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Alzheimer's Disease Megacommunity

The Path Ahead

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Alzheimer’s disease is a growing epidemic that will have an increasingly severe impact on our nation’s economy and healthcare system if left unchecked. Today, as many as 5 million people suffer from Alzheimer’s disease and, as baby boomers age and life expectancy increases, that number is expected to grow to 16 million by 2050. Often discounted as simply a disease of the elderly, Alzheimer’s and other dementias afflict around 500,000 people under the age of 65.

Because age is the single biggest risk factor for Alzheimer’s, the disease will become more prevalent as the Baby Boom generation ages and the average lifespan extends. With that growing prevalence will come rising costs; the cost of Alzheimer’s disease to the Medicaid program alone is expected to jump from $21 billion in 2005 to $38 billion by 2025, directly affecting federal and state governments. And with 70% of individuals with Alzheimer’s dependent on their family and friends for day-to-day care, the disease also places an extraordinary financial and emotional burden on caregivers.

There are many groups and organizations across the public, private, and civil sectors that are passionately engaged in the fight against the challenges of Alzheimer’s disease, but they have constraints on their funding and scope and therefore cannot tackle the problem holistically. Addressing the complexities of this epidemic strategically will require the collective efforts of committed stakeholders. They must work together to identify mutual interests and forge new relationships and partnerships. Through this network of stakeholders—which we call a megacommunity (see side bar)—individual members can support and expand their objectives and impact through the combined knowledge and resources in the megacommunity network.

The goal of this megacommunity must be nothing less than finding a cure for Alzheimer’s disease and ensuring access to quality care for those who have it.

What is a Megacommunity?

A megacommunity is a network of organizations, drawn from the public, private, and civil sectors, driven together to engage in solving a compelling problem of mutual interest, such as Alzheimer’s disease.

A megacommunity is not a static organization with a hierarchical structure, but rather a flexible, living network that is scalable and adaptable to its members. Just as the current challenges facing Alzheimer’s disease are dynamic in nature, so too are the organizational roles within the megacommunity. In this way, the megacommunity is able to adapt to the constancy of change facing this looming healthcare crisis.

Alzheimer's Disease: A Megacommunity Approach to Prevention, Detection, Treatment, and Care

On September 17, 2007, the Center for Health Transformation and Booz Allen Hamilton engaged nearly 80 leaders from the public, private, and civil sectors in a simulation to explore how to address the challenges associated with Alzheimer's disease. Booz Allen developed and conducted this strategic event with the following objective:

- Explore how collaboration across the megacommunity can enhance prevention, detection, treatment, and care to mitigate the impact of Alzheimer's disease on patients, caregivers, and society.

The simulation was designed to provide an opportunity for representatives of key industries, advocacy organizations, federal agencies and patients and their caregivers to explore the challenges related to Alzheimer's disease, and enhance stakeholder relationships across the Alzheimer's disease megacommunity. Outcomes focused on:

- Understanding priorities and concerns of the stakeholders
- Identifying integrated priorities across the megacommunity
- Defining a process for how the megacommunity should move forward.

Teams of participants representing academia, devices and diagnostics, government, payors, providers, devices and diagnostics, pharma, public advocacy, and patients and families were tasked with addressing the challenges associated with Alzheimer's disease in cooperation with other teams. A Control Team oversaw the entire simulation, updating the scenario based on team actions, and playing all entities not represented by stakeholder teams, including Congress, the White House, and the media.

Reaching that goal will require a new paradigm for the prevention, detection, treatment, and care of individuals with Alzheimer's disease and their families. Such an ambitious agenda necessitates the collective efforts of committed stakeholders to achieve interim successes and provide motivation for continued progress. Collaboration will depend on communication and technology to enable stakeholders to engage effectively in the megacommunity and accelerate progress toward its goal.

Megacommunity Engagement

Building the Sustainable Megacommunity

The megacommunity provides a framework for engaging the Alzheimer's disease stakeholders. The vision and components of the megacommunity are important for focusing the collective objectives, resources, and capabilities of the stakeholders.

On September 17th, 2007, the Center for Health Transformation and Booz Allen Hamilton engaged nearly 80 leaders from the public, private, and civil sectors in a simulation to explore how they could work together to address the challenges associated with Alzheimer's disease. Booz Allen developed and conducted this strategic event to understand how the megacommunity's constituents could collaborate to enhance prevention, detection, treatment, and care in order to mitigate the impact of Alzheimer's disease on patients, caregivers, and society.

