiscal agent, to which separate libraries submit invoices.
- ? Establishing national partnerships to stimulate local support or partners. National partners also can bring existing resources that are needed. Suggested partners include National Council on Aging for its network and BenefitsCheckUp; American Library Association and various parts that serve public, urban, and small and rural libraries; Chief Officers of State Library Agencies, which advocates for the Library Services and Technology Act (LSTA) grant program; Friends of Libraries USA; American Medical Association's health literacy initiative; American College of Physicians and associations of other health professionals including pharmacists and nurses; more progressive consumer engagement groups; American Hospital Association, especially its patient advocacy section; Integrated Healthcare Association; Health Research and Educational Trust; Corporation for Public Broadcasting and its health literacy project; Joint Commission; public interest groups like the National Governors Association and National Association of Counties; Centers of Disease Control and Prevention; Environmental Protection Agency, Office of Aging; National Institute on Aging; Aging and Disability Resource Centers (ADRC) Technical Assistance Exchange (TAE); Health Resources and Services Administration; Surgeon General; and academic institutions such as the University of North Carolina School of Information and Library Science and the prevention research centers at schools of public health.
- Grants should:
 - ? Be flexible so libraries can get creative, but require collaboration with community partners (similar to grants awarded by the National Library of Medicine and Institute of Museum and Library Services).
 - ? Require involvement of target population even if via a focus group.
 - ? Be made to both libraries and private non-profit organizations working with their local libraries. Most large library systems have foundations, and they need to be able to make subgrants to library branches. Smaller libraries are least likely to have a foundation.
 - ? Allow libraries to hire staff to coordinate the program.
 - ? Ensure grantees have a good plan for actually engaging older people and caregivers — including hard-to-reach populations — in their marketing, programming, information resources and service. For example,

transportation must be figured out so information and services will be accessible.

- ? Make a long-term commitment of five or more years to get better results. However, such commitments must be sufficiently flexible so libraries can respond to changing community needs and opportunities.
- ? Cap indirect at 10-12 percent.
- Regarding local library efforts with their partners:
 - ? The majority of time spent doing community assessments will be deciding what to do than collecting and analyzing data on needs.
 - ? Overall library capacity makes a difference.
 - ? Collaboration is essential.
 - ? One promising opportunity is for intergenerational programs in which youth or younger people assist older people.
- To develop sustainability, the initiative must have a deliberate strategy to give the initiative a voice. One option is to give grants to or contract with organizations that will advocate for continued investment in consumer health information and services with other funders. Another option is to create a process that organizes stakeholders for advocacy.
- The evaluation should :
 - ? Collect data that local policy makers consider important. Currently, these tend to be utilization measures, which vary by the particular demographics served by the library.
 - ? Use population-level measures to assess impact. For example, the evaluation could examine changes in the percentage of individuals who have or use better information or know information. Krantz and others have developed measures. Another option is individuals who are connected to community resources.
 - ? Employ community measures that assess changes in community parlance relating to engagement in health and health care, accessibility of information and the embedding of information in community.
 - ? Consider using insurer reimbursement for the provision of health information as a macro measure of success.
- Figure 6 (Community Partners): Partnerships with or buy-in from senior centers and other aging network members is essential. Other partners that could be added to Figure 6 include local aging and disability resource centers; Racial and Ethnic Approaches to Community Health (REACH) coalitions; partnerships in the Steps to a Healthier U.S. initiative; campus-community partnerships; community action agencies; Urban League community affiliates; and Healthy Communities, Healthy

Cities programs. Also, community partners need to connect with state-level resources such as state health insurance programs, chronic disease directors, aging directors, councils of mayors and elected officials, and groups that help with the process of getting quality health care, not just the knowledge.

Miscellaneous Resources Suggested

- American Library Association's incoming president will have her initiative focus on consumer health information
- Joint Commission's *What Did My Doctor Just Say?* publication

APPENDIX F

National Library of Medicine Teleconference Notes

On March 26, the Center and officials from the National Library of Medicine (NLM) discussed the potential strategy of public libraries serving as a focal community resource for improving the health and quality of life for older people.

CAH Participants

- Jessie Gruman, PhD, President (Chair)
- Molly French, Consultant
- Margaret Holmes-Rovner, PhD, Visiting Professor

National Library of Medicine Participants

- Betsy Humphreys, Deputy Director, NLM
- Lisa Boyd, Consumer Health Coordinator, NN/LM Office, NLM
- Becky Lyon, Deputy Associate Director for Library Operations, NLM
- Angela Ruffin, PhD, Head, National Network of Libraries of Medicine Office, NLM

Main Points

- The idea is feasible, especially if scaled back so that the goal is reaching many (but not all) public libraries and U.S. communities. Also, only a few behaviors should be the focus.
- Success will take more than five, even 10 years. The initiative must have a clearly defined outcome and use a clear message with libraries.
- The whole initiative will take a fair amount of money not only to provide resources to communities and libraries, but also to plan and manage it.
- Because the Engagement Framework is an untested approach, the key challenge will be how to structure the initiative so it can have the most impact. Iterative phasing could allow NLM to capture and apply lessons to subsequent funding.
- A missing — and needed — ingredient is a list of effective interventions to accompany the Engagement Framework. Libraries will want to understand the range of interventions that are effective, gaps that exist and factors that contribute to success.
- Libraries most likely to succeed are those that have existing community partnerships. A process for community engagement should be a grants requirement. Conversely, NLM experience with information outreach has been that grants to community-based organizations have more impact when a library receives the

funding. Both the request for proposals (RFP) and the evaluation criteria can influence community involvement.

- Sustainability: After their grants end, librarians will continue to promote good information resources. However, funded activities, such as health fairs, may taper off. While sustainability models can be identified, ultimately each community must find its own path. It should be part of the RFP and a priority throughout the initiative.
- Evaluation: The initiative should have a high-end evaluation of some projects, but should not require all libraries to participate in it. Instead, libraries should report on a few basic measures, and the rest of their measures should reflect local goals.
- Possible NLM Roles: NLM is a logical home for developing a centralized information resource for older people and their caregivers to help them engage in their health and health care, along with training and materials to help librarians use the centralized resource with patrons. NLM is very interested in evaluating what works. Also, it is interested in administering the grants and has several successful models that could be adapted to the initiative. For example, one is a two-stage approach (first seed funding to assess community engagement, then full project funding if warranted). Historically, NLM and the National Network of Libraries of Medicine have provided minimal hands-on technical assistance.
- NLM could potentially sustain the centralized information resource once it is developed.

APPENDIX G

American Library Association Teleconference Notes

On March 28, the Center and officials from the American Library Association (ALA) discussed the potential strategy of public libraries serving as a focal community resource for improving the health and quality of life for older people.

CAH Participants

- Jessie Gruman, President (Chair)
- Molly French, Consultant

American Library Association Participants

- Keith Fiels, Executive Director
- Cathleen Bourdon, Associate Executive Director of Membership
- Joan Claffey, Director, Office of Development

Main Points

- The idea is feasible and needed. For example, one state library study found half of reference questions pertained to health. Overall, health information is an under-recognized library service.
- To reach disadvantaged communities, the initiative must work with both rural and urban libraries, even suburban ones because recent urban renewal is displacing low-income groups to suburbs.
- One potential grantmaking model is ALA's new investor education initiative. They are identifying about 100 libraries with exemplary investor education programs to invite to apply for grants of \$5,000 to \$100,000. Applicants must have existing partnerships with local agencies. To get a distribution of projects, ALA is using categories for urban, small and rural, library regional networks or co-ops and book mobile programs. ALA can share the request for proposals once it is released.
- Grant Program Structure: The initiative should have a closed competition for grant funding, but enable all libraries to access centralized resources.
 - Although demanding, iterative grant funding enables ALA to apply what is learned with the early adopters. The initial rounds can develop models and best practices that applicants/grantees can use by the third round. It may make sense to do about 100 grants in first round, then 150 grants in subsequent rounds.
 - Categories can help assure that funding gets to libraries serving disadvantaged communities. They also assure the development of models that apply to different types of communities and may help level the playing field for libraries that have less grant-writing capacity, but high programmatic potential.

- Three-year grant periods would provide public libraries with time to ramp up and get footing for sustainability (such as getting consumer health into the library's strategic plan and securing other funding). Eight years might be too long for grants, but up to five years would be okay.
- Mini-grants of \$5,000 to 10,000 are a good way to have broad impact. Libraries could use funds for planning, building collections, collating information and perhaps doing some implementation. Larger libraries would need larger mini-grants to entice their participation.
- All libraries have a way to spend grant funding. Some might have to get permission, but the county or city often expedites these types of requests. Libraries should be allowed to use grants to offset existing personnel costs, but do so in a way that they do not undermine future public funding for staff positions.
- About 20 state libraries could be helpful to the initiative, especially those that have some programs in consumer health. To learn from their experiences, the initiative implementing organizations need to build a partnership with these state libraries or put them on an advisory committee.
- Public relations campaigns can really magnify impact by increasing awareness.
- Possible ALA Roles: ALA can offer a continuum of services to implement the initiative. This includes proposal review by expert panels, grants administration, technical assistance, centralized technical resources and a public education campaign. ALA is essential to any effective public campaign at both local and national levels, but needs enough funding to do both.
- ALA brings credibility with all types of libraries and unparalleled reach into the sector. From prior partnerships with funders, ALA can suggest a range of capacity-building models.

APPENDIX H

Americans for Libraries Council Teleconference Notes

On March 30, the Center and officials from the Americans for Libraries Council discussed the potential strategy of public libraries serving as a focal community resource for improving the health and quality of life for older people.

CAH Participants

- Jessie Gruman, President (Chair)
- Molly French, Consultant

Americans for Libraries Council/Libraries for the Future Participants

- Diantha Schull, President
- Bruce Astrein, Executive Director
- Chris Johnson, National Program Director, Access Programs
- Abby Long, HealthAccess Program Manager

Main Points

- The concept of building library capacity to provide older adults with information, education and assistance corresponds with ALC's work since 1995 with HealthAccess (one of the Appendix I profiles) and LifelongAccess, which is the LFF initiative to deepen library services for older Americans.
- State libraries can be good lever for change, but there is considerable variation in their capacity, vision and goals. In the unstructured landscape of libraries, state libraries are one commonality. State librarians tend to know their constituents well, have capacity for grantmaking, and have important convening and leadership functions. To encourage systems change, the initiative could have a grant category for state libraries with the purpose of increasing their focus on consumer health; the intended outcome would be influencing how state libraries prioritize the resources they administer. Perhaps 10 to 12 state libraries really understand the opportunity presented by consumer health information services.
- Having a 10- to 15-year horizon lends a unique opportunity because the initiative can go beyond a set of really good pilots to generate the content and momentum that will drive a decade's worth of work and produce the desired outcomes.
- Because of the potentially long horizon, initiative leaders must keep in mind the Center for Budget and Policy Priorities' projection of a coming squeeze on state budgets, which will mean few libraries would have sufficient resources to sustain the new capacity. Initiative planners might need to do an initial library outlook analysis to inform the development of a sustainable set of technical supports, funding, leadership and partnerships for consumer health services after The Atlantic Philanthropies' initiative ends.

- Grants: The initiative should invest in both strong-capacity and small-capacity libraries. There are benefits to doing both state-level and national grantmaking, but sometimes using state intermediaries increases administrative costs.
- Sustainability and Maximize Impact: The current approach proposed by the Center in the background paper lays out a systematic way to move libraries along the continuum. For the Langeloth Foundation, ALC is convening a task force to define a continuum of library consumer health services and consulting on the development and refinement of a training curriculum to advance libraries along that spectrum. ALC is incorporating the Engagement Framework into the levels of excellence and associated training. The framework is very useful because it will help libraries their community partners develop a concrete focus, which is essential to having an impact. The Engagement Framework also will help libraries pull the right partners to the table.
- To achieve full impact, the potential Atlantic Philanthropies initiative must be deliberate in how it plans to achieve systems-change, which is necessary for sustaining consumer health information services after their funding ends. Based on ALC's work with libraries seeks system-changes, system-change components include the following.
 - Readiness and capacity-building. The model being developed for Langeloth currently has five levels of assistance for building library capacity. Libraries can proceed along the continuum as they are ready. Organizing technical resources for different capacities will enable ALC to help libraries whether they are just getting started or are relatively advanced.
 - Mobilize leadership: Libraries tend to be followers, so ALC seeks to nurture and move forward the innovators in order to advance the field. Also, messaging must be on target to hook the later adopters.
 - Training: The initiative should think beyond training sessions for participating libraries to try to effect changes in professional training and continuing education. The goal would be integrating consumer health information and services for older adults into librarian training systems.
 - Models of excellence: The library field lacks models of excellence, as other fields have. Smaller libraries, in particular, need such models.
 - Coordination of effort for synergies: The initiative must have a systematic approach to systems change. This means carefully coordinating each component to create sufficient synergy to achieve ultimate sustainability.
- Possible ALC Roles: ALC proposed a division of responsibilities that would leverage its and the National Library of Medicine's (NLM) existing resources and areas of expertise, respectively, in community-based programming and health reference. In this scenario, ALC would have the lead on curriculum, training and

grantmaking — in partnership with the NLM, which would oversee the development and dissemination of resource materials, recommendations for consumer health collections and other supports. The American Library Association's unique position in the library field could be used to raise the visibility and prominence of public libraries as centers for health information through a communications campaign.

Another approach is to organize capacity-building at both the national and state level because it would allow The Atlantic Philanthropies to seed change and activity across the country while simultaneously concentrating resources in key states. In this scenario, ALC could lead state-based efforts that would both a) build off existing LifelongAccess, HealthAccess and EqualAccess efforts and infrastructure; and b) use the leadership and rollout capacities of state libraries to impact change at a broader level.

A third approach would be for ALC to lead the proposed Advisory Council. ALC has experience convening national forums and leadership groups.

- ALC has the advantage of considerable experience helping libraries expand their services, programming and community partnerships via HealthAccess and LifelongAccess. It has a track record of organizing training, technical assistance and grants that has built the capacity of public libraries and state libraries. More broadly, ALC also has expertise in library advocacy and coalition development.

The Center asked ALC to describe in writing some of the challenges it believes must be considered carefully in the potential initiative. The following text is ALC's response.

Public Libraries and Health Information and Education

The public library is the primary public source of free electronic and print information — a necessary and vital link in the information chain that stretches from health-service providers and community-based organizations through researchers, educators, and policymakers. At the local level, some libraries are responding to the needs of health consumers by developing new services, collections, partnerships, and programs. They have started to create health information centers, expand collections in relation to local language and cultural backgrounds, collaborate in the organization of online health reference resources, partner with local health agencies and schools, reach out to vulnerable and underserved populations, organize health-related programming, and, most recently, address issues of health literacy.

The nation's 16,000+ public libraries are poised to function more systematically as a center for health information and health education. They face several barriers to achieving this potential, however, including:

1. Inadequate training opportunities for librarians to develop skills in reference, community outreach, partnerships, and program development;
2. Lack of an infrastructure for exchanging ideas, strategies, and best practices;
3. Minimal public awareness of libraries' health information resources;
4. Insufficient funding for program development, replication, and expansion;
5. Lack of a common vision for the health information roles of public libraries.

1. Training

There is growing recognition that librarians benefit from training in a variety of skills that enable them to find the best information, present it most effectively to the user, and take advantage of information assets outside the library. The National Network of Libraries of Medicine (NN/LM), to cite one example, is enlarging its training for public librarians. Another training initiative is HealthAccess, an approach developed by Libraries for the Future that covers both traditional health reference skills, such as conducting a health reference interview and collection development, and community responsive programming skills, such as outreach and partnership development.

2. Exchange of Ideas

In a rapidly evolving field such as health information it is critical that professional staff have access to the experiences and best thinking of peers around the nation. The National Commission on Library and Information Science (NCLIS) recently gave formal recognition to the health-information role of public librarians through an annual Blue Ribbon Awards for Model Consumer Health Information Programs, which is an important step in showcasing best practices. Much more is needed, including the development of a national infrastructure for disseminating or evaluating such models across the library community or for ensuring adequate information exchange as new models are developed, tested, and evaluated.

3. Public Awareness

Though health inquires are the most common reference question, there is little public awareness of the health resources of the library. The gradual development of library-based health information centers, which showcase the library and its partners' health information and services, have slowly begun to address this issue. Additional outreach and partnership, coupled with local and national public awareness campaigns, will help further raise the visibility of this hidden community treasure.

4. New Funding

Policymakers and librarians are increasingly aware of the need to provide more accessible and useful health information and education. A promising approach would be

to establish a public-private commitment to increase funding for testing, promoting, and disseminating new library based health programs and partnerships. That would ensure resources for a sustained approach by the network of institutions that will have a greater and greater role to play in helping individuals protect their health and cope with the nation's complicated health-care system.

5. Vision

Finally, there is an urgent need to create and promote a framework that helps libraries assess their current level of health services and chart a course for deepening their programming. Libraries for the Future is leading one such effort, the HealthAccess Levels of Excellence (see DRAFT attached), which it hopes to use for encouraging a national discussion around the expanding role of libraries in providing health information and education.

A Program for the Future

The efforts and initiatives briefly noted above suggest that some libraries and library systems, as well as national nonprofit and federal agencies, have begun to take important steps to realize the full capacity of libraries as centers for health information. These efforts will build the capacity of libraries to sustain and expand health services to people of all economic and cultural backgrounds across the lifespan. But these individual efforts need a broader and unifying national framework to have maximum impact. The scope and comprehensive nature of the project currently being considered by The Atlantic Philanthropies has the potential to provide such a frame by shoring up and promoting existing best practices, seeding innovation, encouraging replication and expansion, and attracting additional private and public support for library based health information and education.

