



Innovations in Health Advocacy for Older Americans

Expanding the Role of the Internet in Health Advocacy for Older Americans

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A research and development report
prepared by the

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INNOVATIONS IN HEALTH ADVOCACY FOR OLDER ADULTS

Expanding the Role of the Internet in Health Advocacy
For Older Americans

Executive Summary

Advocacy is essential to the democratic process that shapes public policy in the United States. Traditionally, advocacy has relied on trust and personal contact between policymakers and lobbyists. However, the Internet has changed advocacy by providing everyone virtually unlimited access to information and by giving unprecedented numbers of constituents — many of whom have traditionally written letters — the opportunity to express opinions to lawmakers via a flood of e-mails. This change is particularly significant for older Americans, who represent a large percentage of the voting public and who are a growing proportion of Internet users.

With this in mind, the SPRY (Setting priorities for Retirement Years) Foundation asked: What potential does the Internet hold as an advocacy tool for older Americans? Beginning in the spring of 2002, the SPRY Foundation launched a research project to address this question. A literature search revealed that little creativity has been applied to using the Internet for advocacy. Almost no empirical research, case studies or even anecdotal material on it exist. Internet advocacy has been primarily limited to sending e-mails. Instead of transforming advocacy, the Internet has, so far, served as a surrogate for the traditional advocacy method of sending mail and has had but superficial impact.

Baseline research led SPRY to hold a work-group meeting in July of 2002 to develop innovative ideas for Internet advocacy. The conference produced a list of ideas for factors critical to the success of using the Internet for advocacy; a short list of new ideas; and a model (for enhancing Internet advocacy) for development and testing. The model is a personalized, web-based, short, self-running video segment designed to deliver personal, documentary-style constituent messages via the Internet to legislative offices.

The SPRY Foundation has developed a prototype of this model and is making this prototype available to the aging community for testing and modifying in real-life settings.

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BACKGROUND

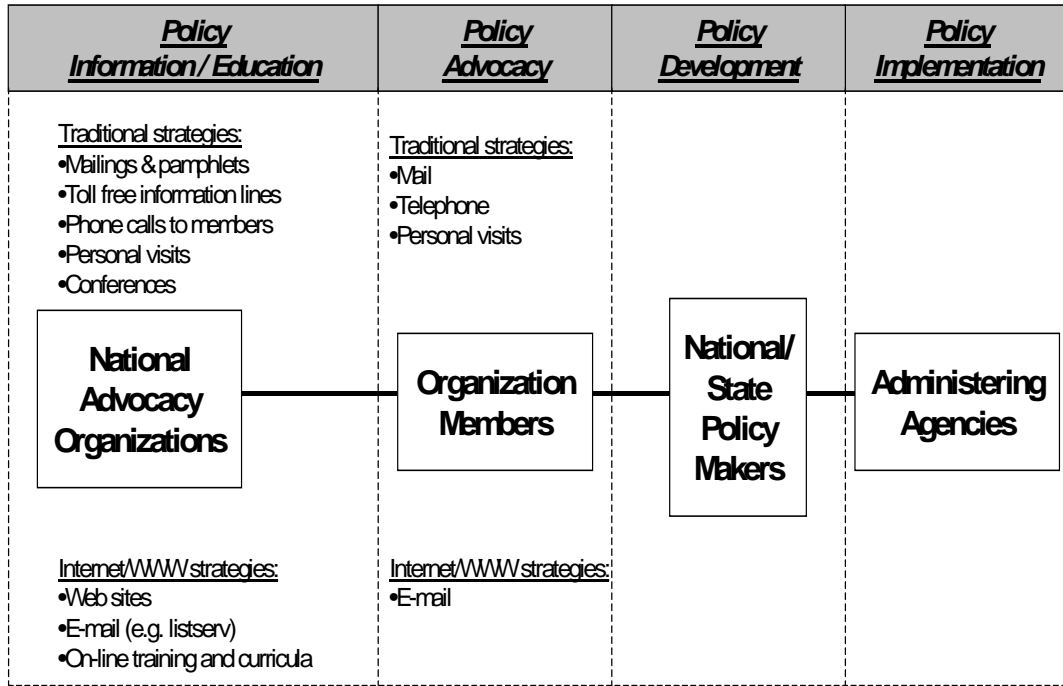
For more than 200 years, advocacy has been essential in shaping public policy in the United States. As representatives, American lawmakers are responsible for making decisions that reflect their constituents' opinions. Early advocacy campaigns were championed mostly by individuals. But such campaigns have since become larger and more organized, with entire organizations that work to protect existing policies or promote new ones on behalf of large numbers of citizens.