The insights drawn from that simulation serve as a foundation for the Alzheimer's megacommunity's efforts to continuously reevaluate strategies and priorities, as well as monitor progress in prevention, detection, treatment, and care. The megacommunity's cross-sector membership (from the public, private, and civil sectors) provides the perspectives and interests necessary for sustaining this collaborative network. Individual member organizations can, in turn, support and expand their objectives and impact through the combined knowledge and resources in the megacommunity. The creation of the megacommunity network will follow a phased approach (see Exhibit 1) that builds on the relationships and insights gained through the Summit. The four-step process takes the megacommunity from concept to execution, building in mechanisms to focus the megacommunity and drive it toward its goal.

Critical Roles in the Megacommunity

The megacommunity is designed to be an elastic network that can adapt to meet the ever-changing landscape of challenges associated with Alzheimer's disease, so it is dependent upon its members to sustain its success through involvement, resources, and thought leadership. Given the flexibility and scope of the megacommunity's objectives and vision, there are several primary roles that should rotate among members to ensure continued collaboration:

- Interim Advisory Council: Comprised of organizations that will focus on initiating the Alzheimer's Disease Megacommunity, the Interim Advisory Council will further establish the network and refine roles and responsibilities within the megacommunity. This council will act as the convener for the first six months of megacommunity activity, and will remain active for an additional 18 months to ensure the network's successful launch.

Opportunities for Collaboration

The simulation participants identified and explored several key challenges that might best be conquered through collaborative efforts:

- Recognizing the Epidemic
- Empowering the Patient and Caregiver
- Transforming the Care Model
- Finding a Cure

- Convener: Acts as a catalyst for driving the megacommunity agenda and progress by assembling the critical stakeholders from the private, public, and civil sectors. The convener's responsibilities may include scheduling and organizing meetings, ensuring broad participation, and driving the strategic vision ahead.
- Program Manager: Serves to facilitate the megacommunity agenda, activities, and outcomes. The program manager will monitor working group progress, maintain communications within the megacommunity, and reach out to new organizations to fill gaps in the megacommunity.
- Members At-Large: Provide the resources necessary for broad engagement as well as specific initiatives. All members share the responsibility for providing operational, financial, and/or intellectual expertise in order to initiate and sustain the megacommunity and

Exhibit 1
Megacommunity Formation and Sustainment

Define the Agenda	Energize the Megacommunity	Mobilize the Megacommunity	Sustain and Optimize the Megacommunity
▪ Refine the insights gleaned from the summit to create the megacommunity agenda ▪ Define the level of engagement and top priorities for the participants	▪ Develop organizational mechanisms for the megacommunity network, which will define capabilities, duration, focus, and roles and responsibilities ▪ Develop program management initiatives to institutionalize megacommunity management	▪ Encourage relationship building and information sharing ▪ Facilitate working groups to address specific Alzheimer's disease issues	▪ Measure progress of milestones toward achieving vision ▪ Develop and engage megacommunity leadership for direction and self sustainment

Source: Booz Allen Hamilton

its initiatives. Any individual or organization with an interest in Alzheimer's disease can participate as a member of the Alzheimer's Disease Megacommunity.

Rotating Megacommunity Leadership Structure
By definition, a megacommunity has no single leader, but instead is driven by an interconnected network of leaders. Thus, the Alzheimer's Disease Megacommunity can draw on the resources of all its members to sustain its continued evolution. The megacommunity's use of a rotating model (see Exhibit 2) will allow numerous members of the megacommunity to hold the primary roles.

This model provides an inclusive framework to engage all members in addressing the four opportunities for collaboration identified during the simulation: Finding a Cure, Recognizing the Epidemic, Empowering the Patient and Caregiver, and Transforming the Care Model.