DRAFT — Americans for Libraries Council

LEVEL OF EXCELLENCE	SAMPLE INDICATORS	HEALTH TRAINING	PROJECT GOALS
<p>ONE Basic Health Reference Services</p>	<p>Internal Assessment</p> <ul style="list-style-type: none"> • Existing print and online consumer health collection assessed, organized, and promoted • Health reference requests and services tracked and documented • Staff person trained in providing health information 	<p>Health Reference</p> <ul style="list-style-type: none"> • Courses include those offered by MLA, NNLM, ALC, Others 	<p>Capacity Building Emphasis on increasing access and awareness to health information and education</p>
<p>TWO Mid-level to Advanced Health Reference Services</p>	<p>Community Assessment and Internal Capacity Building</p> <ul style="list-style-type: none"> • Additional training for new and or existing health reference staff — with an emphasis on outreach and program development • Initial assessment of local health issues and resources completed • Consumer health collection enriched • Partnerships established with medical libraries and/or others to assist with complex patron health information requests 		

<p>THREE + Basic Programming and Outreach Services</p>	<p>Partnership and Planning</p> <ul style="list-style-type: none"> • Health Advisory Council • Needs and resources detailed • Work Plan developed • Initial expansion of health programs and services 	<p>Outreach and Programming</p> <ul style="list-style-type: none"> • Courses include those offered by ALC, PLA, NNLM, Others • <i>To be developed:</i> Engagement Framework courses 	<p>Constituency Building</p> <p>Emphasis on building a network of CBOs, including the library, to meet the health information and education needs of the community, as well as to improve individuals' ability to positively impact their health</p>
<p>FOUR + Advanced Programming and Outreach Services</p>	<p>Outreach and Program Development</p> <ul style="list-style-type: none"> • Outreach and programming for target populations is coordinated, expanded, tailored and promoted in partnership w/ other CBOs, • Health Information Centers created • Multi-pronged, evidenced based programming that assists individuals in preventing, mitigating, and addressing health issues 		
<p>FIVE Community Coalition to Build Awareness and Support for Health Information and Programs</p>	<p>Public Awareness and Advocacy</p> <ul style="list-style-type: none"> • Social marketing, community forums, etc. to increase awareness of consumer health issues • Root causes of inadequate health information and poor health assessed 	<p>Advocacy</p> <ul style="list-style-type: none"> • <i>To be developed:</i> From existing resources and trainings 	<p>Community Building</p> <p>Emphasis on creating a common vision for effective health information services and a plan for actualizing that vision</p>

APPENDIX I

Profiles of Consumer Programs

This appendix presents profiles of some model programs that aimed to improve consumer access to and use of reliable health information. Other profiles highlight initiatives to transform libraries to meet the public's ever-changing information needs. The collection showcases exemplary programs, but is not an exhaustive or scientifically representative list of all such initiatives. When selecting programs to profile, the Center strived for a collection that:

- Illustrates how libraries can serve as rich, proactive centers for senior health resources in the communities in which they are located.
- Demonstrates the feasibility of an initiative that builds such capacity in public libraries and subsequently increases the number of consumers who are obtaining assistance with health and health care decisions.
- Indicates the types of support that national organizations can provide to create economies of scale.
- Highlights existing efforts of libraries to transform services and supports to meet community needs.
- Explores non-library community institutions as potential agents.

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Profiles by Characteristic

<i>Target Audience</i>	<u>Program Reference Number</u>
Caregivers	1, 3, 15
Consumers (in general)	2, 4, 6, 7, 8, 9, 13, 14
Older Adults	1, 2, 3, 5, 7, 11, 12, 15
Underserved Populations	1, 4, 7, 9, 10, 11, 13, 14, 15

<i>Intervention Levels</i>	<u>Program Reference Number</u>
National → Regional → Local	14
National → State → Local	1, 8
National → Local	2, 3, 6, 10, 11, 16
State → Local	12, 15
Local Only	4, 5, 7, 9, 13

<i>Other Characteristic</i>	<u>Program Reference Number</u>
Library Involvement	1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15
NLM or NN/LM ^c Support	4, 5, 6, 7, 8, 9, 13, 14
Volunteers	1, 3, 5, 6, 7, 10, 11, 12, 13, 15

^c National Library of Medicine (NLM); National Network of Libraries of Medicine (NN/LM)

#1

Ageing & Disability Resource Centers

*Administration on Aging and Centers for Medicare and Medicaid Services
Virginia Department for the Aging and Senior Navigator*

National/Virginia

Consumer Focus:	Older adults, persons with disabilities and caregivers
Topic(s):	Long-term care
Intervention Level(s):	National → State → Local
Capacity-Building Resources:	Grants, training, technical assistance, education,
Begin/End Dates:	2003-present (national program); 2005-present (Virginia)
Primary Funder:	\$756,670 (Virginia) from the Administration on Aging and the Centers for Medicare & Medicaid Services

Overview

The Aging and Disability Resource Center (ADRC) program — a joint initiative of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS) — assists states in creating a single, coordinated system of information and access for all persons seeking long-term support services. The goal is to minimize confusion, enhance individual choice and support informed decision-making. The federal agencies jointly fund grants and technical assistance to enable states to create ADRCs. The initiative is part of the President's New Freedom Initiative, which aims to eliminate barriers to community living for people with disabilities of all ages.

To date, \$40+ million in ADRC initiative grants have enabled 43 states to establish ADRC projects in more than 100 communities. To illustrate the ADRC program, this profile features Virginia. As a 2005 grant recipient, Virginia established a public/private partnership for its "No Wrong Door" program that connects consumers, family caregivers and health and community support providers with information and services.

National-Level Project Structure

The ADRC initiative streamlines access to long-term care for seniors and individuals with disabilities by establishing resource centers that provide personalized information on specific long-term care options^d in clients' communities. With financial and technical supports from AoA and CMS, states streamline aging, Medicaid and disability services through partnerships with existing long-term care resources. The ADRC goal is to establish centers in all states and U.S. territories by 2012 or 2015.

ADRC grants underwrite the development and expansion of statewide resource networks. To obtain a grant of up to \$800,000 for three years, states assure the provision of all three

^d Such as meals-on-wheels, personal care, housekeeping, specialized transportation, respite, assisted living and nursing home care.

core ADRC functions — information and awareness, assistance and access — to individuals ages 60 years and older and one or more populations of younger adults with disabilities. The program requires grantees to create three structural elements that are tailored to community assets and needs.

- Streamlined access to long-term care supports
- Information technology systems to support core ADRC functions
- A way to sustain the services after grant funding ends

Most states are creating their ADRC networks in stages, and nearly all supplement their ADRC grants with Older Americans Act funding, Medicaid, state and local revenue and grants from other sources. AOA was able to award continuation awards to 2003 grantees whose initial grant awards ended in September 2006; continuation awards are helping to support statewide expansion.

AoA and CMS jointly fund the ADRC Technical Assistance Exchange (TAE), which is administered by the AoA-funded Lewin Group and supported by the CMS-funded Community Living Exchange Collaborative. Focusing on policy and program infrastructure development, ADRC-TAE provides one-on-one consultation, group technical assistance, semi-annual ADRC national meetings, weekly newsletters, monthly Web-casts and a variety of other supports on the Web site. Subjects cover the nuts and bolts of starting, improving and sustaining ADRC operations (Web site available; last updated in February 2007). ADRC-TAE is constantly adding new materials, and staff review and periodically update some tools.

State-Level Project Structure

States have structured their ADRC initiatives in different ways. Some have created centralized systems, and others use a decentralized approach. Some systems have developed ADRCs at physical locations, while other states have established online services with access in libraries or other community venues. State-driven management is more common than locally driven management. Thus, Virginia is just an example of ADRC project structure, but may not be typical.

In 2006 the Virginia Department of Aging received a total ADRC award of \$756,670 for a three-year period. Additional funding for No Wrong Door comes from state and local governments, area agencies on aging (AAAs), local foundations, corporate philanthropy and local providers.

The main No Wrong Door service is a web-based portal that gives a virtual single entry-point and web-based tools that provide easy access to information and services that patients, family caregivers and ADRC providers need concerning physical disability, aging and long-term care services. The Web site and web-based tools, called GetCare, also facilitate information exchange and coordination among community organizations that provide services to seniors and adults with disabilities.

The Virginia strategy integrated No Wrong Door into its existing infrastructure that connects consumers and caregivers to health and aging services in their community. A statewide non-profit organization, SeniorNavigator, has served older Virginians since

2000 as both an online clearinghouse and a network of 467 access points for in-person assistance. With funding from the Virginia Department for the Aging, SeniorNavigator added disability resources to its existing database of thousands of local health and aging programs and services. No Wrong Door is also leveraging SeniorNavigator Centers, which provide free access to and assistance with the Web site, especially for people who lack computer or Internet access. SeniorNavigator also provides training and outreach materials to SeniorNavigator Centers including: public libraries, senior centers, local governments, faith-based communities and community-based organizations. Beyond support from the ADRC grant, SeniorNavigator's funders include Anthem, Dominion, Verizon, ten health systems, local governments and community partners.

A statewide advisory council oversees the implementation of No Wrong Door. Members include state agencies and offices involved in long-term care, representation from local pilots, SeniorNavigator, 211 and consumers.

Like Virginia, other states have ADRC Web sites that give consumers easy access to information on specific services available in their communities. Some ADRC initiatives co-located staff from multiple agencies in a single location and developed computerized information systems to assess client needs, activate service delivery and monitor quality. All entail state- and local-level partnerships among aging, Medicaid and disability organizations to streamline information and access to long-term care services and empower consumers to make informed decisions. Local partners include government agencies, community providers, libraries, advocacy organizations and existing community networks.

To market services to aging and disability populations, most grantees use brochures and fliers, forums, presentations, health fairs, newsletters and direct mailings targeting these audiences. To a lesser extent, ADRCs rely on advertisements or public service announcements in radio, television and newspapers. Several states have developed marketing materials and strategies specifically for underserved populations.

A key federal expectation is that states will sustain their ADRC services after their federal grants end and provide ADRC services in all areas of their states. Some of the most common sustainability strategies are:

- Seeking Medicaid reimbursement.
- Developing partnerships with businesses and community groups for both volunteers and funding.
- Codifying the ADRC initiative in state law or institutionalizing the program through an interagency structure.
- Using community volunteers.
- Requesting grants from private foundations.
- Asking for voluntary donations or piloting user fees.

To foster sustainability at the federal level, Congress embedded the ADRC program in the reauthorized Older Americans Act of 2006. AoA officials are integrating ADRC into

other federal initiatives, such as the CMS Medicare Senior Risk Reduction Demonstration.

Support for Building Local Capacity

With grants from the Virginia Department for the Aging and technical support from SeniorNavigator, three Virginia area agencies on aging are piloting No Wrong Door in their regions. In 2007 and 2008, six additional regions (all area agencies on aging) will join the initiative. Each region uses the information available online at SeniorNavigator.org and the GetCare tools to:

- Expand and update the online directory of service providers.
- Identify the best options for consumer referral.
- Automate referrals within the regional network.
- Coordinate use of the Uniform Assessment Instrument (screening and assessing needs and eligibility) by state and local governments and care providers.
- Coordinate services for clients that best match their needs and preferences using a Web-based case management system.
- Enroll and track client progress in programs.
- Record service units and unmet needs.
- Participate in the No Wrong Door evaluation (see information below).
- Identify and address gaps in community long-term care support services.

To help both public and private organizations adopt the case management system and database, Virginia Department for the Aging and SeniorNavigator analyze existing business processes and interactions with other providers. Together they examine how the technology can improve the organizations' services and how to alter business processes to integrate the new technology. This close work with community organizations prompted Virginia to modify the global case management system so that a section can be customized by the implementing agency to meet its specific operational needs.

In each region, local multi-disciplinary advisory councils guide the ADRC. Start-up funding and in-kind public relations expertise from Dominion helped each pilot launch the No Wrong Door initiative in their community. Additionally, each pilot area agency on aging built a coalition of local providers, governments and consumers to ensure each "resource center" access point delivers all ADRC functions.

Both the Virginia Department for the Aging and SeniorNavigator are actively pursuing opportunities to sustain No Wrong Door when the federal ADRC grant ends in 2008. Funding from both public and private sources will be essential to sustain the public/private partnership.

Evaluation Methods and Results

In Virginia, the Center for Gerontology at Virginia Polytechnic Institute and State University (Virginia Tech) is directing the evaluation. The center is working with the Virginia Department for the Aging, pilot sites and SeniorNavigator to document system users, referrals, service delivery and outcomes. As much as possible, existing data

sources (e.g., the Uniform Assessment Instrument and the case management system) are used.

Although the No Wrong Door initiative was recently launched, the case management information system has more than 27,000 client records. With the expansion of SeniorNavigator to serve adults with disabilities, the database now provides information on more than 21,000 programs and services and represents more than 9,000 public agencies and private organizations. In 2006, SeniorNavigator attracted more than 460,000 visits, many by seniors and caregivers in search of services.

Nationally, the Lewin Group developed evaluation guidelines for ADRC projects and is collecting and synthesizing state grantee evaluation data. An interim report in 2006 used data from semi-annual reports from 2003 and 2004 grantees, site visits, telephone interviews, ADRC-TAE Web site statistics and other sources. Overall, the centers are improving access to long-term care information and services through an array of entry points. In particular, options counseling is increasing awareness of available support services, providing in-depth information about each support and assisting clients in making informed decisions. Use of information technology and effective partnerships have created an efficient process for consumers, providers and administering agencies.

The interim evaluation report also indicates:

- More than 750,000 consumers and providers contacted ADRCs in a two-year period; just over half were new users. The significant proportion of repeat contacts suggests ADRCs are viewed as trusted information providers.
- Marketing brochures, Web sites and advertisements helped stimulate about 17 percent of ADRC contacts. Referrals from libraries, AARP, public agencies and others also generated contacts.
- At least one third of ADRC contacts were not about long-term care; many of these sought information on the Medicare prescription drug benefit and Hurricane Katrina and Rita relief.
- In pilot sites reporting data, ADRCs may have helped reduce institutional placements and increased home- and community-based services.
- Extensive partnerships enabled ADRCs to offer a broad scope of services, reach out to diverse populations and secure new resources.

All grantees in the interim evaluation faced one or more substantial challenges in planning and implementing their programs. Information technology challenges were the most common. Others pertained to staff and leadership issues, challenges in establishing partnerships and difficulties in streamlining access. To avoid or overcome these challenges, states invested time and resources in engaging partners, assessing needs, involving end users in the planning and development processes, proactively managing changes in state government leadership and cross-training staff. Taking incremental steps was another strategy to set the stage for success.

The Lewin interim evaluation indicates all states were using multiple strategies to pursue sustainability. Even so, long-term financial and resource commitments were uncertain.

Would they have the means to sustain operations or expand to all areas of the state?
Upgrade information technology? Continue providing ongoing professional training?
Enhance and expand partnerships?

Lessons Learned^e

- The provision of information by itself does not empower older adults to make informed long-term care decisions. Trusting relationships and an ongoing process to provide assistance, such as short-term case management, appear to be necessary components.
- No two states are the same. Thus, a flexible model is essential to nationwide adoption.
- Using existing assets — state health insurance assistance programs, AAAs, 211 referral systems and provider networks — increases the odds for positive outcomes and long-term sustainability.
- Traditionally, aging and disability programs have followed different service paradigms and administrative models. These differences can slow the process of establishing relationships between these two networks.
- An active program champion is critical for cultivating effective partnerships and securing financial support for expansion.
- One way for resource centers to increase consumer contacts is to establish partnerships with hospitals, physician offices, rehabilitation nursing homes and other community providers that are often entry points into long-term care.
- Partnership difficulties as well as delays and cost-overruns with information technology systems can be frequent challenges.
 - ? To put partnerships on a solid footing, partners must be engaged early and often.
 - ? To receive the maximum value of new technology, participating organizations must modify business processes.
 - ? To maximize participation in a global technology application, organizational clients must be able to customize the system so it provides data or tools specific to their operations.
- Some of the best ways to involve consumers are developing a consumer advisory board and creating other opportunities for them to provide substantive input.
- A new initiative can sometimes be fast-tracked when partners have done their homework, a champion engages partners with a clear vision, existing assets are leveraged and the structure fits with how partners are used to doing business. Even so, flexibility and incremental implementation are essential because unforeseen challenges always arise.
- Multi-county regions work well because consumers already access services in a broad geographic region and, through AAAs, public and private organizations

^e The Lewin Group report captured lessons learned on many facets of implementing ADRCs. The following points are a selection of lessons that best pertain to a potential initiative to make public libraries a focal community resource for improving the health and quality of life for older people. For example, the list omits challenges relating to standardizing screening and intake processes.

often have existing relationships. Restricting resource centers to a single county can have the unintended consequence of reducing access.

- Physical access points for consumers can be created through partnerships with community organizations where older adults already go for information and assistance.

