



Center for the
Advancement of Health

2000 FLORIDA AVE. NW • SUITE 210
WASHINGTON, DC 20009-1231
TEL: 202.387.2829 • FAX: 202.387.2857
www.cfah.org

ENGAGING DISADVANTAGED OLDER PEOPLE
IN THEIR HEALTH AND HEALTH CARE:

BUILDING THE FIELD OF ENGAGEMENT

Prepared for The Atlantic Philanthropies

December 2007

The Need for a Field of Engagement Research and Implementation

A coherent field and social movement require shared vision and actions that, even if not perfectly coordinated, take place recognizing the range of related efforts underway to achieve common aims. Leaders within health plans, CMS, aging services, state Medicaid programs, medicine, and nursing all have a stake in ensuring that all older people are able to respond effectively to new demands to actively engage in their health and health care.

These disparate groups all sponsor efforts to support older people in accepting responsibility for a limited number of behaviors that are relevant to the interests of their sector. But they have not recognized that each sector defines "engagement" differently, and as a result, none of them recognizes the profound change in roles nor the sheer number of new behaviors older people are expected perform in order to fully participate in their health and health care. As a result, they do not identify as critical the policy changes that could reduce barriers and help those who need special help in adopting this new, active role.

The Center for the Advancement of Health proposes to serve in an overall coordinating role to help recruit, unify and support the various strategic partners and initiatives at work on multiple levels to engage older Americans in their health and health care while encouraging the development of an intellectual basis for such activities. This role is consistent with the Center's mission to build and implement the field of science-based health behavior. It takes advantage of the Center's extensive network of health professionals, institutions, researchers, professional societies, foundations and advocacy groups and its history as a neutral convener. And it makes use of its strong national and international media and communications capacities.

The Center would carry out several specific elements that together comprise an important "central nervous system" for providing the consistent framework, resources, tools, public communication and feedback needed to develop a coherent field and an active, effective social movement. To carry out the proposed coordinating initiative, the Center would seek grant support from The Atlantic Philanthropies and would be supported in part by additional unrestricted and restricted funds raised by the Center for the Advancement of Health.

What Would This Initiative Look Like?

The Center provided a scenario to researchers, advocates and stakeholders from the public and private sectors, for discussion. The description below incorporates the advice and comment of experts and stakeholders.

Many current efforts to address strategies in the Engagement Blueprint would benefit from a centralized focus that can lay out shared aims and then legitimize, support, monitor, and promote a coherent set of tools, best practices and resources. Given time,

resources and commitment, the mobilization of this social movement will result in a change in what is considered "normal" health behavior among older people and the widespread implementation of support for those who are unable, because of physical, mental or material conditions, to meet the norm.

The components described below would comprise the core features of this coordinating role, and are activities that the Center is uniquely qualified and positioned to carry out.

Build the Intellectual Base

A new "field" needs an intellectual base: documents published in peer reviewed scholarly journals and as reports that define the topic, document the challenge and the risk of not addressing it, synthesize the evidence, make the argument, and frame the solutions. A plan for field-building includes the following:

Through the initial grant from the Atlantic Philanthropies, the Center for the Advancement of Health has written a number of the core documents that define the field and will publish them in peer reviewed journals. They have been used already to stimulate discussion among stakeholders, a process that will continue. However, much more work – by a wide range of researchers, clinicians and health and aging leaders – is needed to quantify the stakes of engagement and to legitimize it as an area of interest that requires attention and resources.

- The Center will continue to convene the small steering group that worked on this initiative. Members of this group are leaders in the field. Their participation will ensure that the intellectual capital produced through this initiative makes its way into the academic and public media.
- The Center will continue to communicate with the public via columns, op-ed essays, letters to the editor, public speaking, media interviews, reports and peer-reviewed papers that describe the challenge and the field.

Develop an Epidemiology of Engagement of Older People

The charge by the Atlantic Philanthropies to the Center for the Advancement of Health was to "move the needle" on older people's engagement in their health and health care. A case cannot be made for investment in supporting engagement and interventions cannot be targeted to those most likely to benefit from such interventions without understanding older people's current attitudes and behaviors. Further, it will be important to monitor trends in engagement as the baby boomers age in order to adapt methods to emerging needs. Resources must be devoted to establishing a base rate for engagement and looking for changes over time.

We propose to field a national survey of older people to determine current attitudes, beliefs and behaviors related to their participation in their health and health care. We will

a) make use of items from existing surveys, such as the Behavioral Risk Factor Survey (BRFS), Medical Expenditure Panel Survey (MEPS), the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey, the MacArthur Foundation MIDUS survey and others; b) conduct focus groups and interviews to identify additional items; c) perform cognitive testing on new items; c) field the survey at least twice in a five-year interval; d) report publicly on survey results; e) use the results to justify and structure Center-sponsored activities; f) encourage stakeholders to use results to guide planning.