Insights of the Alzheimer's Disease Megacommunity Event

While there have been many forums for stakeholders to discuss Alzheimer's disease, the September 17th simulation was the first opportunity for many participants representing different perspectives to share their insights collectively. During the Summit, several common themes emerged:

Exhibit 2
Alzheimer's Disease Megacommunity Model

Source: Booz Allen Hamilton

Recognizing the Epidemic: Opportunities for Action

- *Creating a Unified Voice:* Provide advocacy tools so that the Alzheimer's disease megacommunity can articulate a unified message
- *Putting a Face on Alzheimer's Disease:* Identify early-stage patients to serve as the voice of Alzheimer's disease for use in communications materials
- *State Legislation:* Advocate to draft standard legislation for use by state governments recognizing Alzheimer's disease as an epidemic that needs to be addressed and where possible, allocating funds

Recognizing the Epidemic
Many people who have not directly experienced the impact of Alzheimer's disease are unaware of its cost, its severity (it is the seventh leading cause of death in the United States), and the intensity of care it requires. So, while many organizations are actively articulating the impact of Alzheimer's disease, there remains significant opportunity to lobby the American public and policymakers to recognize the urgent need to address this disease and the severe consequences of failing to do so: burdened caregivers and the growing toll on the workforce because of their requirements, a stressed medical and long-term care system, a strained national economy, an increase in Alzheimer's disease deaths, and a growing toll on the workforce due to caregiver requirements.

The megacommunity must make a concerted effort to present the compelling case for addressing Alzheimer's disease. Focusing the resources of individual stakeholders and groups within this megacommunity can build a level of awareness that no single entity has so far been able to accomplish alone. The megacommunity can develop a communications campaign that leverages the personal experiences of patients and caregivers to dispel the myth that

Alzheimer's disease only affects the elderly. Putting a "face" on the disease will also invigorate a grassroots communications campaign to spread the word and reduce the stigma associated with the disease through personal interactions, such as face-to-face communication, advocacy events, and web-based forums. It is only through universal recognition of the magnitude of the Alzheimer's disease epidemic that the megacommunity will be able to motivate the public, private, and civil sectors to support its efforts.

Empowering the Patient and Caregiver

Contrary to common expectation, patients and their families express their desire to know about the diagnosis of Alzheimer's disease as early as possible, even though there is not yet a cure or treatment to halt progression. Unfortunately, the diagnosis relies on a complex set of procedures that can take from 12 to 24 months to complete from the onset of symptoms. Improving early diagnostic techniques will provide much-needed time for Alzheimer's disease patients and their families to make decisions together about caregiving, treatment options, and finances, and to prepare emotionally for what lies ahead.

Empowering the Patient and Caregiver: Opportunities for Action

Online Alzheimer's Disease Community: Create a single website to aggregate and organize Alzheimer's disease information. The Online Community can serve a variety of purposes:

- *Information Repository:* Serve as a forum to collect best practices in prevention, detection, treatment and care
- *Communication Portal:* Provide an outlet to share personal experiences with Alzheimer's disease through blogs, chats, and web forums
- *Publicize Advocacy Opportunities:* Create a calendar of advocacy opportunities and public policy initiatives

Alzheimer's disease patients, their families, and caregivers also face enormous frustrations in accessing information on care and treatment. Many organizations provide valuable information, but it is scattered and difficult to collect. Too often, events and dialogues that should involve the patient and family occur without their active engagement. Patients, caregivers, and others need a single integrated, comprehensive online location that provides the most up-to-date information and resources along with a communications forum for the Alzheimer's disease megacommunity at-large, including patients and families. An Online Alzheimer's Disease Community can serve as a platform for the megacommunity to harness technology for improved live interaction.

Such an online community can be a venue for dialogue among patients and caregivers, while also serving as a hub for sharing and dispersing information quickly. It may provide a mechanism for patients and caregivers to express their thoughts and needs through open communication with doctors, companies, and other organizations. It could serve as a forum for virtual collaboration on key megacommunity documents and a tool for organizing megacommunity members around public advocacy opportunities. This central location may also help patients or caregivers partner with private or civil sector efforts to lobby for additional funding for research, care, and other disease-specific needs, better enabling them to impact the future course of Alzheimer's efforts.

Transforming the Care Model

From both a care delivery and a financing perspective, today's healthcare system is primarily focused on handling acute conditions. But Alzheimer's disease patients require a chronic care delivery model that recognizes the need for, and cost of, both medical and social services. For most Alzheimer's patients, the home is the best and the only option for care. However, the current care system provides inadequate funding to ensure the safety, well-being, and health of Alzheimer's disease patients in this setting. In addition, there are limited options for getting Alzheimer's disease patients the social and mental stimulation that is critical to managing symptoms and possibly delaying progression.