Web Site and Other Information Sources

[http:// www.adrc -tae.org](http://www.adrc-tae.org)

<http://www.aoa.gov>

<http://www.healthlit.org/index.htm>

<http://www.seniornavigator.com/findcenter.php>

<http://www.aging.state.va.us/nowrongdoor.asp>

G. Case and L. Swann, personal communications, February 28 and March 21, 2007.

K. Roeper, personal communications, February 22 and March 12, 2007

Lewin Group. (2006). *The Aging and Disability Resource Center (ADRC) demonstration grant initiative: Interim report*. Retrieved February 8, 2007, from [http://www.adrc -tae.org/documents/InterimReport.pdf](http://www.adrc-tae.org/documents/InterimReport.pdf).

#2

Be Well Informed @ your library

Reference and User Services Association, American Library Association

National/Regional

Consumer Focus:	Consumers, especially Medicare beneficiaries
Topic(s):	Chronic disease prevention and management, Medicare Part D, medication safety
Intervention Level(s):	National → Local
Capacity-Building Resources:	Grants, training, tools, technical assistance and resources
Begin/End Dates:	2004-2006
Primary Funder:	\$427,301 from Walgreens

Overview

To promote libraries as sources of accurate, reliable health information, the American Library Association (ALA) partnered with Walgreens to conduct the Be Well Informed @ your library demonstration project. Ten library systems in large cities received \$25,000 grants and other technical supports to plan, promote and host four consumer health education seminars. Local Walgreen pharmacists presented the seminars in libraries using curricula developed by other Walgreens pharmacists with input from librarians.

National-Level Project Structure

The project goal was to promote public libraries and pharmacists as sources of accurate, reliable health information. Objectives were twofold: a) provide grants and other support to ten U.S. library systems; and b) deliver health education services to consumers.

An advisory committee, with both librarian and Walgreens pharmacist members, reviewed program materials and midcourse data. In addition to providing ALA with a \$427,301 grant, Walgreens developed the curricula for the library seminars, mobilized local stores and pharmacists and enabled its public relations firm, Fleishman Hillard, to provide participating libraries with technical guidance on marketing seminars. The National Library of Medicine participated on the advisory committee. With the exception of a Web site resource section, ALA supports for public libraries ended with the grant.

Support for Building Local Capacity

Participating library systems each received a \$25,000 grant from ALA. Allowable uses of the grant included staff, consumer health books and other resources, local media promotion and seminar costs (including promotion and refreshments). Participating libraries also received the following supports:

- Monthly teleconferences, which ALA organized, that enabled cross-fertilization of marketing strategies and timely guidance from Fleishman Hillard
- Connections to local Walgreens pharmacists
- A set of core reference books for consumers on health and health care

- Be Well Informed planner's manual
- Communications toolkit with posters, bookmarks, bookplates and gift items for seminar participants
- Electronic discussion list
- In-person initial training session for project managers on planning and promoting the seminars

ALA created a new section on its Web site so that all librarians can access a subset of Be Well Informed resources. Offerings include bibliographies of core reference sources, both print and online, for consumers on health and health care. Hypertension, the Medicare drug discount card and children's health and nutrition each had a separate bibliography (Web site available; last updated in February 2006).

Project Structure at the Community Level

Each participating library system selected five branch locations to host a set of four consumer seminars. Topics included Medicare Part D, diabetes, asthma and medication safety. Walgreens pharmacists were the primary local partner because they were the main seminar presenter. During the seminar, the hosting librarians acquainted attendees with relevant library services.

Most attendees learned about the seminars at the library; others heard about them in local media. Libraries primarily relied on signage, such as external banners, and notices on their Web sites and in newsletters. Both library and Walgreens store staff informed patrons about the seminars. Public, commercial and religious partners posted information. Local media outreach efforts — public service announcements (PSAs); opinion editorials; and media alerts — had mixed success. Finally, some libraries taped each seminar and provided the videos to city cable stations.

At least one of the participating library systems planned additional consumer health projects with community partners and Walgreens. Another system indicated interest in using the new capacity to plan future consumer health projects.

Evaluation Methods and Results

ALA provided each library system with standardized evaluation forms to collect data from attendees, librarians and the presenting pharmacists. Total attendance for all 184 seminars exceeded 2,600, for an average attendance of 14 per seminar. Attendees tended to be female (75 percent); African-American (48 percent); and aged 70+ (42 percent). On a five-point scale, about two thirds of attendees strongly agreed that the seminars improved their understanding of the topic, that the seminars were "excellent programs" and that they were more likely to ask pharmacists and librarians questions.

On separate forms, librarians and pharmacists rated each seminar on a five-point scale, and the former documented "hits" and "misses." Success factors included food and gifts for attendees, seminar time devoted to attendees' questions for the pharmacist, transporting attendees to seminar by bus, raffles and pharmacists' presentation and knowledge. Problems included insufficient lead time to promote the first seminar, delays

in pharmacists learning about the seminars and lack of awareness among some local Walgreens stores.

Finally, project managers in each library system rated Be Well Informed materials and services on a six-point scale. Project managers rated all materials as "excellent" or "very good," except for the sample op-ed and electronic discussion list. "Very helpful" supports were the kick-off training session, conference calls and ALA staff assistance.

Lessons Learned

- An advisory committee can be useful if it provides a mechanism for obtaining multi-disciplinary review and guidance.
- Adult education programs are very difficult to do in part because of people's busy schedules.
- Libraries and others offering health education classes about a specific condition (e.g., diabetes) need to take into account people's concerns about health privacy in order to attract participation.

Web Site and Other Information Sources

<http://www.ala.org/ala/rusa/rusaprotocols/bewellinformedyourlibrary/wellinformed.htm>

American Libraries Association. (2006). *Be well informed @ your library: Final report*. Retrieved November 1, 2006, from <http://www.ala.org/ala/rusa/rusaprotocols/bewellinformedyourlibrary/FinalReport.pdf>

American Library Association. (n.d.). *Programs and partners*. Retrieved November 2, 2006, from <http://www.ala.org/ala/ourassociation/annualreport/programsandpartners/programsandpartners.htm>

C. Bourdon, personal communication, November 7, 2006.

#3

Communicating Effectively with Healthcare Professionals

National Family Caregivers Association

National

Consumer Focus:	Caregivers
Topic(s):	Health
Intervention Level(s):	National → Local
Capacity-Building Resources:	Training
Begin/End Dates:	2000-present
Primary Funders:	\$525,290 from The Jacob and Valeria Langeloth Foundation and \$307,694 from the Administration on Aging

Overview

Family caregivers are often a hidden part of the health care system, providing essential services, including helping care recipients get medical care. To improve the health and wellbeing of care recipients and family caregivers, National Family Caregivers Association (NFCA) created *Communicating Effectively with Healthcare Professionals*. Trained workshop leaders use the *Communicating Effectively* curriculum to teach family caregivers how to communicate effectively in health care settings.

As a national non-profit organization, NFCA empowers family caregivers by providing education and support and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness, disability or the frailties of old age.

National-Level Project Structure

With a goal of improving the health and wellbeing of family caregivers and care recipients, *Communicating Effectively* empowers family caregivers by teaching effective communication and advocacy techniques for interacting with the health care system.

Specific workshop objectives are as follows.

- Train family caregivers to advocate on behalf of their loved ones, deliver continuity of care and access resources needed by both the caregiver and the care recipient
- Provide family caregivers with specific communication skills for a variety of medical contexts (e.g., emergency room (ER) and physician's office) and helpful hints for dealing with others such as insurance companies)
- Allow family caregivers to function as a member of a health care team

An advisory committee with representatives of caregiver organizations and experts in health care and communications guided NFCA in developing *Communicating Effectively*. The committee, together with NFCA staff, identified topics based on the literature and the association's experience with assisting family caregivers. Two experts in communications, curriculum development and training wrote the program. It was pilot

tested with a group of family caregivers and suggestions for improvement were used to modify the program before actual trainings began. NFCA solicited reviews and feedback from family caregivers to ensure it would be useful in real-life situations.

The resulting curriculum not only trains family caregivers in basic communications techniques, but also imparts information and techniques specific to common health care situations. The caregiver workshops are interactive sessions that allow for role-playing in ERs and physician office settings. The accompanying take-home manual for family caregivers provides practical tools and information such as a planner for upcoming health care visits and tips for recording care recipients' symptoms and maintaining a medical record.

For Communicating Effectively, NFCA received grants from two organizations totaling \$832,984 over a four-year period.

- The Jacob and Valeria Langeloth Foundation's initial grant of \$204,952 over two-years enabled the development of the curriculum and the hosting of a national conference to train 50 workshop leaders.
- The Administration on Aging, as part of the National Family Caregivers Support Program, provided two awards, \$150,000 in year one and \$157,694 in year two. This funding, plus additional funding from the Langeloth Foundation, supported 10 regional conferences to train workshop leaders, the development of a controlled-access Web site for workshop leaders. NFCA also conducted booster training sessions via teleconferences.

Although the initial grants have ended, NFCA continues to pursue opportunities to bring Communicating Effectively to caregivers across the nation. For example, the organization has sought funding for an initiative in which workshop leaders team up with hospitals both to conduct Communicating Effectively sessions and to develop hospital staff skills so they can deliver the curriculum. In addition, the initiative would develop video versions of the curriculum to broadcast in-room televisions, as well as CDs that family caregivers can listen to in their cars and view on their computers. NFCA piloted a telephonic version of the Communicating Effectively curriculum with AT&T as part of its work/family program. NFCA plans to further develop offerings for delivery in workplace settings. In the interim, NFCA has posted some Communicating Effectively materials online.

Support for Building Local Capacity

The Communicating Effectively training conferences created a cadre of workshop leaders who then delivered the curriculum in community settings. Conference participation was open only to professional trainers who, with their supervisor's support, pledged to conduct at least two workshops within a year. Typical participants were professionals who worked for hospitals, private home health care providers, area agencies on aging, local American Red Cross agencies and community foundations. Some attendees received continuing education credits. Upon successful completion of the program, participants received a certificate of training from NFCA.

NFCA continues to support workshop leaders by providing manuals, evaluation forms, and tools for marketing, such as a press release template. A password-protected area of the NFCA Web site lets workshop leaders order workshop materials, post information about upcoming workshops, enter data from evaluation forms and learn from each other. In the past, telephone booster sessions enabled workshop leaders to exchange ideas and obtain peer guidance.

To promote the training conferences and attract potential workshop leaders, NFCA worked with national organizations such as the American Society on Aging, Hospice Foundation of America, Alzheimer's Foundation of America and the National Association of Area Agencies on Aging. Organizations located within upcoming training city destinations were also approached.

Project Structure at the Community Level

Across the nation, Communicating Effectively leaders have organized workshops in their communities. Some did so with the support of their employers, and others engaged community partners. Workshop leaders use the three-hour curriculum as a base but have the flexibility to condense workshops to a one-hour session in order to attract participants. Others adapted the curriculum for specific needs, such as caregivers of persons with multiple sclerosis.

Evaluation Methods and Results

Communicating Effectively is helping to fill a gap. One indication is that NFCA added 10 additional training conferences to meet the demand generated by its initial training conference. Some of the 400+ workshop leaders who received certificates remain active today. More than 10,500 family caregivers have learned new skills and gained more confidence by attending these workshops. Once caregivers participated in Communicating Effectively, they often wanted more.

Two small studies suggest Communicating Effectively builds the confidence, knowledge and self-efficacy of family caregivers in actively serving as the care recipients' advocates in health care settings.

- NFCA's master trainer who directs the social work program at Skidmore College used qualitative telephone interviews and a quantitative mail survey of workshop participants regarding behaviors before and after the workshop. Data indicate significant increases in participants' assertiveness, note taking and document preparation; respondents also reported improved quality of communications with the care recipients' health care provider. Additional pre-/post-evaluation studies are planned with the Albany Veterans Affairs Medical Center in the summer of 2007.
- In a separate study, a research team from the Veterans Affairs Maryland Health Care System and the University of Maryland adapted the curriculum for caregivers of people with multiple sclerosis. Pre-/post-session questionnaires of the 11 workshop participants suggest the adapted Communicating Effectively session raised caregivers' confidence and comfort level in effectively communicating with health professionals and serving as an active member of the health care team, greater self-efficacy, and improved communications skills and knowledge. This

research effort won two of four awards given when presented at the annual meeting of the Consortium of Multiple Sclerosis Centers in 2005.

Lessons Learned

- The curriculum is sufficiently flexible that workshop leaders could structure sessions in shorter or longer formats and tailor it to specific groups of caregivers.
- Workshop leaders have had to be creative, with assistance from NFCA, to get family caregivers to attend Communicating Effectively sessions. Many caregivers are employed, so sessions had to be scheduled to fit with their work and caregiving schedules. One-hour workshops often attracted more attendees than did longer sessions.
- Getting Communicating Effectively into other mediums, such as electronic formats and teleconferences, will enable the curriculum to reach more family caregivers in a variety of settings.

Web Site and Other Information Sources

http://www.thefamilycaregiver.org/caregiving_resources/communicating_effectively_workshops.cfm

<http://www.familycaregiving101.org>

http://www.langeloth.org/grants_more.php?id=4

Administration on Aging. (n.d.). *Promising practices in the field of caregiving*. Washington, DC: U.S. Department of Health and Human Services. Retrieved on February 2, 2007, from http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/nfcsp_projects/PromisingPractices.pdf.

Martin, C. A., Costello, K., & Ehrmantraut, M.E. (n.d.) *Empowering family caregivers for individuals with multiple sclerosis*.

S. Mintz and C. Willingham, personal communications, February 20 and March 20, 2007.

Moore, D. (in press). *Communicating effectively with health care professionals: a curriculum for family caregivers*. Home Health Care Services Quarterly.

National Family Caregivers Association. (2005). *Meeting today's needs, planning for tomorrow*. Annual report (July 2004-June 2005). Retrieved on February 2, 2007, at <http://www.thefamilycaregiver.org/pdfs/AnnualReport2005.pdf>.

#4

Community Outreach Information Network

*Tompkins-McCaw Library for the Health Sciences, VCU Libraries
Virginia Commonwealth University*

Richmond, Virginia

Consumer Focus:	Consumers, including low literacy groups
Topic(s):	Health, health literacy
Intervention Level(s):	Local
Capacity-Building Resources:	Outreach, coordination of network members
Begin/End Dates:	2002-present
Primary Funder:	\$119,977 total for three National Library of Medicine outreach grants

Overview

The Community Outreach Information Network (COIN) comprises four consumer health information centers, each of which is affiliated with the Virginia Commonwealth University (VCU) and its health system. Coordinated by VCU's medical library, COIN pursues its mission of increasing access to high quality health information for the greater Richmond metropolitan area's high-risk population by providing the right information at the right time and place and in the right format. COIN strengthens ties among its member centers, connects them to local organizations and provides outreach and marketing support.

Regional-Level Project Structure

Together with its members, COIN seeks to empower individuals to learn more about their health. To achieve this goal, COIN:

- Promotes awareness and use of the four consumer health information centers:
 - Community Health Education Center (CHEC)
 - Massey Cancer Center Linen-Powell Resource Library
 - Massey Cancer Center Patient Resource Center
 - Women's Health Resource Center at Stony Point
- Strengthens relationships among the four centers.
- Connects the centers with appropriate community agencies.

The administrative home for COIN is the Tompkins-McCaw Library for the Health Sciences at VCU. A variety of other VCU affiliates support the network and/or its individual centers, including the Cancer Information Service (CIS) and VCU Community Solutions.

The National Library of Medicine (NLM) has supported COIN outreach initiatives with funding. Specifically, three NLM awards totaling \$119,977 supported an initial community needs assessment, the creation of COIN and COIN efforts to promote the centers and conduct community training sessions. COIN received additional NLM

funding of nearly \$100,000 per year to support two fellows. National Network of Libraries of Medicine (NN/LM) trainers help to update skills of center staff and other VCU health system professionals.

The COIN advisory councils include representatives from the public library systems in Richmond and surrounding jurisdictions. Funders, community-based organizations and community representatives also participate as council members.

VCU has sustained COIN largely because of the ongoing need to increase awareness of the centers and encourage their use to improve the local community's health status. Tompkins-McCaw Library contributes staff and enables COIN to use its systems. Occasional grants fund support for the network itself.

Support for Building Local Capacity

COIN primarily provides its services through outreach and marketing to VCU patients and to underserved populations in the community. The COIN Web site, telephone number and virtual reference desk offer multiple entry points for consumers who may be unsure which information center to use. The COIN network refers consumers to the most relevant and accessible center.

COIN develops messaging that emphasizes the availability of reliable, quality health information through the centers' technology resources and personalized assistance. Publicity tactics include exhibits at health fairs, local media and patient give-away items, such as pens and bookmarks. COIN and its centers use their health education programs as ways to attract users. With support from separate NLM awards, COIN services are also promoted via information prescriptions that VCU Health System professionals give to patients.

COIN helps the individual centers engage external partners and coordinate services, such as community training sessions. Through COIN planning efforts, free health clinics and the Virginia Hispanic Chamber of Commerce were provided computers for ready access to health information.

Project Structure at the Community Level

The centers support consumers' health information needs through collections, Internet access, reference services, community referrals and information packets. To meet the diverse needs and abilities of users, health information is available in multiple formats and languages suitable for low literacy individuals. In addition, one center, the Community Health Education Center (CHEC), has a designated area for children 14 years and younger that offers age-appropriate health information.

Trained librarians assist users to locate appropriate health information resources, and users can have staff read these materials to them. The centers also conduct or host a variety of health programs, including health education classes, health fairs, lectures and support groups; some of these are possible through partnerships with local voluntary

health agencies and community-based organizations. Trained volunteers work as center receptionists, field simple questions and take book carts to hospital patients.