Develop Language and Key Messages

Current efforts to make the case that it is now critical for older Americans to take on this new role of active – rather than passive – participant in their health and health care are non-existent. And generic messages about being a "good health care consumer" are undermined by confusing language, lack of specificity and mixed messages about what people are supposed to do, why they should do it, and how they should do it. There is a danger in talking about engagement in ways that sound punitive and suggests victim-blaming, rather than affirming older people's rights, autonomy and self-protection. Older people are no more homogeneous than the rest of the population and the case for engagement must be tailored to the interests of the major subgroups.

We propose to work with experts in communication to conduct formative and qualitative research with older people and caregivers to identify and test language, framing and messages that are clear and compelling. Messages will be targeted to various subgroups about why and how they must engage in their health and health care. Messages and language will be shared with the network of strategic partners to support consistent follow-through.

Build a Community of Stakeholders

Our research found a number of potential strategic partners who are already working on "engaging" members / constituents / patients in their health and health care but have not yet defined exactly what this means. These partners include patient advocacy groups, health plans, public and private payers, quality measurement groups, health professional associations, and foundations. We have identified a number of high priority potential partners based on their current level of interest and activity and their ability to leverage change among their beneficiaries / members / constituents.

We will identify and meet with key leaders in organizations that are strategically positioned to influence public and private sector action needed to implement the Blueprint. The aim will be to seek alignment of their existing and planned efforts with the goals and strategies of the Blueprint and to find ways to leverage influence and action to focus on groups at risk of not being able to engage fully in their health and health care.

For example, our assessment of health plans, especially those with Medicare Advantage products indicates that there is a high level of interest among a number of plans in increasing member engagement in their health care (although what this means remains

vague). We would develop an affinity group composed of representatives of such plans and would a) facilitate their interactions to solve problems in supporting engaging their members; b) encourage their use of the results of the language and message development we will develop; c) include members in the development of Best Practices (see below); and d) use them as a source and audience for interventions described in the Compendium of Engagement Tools.

Compendium of Products and Interventions to Support Engagement

Our research found that many of those charged with increasing engagement among their members and constituents have not specifically defined what this means. The Engagement Framework identifies the behaviors that constitute engagement. Using the Framework, the compendium will allow health plans, employers, and health professionals to easily find evidence-based tools that have been developed to help people learn the skills to perform these new behaviors.

We will develop and maintain an inventory of practical, ready-to-use products, ranging from patient visit preparation forms to manualized interventions that have been shown to teach smoking cessation. Current interventions that are implemented to train older people to engage in their health and health care focus mostly on health promotion, disease prevention and chronic disease self-management. This compendium would expand the universe of tools to be used for this purpose.

Mindful of other efforts to consolidate knowledge of behavior change interventions on a health related topics (e.g., diabetes self-management, cancer prevention) the compendium will consist of annotated links to evidence-based interventions that will allow users to identify interventions directed at the individual, intermediary, and institutional or community level. Such a compendium, requiring ongoing updating to remain current and comprehensive, will include implementation information, with case examples and accounts of successful real-world efforts of older people taking actions that make a difference in ways they view as positive. The compendium will avoid the creation of new content, but rather will carefully select the best Web-based information to provide planning tools for stakeholders as they make strategic choices among the interventions available to support specific behavior changes in older people.

Development of Best Practices for Getting Tools Used

The development of new interventions to help older people participate more actively in their health and health care has been stalled by lack of interest in them on the part of their intended audience. Millions of dollars have been devoted to developing decision support tools for choosing disease treatments, comparative quality ratings, weight-loss programs and navigator services, and health information Websites. But the use of these tools by the public has been disappointing.

This aspect of field building will focus on developing best practices for getting specific tools used. Because evaluation of implementation efforts is rare, this will involve

identifying high priority tools; conducting environmental scans; convening researchers, clinicians and practitioners to agree upon the parameters of effective implementation; dissemination of the best practices via the community of stakeholders; and making the best practices publicly available.

Legislative and Regulatory Policy

There is a steady stream of minor legislation and frequent regulatory hearings about national health care policies – particularly with regard to Medicare – that are relevant to the expectation that older people will engage actively in health and health care. The vast majority of these take place without any representation from older people and their caregivers and virtually none of the patient testimony focuses on the burden that regulations place on those who are unable to actively engage in their health care.