Transforming the Care Model: Opportunities for Action

- *Demonstration Project Funding:* Lobby for demonstration projects that show the financial and health outcomes of different models of financing social services
- *Education:* Educate clinicians on the symptoms and treatment of both Alzheimer's disease and its co-morbidities
- *Local Resource Guide:* Create a resource guide for patients and caregivers with treatment options, coping mechanisms, and healthcare guidance

The megacommunity can transform the medical care model to focus better on the unique needs of Alzheimer's disease. Like many chronic diseases, a broad spectrum of providers treat Alzheimer's disease or aspects of it—family members, psychologists, social workers, nurses, general practitioners, neurologists, endocrinologists, and coronary care specialists, among others—and all must be better-informed about the signs and symptoms of the disease. Primary care physicians in particular require access to the latest treatment methods and studies or trials that may benefit their patients. The chronic and degenerative nature of Alzheimer's disease requires increasing levels of information and support as the disease progresses. Through access to educational support and resources, caregivers have the opportunity to learn caregiving best practices, locate products to enhance in-home care, and access medical care from professionals well versed in the challenges of the disease. Furthermore, managing co-existing conditions such as diabetes may be more complicated in a patient with Alzheimer's disease; thus it is essential that specialists, in addition to primary care physicians, have access to appropriate tools and techniques.

The megacommunity must also address the financial ramifications of transitioning to the patient-centered care model that families and specialists prefer. Studies have shown that Alzheimer's disease patients cared for at home have a longer life expectancy with a better quality of life, but such individualized care can be especially costly. Home health aides were paid an average of $19 per hour in 2006, and adult day service can cost from $25 to $100 dollars a day and families bear the lion's share of this burden. Home care also comes at a high cost to the community by drawing healthcare workers away from hospitals and other institutions, where they are already in short supply. The Alzheimer's disease megacommunity must develop a care model that accommodates the increasing expense of care. This calls for an updated reimbursement model that is chronic-care focused to reduce the cost of Alzheimer's disease to individuals and society. One way this process could begin is by reimbursing novel and cost-reducing ways of caring for Alzheimer's patients.

But a new reimbursement model will not be enough. While Medicaid already provides coverage for some treatment and care associated with Alzheimer's disease, it is mainly left up to the states to organize these programs. To alleviate the cost burden, providers, payors, government, and pharmaceutical companies also need an increase in state and federal funding to Medicare and Medicaid in order to respond to the growing number of Alzheimer's disease patients. Recent studies have shown that, without significant reform, the Medicare program will be bankrupt by 2019. That fact alone should compel the megacommunity to push for change.

Finding a Cure

Currently available treatments for Alzheimer's disease manage symptoms, but do not delay its onset or slow its progression. While researchers have identified two key characteristics of the disease, they are still unsure of its causes. Therefore the best hope of delaying disease onset, slowing disease progression, or even preventing Alzheimer's disease requires a focused effort to identify and understand the basic biological processes that lead to the development of the disease.

Finding a Cure: Opportunities for Action

- *Epidemiological Studies:* Embark on epidemiologic studies while mining existing epidemiological and clinical trials data
- *Collaborative Data Collection:* Enhance collaboration through initiatives likes the Alzheimer's Disease Neuroimaging Initiative (ADNI) in which data and samples are shared within the megacommunity
- *Define Regulatory Requirements:* Develop clear definitions of regulatory requirements through collaboration between pharma, clinical trials partners, and the government

Such studies will reveal additional biological targets for innovative advances in detection and treatment that may provide the opportunity for treatment earlier in the disease progression, perhaps even before mild symptoms appear. An increase in basic research efforts, a free exchange of data from existing clinical trials, and broad access to research tools and samples can pool scientific knowledge and accelerate progress toward identifying the causes of Alzheimer's disease. With megacommunity commitment to this sort of initiative from public, private, and civil sectors, the near-term goal of providing Alzheimer's disease patients with treatments that delay onset or progression of the disease may soon be achievable.

Improved communication and collaboration across the megacommunity promises to accelerate the translation of new discoveries in basic science into available treatments for patients. Utilization of information technology systems that share research efforts and findings in real time across the various sectors can provide a research infrastructure (encompassing National Institutes of Health, academia, pharma, and other privately funded research) that increases transparency and cooperation, while reducing redundancy in a way that protects the individual interests of the group. Such efforts will ensure that any new knowledge is disseminated throughout the megacommunity in the fastest and most accessible format.