The centers are trying some innovative approaches to extend their reach and their impact.

- COIN is working with other VCU partners to integrate consumer health information services into the pre-admissions process.
- To attract patrons, one network member opened a "business center" that enables patients and their visitors to check e-mail, communicate with employers and conduct other personal business over the Internet.
- Staff from another center makes daily rounds to discuss information needs with patients. To follow up, the center prepares individual packets that hospital then review with their patients.
- COIN participated in a demonstration project where information prescriptions were issued to patients.

Beyond consumers, the centers provide and facilitate training sessions for VCU and its health system professionals. As an example, CHEC offers a health literacy continuing education class.

Individual centers have their own sources of funding from VCU affiliates and community sources. With funding from the Urban League of Greater Richmond and Central Virginia Care Connection for Children, CHEC serves as their resource centers. Several of the centers use donated space.

Evaluation Methods and Results

An initial community assessment has helped COIN and its centers to understand local interests and needs. One finding was that area residents prefer to talk with someone about their health and information needs. For this reason, marketing materials emphasize the availability of personalized assistance and the network established its virtual reference desk whereby "visitors" can receive live, online help.

To monitor use and obtain feedback, COIN centers collect data with standardized COIN user surveys (print and online). Informal feedback from users and input from the COIN advisory committees also have influenced programs and services. Data indicate the usage of COIN services has increased each year since 2002. From 2002 to 2005, nearly 25,000 persons used the COIN network, and 11,600 persons attended 185 health education sessions. For CHEC, an evaluation funded by the local area health education center found that 97 percent of CHEC users were very satisfied with the information they obtained.

Lessons Learned

- To be effective, consumer health information services must be tailored to the target market, in part by engaging trusted community leaders, including librarians and teachers, in the design process.
- Consumer health information centers must continuously evolve to meet changing needs, take advantage of new opportunities and increase usage. This requires an annual review and planning process.

- Convenience increases the odds that services will be used and will make an impact. Indeed, health information centers can take their services directly to patients and offer non-traditional services to raise awareness and increase usage.
- Services must be delivered in a way that protects patients' health privacy.
- The human touch is still important.
- Consumer health information centers lack standardized performance benchmarks, which would be useful when prioritizing areas for improvement.

Web Site and Other Information Sources

<http://www.library.vcu.edu/coin>

J. P. Shipman, personal communications, November 9, 2006, and January 15, 2007.

U.S. National Commission on Libraries and Information Science, Libraries and Health Communication Task Force. (2006). *Libraries and health information: Awards initiative and report*. Washington, DC: U.S. Government Printing Office. Retrieved September 12, 2006, from <http://www.nclis.gov/award/healthawards06.html>

#5

Computer Health Literacy for Seniors

*DeArmond Consumer Health Library, Wood Medical Library
Kootenai Medical Center*

Coeur d' Alene, Idaho

Consumer Focus:	Older adults
Topic(s):	Health literacy
Intervention Level(s):	Local
Capacity-Building Resources:	Web site, training, consumer health information
Begin/End Dates:	2003-2004
Primary Funder:	\$43,885 from National Network of Libraries of Medicine

Overview

The mission of the DeArmond Consumer Health Library is to ensure that every citizen of North Idaho has access to the resources they need to make informed choices about their health care. In order to increase access to good health information for senior citizens, the library organized a computer health literacy project. Senior citizens received individualized basic computer skills training to develop skills in obtaining current health information. The project also resulted in improved hospital discharge instructions. Focus groups of seniors advised the project managers on the usability of the hospital and the consumer health library's websites, resulting in the creation of a user-friendly website that meets the health information needs of seniors.

Project Structure at the Community Level

With a \$43,885 grant from the National Network of Libraries of Medicine, the library pursued its goals of increasing older adults' awareness about healthy lifestyles and their ability to be more involved in healthcare decision-making. Believing that health literacy is essential to improving health, project objectives included developing the information skills of older adults and improving access to electronic health information resources.

During the planning phase, the library assessed how well older adult volunteers could read and comprehend health and medical terminology. The assessment informed the development of the computer skills training sessions for seniors and a Web site tailored to their health interests and needs (<http://dearmond.nicon.org/seniors.html>). The Kootenai Medical Center also used the assessment to modify its home-care instructions in order to make them more accessible to older patients' needs.

Library staff trained seniors in computer skills and online health information as well as developed the senior health Web site. Four senior centers, which hosted the computer skills training sessions, were the library's primary project partner. Each center received a computer and Internet access to give seniors easy access to electronic health information. Library staff and volunteer trainers obtained informed consent from each individual participant prior to training, conducted pre-/post-testing and provided some basic

computer training. On an informal basis, trained seniors may have helped their peers access health information.

Other project partners included churches, human services agencies, and other community-based organizations that helped recruit older adult volunteers. Also, a local electronic communications network hosts the senior health Web site. Beyond the grant award for the project, the National Network of Libraries of Medicine provided general professional development support to both Wood Medical and DeArmond libraries. Indirect support also came from the Idaho Commission for Libraries, which assists library consortia in accessing databases.

Library staff developed a brochure that promoted the senior health Web site and provided background about the project. At health fairs and in senior centers, the library distributed the brochure along with bookmarks and flyers about the library and MedlinePlus. Other communications strategies included the county fair and a regional conference exhibit, radio and cable announcements, newspaper advertisements and columns, and notices in senior newsletters.

With support from the Kootenai Medical Center (as part of its operating budgets for community relations and patient education functions), the library sustained some parts of the project.

- Reference services for senior centers and the local area agency on aging
- Exhibit at the annual conference of the local area agency on aging
- The senior health Web site (Website available as of December, 2006; unable to determine last update)
- Individualized training, as requested by seniors and others at the DeArmond Consumer Health Library

In addition, the computers remained at each senior center, and each senior center is responsible for maintaining the Internet connection.

Evaluation Methods and Results

Standard tests assessed community seniors' health literacy and computer anxiety. A modified questionnaire collected data relating to MedlinePlus and the Internet as health information resources. In addition, seniors in focus groups evaluated the existing Web site for usability; these results prompted the development of a Web site specifically for seniors. Library staff designed and maintained the new Web site.

The project trained about 40 seniors in 120 individualized, computer training sessions. Also, the medical center altered patient discharge instructions to correspond with community literacy levels.

In 2004, the National Commission on Libraries and Information Science recognized Computer Health Literacy for Seniors as a model program.

Lessons Learned

- Focusing on a target population helps maximize project impact.

- Many seniors were not interested in participating in the testing for reading and comprehension. Influencing factors appear to have been concerns about being "tested" (and potentially failing) and an observed tendency for adults in their 70s and older to gradually withdraw from involvement in civic activities. Seniors were most comfortable participating in the initial assessment in their own homes.
- The opportunity to help others seemed to be the greatest motivator for seniors who participated in the project.

Web Site and Other Information Sources

<http://www.kmc.org/body.cfm?id=221>

<http://dearmond.nicon.org/seniors.html>

E. Hill, personal communications, November 17, 2006, and January 11, 2007.

Horner, M. (2005.) *Computer health literacy for seniors in Northern Idaho: An access to electronic health information outreach 2003 project*. Coeur D'Alene, ID: Kootenai Medical Center. Retrieved November 14, 2006, from <http://nnlm.gov/pnr/funding/reports/ComputerHealthFinalReport.pdf>

U.S. National Commission on Libraries and Information Science, Libraries and Health Communication Task Force. (2004). *Libraries and health communication: Model programs in health information provided by libraries throughout the nation*. Washington, DC: U.S. Government Printing Office. Retrieved September 12, 2006, from <http://www.nclis.gov/award/healthawards06.html>

#6 Consumer Health Information Toolbox (and Other Supports)

Medical Library Association (MLA), Consumer and Patient Health Information Section (CAPHIS)

National

Consumer Focus:	Consumers
Topic(s):	Health
Intervention Level(s):	National → Local
Capacity-Building Resources:	Toolbox for providing consumer health information
Begin/End Dates:	1997-present
Primary Funder:	In-kind support from the Medical Library Association and members of Consumer and Patient Health Information Section

Overview

To help librarians set up and run a consumer health library, the Consumer and Patient Health Information Section (CAPHIS) of the Medical Library Association (MLA) developed an online toolbox. Additional CAPHIS and MLA resources assist librarians with providing consumer health information services. One of these other supports is a 1996 MLA policy identifying librarians' roles in consumer health information and patient education.

National-Level Project Structure

MLA is a professional organization of more than 1,200 institutions and 3,800 professionals in the health information field. CAPHIS, one of 23 MLA sections, provides a forum for librarians in the area of consumer health information and patient education.

Developed by a CAPHIS task force, the 1996 MLA policy statement defines six roles for librarians in consumer health information and patient education. Specifically, librarians can contribute to collection management, knowledge and resource sharing, advocacy, access and dissemination of information, education and research. The exact mix of roles depends on the mission and policies of the librarian's organization.

In 1997, CAPHIS launched the managing a consumer health library Web site (<http://caphis.mlanet.org/resources/index.html>) to inform librarians, including those in public libraries, about the nuts and bolts of offering consumer health information services. CAPHIS member-volunteers did a major update of the toolbox in 2001, and a third is underway. In between revisions, the section makes small modifications as needed (Web site available; last updated in April 2007).

CAPHIS relies on members and partners to mention the consumer health library Web site in publications, listservs and blogs. When people ask questions relating to consumer

health information services, CAPHIS members refer them to the toolbox and other relevant resources.

CAPHIS efforts to encourage the development of consumer health information services are supported entirely by section members who volunteer their time and expertise. MLA hosts the CAPHIS Web site.

Support for Building Local Capacity

Rather than develop original materials, CAPHIS chose to direct toolbox users to reliable resources, which are grouped by topic. Highlights of the consumer health library toolbox include:

- MLA's 1996 policy on the librarian's roles.
- Annotated resource list for a variety of steps involved in planning consumer health information services.
- Linkages and contact information on topics such as collection development, budgeting, marketing and volunteer training.

The toolbox features several National Library of Medicine (NLM) and National Network of Libraries of Medicine (NN/LM) resources, including the NN/LM online manual for consumer health information. (NLM submits occasional articles to the section's quarterly newsletter, *Consumer Connections*.)

MLA or CAPHIS also offers additional resources.

- *"For Health Consumers" Web site* — this bibliography presents the top 100 Web sites providing trustworthy health information (Web site available; last updated in January 2007). It is updated each year by a team of CAPHIS members who evaluate individual Web sites using criteria such as currency, credibility, content, sponsorship/authorship, ease of navigation and audience. The team then selects the best Web sites to include in the list.
- *Consumer Health Library Directory* — this online, searchable database has information about CAPHIS member libraries, most of which are medical libraries (Web site available; last updated in 2006). Librarians can search for library management information; consumers and librarians can search by subject areas, geographic location and other areas of interest. In 2006, the section decided to stop updating the directory and instead link to the NLM database of libraries providing consumer health services.
- *Individualized assistance* — by request, CAPHIS members provide one-on-one assistance to both members and non-members.
- *Consumer Health Information Specialization* — this series of coursework and certification from MLA enables librarians, allied health professionals and information specialists to develop expertise in consumer health information. The specialization program has about 150 active participants.
- *MLA exchange* — this service facilitates the exchange of health sciences books and periodicals among the association's institutional members.

Evaluation Methods and Results

Due to resource constraints, CAPHIS does not formally evaluate its resources, but instead relies on feedback and questions in the CAPHIS listserv, e-mails to the section and other communications. These anecdotal data suggest medical and public librarians are the primary users of the consumer health library toolbox. Secondary users include students in library sciences courses, health educators, nurses and people setting up health information services.

CAPHIS periodically examines Web statistics, member comments and listserv messages to ensure the toolbox continues to attract visitors and is meeting users' needs. Each CAPHIS newsletter generates approximately 800 downloads per issue.

Lessons Learned

- The use of volunteers ensures CAPHIS resources capture the intellectual capital of decades of members' experiences in a wide variety of settings and is a way to activate membership. However, project delays can occur when relying on volunteers.
- When content fulfills the information needs of users, a practical Web site can suffice. Bells and whistles are not necessary to provide value.
- The MLA operating philosophy of member-driven services and outreach fosters a learning environment. CAPHIS and other MLA sections provide forums for members to learn from each other and work together to advance the field.

Web Site and Other Information Sources

<http://caphis.mlanet.org/resources/index.html>

<http://caphis.mlanet.org/consumer/index.html> (CAPHIS Top 100 List: Web Sites You Can Trust)

http://caphis.mlanet.org/directory/find_a_library.html (Consumer Health Library Directory)

Fuller, H. Personal communication, January 26, 2007.

Medical Library Association. (1996). The librarian's role in the provision of consumer health information and patient education. *Bull Med Libr Assoc.* Apr; 84(2): 238-9. Retrieved January 22, 2007, from http://caphis.mlanet.org/resources/caphis_statement.html.

#7

Grillo Health Information Center

Boulder Public Library

Boulder, Colorado

Consumer Focus:	Consumers, especially older adults
Topic(s):	Health
Intervention Level(s):	Local
Capacity-Building Resources:	Not applicable
Begin/End Dates:	1998-present
Primary Funder:	Substantial operating (non-financial) support from Boulder Public Library. Financial support from other community partners and foundation grants.

Overview

Grillo Health Information Center offers a range of consumer health information resources in an environment designed to put consumers at ease and provide individualized assistance. The center is unique in its extensive use of trained volunteers and its structure as an independent non-profit organization that closely collaborates with the Boulder Public Library.

Project Structure at the Community Level

Spurred by the vision of a local professor, Virgil Grillo, the Grillo Health Information Center was established in 1998 to enable area residents to become informed about their health and health care. Grillo Center fulfills this goal by offering a comfortable, confidential setting for people to research and access the most current and trustworthy information. Specific objectives are to help center patrons:

- Gain a better understanding of their medical diagnosis (or a health topic), including treatment options, clinical trial information and complementary and integrative approaches.
- Partner with their physician or other health professional in making health care decisions.
- Read up-to-the-minute medical research and preventive health news.
- Find support groups and community services.

The Grillo Center is housed at Boulder Public Library (BPL), its main partner. Because of the close collaboration, BPL provides:

- Dedicated space in the library so Grillo patrons can receive confidential assistance in a convenient location.
- Use of its facilities for the center's periodic health lectures.
- Access to its health information and materials collections. This avoids duplication and helps integrate the Grillo Center into the library's other services. The library's collections development staff work closely with the Grillo co-directors in selecting new acquisitions.

- Volunteer recruitment and screening services.
- Supervision of the Grillo Center's co-directors.
- E-mail and telephone service and supplies.

Grillo Center offers patrons a wealth of health information and assistance. Patrons seeking help can receive assistance from a well-trained volunteer when they visit BPL or contact Grillo by telephone or e-mail. Grillo has a dedicated set of computers that provide access to reliable health Web sites, including a couple available only by subscription, such as MD Consult. Through the BPL partnership, patrons can use the library's extensive collection of medical reference books, health magazines and videotapes. Grillo maintains an updated set of pamphlets and brochures to assist users in connecting with community resources. If patrons want a publication that is not in the collection, Grillo can get it through interlibrary loan, including the system administered by the National Network of Libraries of Medicine. Rounding out the center's services is a series of free lectures by health professionals on timely health topics. (For example, the February 2007 lecture discussed the HPV vaccine.) The community cable station broadcasts videotapes of these lectures on a rotation schedule, and patrons can borrow the videos from the library.

Grillo Center takes its resources out to the community to reach underserved residents. With seed funding from the National Library of Medicine, Grillo developed partnerships with a local health clinic and a resource center for families. At these sites, a bilingual Grillo Center volunteer has provided clients with online health information in Spanish. Once its partners emerge from organizational transitions, Grillo Center intends to continue these weekly outreach efforts and perhaps start providing similar services at the women's health center. Grillo's partnership with the Boulder High School librarian ensures students have access to reliable health information resources at their school library.

Volunteers are a core asset because they provide the one-on-one assistance that makes Grillo effective. About 30 to 40 volunteers support the center; 19 serve a two-hour shift each week, with the others working as substitutes. BPL recruits and conducts the initial screening of professionals, seniors, university students preparing to be health professionals and others who constitute the volunteer pool. One of the Grillo co-directors conducts a second interview of volunteer candidates, and each new volunteer receives individualized training by the co-directors. Each year active volunteers must attend three or four training sessions that the co-directors organize. Outside experts, including representatives from the National Network of Libraries of Medicine, conduct the training.

The primary role of volunteers is to provide Grillo patrons with good information from a legitimate source. The individualized service creates a personal touch that many patrons value. The assistance begins with a volunteer starting an intake form that collects basic data about the patron (who can opt to be anonymous). The form also documents the information request and assistance provided. To maintain the center's high service quality, Grillo's co-directors review each intake form and follow up with patrons as

needed. The co-directors also are available to volunteers during their shift to give assistance and support.

Volunteers and substantial non-financial support from the Boulder Public Library enable the Grillo Center to sustain operations on an annual budget of about \$55,500, which includes salary for the co-directors. This estimate excludes the \$59,400 value of the library in-kind contribution to Grillo. The local newspaper also provides non-financial support by regularly printing an ad for Grillo and sponsoring a monthly "Ask the Grillo Center" column. The primary sources of income are contributions from the Boulder Community Hospital, Boulder Public Library Foundation and two major employers (IBM and Roche Colorado). Because of a decline in the community hospital's ability to contribute, Grillo is starting a fundraising drive and is pursuing more grants.