As illustrated in Figure 1, the advocacy process at the national level can be described in four stages:

- (1) An advocacy organization informs and educates its membership about perspectives concerning policy issues specifically related to their interests. It also provides guidance to the members on how they can influence the policy maker's decisions. Advocacy organizations have often mailed literature, held media conferences, produced journal articles, written op-ed pieces and, more recently, placed information on their websites or e-mailed it directly to their members.
- (2) The role of the advocacy organization's membership is to take action by communicating its personal views on policy issues both directly to policy makers, and to others who influence the policy maker's decisions. Traditionally, advocacy organizations have encouraged their members to make personal phone calls or write letters directly to their congressional representatives, sign petitions, join the organization's lobbyists in personal meetings with congressional representatives and their staff and, more recently, send e-mails to their members of Congress.
- (3) Congressional representatives assess the varying views of their many constituents and use this information in developing and navigating the passage of new policy in the legislative process. They also want to continue to hear from their constituents about any



Figure 1. The role of the Internet in health advocacy for older Americans



additional changes or protections in policies that are necessary to assure a better quality of life for all Americans.

- (4) The role of governmental administrative agencies is to interpret legislative policy established by congressional mandates, and implement the programs accordingly. They are especially sensitive to the opinions of constituents who are the beneficiaries of the policies, particularly when these are active constituents such as older Americans, who traditionally vote in great numbers.

Traditionally, the advocacy process has been a personal one, built on trust, commitment, and face-to-face contact between policymakers and lobbyists. The Internet is changing that, whether it is advocacy at the national, state or local level. Internet use is growing exponentially in the United States. Information, goods and services that used to be located in specific venues are now available to anyone at any time. Moreover, the Internet does not require physical interaction between people. Instead, information, goods and services can be exchanged from a distance. The quantity and quality of information available for congressional representatives and their constituents is now virtually unlimited, and this represents an unprecedented opportunity for advocacy organizations.

The Internet's role in advocacy increased even more after the events of September 11, 2001. Because of the anthrax scare and new security measures, lawmakers have become less accessible. Letters mailed to Capitol Hill can take as long as 30 days to reach their destinations after being processed in at least four sorting and irradiation facilities. Major carriers such as FedEx and UPS, as well as local couriers, also have struggled to gain access to key offices. Similarly, personal visits to lawmakers have been curtailed because of increased security precautions.

This curtailed access to congressional officials has especially impacted older Americans. Many seniors issues, such as Social Security, Medicare, Medicaid, and prescription drug

benefits are decided upon by government agencies, both at the state and national levels.

Seniors comprise the fastest-growing demographic group in the United States, they vote in great numbers, and they are one of the most reliable voting constituencies. For these and other reasons, congressional representatives want to hear from older Americans. Yet tapping into their “voice” is getting increasingly difficult. Older adults have traditionally communicated their opinions to representatives by writing letters. Unfortunately, letter delivery to Capitol Hill is less reliable than it used to be.

Yet the Internet is a key source of communication for baby boomers now, and it will continue to be when they are retired. Internet use among the elderly is rising rapidly, as well. The Internet is positioned to become an important source of access to Congress for seniors across the country. With this in mind, the potential that the Internet holds as an advocacy tool for older Americans takes on new urgency.

In the spring of 2002, the SPRY Foundation launched a four-phase project to address this topic:

- Phase I: Baseline assessment of current use of the Internet as a tool for advocacy;
- Phase II: Think-tank/working-group session to brainstorm about new and innovative ways to use the Internet as a tool for advocacy;
- Phase III: Development of innovative model for testing in real-life setting; and
- Phase IV: Invitational conference (with leaders in technology and advocacy) to analyze the merits of using and/or modifying the model, and to discuss the model’s impact on emerging advocacy trends and issues.

Phases I, II and III are complete and their results are presented in this report.

PHASE I: BASELINE ASSESSMENT

As a first step, the SPRY Foundation wanted to learn the state-of-the-art uses of the Internet for advocacy, particularly as it applied to older adults and health issues. Given the Internet's fast-changing nature, only information published within the past three years was reviewed. SPRY reviewed 100 titles and selected 20 advocacy organizations for more detailed examination. Most of the advocacy organizations selected dealt with issues of age-related diseases or advocated for federal programs that affect seniors. Five of these organizations deal with non-senior issues (one environmental group, one women's group, two AIDS groups, and one, multi-purpose advocacy group). Fifteen of the 20 organizations were selected for more in-depth analysis, including AARP and the California Senior's Coalition. The organizations ranged in size from 200 to several million members. All the groups were identified using search engines, health-issue portals and individual recommendations.