Improving the underlying tools that enable us to conduct quality clinical research can enhance our understanding of Alzheimer's disease and improve the clinical trials process. In the absence of a working animal model that scientists and clinicians can use to substitute for the human disease in testing, the establishment of a national or international Alzheimer's disease patient registry can help by providing a large repository of epidemiologic data, better enabling scientists to create more accurate disease models. This would be akin to the Framingham Heart Study, which proved invaluable to the advances in prevention and treatment of coronary heart disease. Such an effort will require researchers, payors, and providers to communicate openly and share resources to further the understanding of disease processes so that clinically effective therapies can be discovered for each stage of Alzheimer's disease.

Enabling Tools

To better facilitate collaboration, the megacommunity can empower its members through the use of enabling tools. Throughout the Summit, participants echoed the need for two broad tools to enhance collaboration—technology and communications:

Harnessing Technology

Technology will not only enhance collaboration and the transfer of information, but it also will drive innovation for the prevention, detection, treatment, and care of Alzheimer's disease. Harnessing technology may offer researchers and physicians better tools for understanding the science of the disease and diagnosing the disease more accurately. Enhanced

Enabling Tools

- Harnessing technology
- Enhancing communications

technology also offers hope for patients and families dealing with the day-to-day stress of the disease—with the potential to streamline medical appointments, improve mechanisms for handling the physical limitations of Alzheimer's disease patients, and develop a national patient registry for better tracking of patient clinical information. Progress on support and care innovations, such as technologies for "smart" homes that may better allow an Alzheimer's disease patient to live safely and independently for a longer period of time, also needs to be accelerated. The megacommunity is challenged to identify, develop, adopt, and disseminate technology to improve the lives of Alzheimer's disease patients and their caregivers. By developing suites of tools that target specific sectors, the megacommunity can better leverage current technology and drive innovation to advance the prevention, detection, treatment, and care for Alzheimer's disease.

Enhancing Communication

The power of communications and its inherent ability to foster understanding and awareness will support the megacommunity in achieving consensus on its priorities as well as raising a unified voice to the public. A common vernacular can be built by using both internal and external communications tools, better enabling the launch of a national public relations campaign to raise Alzheimer's disease awareness. The megacommunity shares the power to enhance awareness through the collective use of strategic messaging, media campaigns, and issues advocacy. The success of these efforts can only be achieved through consensus and consistency in articulating a unified public message. By improving communications within the megacommunity, it will be easier for its members and the general public to more actively address Alzheimer's disease.

Conclusion

The ultimate goal of the megacommunity is to create a world without Alzheimer's disease. Until that happens, we must take care of Alzheimer's disease patients and their families in a more comprehensive, compassionate, and collaborative manner than we currently do. The megacommunity offers the opportunity to identify and address the most urgent priorities with the collective resources of all the stakeholders. Organizations from each of the three sectors—public, private, and civil—must all collaborate in determining the best way to achieve this, and the best course of action to make this vision a reality.

As a first step to articulating and achieving this vision, initial leaders of the megacommunity must be identified and brought together to develop a preliminary operating framework and facilitate broad tri-sector engagement.

The initial megacommunity leadership must coalesce immediately to maintain the momentum achieved at the Summit. Several respected organizations have already expressed interest in joining the Megacommunity Interim Advisory Council. This Interim Advisory Council, once finalized and formed, will convene the megacommunity for the first six months of its activity and facilitate broad participation across the public, private, and civil sectors.

Establishing a plan for continued megacommunity engagement through use of technology, in-person meetings, and communications products will better connect its broad network of members. Outreach will be jump-started by publicizing the broad insights gained at the Summit through a press conference and distribution of those insights within the megacommunity. Together, the larger megacommunity network can work to refine these challenges and priorities to further define and sharpen its vision for the future of Alzheimer's disease.

The Alzheimer's disease megacommunity is a vital force in realizing the vision of a new world where Alzheimer's disease is no longer a fatal sentence. It is through collaboration that the challenges and opportunities highlighted in this report can be seized through the use of an enhanced set of technologies and the implementation of a well-structured communications strategy. Ultimately, megacommunity participants are given a unique window into one of the most pressing issues facing this nation, a clear path towards making an impact, and an opportunity to address the disease collaboratively in a way more powerful than any single group could achieve alone.

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