Grillo is well known in Boulder, yet gaps remain in residents' awareness of the center. BPL's reference librarians and other staff refer people to Grillo, especially as they rarely have a private setting or sufficient time to provide in-depth assistance. Newspaper ads and the Grillo column connect some patrons with Grillo, as do the lecture series, community cable broadcasts of the lectures, the center's Web site, referrals from faith-based and other community organizations and word of mouth (Web site available; last updated in February 2006). As previously noted, Grillo brings its services to the community by sending volunteers offsite and being accessible by both telephone and e-mail.

Evaluation Methods and Results

Data on intake forms indicate about 75 percent of Grillo patrons are older adults. Many have one or more health conditions, do not own a computer and may lack basic computer skills.

To evaluate services, patrons receive a questionnaire at the end of their visit. These forms provide useful feedback and many testimonials. For example, one patron wrote, "Very helpful — volunteer took the necessary time to locate many articles on my research question and was especially helpful in extracting the most relevant from a vast amount of material." Another comment was "This research will assist me in asking questions when I go to the doctor regarding tests that I may need...." Patrons report valuing the professionalism and listening skills of the volunteers and co-directors, provisions of caring support, comfortable environment and thorough assistance. Some report that the Grillo Center was the first place they turned to after receiving a diagnosis. Patrons have described the Center as part of their health care team.

In addition to intake forms, the center also maintains statistics on patrons coming to the center and on e-mail and telephone requests. In 2006, Grillo directly served 529 patrons, an increase of almost 15 percent above the 2005 patron usage level. Also, center data indicate staff and volunteers spent an average of three hours per patron, which reflects the one-on-one service that is the hallmark of the center. This level of usage meant Grillo staff and volunteers were actively working on patrons' needs during almost all hours the center was open.

Lessons Learned

- The personal leadership of Dr. Grillo and another founding professor, Gary Stahl, their strong community connections and the right timing were instrumental in establishing the Grillo Center.
- Along with the BPL health collection, Grillo's high quality services, prestige in the community and sizable volunteer pool took years to build.
- Creating consumer health information centers in libraries may meet with resistance, but this can be overcome with tact by including reference librarians from the beginning so they understand the potential benefits (such as enabling them to spend more time assisting patrons).
- A volunteer program can be successful with good training, attentive supervision and a satisfying experience for the volunteers. In particular, volunteers need to feel supported by accessible and present staff. Supervising volunteers helps assure high quality services, as is letting volunteers know they are valued.
- Many volunteers, especially university nursing and pre-med students, are motivated by the opportunity to hone health research skills and individually assist patrons.
- No community outreach partnership is immune from organizational change and logistical challenges. By continuing to stay in touch, outreach efforts can be re-established.

Web Site and Other Information Sources

www.grillocenter.org

C. Engleman, personal communication, January 17, 2007.

C. Engleman and C. Salter, personal communications, January 10 and March 8, 2007.

C. Salter, personal communication, December 20, 2006

Zeisel, W. (2005). *Community health connections: Emerging models of health information services in public libraries*. New York, NY: Americans for Libraries Council. Retrieved September 12, 2006, from <http://www.lff.org/publications.html>

Libraries for the Future, Americans for Libraries Council

Arizona, Massachusetts, New York and Pennsylvania

Consumer Focus:	Consumers
Topic(s):	Health
Intervention Level(s):	National → State → Local
Capacity-Building Resources:	Model development, professional development
Begin/End Dates:	2003-present
Primary Funder:	Multiple foundations support HealthAccess and its parent initiative, EqualAccess

Overview

By using the HealthAccess model and professional development program, public libraries develop the capacity to meet the increase in the public's need for reliable health information and programs. Library-community partnerships serve as the foundation for building and sustaining HealthAccess libraries, which are community-responsive centers that improve residents' health and wellbeing. These partnerships coordinate health programs and outreach, extend library capacity as a community health resource and increase use of libraries as health information resources by residents and community institutions.

National-Level Project Structure

HealthAccess is a program within Libraries for the Future's (LFF) EqualAccess initiative. EqualAccess is not only a model of libraries as community-responsive centers for information and education, but also a professional development program to give library professionals the prerequisite skills to realize the model. EqualAccess core competencies are community assets and needs assessment, work plans and evaluation, outreach, collaboration with community partners, and public awareness and advocacy. Currently, four states are part of the EqualAccess initiative: Arizona, Massachusetts, New York and Pennsylvania. In spring 2007, EqualAccess training will begin in California, Connecticut, Florida and New Hampshire.

With goals of improving health literacy and increasing access to accurate, understandable health information through libraries, HealthAccess uses the EqualAccess model and core competencies.^f In addition, HealthAccess goes beyond to develop skills for helping the public access reliable health information. Via the HealthAccess program, library professionals participate in both EqualAccess training institutes and in HealthAccess program sessions. Libraries receive HealthAccess technical assistance and tools — such as a community assessment template and benchmarks — to help them progressively extend and enhance community-responsive health information and programs. Each

^fTwo other programs using the EqualAccess model and core competencies are LifelongAccess and YouthAccess.

participating state has an Access program manager who coordinates training and technical assistance.

EqualAccess received a challenge grant from the Bill & Melinda Gates Foundation. Grants from several foundations support different aspects of the HealthAccess program. Three recent grants build off the EqualAccess model but will test new program models.

- *Wellness Information Zone* funded by the Humana Foundation. An initial grant of \$500,000 in 2006 will support the development of eight library-based health information centers in Atlanta, Georgia, librarian training and development of a consumer health Web site.
- *HealthAccess: Strengthening Public Libraries as Centers for Health Information and Education* funded by the Langeloth Foundation. A grant of \$300,000 received in 2006 will support the convening of a national advisory council to define a continuum of library health information services and develop a cadre of HealthAccess Fellows throughout New England.
- *Fit for Life* funded by the MetLife Foundation. A \$350,000 grant in 2006 is supporting fitness and nutrition programming in 14 urban library systems across the country. Regrants ranging from \$8,000 to \$20,000 are supporting programs of all sorts, from yoga and hiking, to cooking, to traditional health and wellness information services.

HealthAccess is currently in progress, and LFF has secured grants from multiple funders to further develop and expand its reach. At the state level, at least one of the four participating state libraries plans to hire the Access program manager once the three-year program ends. At the community level, the HealthAccess strategies for sustainability are twofold. First, the libraries foster public support for consumer health services by developing strategic partnerships and community-responsive programming. Second, they are integrating HealthAccess practices and programs into the ongoing work of the library.

Support for Building Local Capacity

State libraries are LFF's principal partner in the EqualAccess initiative, including the HealthAccess program. An LFF employee works on-site in each participating state library to manage EqualAccess professional development institutes and coordinate the provision of technical support specific to HealthAccess and other programs under the EqualAccess umbrella. The Access program manager identifies local presenters and organizes and promotes the training sessions. National Network of Libraries of Medicine (NN/LM) experts conduct the health reference training component of Health Access. In addition, the Access program manager arranges technical assistance for the participating libraries, facilitates communication among participants and partners, and coordinates the Access initiative with other state library efforts to foster library development.

Libraries participating in HealthAccess receive training and technical support over a three-year period. (One state library offers \$5,000 grants to libraries participating in training to help them conduct and act on assessments of local assets and needs.) The three-year span supports the changing needs of libraries as they progress through three levels of the HealthAccess service continuum, each of which has specific benchmarks.

- *Level One Benchmarks:* basic health information services, guidance from a health advisory council, at least one librarian trained in health reference services and marketing of consumer health information resources on the library Web site
- *Level Two Benchmarks:* enrichment of the library's consumer health resources, additional staff trained in health reference services, and availability of information and services for users with low health literacy levels
- *Level Three Benchmarks:* library leadership and participation in community coalitions; requests from other community organizations for library participation or assistance

Through demonstration projects within Health Access, additional technical assistance or small grants are sometimes available. For example, Fit for Life demonstration grants help build library capacity in developing fitness and nutrition programs for youth and parents.

Other project partners provide technical support. WebJunction,^g offers online technical resources for all Access programs. HealthAccess resources on WebJunction include program benchmarks, brief snapshots of model programs, templates for assessments of community assets and needs, and guidance on developing consumer health collections. NN/LM provides in-kind support by training librarians in health reference skills as part of the HealthAccess training; in addition, other organizations lead parts of the HealthAccess training sessions. At the national level, LFF partners advise the organization on library trends and opportunities. These partners include the Institute of Museum and Library Science, the New York Academy of Medicine, National Library of Medicine and its network, practitioners from libraries offering model consumer health information services, among others.

To reach libraries in other states, LFF hosts EqualAccess training workshops at the Public Libraries Association's conferences. The EqualAccess and HealthAccess resources on WebJunction are available to all.

Project Structure at the Community Level

HealthAccess libraries:

- Assess community assets and needs.
- Establish health advisory councils and, eventually, community health partnerships. Hospitals, medical clinics, community-based organizations and human services agencies are typical members.
- Provide health information and sponsor or participate in programs to meet community needs.
- Assure library staff has health reference skills.
- Develop consumer health information collections and resources in a variety of formats and for different literacy levels.
- Offer online access and consumer training.
- Promote use of consumer health information and services by both residents and community institutions.
- Coordinate health programming and outreach in the community.

^g See also the profile on the U.S. Libraries Initiative.

Library professionals assist users with finding answers to their health questions. LFF is testing a model for more extensive use of trained volunteers in supporting consumer health resources at libraries.

To encourage use of consumer health resources, HealthAccess libraries train local health professionals as well as work with community partners to integrate library resources into their services. Also, senior centers, voluntary health agencies, local media and other community partners help publicize HealthAccess library resources.

Evaluation Methods and Results

Participating libraries rely on traditional counts of users, in part due to the responsibility of protecting the confidentiality of health information. For example, they may track the number of reference questions related to health. In EqualAccess training, participants learn how to survey program participants, other library patrons and community organizations to assess needs. The field has yet to develop replicable quantitative models for tracking impact of library usage on health and health care.

Because EqualAccess libraries are to be a catalyst and community resource, one gauge of their success is their community fundraising. Collectively, EqualAccess libraries in their second year attracted \$1 million to support their work. The LFF evaluation is also collecting data on partnerships, speaking events and features in local media.

Lessons Learned

- The role of libraries in providing health information is growing because of changes in the health care system and librarians' increased understanding of their potential role.
- Marketing public libraries as community centers for health information and programs must occur alongside efforts to build library capacity to offer services relevant to community needs.
- Modest regrants to individual libraries significantly enhance their ability to expand their health programs.
- The creativity and success of Fit for Life Libraries indicate the importance of continuing to invest in new models of library-based health services.
- Local HealthAccess libraries are more likely to succeed when the state library actively promotes the public library as a community health information resource.
- To improve health information services, public libraries need connections with medical schools, medical libraries and other public agencies.
- Local librarians need ongoing training to keep their skills and knowledge current.

Web Site and Other Information Sources

<http://www.lff.org/programs/health.html>

<http://ea.webjunction.org>

Americans for Libraries Council. (2006). *Designs for change: Libraries and productive aging*. New York, NY: Author. Retrieved September 12, 2006, from <http://www.lff.org/publications.html>

Americans for Libraries Council. (2005). *Access program benchmarks for success*. New York, NY: Author.
Retrieved November 20, 2006, from <http://ea.webjunction.org>

Americans for Libraries Council. (n.d.). *Libraries for the future: Innovation in action*. New York, NY:
Author. Retrieved September 12, 2006, from <http://www.lff.org/publications.html>

C. Johnson, personal communications, November 15, 2006, and January 18, 2007.

#9

Health Information Center, Wheaton Library

Montgomery County Public Libraries

Montgomery County, Maryland

Consumer Focus:	Consumers, especially minority populations, socio-economically disadvantaged groups and older adults and their caregivers
Topic(s):	Health
Intervention Level(s):	Local
Capacity-Building Resources:	Training
Begin/End Dates:	1988-present
Primary Funder:	Initial seed grant from a federal grant via the Maryland State Department of Education. Currently, Montgomery County covers annual operating costs.

Overview

The Health Information Center (HIC) provides consumers with access to reliable and up-to-date health materials, services and information. HIC also supports consumer health information services in other library branches in the system and surrounding counties.

HIC was one of the first consumer health information centers in the country. In 2004, the center received a Blue Ribbon Consumer Health Information Recognition Award for Libraries from the National Commission on Libraries and Information Sciences.

Project Structure at the Community Level

As a direct provider of consumer health information services, HIC aims to help consumers make informed health care decisions by providing the public with access to current, reliable and relevant health information. Located in a dedicated space at a public library branch, HIC provides:

- Consumer health information and resources in print, video and online formats.
- Enhanced health reference assistance from trained staff.
- A 24/7 messaging service for senior citizens and their caregivers to request health information.
- Referrals to local and national health-related organizations and resources.
- A consumer health Web site with links to reliable information sources and online access to databases (Web site available; date of last update is unknown).

Through partnerships, HIC also offers a range of health programs. Examples include:

- Monthly blood pressure screenings via the local American Red Cross chapter.
- Health insurance counseling and advocacy via the Montgomery County Office of the University of Maryland Cooperative Extension Service and the Montgomery County Department of Family Resources, Division of Elder Affairs.

HIC is a member of the National Network of Libraries of Medicine (NN/LM), which enables access to DOCLINE®, the interlibrary loan system for libraries. Through NN/LM, HIC librarians also receive periodic training.

HIC promotes its resources using traditional marketing strategies such as flyers and brochures, library-hosted educational and health screening programs, health fairs and other events with community partners, and newspaper articles written by HIC staff. An outreach coordinator works to increase awareness of the center among minority groups. One creative strategy is providing homework assistance to children in grades 1-8 as a way to draw parents into HIC.

County funding largely sustains HIC, covering the center's annual operating costs of ~\$91,000 (excluding personnel). The center made the case for initial support based on the results of a community assessment that revealed residents wanted a source for health care information outside medical settings. Providing effective consumer health services has kept customer satisfaction high and helped maintain strong community support.

Support for Building Local Capacity

In addition to providing direct consumer services, HIC also offers technical support to other regional library branches.

- Provides health information to all other public library branches in county and neighboring metropolitan areas
- Trains library associates in other branches and in surrounding region

For the Maryland Department of Education, Division of Library Development and Services, the HIC librarian developed a training curriculum. This training is now available online through the division.

Evaluation Methods and Results

HIC keeps some statistics on DOCLINE requests and informally tracks reference questions. Overall, though, the Wheaton branch does not collect any data specific to HIC.

Lessons Learned

- Effectively reaching minority populations is difficult and requires tailored strategies. For example, immigrants may not understand how public libraries can be helpful and that services are free.
- Obtaining and sustaining core support from a local government is possible.
- Community partners are ready to offer health programs through the library.
- A single health information center can serve a library system in a metropolitan county through effective community outreach, use of messaging and online services, and training and assisting other library branches.

Web Site and Other Information Sources

<http://www.montgomerycountymd.gov/libtmpl.asp?url=/content/libraries/HealthInfo/hic.asp>

- Chobot, M.C. (n.d.) *Health information outreach: Case studies from a field test at eight public libraries*. Annandale, VA: Mary C. Chobot and Associates. Retrieved November 1, 2006, from http://www.healthlit.org/health_outreach/documents/FieldTestReport-Nov03-Rev..pdf.
- Chobot, M.C. (n.d.) *The challenge of providing consumer health information services in public libraries*. Washington, DC: American Association for the Advancement of Science. Retrieved November 1, 2006, from <http://www.healthlit.org/pdfs/AAASFINAL.pdf>.
- U.S. National Commission on Libraries and Information Science, Libraries and Health Communication Task Force. (2004). *Libraries and health communication: Model programs in health information provided by libraries throughout the nation*. Washington, DC: U.S. Government Printing Office. Retrieved September 12, 2006, from <http://www.nclis.gov/award/healthawards06.html>.

#10

Literacy in Libraries across America (LILAA)

*Office for Literacy and Outreach Services, American Library Association with the
Wallace Foundation*

National/Local

Consumer Focus:	Low literacy consumers
Topic(s):	Literacy
Intervention Level(s):	National → Local
Capacity-Building Resources:	Grants, technical assistance, training, tools, community of practice
Begin/End Dates:	1996-2000
Primary Funder:	\$4 million from The Wallace Foundation (with \$1.3 million to the American Library Association)

Overview

Literacy in Libraries across America (LILAA) supported public libraries in their efforts to improve adult literacy programs. The goal was to identify strategies that increase the length of time that learners participate in literacy programs in order to achieve significant gains in literacy levels ("learner persistence").

The program partners — the American Library Association (ALA) and the Wallace Foundation — designed the initiative and selected 13 public libraries to participate. Each of the chosen libraries had excellent adult literacy programs and so used the multi-year LILAA supports to take their programs to the next level. ALA provided technical assistance and training, and participating libraries received grants directly from the Wallace Foundation.

National-Level Project Structure

The 13 LILAA libraries used their grants and technical supports to increase their capacity to provide adult literacy services and enhance the effectiveness of those services, especially in terms of learner persistence. ALA and the Wallace Foundation worked closely together to develop the initiative and select the participating libraries. The primary selection criterion was existing excellence in adult literacy services.

The Wallace Foundation support enabled ALA to create a new literacy officer position, which served as the LILAA project director and as the ALA point person on adult literacy. As ALA subcontractors, the Illinois Literacy Resource Development Center (ILRDC) and Literacy South provided technical assistance to the LILAA libraries. ILRDC was the main provider, while Literacy South served only a short period.