The organizations' websites were examined for Internet advocacy use. Researchers answered these questions: (1) What advocacy actions does the organization request?; and (2) How does it accomplish, and promote, these actions? The research team looked for specific advocacy web pages and examined the software packages used. Thirty-two individuals (see Attachment A) from the 20 organizations were interviewed, in person when possible, or by phone (see Attachment B for telephone interview protocol).

The research team revealed a number of important findings, including:

- **The Internet is widely used by advocacy organizations and legislative offices.** All of the advocacy organizations and congressional offices had web pages. Generally, their websites were consistent in design and intent, and virtually all of the advocacy-group websites included tailored messages (issue-driven pages, issue alerts and newsletters).

- **Internet use among older adults is expected to increase dramatically.** Compared with younger generations, older adults have not been active users of the Internet. One interviewee explained that his organization had not put advocacy efforts on-line because its members were inexperienced with the Internet. Literature and interviews were found to be consistent with one another in that they agreed that older adults are rapidly becoming Internet savvy. Most stated that the future shows promise for this population.
- **Current understanding of Internet advocacy is limited.** Although Internet use is widespread, understanding of Internet advocacy was found to be limited. The literature, interviews and website analyses yielded neither substantive scientific research nor anecdotal evidence about Internet use for advocacy; most of the organizations had not analyzed their Internet advocacy use. At the same time, children and grandchildren increasingly are assisting older adults in using the Internet, which is part of a growing inter-generational trend.
- **Internet advocacy is largely limited to e-mail.** Internet advocacy was found to be almost exclusively limited to encouraging site visitors to e-mail legislators about specific issues (aside from using web pages as a virtual basis). Websites encouraged site visitors to contact lawmakers through direct e-mails, e-faxes, e-postcards, and e-petitions. This indicates that advocacy groups are using the Internet to substitute traditional advocacy methods (i.e., hand-written letters). Congressional offices reported being inundated by as many as 300 e-mails per day (Fitch 2002).
- **The government has been generally slower than the private sector in adopting Internet technology.** Government agencies, more so at the federal level than the state level, are generally behind the private sector in Internet technology usage (Steyaert 2002). The Internet has yet to be fully utilized by state and federal government agencies. There is no centralized congressional information system, and it is not

unusual for different offices to have differing, often outdated, versions of software. In August 2002, SPRY surveyed, in a separate study, all official websites of U.S. senators to determine the sites' characteristics and examine the consistency between them. The sites were found to vary widely content, design sophistication, and application of hardware and software.

- **Personal contact remains the primary and preferred method for advocacy.** The "personal touch" and trust are still perceived as essential to successful advocacy, according to advocacy groups and congressional staffers alike. Sources reported that many in Congress believe that constituency interest in an issue is best judged through person-to-person contact, or through other personalized forms of communication. Congressional staffers perceive e-mail as impersonal and not as efficacious as face-to-face advocacy (Fitch 2002).

These results indicate:

- **The Internet has not replaced traditional methods of advocacy.** Most advocacy organizations and congressional offices still prefer traditional forms of advocacy. Many legislative offices, especially at the federal level, are resisting e-mail-based Internet advocacy. Some lawmakers are wary that a flood of e-mails could force them to take a position too hastily. Others fear that e-mails could be forged, or otherwise misused, by opponents. The research suggests that advocacy groups have been successful in using the Internet to educate their members, but have been unsuccessful in giving members effective on-line vehicles to leverage that information. As a result, most advocacy organization members are on information overload.
- **The Internet may be creating a false sense of participation in the democratic process.** The research suggests that e-mails often do not reach their intended target audience on Capitol Hill. Yet the advocacy members who send e-mails are likely to be

unaware of this, assuming instead that e-mails enable fast, free, and unfettered communication with their elected representatives. This disconnect weakens the power of constituents to influence legislation, thus limiting the legislators' ability to make informed decisions. Some advocacy organizations already recognize this. Yet they continue to promote the flood of e-mails, rationalizing this as a form of membership participation and integral to membership-retention strategy.