We will monitor legislative and regulatory initiatives that can serve to promote the Blueprint – or support for sections of it – at the national level. We will respond to all relevant regulatory changes through written and personal testimony, organize allies to testify and lead or enjoin ongoing lobbying efforts to support regulatory changes and legislation directly related to this aim. This will complement the policy-related activities of community coalitions at the state and local level.

We are particularly concerned that the upcoming debate on health care reform that will take place immediately following the 2008 election will focus solely on coverage and will ignore the need to support older people and their caregivers in making complex decisions about coverage, treatment and doctors. We will work to ensure that the faces and voices of older people are a part of this national discussion and that these needs are considered as part of new legislation.

Dissemination and Promotion

Key to building a field and creating a social movement is making visible the scope of the problem and the possible solutions to all interested parties. Communications should target professionals with a stake in older people's ability to engage in their health and health care in the aging community and in health care, as well as the general public – particularly older people, their families and other caregivers.

To disseminate and promote the goals, objectives, and strategies of the Blueprint for Engaging Older People in their Health and Health Care (attached) and the progress of the movement and field in achieving active engagement of older people in their health and health care, we will develop a detailed communications plan that shares new information regularly with our strategic partners. It will inform those with a stake in older people's engagement in health of the opportunities and developments in the field.

We will also target the general public via the media with news stories describing new findings about older people's engagement in their health and health care. The Center has a long history of working with the media to increase the public visibility and priority of

addressing health behavior via the Center's Health Behavior News Service (HBNS), which has operated for the past 15 years in the model of Reuters (although with less volume and at no cost to journalists) to produce and disseminate news stories relevant to people making evidence-based decisions about their health and health care. For example, new scientific findings that document the burden placed on older people by health care as it is currently delivered and news stories about unsafe, poor quality care provide a hook for which we write and place opinion essays and letters to editors of national and large urban newspapers.

Advisory Council

To provide guidance and oversight for the Center's proposed coordinating role, we would create an Advisory Council of leaders representing key sectors: Area Agencies on Aging, geriatrics, geriatric nursing, Medicare Advantage health plans, clinical professional societies, public payers, private payers, quality measurement and foundations. Such an advisory council will help to unify and coordinate elements of the field by involving key individuals in this advisory capacity. The group will meet twice per year and would advise the initiative on an ad hoc basis.

Attachment

A Blueprint for Engaging Disadvantaged
Older People in Their Health and Health Care

Prepared for The Atlantic Philanthropies

Rationale	8
Vision	10
Goals	11
Strategies	11
What It Will Take To Succeed	13

RATIONALE

Getting good care and making good use of health information increasingly requires that individuals take effective action. Thus, the stakes of not participating in their health and health care increase: there is greater potential for patient and provider error and poor adherence to treatment, both of which lead to poorer health outcomes. The inefficient use of health care resources is costly to individuals, clinicians, health plans and payers. People who are educated and wealthy are more likely to be able to assume this new role as an active participant in health and health care and thus benefit more from the knowledge, technology and skills available. The converse is also likely that those who do not participate – for whatever reason – will benefit less.

And so our nation will require a dramatic change in the awareness, willingness and capacity of most people – and particularly most older people, who are more likely to be ill and to use health care – to assume a new role and a wide range of personal responsibilities if they are to fully benefit from advances in health knowledge and care. The fragmentation and complexity of health care in the US today demands that older people perform most of the actions described in the Engagement Framework (attached) to avoid needless suffering.

Such a change will not appear spontaneously.

Tradition and habit on the part of individuals and health professionals alike help ensure the preservation of the status quo in the face of mounting evidence that it is both dangerous and foolish for individuals to be passive about their health and health care.

But more significant is the lack of information about *why* older people need to engage in their health and health care and *how* they (and their caregivers) can take effective action actions. Further, there is scant recognition – not to mention support – for those who are unable to perform these behaviors because they are ill and alone, because they don't believe that doing so makes any difference or because they lack the mental, physical or material resources.

This Blueprint describes a vision of what the country would look like if older people and their caregivers were fully engaged in their health and health care. It then lays out a plan achieving this vision. It describes actions that move from the community to the national level with partners in the public and private sector aligned to ensure that *all* older people – not just those who are educated and savvy – will benefit.

VISION

The vision of the proposed initiative sees a nation in which older people – alone or with support from a caregiver – actively engage in their health and health care. Achieving this vision will require that public and private agencies and health professionals will take proactive steps to ensure that:

1. Older people and their caregivers see the value of actively engaging in their health and health care and view doing so as normal.
2. Older people strive to perform healthy behaviors and feel competent to do so.
3. Older people and their caregivers have the ability to find and use valid information, and have access to local skilled advisers who can help them find information that will help them make decisions about health-related services, providers and institutions.
4. Older individuals and their caregivers understand their health conditions and how to manage them by themselves and seek appropriate care when they are unable to do so.
5. Older individuals, their caregivers and their providers communicate effectively and are responsive to one another.