After LILAA ended, ALA made the literacy officer into a permanent position that directs the association's adult literacy initiatives. The success of LILAA and the presence of an

ALA literacy infrastructure enabled the association to secure grants from other national foundations for initiatives to strengthen adult literacy programs and services in libraries.

Support for Building Local Capacity

LILAA libraries received considerable financial and technical assistance to build state-of-the-art literacy programs and services. The Wallace Foundation directly awarded multi-year grants totaling about \$500,000 to each the 13 libraries. The primary purpose was to support the libraries in expanding and improving their adult literacy services. Grantees used the funding to purchase hardware and software, add to their collections, expand or produce their own literacy materials, retain consultants, pay for staff time devoted to the project and cover travel expenses.

ALA provided a variety of technical supports, including organizing semi-annual training conferences. All 13 libraries participated in these meetings to develop expertise, learn from the nation's leading literacy experts and build relationships for peer modeling and mentoring. Onsite and telephone technical assistance covered six tracks: assessment and evaluation, technology, staff development, tutor training, community collaborations and learner issues (such as recruitment and retention).

During LILAA, ALA compiled bibliographies to assist the sites. After the Wallace Foundation funding ended, ALA self-published the main tools resulting from LILAA. One such book is *Literacy and Libraries: Learning from Case Studies*, which is widely used today in library schools as the standard for literacy services. The second publication, *The Adult Literacy Assessment Tool Kit*, features assessment tools developed by and for library literacy programs. These unique tools measure and assess learner progress. Both publications are available and still in use today.

LILAA set the foundation for the ALA sequel, Build Literacy, which aimed to share the significant learning that had occurred through LILAA with nonparticipating libraries and community literacy programs. (The Wallace Foundation support did not extend to dissemination.) With grants from the Verizon Foundation (the philanthropic arm of Verizon Communications), ALA launched www.BuildLiteracy.org in 2000 to help libraries develop, build and expand community literacy services and outreach programs. Verizon funding enables ALA to:

- Disseminate LILAA materials, including the literacy-readiness inventory and success stories from LILAA libraries.
- Develop and promote the use of additional technical resources such as a toolkit and a virtual reference desk.
- Develop the Literacy Readiness Inventory (LRI), a tool that guides libraries through the process of identifying, articulating and reflecting upon how they approach literacy service delivery.
- Engage libraries in creating new or enhancing their literacy programs through training programs at the ALA annual conference and publishing the toolkit in *American Libraries*.

The primary dissemination vehicle is the BuildLiteracy.org Web site (Web site available, last updated in 2004). Resources and tools on BuildLiteracy.org equip libraries, literacy programs and community partnerships to provide more effective literacy programs and services for adult learners.

After the first phase with ALA ended, the Wallace Foundation extended its support for library-capacity building, continuing its model of working directly with libraries. Participating libraries in the second phase implemented the promising strategies identified in the initial phase and an independent evaluation studied the effectiveness of the strategies.

Project Structure at the Community Level

Libraries used their grants and technical assistance to focus attention on what their communities needed, and then created plans to meet those needs. Beyond building their own capacity, community partnerships with human service organizations, civic groups and other community-based organizations helped libraries recruit and retain learners. Trained volunteers served as literacy tutors.

Many of the 13 libraries used their grants to develop materials such as handbooks for libraries, materials for tutors and learners, program summaries, training manuals, tools for program assessment, case study analyses of persistent learners and more. Because computer technologies were just entering some libraries, these materials provided timely insights into how to integrate computers into literacy services.

Evaluation Methods and Results

Although ALA did not conduct a formal evaluation program, evidence suggests the initiative was successful. Namely, ALA institutionalized the new capacity by creating a permanent leadership position for adult literacy issues, adopting literacy as one of ALA's five priority action areas and securing new resources to continue building libraries' literacy programs. Also, major players in the literacy arena now reach out to ALA before proceeding with major initiatives. (Prior to LILAA, libraries were often viewed as a secondary.)

LILAA benefited the adult learners in the libraries that developed superior literacy programs. The resulting models also assisted literacy providers across the nation.

More than 10 years since the start of LILAA, ALA reports that the 13 libraries remain leaders in adult literacy and act as an ad hoc resource group for the association and its Office for Literacy and Outreach Services (OLOS). For example, the LILAA libraries serve on ALA task forces, contribute to articles and serve as ALA adult literacy speakers.

Lessons Learned

- At the community level, libraries have tremendous capacity and creativity in how they meet local needs.
- Even libraries with successful programs can, with financial and technical resources, make them state-of-the-art and advance the field.

- The LILAA-only training conferences were instrumental in helping the participating libraries achieve programs of excellence. However, the closed format slowed the transfer LILAA models and practices to other libraries.
- Sustaining a national network with libraries is challenging because libraries are so focused on their community. It takes grants and other national-level resources to motivate their involvement.
- The initiative lacked a formal mechanism to disseminate lessons learned, models and other knowledge and information. This delayed ALA in providing non-participating libraries with tools.

Web Site and Other Information Sources

<http://www.ala.org/ala/olos/outreachresource/servicesnewnonreaders.htm>

<http://www.ala.org/ala/ourassociation/annualreport/programsandpartners/programsandpartners.htm>

<http://www.buildliteracy.org>

D. Lipschultz, personal communications, January 5, February 5, and March 14, 2007.

Illinois Literacy Resource Development Center. *Materials from libraries participating in the Wallace Foundation library literacy initiative*. (2003.) Champaign, IL: Author. Retrieved January 19, 2007, from http://www.ilrdc.org/Wallace_Materials.pdf.

Porter, K. E., Cuban, S., Comings, J. P., & Chase, V. (2005). *"One day I will make it." A study of adult student persistence in library literacy programs*. New York, NY: MDRC. Retrieved November 1, 2006, from http://www.mdrc.org/project_32_22.html.

#11

Medicare Education Project

Cooperative State Research, Education and Extension Service (CSREES)

Idaho, Nebraska, Nevada, South Dakota and Wyoming

Consumer Focus:	Older adults, especially in rural and underserved communities
Topic(s):	Medicare
Intervention Level(s):	National → Local
Capacity-Building Resources:	Training, tools, dissemination, public information/outreach campaigns
Begin/End Dates:	2004-present
Primary Funder:	Centers for Medicare and Medicaid Services

Overview

In five demonstration states, the Cooperative Extension System uses multiple channels to educate rural and traditionally underserved Medicare beneficiaries about the new choices and expanded benefits — especially prescription drug coverage or Part D — provided in the Medicare Prescription Drug, Improvement and Modernization Act of 2003. The Medicare Education Program is a joint initiative of the Cooperative State Research, Education and Extension Service (CSREES) and the Centers for Medicare and Medicaid Services (CMS).

The nation's 100+ land-grant colleges and universities have a critical mission: extension, which means "reaching out." Along with teaching and research, land-grant institutions "extend" their resources by solving public needs with college or university resources through non-formal, non-credit programs. These programs are largely administered through thousands of county and regional extension offices that bring land-grant expertise to the most local of levels. Both the universities and their local offices are supported by CSREES, the federal partner in the Cooperative Extension System. CSREES plays a key role in the land-grant extension mission by distributing annual congressionally appropriated formula funding to supplement state and county funds. CSREES affects how these formula funds are used through national program leadership to help identify timely national priorities and ways to address them.

National-Level Project Structure

The Medicare Education Project seeks to educate rural and underserved audiences about Medicare changes and provide enrollment assistance so beneficiaries make informed decisions about the new benefits. To achieve these goals, CSREES and CMS selected five land-grant universities to participate in the pilot project: Idaho, Nebraska, Nevada, South Dakota and Wyoming. The universities, in turn, support community-based outreach and education efforts. The target audience tends to have limited access to human services, educational opportunities, transportation and technology.

At the state level, the federally-funded senior health insurance and assistance program (SHIP) offices are a critical partner. Located within each state's insurance department, the programs assist consumers with Medicare prescription drug card questions and issues. The program offices supplied Extension networks with accurate information, and some assisted with enrollment activities. Many community-level partners are helping raise awareness, provide education and assist with enrollment.

CSREES and CMS are sustaining the program because Medicare beneficiaries have an ongoing need for assistance in selecting a prescription drug plan that best meets their needs. Indeed, because the Medicare Education Program has been so successful, the agencies are planning a new health promotion initiative in which Extension educators will help CMS reach underserved beneficiaries.

Support for Building Local Capacity

The Families, 4-H and Nutrition Unit of CSREES provides tools and training to Extension professionals. Beyond the annual funding provided through CSREES, each university received a one-time \$54,000 grant for Medicare outreach education projects. The universities have the lead in:

- Developing state-level partnerships to support community-level efforts.
- Training and providing technical support to Extension educators.
- Reporting data to CSREES.

Project Structure at the Community Level

At the county level, Extension educators:

- Design and coordinate public information and outreach campaigns for Medicare beneficiaries as well as their families and caregivers.
- Establish partnerships for disseminating information.
- Coordinate and conduct educational sessions.
- Provide enrollment assistance.
- Recruit and train volunteers.
- Provide assistance over the telephone.

Some county Extension offices may have received some project funding from their university to support some of these activities.

Among the primary partners are libraries, health care providers, senior centers, area agencies on aging, AARP, faith communities and human service agencies that have routine contact with Medicare beneficiaries. These partners assist with disseminating information and offering enrollment and education programs. In-kind support includes providing facilities for sessions. Also, volunteers help some local Extension offices disseminate materials. Trained volunteers provide one-on-one counseling and enter data from handwritten forms into the Medicare enrollment Web site.

Because the audience is difficult to reach, the information and outreach campaigns use multiple channels. Community partners post notices and place public service announcements in newspapers and on radio and television (both paid and in-kind). Flyers

and newsletters provide information and recommend resources. In addition, educational sessions often set aside time for individualized assistance.

Evaluation Methods and Results

Universities work with Extension educators to collect data on the number of people educated, assisted and enrolled in a prescription drug plan. Testimonial data from program participants suggests enrollment would have a positive effect on their lives or wellbeing. Some Extension offices ask program participants to complete short surveys and track data such as calls received by community partners in response to a public service announcement.

The Medicare Education Program received a community partnership award from the National Extension Association of Family and Consumer Sciences. As reported by CSREES, program successes are as follows.

- In the initial nine months of the program, Extension and its partners helped generate increases in Medicare prescription drug plan enrollment by 15 to 128 percent in the five states. The average increase exceeded 66 percent.
- Enrollments could generate \$1.6 million for Medicare beneficiaries. Personal savings related to prescription drug plan enrollment enabled beneficiaries to buy other necessities, which indirectly contributed to community economies.
- Extension engaged almost 300 community partners in outreach and education.

Lessons Learned

- Reaching and educating underserved programs is difficult at best.
- A variety of marketing channels can improve the odds of connecting with these audiences.
- The Extension network can provide effective, quick response on time-sensitive consumer health opportunities.

Web Site and Other Information Sources

http://www.csrees.usda.gov/nea/family/part/family_part_medicare.html.

C. Crocoll, personal communications, November 21 and 27, 2006, and January 16, 2007.

Cooperative State Research, Education and Extension Service. (2006). *Extension Medicare education project*.

#12

Medicare Part D Educational Outreach

*AARP Iowa with the
State Library of Iowa, Iowa Senior Health Insurance Information Program,
Iowa Communications Network, and Social Security Administration*

Iowa

Consumer Focus:	Medicare beneficiaries
Topic(s):	Medicare
Intervention Level(s):	State → Local
Capacity-Building Resources:	Online training
Begin/End Dates:	Fall 2005 and Spring 2006
Primary Funder:	AARP Iowa and project partners provided in-kind support

Overview

At public libraries and other community classrooms of the Iowa Communications Network (ICN), older adults attended educational sessions about the new Medicare prescription drug benefit. AARP Iowa and its partners trained human services professionals in Medicare Part D enrollment, including the low-income subsidy.

Six state-level organizations comprised the informal public-private partnership: AARP Iowa; State Library of Iowa; Iowa Senior Health Insurance Information Program (SHIIP);^h Social Security Administration (SSA); and ICN.ⁱ

National-Level Project Structure

To maximize enrollment of Medicare beneficiaries in the new prescription drug plan and assure eligible persons obtained the low-income subsidy, a public-private partnership of state organizations collaborated on a two-part initiative.

Professional training. In fall 2005, the partnership used the ICN to conduct a training workshop for frontline human services professionals. Participants learned how to help Medicare beneficiaries enroll in a prescription drug plan and apply for a low-income subsidy.

Consumer education. In May 2006, the partnership sponsored a single, statewide consumer educational session to help older adults that had not enrolled in Part D to compare benefit plans, learn if they were eligible for the low-income subsidy, and connect with helpful resources, including hospitals, community clinics, libraries and

^h The State Health Insurance Assistance Program, or SHIP, is a state-based program that offers local one-on-one counseling and assistance to people with Medicare and their families. Through grants from the Centers for Medicare and Medicaid Services, state SHIP offices provide free counseling and assistance via telephone and face-to-face interactive sessions, public education presentations and programs, and media activities. Trained volunteers provide many SHIP services.

ⁱ ICN is the statewide network for educational videoconferencing.

human services agencies. This occurred 10 days before the first enrollment deadline as a final attempt to reach older adults who had not taken advantage of the new benefit.

Each of the six partners provided in-kind contributions.

- *AARP Iowa* funded its participation through the Medicare outreach and education line item in its budget. Besides providing staff, the office purchased advertising from local newspapers, provided a single-page handout for consumers that gave step-by-step instructions about online enrollment, and distributed *AARP Medicare Rx* program books along with the telephone number of *SHIIP* to libraries and other community-based organizations.
- *State Library of Iowa* scheduled use of the ICN system for the two sessions and also communicated with and recruited public libraries to make their ICN rooms available for the session.
- *SHIIP* and the *Social Security Administration (SSA)* worked together to develop and deliver the curricula for the professional training and consumer educational sessions.
- *SHIIP* staff coordinated the training and worked with the community sites.
- *ICN* enabled live video broadcasting of the educational and training sessions in its classrooms in public libraries and other community sites across Iowa.

In the most recent enrollment period, ending December 31, 2006, the partnership did not conduct any additional sessions for professionals or consumers. However, given the history of changes to Medicare and other public benefits for older adults, *AARP Iowa* foresees the need, and willingness of the partners, to replicate the model in the future.

Support for Building Local Capacity

Because many frontline human services professionals were not adequately prepared to assist Medicare beneficiaries' with the new prescription drug program, the partnership sponsored a four-hour training on Medicare Part D enrollment, including the low-income assistance benefit. Designed and delivered by *SHIIP* and *SSA* officials, the session was broadcast live over the ICN. To promote the training, the partnership organized a direct mailing to county human services offices, hospitals, etc., using a large database.

Project Structure at the Community Level

Public libraries provided the venue — their ICN classrooms — for the consumer educational sessions. In addition to setting up the rooms, libraries posted notices about the session and, in some sites, library staff attended. Public libraries offered free computer access, which enabled Medicare beneficiaries to complete the required online enrollment; some libraries used the *AARP* single-page instructions as a handout.

AARP advertised in and sent news releases about the sessions to the local newspapers in the participating libraries' communities. Some members of the Iowa newspaper association ran the ad a second time as an in-kind contribution.

The one-hour session — delivered by *SHIIP* and *SSA* officials and broadcast live over the ICN — gave participants information about how to enroll and how the low-income

subsidy worked. AARP Iowa volunteers joined SHIP volunteers who attended the consumer sessions and provided follow-up assistance.

Evaluation Methods and Results

Although the initiative did not have a formal evaluation, AARP Iowa provided some anecdotal information and participation data.

Consumer education. Of the 50 public libraries with ICN classrooms, 21 hosted the consumer educational sessions. Participating libraries seemed to view helping Medicare beneficiaries with information and education about Part D as part of their mission to serve the community. Libraries that declined to participate expressed several concerns.

- Medicare plan enrollment is peripheral to a core library mission.
- Library staff would be unable to answer patrons' technical questions about prescription drug coverage.
- By participating in the session, already inadequate public computer resources would be overwhelmed.
- The federal government had not provided public libraries with funding to support their role in the Medicare prescription drug coverage roll out.

The average attendance per site was five people. Because the session was so close to the enrollment deadline, many Medicare beneficiaries had already signed up for a prescription plan. Those that did attend the session asked many questions for which they otherwise may not have been able to obtain answers.

Professional training. More than 800 professionals registered for the training. Although the majority was human services professionals, some library staff also participated.

Lessons Learned

- Medicare beneficiaries want and need educational and outreach programs.
- In small towns, public libraries are a key civic center.
- Directly reaching many consumers requires sufficient lead time, especially if tight budgets require a reliance on mass media communications.
- Libraries are a great venue for delivering consumer education and providing consumers with assistance, if they have sufficient resources to support the activity.
- The ICN provided an efficient way to deliver education and training, to both professionals and the public.
- The broad partnership was able to reach both consumers and human services professionals.

Web Site and Other Information Sources

<http://www.aarp.org/ia>

A. Black, personal communications, December 12 and 15, 2006.

S. Dixon, personal communication, January 11, 2007.

#13

Memphis Health Information Center

Memphis Public Library and Information Center

Memphis, Tennessee

Consumer Focus:	Consumers, including low literacy, low income groups
Topic(s):	Health
Intervention Level(s):	Local
Capacity-Building Resources:	N/A
Begin/End Dates:	1998-present
Primary Funder:	\$750,000 from the Assisi Foundation and in-kind support from Memphis Public Library and Information Center

Overview

Motivated to help transform Memphis from an unhealthy to a healthy city, the Memphis Public Library and Information Center established the Health Information Center (HIC) with support from many community partners. HIC is now a recognized community asset for empowering Memphis citizens to improve their health. The center has a strong focus on improving health literacy among low-literacy and low-income residents.