GOALS

The goals of the initiative are to:

- A. Build an effective and sustainable movement aimed at creating the conditions in which it is normal for *all* older people to be actively engaged in their health and health care;
- B. Build commitment and mobilize and target resources to generate the evidence, information, and experience needed for the movement to be successful.

STRATEGIES

Achieving this vision requires the development and implementation of an integrated set of strategies to mobilize energy, talent, and resources to create the conditions under which older people can actively engage in their health and health care.

Communicate about Engagement

Aim: To communicate clearly to older people what it means to engage in their health and health care, why it is beneficial and how they can do so.

This requires ensuring that all authoritative information sources, including the media, professionals, employers, and civic organizations use this language to reflect that engaging in one's health and health care is possible and normal and that it is worth doing.

Such activities might include:

- Develop and test messages that are clear and compelling to older people and their caregivers about engaging in health and health care. Encourage all possible authoritative information sources to use this language.
- Raise the public visibility of the current status of older people's engagement by conducting surveys and reporting findings to the general and professional media.
- Raise the public visibility of efforts to support engagement by generating and distributing news stories on the imperative vs. the reality, new effective interventions and new policies that support engagement.
- Create and maintain a compendium of successful interventions and approaches to engage older people and their caregivers. The inventory will include both "professionally-oriented" descriptions of interventions/approaches and also "stories" of real older people really taking these actions and seeing it make a difference for them that they define as positive. Promote

its use by intermediaries (e.g., AAAs, libraries, non-profits, health voluntary organizations, CMS, AOA, community service providers, coalitions, health care providers, etc.).

Advocate for Access and Support for Engagement

Aim: To ensure that all older people have access to the support they need to engage in their health and health care, regardless of their mental or physical capacities or resources.

This requires public and private policy and practice changes that make acquiring knowledge, skills and other kinds of support easily accessible for those who need it.

- Encourage federal agencies to support state and local groups to provide the tools and infrastructure older people need to make good use of the services provided to help them and their caregivers engage in their health and health care.
- Realign incentives to give health care providers a stake in supporting older people's engagement in care decisions and health behavior known to improve health and independence.
- Encourage health plans and hospitals to implement effective approaches to helping older people engage effectively in their health and health care.
- Promote the integration of measures that reflect engagement and capacity to engage into existing goals, guidelines, and evaluation tools (e.g., CAHPS, HEDIS, Behavioral Risk Factor Survey, Medical Expenditure Panel Survey, etc.) employed in the health field. Report publicly on findings.

Mobilize Action to Ensure that All Can Choose to Engage

Aim: To build the capacity and commitment of organizations and agencies so that all older people and their caregivers have the choice to engage in their health and health care and the support they need to do so.

Doing this means providing guidance, resources and purpose to stakeholders so that older people and their caregivers in every community in the US are able to engage in their health and healthcare.

- Enjoin players from the local to the national level working on "consumer health engagement" to align their efforts by integrating the focus on behavior and ways to achieve them within their organizational priorities.
- Mount strategically chosen projects that demonstrate how to reshape existing institutions to provide targeted support for older people and their caregivers.

- Add support for engagement to existing efforts to improve access and quality of care for disadvantaged older people.
- Increase the exchange between practitioners and researchers working on supporting the engagement of older people and their caregivers.

WHAT IT WILL TAKE TO SUCCEED

Allies/partners : Patient engagement is a popular topic that is currently "owned" by many individuals, groups and organizations, some of which have the power and authority to spark significant change, others of which have made only a rhetorical commitment. They are each seeking innovative ways to understand, talk about and increase the engagement in a few of the behaviors listed in the Engagement Framework.

Progress toward the goal of increasing engagement can be magnified by bringing together diverse stakeholders to support and strengthen existing efforts, invite new natural allies to "own" engagement and facilitate access to evidence, communication and coordination among the many players.

Time horizon; sustained commitment: A change of this magnitude requires a sustained commitment with sustained funding over the long term. Regardless of shifts in health care financing and delivery, the reality is that people are going to have to assume a greater role in their health and health care. While there is a growing realization that lack of engagement increases the risks of poor quality care and poor outcomes, the message is not widely understood by older people, nor are the specific behaviors they must undertake in order to optimize their health and care. Changing these norms will take time, as will efforts to provide support for these behaviors among people who are unable to perform them.