In 2006, Memphis Health Information Center was one of ten finalists for the 2006 Health Information Awards for Libraries from the U.S. National Commission on Libraries and Information Science (NCLIS).

Project Structure at the Community Level

By many disease and health risk measures, Memphis is an unhealthy city. Related factors are high rates of functional literacy and persistent poverty. To do its part to improve the health of Memphis, the Memphis Public Library and Information Center (MPL) spent a year analyzing community health needs by meeting one-on-one with health care and social services organizations. After these community organizations agreed to work with HIC as partners, library staff developed a strategic plan to enhance both health literacy and health information literacy. Key action steps were creating:

- *Health information center* at the central library, which has dedicated space for the health sciences and consumer health collection in the new state-of-the-art central library building. Three successive grants from the Memphis-area Assisi Foundation totaling \$750,000 underwrote the initial expenses of developing a health collection and databases. MPL supports ongoing acquisitions, space, staff and other operating costs.
- *HIC Advisory Board* with members drawn from community health organizations.
- *Virtual HIC*, which is an online index for 21 specialized topics (Web site available; last updated in February 2007). Library staff developed the Web site, and they update it on a weekly basis. The index connects English- and Spanish-speaking

users to online databases, magazines and other accurate, consumer-friendly resources. MPL hosts Virtual HIC on its Web site.

- *Computer training* at both HIC and community locations, conducted by library staff.
- *Health programming* with community partners; this component is presented below.

HIC customers can receive assistance from library staff with finding information to answer their questions. (Volunteers have limited roles in helping customers get a computer and find a requested Web site.) Multiple formats —including books, magazines, audio, videos and online services — are available. Via the MPL Web site (including Virtual HIC section), visitors can use an online reference service to obtain real-time assistance from a library representative. At other library branches, customers can request something from HIC and receive it the next day. Library staff also take HIC resources out to the community when the partners have time to work out the logistics.

Through visible programming and regular networking with the health care community, HIC has established itself as a health information leader. HIC directly organizes and sponsors a variety of health education and programs with the involvement of community partners. Some examples include:

- *Health information fairs* attracting 1,200 to 1,500 participants. MPL obtained grants from Blue Cross/Blue Shield of Tennessee and engaged more than 70 community partners in providing information, screenings and referrals to the HIC.
- *Health screenings* in conjunction with groups like Memphis Hypertension Preventive Medicine Coalition.
- *Educational programs* at the library and in community venues, including classes in using computers to access high-quality health information. A partnership with the Oncology Public Education Board resulted in a series of programs on types of cancers and therapies, all in lay terms. The center is planning educational programs with the Memphis Area Nutrition Council.
- *Information and displays* address specific health topics. Partners have included the American Dietetic Association, American Heart Association, Iron Disorders Institute, Mid South Transplant Foundation and State of Tennessee.

In addition, the center participates in community events, such as those organized by the Healthy Memphis partnership or employee health fairs sponsored by local businesses.

HIC frequently uses Medline and MedlinePlus to help customers access accurate health information. In addition, the center also has been involved with special initiatives from the National Library of Medicine (NLM) and the National Network of Libraries of Medicine (NN/LM). For example, the center has helped test a pilot service or resource. HIC also has reviewed and made recommendations about improvements to existing NLM or NN/LM products or services.

HIC is currently working to better serve immigrant populations in which English is a second language. It has added online resources for Spanish-speaking groups to Virtual HIC and will expand, in time, to other languages.

To promote its services, HIC relies primarily on earned media, referrals from local health care providers, promotion by community partners and the monthly HIC e-newsletter. With support from local funders, HIC has also used paid advertising to promote its health information fairs.

The MPL general operating funds support HIC, which does not have a line item in the library system's budget. To respond to specific community needs and complete implementation of the HIC action plan, library staff works with HIC partners to secure financial and in-kind support. For example, Methodist Hospital has twice donated interactive software and a touch-screen computer to assist cancer patients and their families. Most donations are for direct expenses, such as advertising and information handouts. MPL plans to develop an endowment fund for HIC to give it financial stability during downturns in public funding.

Evaluation Methods and Results

To monitor its work, HIC uses readily available data, such as common library and Web statistics, program attendance and partnership activities. Data indicate HIC is an active community resource. Specifically, circulation of HIC items increased from 1,593 items per month to 2,509 per month in the center's first three years. Virtual HIC receives more than 600 hits each month. As previously noted, the health fairs are well attended, and anecdotal evidence suggests screenings at these events have saved lives. Educational programs during health fairs are popular, but educational programs at other times tend to attract a small number of participants (such as 10), despite considerable marketing. Those who do attend rank the sessions as highly useful and as providing valuable information.

Active partnerships with community organizations, financial and in-kind donations from community partners and referrals from area physicians are qualitative signs of success.

Lessons Learned

- To achieve changes in health behaviors and improve measures of community health, consumer health information services must be sustained over many years.
- A joint visit by MPL staff and the Assisi Foundation to a vibrant health information center resulted in grants that covered start-up costs.
- HIC successfully laid a foundation for sustainability by adding capacity in phases, focusing on community-responsive services and developing strong community partnerships.
- Core support for HIC comes from MPL, but financial and in-kind contributions from community partners enable the center to expand its services, add capacity and conduct special programs. A key reason why both MPL and community partners sustain HIC is that the center's resources and programs directly relate to the needs of Memphis residents and its health care system.
- The HIC Advisory Board provides a way for the library to regularly engage local leaders and build relationships.
- The key to HIC's success is its tangible commitment to working with the community to determine needs and respond flexibly to opportunities. Even so, reaching target audiences, especially disadvantaged populations, can be difficult.

- Caregivers and patients can have different information needs. Educational sessions may be more effective if they target information to one of these groups.
- External factors make building and maintaining a well-rounded consumer health collection challenging. Library staff have to be savvy to ferret out publications from unreliable sources, consumer-friendly books on some types of diseases are scarce, and the continuous advances in medicine requires active management of the collection.
- Bringing HIC resources into low-income communities is possible through partnerships. However, some grassroots organizations are so busy that they lack time to adequately plan initiatives with library staff.

Web Site and Other Information Sources

<http://www.memphislibrary.org>

<http://www.memphislibrary.org/virtualhic>

U.S. National Commission on Libraries and Information Science, Libraries and Health Communication Task Force. (2006). *Libraries and health information: Awards initiative and report*. Washington, DC: U.S. Government Printing Office. Retrieved September 12, 2006, from <http://www.nclis.gov/award/healthawards06.html>.

Wilson, B. A. Personal communications, February 8 and March 6, 2007.

#14 Outreach Program for Consumer Health Information Services

Pacific Northwest Region, National Network of Libraries of Medicine (NN/LM)

National/Regional

Consumer Focus:	Consumers
Topic(s):	Health
Intervention Level(s):	Regional → Local
Capacity-Building Resources:	Grants, training, technical assistance, tools, education and resource sharing
Begin/End Dates:	2006-2011 (current contract)
Primary Funder:	The NN/LM program is funded by National Library of Medicine. Total proposed funding for all eight regions in the 2006-2011 contracts is about \$51 million, of which a portion supports community outreach efforts.

Overview

Within the National Library of Medicine (NLM), the National Network of Libraries of Medicine (NN/LM) enhances health professionals' and the public's access to health information. As one of eight regional medical libraries in NN/LM, the Pacific Northwest Regional Medical Library (PNRML) operates two outreach programs. The consumer health information services outreach program — the focus of this profile — increases the public's awareness of and access to high quality electronic health information. To accomplish this goal, PNRML and the other seven regional medical libraries (RMLs) develop partnerships with and provide support to public libraries and other community-based organizations. (NN/LM outreach to health professionals brings biomedical information to health professionals who lack access.)

PNRML serves Alaska, Idaho, Montana, Oregon and Washington. Through a five-year contract with NLM, the University of Washington Health Sciences Library hosts PNRML.

Regional-Level Project Structure

Each of the eight NN/LM regional medical libraries, including PNRML, works to realize network goals in its region. The consumer health information services outreach program carries out the NN/LM goal of improving the public's access to information to enable consumers to make informed decisions about their health. Instead of reaching out directly to consumers, PNRML and the other seven RMLs develop collaborations with diverse intermediaries to promote the use of quality health information by consumers. Nearly all intermediary partners are or become network members.

- *Full* members are libraries with health sciences collections, which are primarily in hospitals and academic medical centers.
- *Affiliate* members include some small hospitals, public libraries and community organizations that provide health information services.

NLM and the NN/LM National Network Office are the RMLs' main partners. NLM's primary roles in supporting the NN/LM are fourfold.

- *Leadership* — provide vision and engage partners in developing coordinated responses to emerging trends. For example, NLM worked closely with NN/LM and community-based practitioners on the Symposium on Community-based Health Information Outreach in 2004. Symposium participants explored new models of health information outreach. A particular emphasis was consumer outreach through community-based organizations. The knowledge and insights gained in the symposium informed the recent NN/LM request for proposals for RMLs.
- *Premier resource for credible health information*: build and maintain MedlinePlus, the premier consumer health information portal; NIHSeniorHealth, a portal for older people; ClinicalTrials.gov, a portal with information about clinical research; and Tox Town, an interactive guide on common toxic chemicals, health and the environment. Other NLM consumer-oriented resources include a guide to finding health information and an online tutorial about evaluating Internet health information.
- *Funding agency*: provide funding for NN/LM and for the health information outreach funding programs that the eight RMLs administer.
- *Product development and research*: create and test programs and services. For example, an NLM partnership with the American College of Physicians developed Information Rx, an initiative to educate physicians about MedlinePlus and engage them in referring patients to MedlinePlus for reliable, understandable health information. The RMLs, acting as the field force for NLM, reached out to public and medical libraries to ensure they were ready to help consumers with their information prescriptions. After the successful pilot, NLM began engaging new partners, and NN/LM created a toolkit for community-based organizations.

Together the NN/LM National Network Office and the RMLs support full and affiliate network members in providing health professionals and the general public with health information resources and services. The National Network Office directs and coordinates the work of the eight RMLs, such as overseeing the regional library contracts and putting together task forces to address collective opportunities. The office also contracts services to provide the regional libraries with communications platforms, including a common Web site framework and software for distance learning and collaboration.

The University of Washington receives on average about \$1.14 million per year (including indirect costs) from NLM to operate PNRML. Approximately 46 percent of the yearly budget supports activities and funding programs for consumer health information services.

In the Pacific Northwest region, the total of 377 network members includes 25 public libraries, four state libraries and 80 community-based organizations, such as social service agencies, Indian Health Boards, parish nurse ministries, consumer health advocacy groups, community technology centers, public health clinics and others.

State libraries have been an important partner in the PNR and the other seven regions. For example, many state library representatives have served on NN/LM advisory groups. By working with state library training coordinators, PNRML and the other RMLs have been able to conduct training sessions and exhibit at state library meetings every one to three years. Without these opportunities, outreach to public librarians would be impeded by the time and resources needed to go to geographically dispersed communities.

PNRML also supported an initiative by the Montana State Library called, "What's Your Story?" This multi-year initiative seeks to remind Montana's senior citizens of the value of Montana libraries to the communities they serve. A similar partnership with the Washington State Library is being explored.



Support for Building Local Capacity

To build community capacity to enhance consumer access to quality electronic information, RMLs offer training and professional development opportunities to community-based organizations. Training enables public librarians, network members, health professionals and community partners to help their users obtain and evaluate the quality of online health information (i.e., a train-the-trainer approach). Topics include NLM databases, Internet searches for health information, assessment of the quality of health information and evaluation methods.

PNRML and the other RMLs create and promote tools to help network members and community organizations offer effective consumer health information services. NN/LM tools include user guides to online health information resources, fact sheets, articles and sets of frequently asked questions to assist librarians, health professionals and others serving the public. A key tool is an online resource guide to providing consumer health information services (last updated November 2006).

The priority for the consumer health information services program is reaching racial and ethnic minorities, older adults and low-income consumers. With its community partners, PNRML builds awareness of NN/LM and encourages local organizations to participate in the network and use NLM and NN/LM programs and services. Specifically, PNRML:

- Encourages and consults with network members on collaborating with community organizations working with minority and other underserved populations.
- Connects libraries and community organizations to NLM programs and services.
- Exhibits at health professional and community health meetings. Partners can also obtain marketing materials for NLM resources that they can use in presentations, classes and exhibits.

The NN/LM Outreach Evaluation Resource Center at the University of Washington provides training and consulting services to network members and community groups in measuring the effectiveness of outreach projects. A specific resource from the center is a set of booklets to help organizations plan and evaluate community-based health information outreach projects.

Each of the RMLs funds libraries and community organizations that are network members to conduct health information outreach projects. In 2006-2007, PNRML offered two types of awards for outreach projects (capped at \$12,000 and \$25,000). In general, allowable uses of outreach funding include efforts that:

- Enhance the use of health information by consumers and health care providers.
- Develop partnerships between network members and other community organizations.
- Build local health information expertise in community organizations.
- Increase awareness and use of NLM and NN/LM resources and other online health information resources.
- Identify populations that have inadequate access to health information.
- Expand access to health information and information technology for people who need improved access to information.

Awards of up to \$25,000 are available for MedlinePlus Go Local projects to link MedlinePlus users to health services in their community related to the health topic they are researching. Conversely, the project also directs users of the Go Local site to MedlinePlus health topics.

Small awards programs for up to \$500 or \$2,000 are available for training, assessment and planning, connectivity and exhibiting. Some network members obtain a small award to conduct a community needs assessment and then another to plan the outreach project. These small awards help organizations get ready to apply for one of the larger funding programs.

To help organizations develop successful proposals, the PNRML Web site offers information about current and past outreach projects. Community-based organizations can receive PNRML's assistance in creating partnerships with network members and other resources in their areas.

Evaluation Methods and Results

In September 2002, the Outreach Evaluation Resource Center facilitated a Public Libraries Outreach Evaluation Task Force to explore ways to strengthen NN/LM health information outreach to the public via public libraries. The task force recommended strategies to increase public librarians' awareness of credible online health resources and of their community partners in the NN/LM. As a result, the eight RMLs developed a Web site for public libraries with interests in community outreach and four workshops to increase skill and confidence with answering health-related questions and finding credible health information online. Per anecdotal data from RML trainers, public

librarians who have participated in one or more of the workshops like learning about how to look at health information with a more critical eye. They also indicate that they feel more confident about answering health-related questions. They appreciate having a list of trusted resources when they finish the classes.

Overall, in the 2001-2006 contract period, RML staff and network members in all eight regions conducted 2,644 outreach activities (presentations, courses, demonstrations, exhibits and partnership activities) involving public libraries. All RMLs increased both the number of public library and community organization network members and the number of funded projects involving either type of organization.

In 2005-2006, the Outreach Evaluation Resource Center also conducted a national-level follow-up training survey to assess satisfaction and impact of NN/LM classes with content about PubMed and MedlinePlus. Based on a 41 percent response rate from public librarians in these classes, results indicate: a majority felt training improved their search skills and confidence in using PubMed or MedlinePlus to answer health questions. Asked if they have used the resources since the training, 58 percent reported using PubMed and 74 percent reported using MedlinePlus.

Several RMLs use program evaluation management tools to plan regional program objectives, such as a logic model with activities, outputs, outcomes and indicators. Collecting evaluation data on long-range outcomes is not easily done. However, each RML cooperates in collecting selected process indicators. Data collection methods include tracking outreach, including types of outreach participants and activities; maintaining a directory of network member organizations; usability reviews of national and regional Web sites in the NN/LM; and selected needs assessments, case studies, structured discussion groups, post-training session evaluation forms and follow-up evaluation by funded programs.

For example, in the 2001-2006 contract period, qualitative studies in the PNRML indicated a need for additional efforts to inform intermediaries and community-based organizations about the value of the NN/LM, especially network membership, access to and training in online resources, technical assistance and funding to help vulnerable populations access high-quality health information.

All RMLs encourage applicants for funding to use the network's planning and evaluation guides to develop outcome indicators and plans to acquire both process and outcome data. The guides offer blank worksheets and instructions on developing logic models. Funding recipients must describe evaluation activities and findings in their periodic reports.

Because each funding recipient has unique evaluation measures and methods, the results of RML-funded projects cannot be aggregated. However, a review of final project reports on the PNRML Web site illustrate local successes and challenges in improving consumer access to electronic health information. The final reports also provide information about funding recipients' continuation plans.

For example, Associates in Cultural Exchange, a not-for-profit based in Seattle, used a PNRML outreach award to train family advocates assisting families that have children with developmental disabilities in ethnically and linguistically diverse communities. The 15-month project increased the family advocates' skills and knowledge related to finding high-quality health information and the number of families receiving relevant, quality health information from their family advocates in their own language. It also strengthened relationships among community partners.

(In this collection of profiles, several programs have used funding and technical supports from NN/LM and NLM: Community Outreach Information Network (#4); Computer Health Literacy for Seniors (#5); Consumer Health Information Toolbox (#6); Grillo Health Information Center (#7); HealthAccess (#8); Health Information Center (Wheaton Library) (#9); and Memphis Health Information Center (#13).)

Lessons Learned

- Public librarians have amazing skills and knowledge. Even so, helping library patrons' find accurate and reliable health information can be daunting, especially if the information could impact the patrons' health and health care.
- Network membership and training have been well received by public librarians. They need this type of free support to update skills and knowledge, add resources for helping patrons and have referrals to access more specialized health information.
- Relationship-building with intermediaries, especially community-based organizations, takes time and a long-term commitment. The partners need time to explore what consumer health information outreach means for the community, articulate expectations and needs, and design a strategy. The most effective outreach projects are those in which the community organization develops the goals and activities together with PNRML or the medical library partner.
- The train-the-trainer approach, when combined with regular follow up (including return visits) from the RMLs' outreach specialists, are necessary to assist local health professionals and community leaders in making health information access a priority.
- Evaluating consumer health information outreach projects is difficult, but the use of logic models and the Outreach Evaluation Resource Center's tools result in more useful findings. Evaluation must be meaningful for the community.
- Community-based organizations are often unfamiliar with language and vocabulary used by medical librarians. Outreach messages to community-based organizations and intermediaries must be carefully crafted.

Web Site and Other Information Sources

<http://nnlm.gov>

<http://nnlm.gov/pnr/>

<http://nnlm.gov/outreach/>

C. Burroughs, personal communications, January 19 and 26, 2007.

Fuller, S. (2004). *Tribal connections: Lessons for the future*. The Northwest experience: 1998-present. Presentation at the Symposium on Community-Based Health Information Outreach, Washington, DC, December 2004.

Kwan, G. *Technology training for trusted sources in diverse communities project. Final report*. Seattle, WA: Associates in Cultural Exchange. Retrieved January 19, 2007, from <http://nmlm.gov/pnr/funding/reports/TechTrainingFinalReport.pdf>.

National Network of Libraries of Medicine (NN/LM) Services. *Contract summary, 2006-2011: Statement of work*. Retrieved January 8, 2007, at http://nmlm.gov/pnr/about/Contract_Summary2006-2011.pdf.

#15

Powerful Tools for Caregivers

North Carolina Cooperative Extension

North Carolina

Consumer Focus:	Caregivers
Topic(s):	Health (wholistic)
Intervention Level(s):	State → Local (using a national program)
Capacity-Building Resources:	Training for county extension agents
Begin/End Dates:	2000-Present
Primary Funder:	Administration on Aging through NC Division of Aging and Adult Services; Cooperative State Research, Education, and Extension Service; NC AARP; NC Area Agencies on Aging

Overview

Providing care for a family member, friend or neighbor can be rewarding, but also can strain caregivers' health and finances. To empower caregivers to take care of themselves in order to improve their caregiving, North Carolina (NC) Cooperative Extension trained its extension agents and others to conduct Powerful Tools for Caregivers educational workshops for caregivers. Powerful Tools is a nationally recognized training course for family caregivers that extension agents and other class leaders conducted in communities across the state.

NC Cooperative Extension is part of the Cooperative Extension Service (see profile #11, Medicare Education Project, for a description of the system). The state's two land-grant institutions, NC State University and NC A&T State University, administer NC Cooperative Extension's community-based outreach programs in all 100 counties and the Cherokee Reservation.

State-Level Project Structure

In 2000, Congress created the National Family Caregiver Support Program and authorized the Administration on Aging to give grants to states to expand education and training programs for family caregivers and provide other support services. The lead agency for the NC Family Caregiver Support Program is the NC Division of Aging and Adult Services, which distributes grants to area agencies on aging (AAAs). AAAs use the funding to develop and administer a coordinated system of services for family caregivers. From the beginning, NC Cooperative Extension has been a core partner at the state, regional and local level by helping the Division of Aging and AAAs plan and implement the NC Family Caregiver Support Program.

Rather than create from scratch a new educational program for caregivers, NC Division on Aging looked to *Powerful Tools for Caregivers*, an evidence-based curriculum

developed and currently distributed by Legacy Health System of Portland, Oregon. Powerful Tools uses a train-the-trainer approach to create local capacity to educate caregivers. A core feature is that all sessions — whether to train class leaders or actual caregiver workshops — are co-led by a professional educator and a person with family caregiving experience. These session leaders follow a scripted curriculum.

Powerful Tools specifically addresses the needs of family caregivers assisting older adults who have a chronic condition. Through a six-week set of 2.5-hour sessions, caregivers develop the skills and knowledge to manage stress and emotions, improve communications with health professionals and family members, make difficult decisions and find community resources. Participants receive a resource book and often make new friends, who provide essential emotional support.

To bring Powerful Tools to North Carolina, the state division of aging gave NC Cooperative Extension a \$3,000 grant in 2000. This funding paid the travel and registration costs for the extension aging specialist and a Duke Family Support Program social worker to become master trainers by attending a five-day national Powerful Tools training. The division selected Cooperative Extension in part because the authors of the curriculum designed Powerful Tools so extension agents could readily serve as class leaders.

After a few years, AARP North Carolina offered to obtain a Powerful Tools license from Mather Lifeways (former distributor of Powerful Tools) to operate the program in the state. The involvement of AARP infused new volunteer and financial resources into the Powerful Tools delivery network, enabling it to have a statewide reach. This was accomplished by adding eight more master trainers, two of whom were county extension agents authorized to provide Powerful Tools training outside their counties.

Beyond Powerful Tools, NC Cooperative Extension joined with AARP North Carolina to establish the Caregiver Education Leadership Council. Other council members include the NC Division of Aging and Adult Services, Duke Family Support Program, Carolinas Center for Hospice and End-of-Life Care, the Center for Aging Research and Educational Services at the University of NC-Chapel Hill, Project Compassion and other organizations. The council provides a collaborative forum for members to update one another and sponsor joint initiatives. For example, members of the Caregiver Education Leadership Council produced and are currently revising a joint publication, *Family Caregiving in North Carolina: A Guide for Family Caregivers*.

NC Cooperative Extension receives core funding from Cooperative State Research, Education, and Extension Service, which uses a formula established by Congress to distribute funding. The state's land grant universities and its state and county governments also provide core support for NC Cooperative Extension. The state extension office has used these funds to support its involvement in Powerful Tools and other caregiver educational activities.

Support for Building Local Capacity

The two initial master trainers trained five cohorts of Powerful Tools class leaders. Initially, county extension agents were targeted for training, but in subsequent cohorts, AAA family caregiver specialists and AARP volunteers received training. With the addition of more master trainers, the state now has a network of more than 150 Powerful Tools class leaders, comprised of AAA family caregiver specialists, AARP health volunteers and county extension agents. More than 40 extension agents are class leaders. Currently, each geographic AAA region has at least one AARP class leader who can co-lead a workshop in any county in that area.

Project Structure at the Community Level

County extension agents and AAA family caregiver specialists organize and deliver Powerful Tools workshops in communities. Often an AARP class leader serves as the family caregiver who helps co-lead the workshops, but in some cases where the AARP volunteers are trained as class leaders and have experience in doing training, they initiate and lead workshops as well. Hospitals, city governments, assisted living and retirement communities and other partners provide financial or in-kind contributions, such as meeting space, food and respite care while caregivers attend classes. Through the generosity of local partners, some sets of workshops have not charged caregivers for materials or respite services.

To market the Powerful Tools sessions, AARP North Carolina and county extension offices use their own communication vehicles. Local partners also help spread the word, especially AAAs, communities of faith and local media.

Evaluation Methods and Results

To demonstrate the effectiveness of Powerful Tools, Mather Lifeways used baseline and post-participation surveys of family caregivers. Data from 168 participants indicate statistically significant improvements in attitudes and behaviors. For example, fewer respondents reported feeling depressed in the past week, and more respondents indicated they felt confident approaching others for help and making time for their personal needs.

According to Mather Lifeways data, more than 7,000 caregivers have attended Powerful Tools sessions in North Carolina. Data on participant outcomes in North Carolina are not available because the Legacy evaluation tools were too cumbersome to use. Testimonial data indicate that caregiver-participants find the course to be very meaningful.

In 2005, Cooperative Extension programs on family caregiving for older adults (including, but not limited to Powerful Tools) attracted 1,422 individuals. Among these participants who were caregivers, 577 felt more confident as caregivers than before taking the class, 409 gained new strategies for communicating with health providers, 356 adopted self-care practices learned in classes, and about an equal number adopted new practices for communicating with health care providers.

Lessons Learned

- In the initial stages, one difficulty was the Powerful Tools requirement that pairs of class leaders (professional educator plus a person with family caregiving experience) receive training and then conduct the sessions for caregivers. County extension agents had trouble finding persons with family caregiver experience who could participate in a 3.5-day training session for class leaders.
- Statewide capacity-building requires economies of scale. NC Cooperative Extension resources were sufficient to create an initial cadre of class leaders, but the resources of AARP North Carolina ensured every county had available a pair of class leaders.
- Powerful Tools created new relationships between county extension offices and the AAAs, in part due to the requirement of two class leaders.

Web Site and Other Information Sources

<http://www.ces.ncsu.edu/>

<http://www.ncdhhs.gov/aging/fcaregr/careinfo.htm>

L. Bearon, personal communications, January 29 and March 21, 2007

Hampton, N. (2006). Aging network supports caregivers. *Extension Online News*. Retrieved on October 26, 2006 from http://www.ncsu.edu/project/calscommblogs/archives/2006/06/aging_network_s.html.

Mather Lifeways. (2005). *Powerful tools for caregivers: Proven benefits for family caregivers*. Retrieved October 26, 2006, from http://www.matherlifeways.com/re_ptcbenefits.asp.

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#16

U.S. Libraries

Bill & Melinda Gates Foundation

National

Consumer Focus:	Socio-economically disadvantaged populations
Topic(s):	All
Intervention Level(s):	National → Local
Capacity-Building Resources:	Training, technical support, advocacy, grants
Begin/End Dates:	2005-present for current program
Primary Funder:	\$325 million invested since 1997

Overview

The U.S. Libraries initiative partners with public libraries to bring and preserve access to computers, the Internet and digital information to residents of communities throughout the United States. Communities with more than 10 percent of their residents living in poverty are the first priority, because low-income individuals are less likely to have access to technology and, therefore, information as well as economic and educational opportunities. The Gates Foundation's profile of its U.S. Libraries initiative and lessons learned, *Making sure all Americans benefit from computers and the Internet*, is available at <http://www.gatesfoundation.org/AboutUs/OurWork/Learning/USLP/>.

The current U.S. Libraries initiative is an extension of the foundation's original program that brought public access computing (i.e., computers, Internet connections and training) to public libraries across the nation. This original program began in 1997 and concluded in 2003. Since the inception of the U.S. Libraries program, the Gates Foundation has invested a total of \$325 million. The upcoming program starting in 2007 will commit approximately \$25 million annually over the next three years to help libraries upgrade and sustain public access computing.

National-Level Project Structure

The original U.S. Libraries program brought computers and Internet access to about 11,000 public libraries — representing about 75 percent of all public libraries. Now many services enabled through the original program are at risk because of insufficient support from local funders for public access computing. Obsolete hardware or connection speeds endanger services at 63 percent of the original libraries receiving foundation support. A majority of participants in the original phase also report that demand for public access to computers and the Internet far outstrips the current availability of public workstations.

After meeting the original goal of enabling all Americans to have access to information, the Gates Foundation adopted a new goal: to ensure and sustain quality and free access to computers and the Internet for all people through the nation's public library system. Current objectives are to:

- Increase the number of public libraries that can regularly upgrade their computers and provide high-speed connectivity.
- Ensure public libraries have the training and technical support necessary to serve their patrons well.
- Work with partners to improve public funding for libraries so they can continue to invest in technology infrastructure.

The U.S. Libraries initiative has worked closely with state library agencies to:

- Assist public libraries in sustaining their computer and Internet services through training, technology support and, in some states, resources.
- Advocate for the long-term sustainability of public access computing services in libraries. For example, state libraries educate the public and policy makers about the impact of public access computing at libraries.

Virtually all state libraries have served as intermediaries to the foundation by providing grants to public libraries to help them upgrade their hardware and connectivity. In 2007, the Gates Foundation will expand its use of intermediaries to deliver its grants by also using regional (multi-state) library cooperatives in order to obtain economies of scale and consistent leadership.

Florida State University and the University of Washington are research partners that have assessed public support for libraries and public access computing. (See also the evaluation section.) The American Library Association and the Gates Foundation co-sponsored a Florida State University study on public libraries' Internet connections. This study was recently expanded to include trends in public funding for library technology through a grant made to the American Library Association and Florida State University.

The Gates Foundation has sustained its initiative with periodic adjustments to reflect changing circumstances, enhance effectiveness and accommodate the foundation's conversion from an operating foundation to a grantmaking model.

Support for Building Local Capacity

In the original program, most participating libraries received computers and on-site technical support directly from the Gates Foundation. Both Gateway and Microsoft were significant contributors in providing libraries with hardware and operating software specifically designed for public use in libraries. Grantees had to establish a baseline level of readiness to be eligible for these initial grants.

Following the original program, the foundation made several sustainability grants through state libraries to channel grants to public libraries. These grants required an initial matching requirement that many states met using their Library Services and Technology Act funding from the Institute of Museum and Library Services. Starting in 2007, the foundation's hardware grants will support library systems that are struggling to upgrade hardware and connectivity and that are serving high poverty areas (poverty rate of 10 percent or higher).

Current, multi-year grants to state libraries ranged from \$84,000 to \$934,000 for training and building support for public access computing. At least one state, Illinois, developed a statewide Web-based training program for librarians using its Gates Foundation grant. With a three-year grant for \$749,000, the State Library of Iowa used the foundation's support to provide the following services to public libraries.

- Web site hosting
- E-mail hosting
- Technical support via telephone and e-mail from a full-time support person
- Training
- Internet connectivity grants
- Matching grants for computer upgrades and equipment

The Online Computer Library Center (OCLC) is another key partner in building library capacity. Through a Gates Foundation grant, OCLC launched WebJunction, which provides training, tools and other technical support to public libraries. A separate grant to CompuMentor supports the identification of best practices for maintaining public access computers in libraries.

Project Structure at the Community Level

The Gates Foundation invested in public libraries to enable them to not only provide the public with free access to the public to computers and the Internet but also train library patrons in using computers and the Internet.

Starting in 2007, the foundation will require public libraries to secure matching local dollars to help offset the costs of technology training, high-bandwidth Internet connections and software upgrades. This requirement helps the build local commitment to public access computing that is necessary to sustain the services. The upcoming program will also require public libraries to participate in the annual American Library Association/Florida State University survey of libraries and other evaluation activities.

Evaluation Methods and Results

To evaluate the original program, the Gates Foundation utilized a third-party evaluator, Public Access Computing Project, University of Washington. The evaluation has been extensive, with several reports published through 2004. Also, Florida State University has conducted research for the initiative on public library connectivity. Finally, the foundation has had independent researchers examine the demographics of library computer users. The evaluations have employed a variety of methods, such as consumer and library surveys. Some of the key findings from these studies include the following.

- Almost every public library offers public access computing services, whereas only one in four did in 1996. U.S. Libraries grants and technical resources enabled public libraries in all states to offer new or to sustain or improve public access computing services.
- Fourteen million library visitors regularly use library computers to access the Internet.

- Among library computer users, 71 percent report libraries are their primary source for computer access. These users are more likely to be from communities of color, low income, unemployed or without a high school degree.
- Library computers have enabled users to develop technology skills, perform research and communicate with family and friends.
- One third of library patrons used computers to learn about a medical problem.
- Additional computers are a top priority for library users.
- Needed upgrades reported by librarians include adding computers and enhancing the technical skills of staff.
- Onsite training has a positive effect on librarians' ability to sustain public access computing.
- Public access computing increased library circulation, visits and the rate of new patrons.
- Many libraries lack the financial and technical resources to sustain free public access to computers and the Internet. Further, some libraries cannot afford high-bandwidth Internet access, which is not universally available in all rural areas.

Lessons Learned

- With public access computing resources, libraries are a bridge to close the gulf between the digital haves and have-nots. Marginalized populations rely on libraries to obtain critical information, computers and communication services.
- Sustaining public access computing requires that libraries have local commitments for resources, adequate training and technical support.
- Strategic advocacy is necessary to ensure government funding for public access computing. Both libraries and their advocates must promote the case for funding (and develop the skills to do so).
- Requiring a local match, especially from local governments, may increase the odds of government funding to help sustain public access computing.
- Intermediaries can be critical to a capacity-building program. If state libraries are used in this role, better results occur when they receive funding for administrative support.)

Web Site and Other Information Sources

<http://www.gatesfoundation.org/libraries>

Bill & Melinda Gates Foundation. (n.d.). *U.S. libraries backgrounder*. Retrieved September 12, 2006, from <http://www.gatesfoundation.org/UnitedStates/USLibraryProgram/Backgrounder/default.htm>

Bill & Melinda Gates Foundation. (n.d.). *U.S. library program: Summary of research reports*. Retrieved September 12, 2006, from http://www.gatesfoundation.org/nr/downloads/libraries/eval_docs/pdf/researchsummary.pdf

Bill & Melinda Gates Foundation. (2006, June). *Making sure all Americans benefit from computers and the Internet. What we're learning*. Retrieved September 12, 2006, from <http://www.gatesfoundation.org/AboutUs/OurWork/Learning/USLP/>

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J. Nishi, personal communications, December 6, 2006, and January 18 and 25, 2007.

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