- **Internet advocacy could play a major role in the future.** Over the past two years, the number of on-line seniors has increased dramatically (Fox, et. al. 2001). As Internet-familiar baby boomers begin to turn 65 and swell the numbers of older Americans, and as broadband becomes more accessible in homes, the percentage of older Americans and their family members using the Internet as an advocacy tool will increase dramatically. Increasing Internet-use by seniors suggests that, in the future, advocacy groups will have more opportunities to engage seniors in on-line advocacy. Moreover, the Internet helps level the playing field in policy advocacy and development. It provides wider access to timely information and – through intergenerational, local community access, and other innovative approaches – the Internet enables broader participation of such traditionally underserved populations as minorities, persons with disabilities, and individuals with lower income levels.

PHASE II: INNOVATIONS IN HEALTH ADVOCACY

In July of 2002, SPRY took the baseline findings to a team of thought leaders in Palo Alto, California to: (1) brainstorm about ideas for using the Internet more effectively as a tool for advocacy; and (2) select the most practical ideas for testing real life settings. As a first step, participants established some critical success factors for effective Internet advocacy. They concluded that, regardless of which pilot projects would be selected for testing, all models should:

- be simple (i.e., solve just one problem at a time);
- be timely (i.e., focus on a pressing legislative issue);
- be part of a larger campaign that is coordinated with other strategies;
- take advantage of existing systems and networks (i.e., do not reinvent the wheel);
- position the effort as one that is credible and trustworthy;
- utilize early adaptors and leading thinkers;
- include personalized information (customize the issue to the voting district);
- ensure that necessary technology is accessible to users and target audiences;
- utilize a trusted intermediary organization (when necessary) to manage information;
- exploit trends in viral marketing (e.g., sending electronic messages between trusted friends and colleagues) who multiply the distribution exponentially; and
- be sensitive to the needs of diverse audiences, recognizing cultural customs, behaviors, languages, and terminology.

Building on the baseline research, the critical success factors, and the target audience, participants then brainstormed about new ideas for using the Internet as a tool for advocacy.

These ideas included:

- **Moderate an on-line focus group.** Involve a group of seniors in an online focus group, using text-based chat-rooms about a specific seniors' health-related issue in their community. Congressional representatives and/or staff could participate from Washington, DC, or from any other location.
- **Add video clips to website.** An advocacy organization could take between 30 and 90 seconds of digital video footage of one of their members from a particular congressional district (a member whose personal views reflected popular sentiment about a particular issue). The digital footage could be posted to a database on the advocacy group's website as part of an open forum. The advocacy group could notify the congressional representative, media, and others when the footage was posted. These pieces of footage could be updated on an as -needed basis. Constituents' voices would give legitimacy to the advocate's position.
- **Develop web wizard presentation.** An advocacy group could develop a web wizard presentation (a PowerPoint-like slide presentation complete with voiceover) that included education about a particular issue, as well as testimonial from an individual advocate. This presentation could be passed around congressional offices and legislatures.
- **Develop a viral marketing strategy.** An advocacy organization could launch an electronic petition drive on a timely issue using a viral marketing campaign (send a petition to an active, online population and encourage them to sign the petition and forward it to trusted friends and colleagues). This probably is best suited for membership drives, fundraising or quickly assembling members.
- **Conduct online polling.** An advocacy organization could conduct a web-based poll about a particular policy issue or a candidate's position. Congressional representatives and their staff could be presented with an instant reaction from a valid representative

sample, from their own voting district or state. Current techniques for constituent polling provide no guarantee of representative sampling or preventing “spamming.”

Among some of the other ideas generated:

- **Follow an issue through the election.** An advocacy organization could watch a specific issue with respect to how it is shaped (by advocacy), and put its evolving life cycle pictorially on their website, identifying key points for intervention.
- **Demonstrate a voting calendar.** On an advocacy group web page, include a voting calendar, complete with legislation, dates of votes, and even "alarms" that indicate when it is appropriate to act and how. This might also include a list of the legislator's position on specific issues, including his or her voting record.
- **Develop a CD-ROM.** For mass marketing, a four-inch CD ROM could be developed that contains introductory remarks, video testimonials, links to advocacy membership offices, and links to other pertinent sites.

PHASE III: MODEL INTERVENTION FOR ENHANCING INTERNET ADVOCACY

One of the most promising ideas was that of a personalized, web-based video segment. This is conceptualized as a short video segment (of no more than one minute) that delivers messages from constituents directly to legislative offices via the Internet. It is self-running from start to finish and displays streaming video selectable at either low-band width (for 56k modems) or high band width (cable, DSL, or higher). The documentary-style video clips, as well as any audio clips, demonstrate the sincerity of the advocate. The segment is cost effective, which broadens its appeal.

A segment would begin with a video introduction by the president of an advocacy group making a personal appeal to a specific legislator about the importance to constituents of a given issue. The president would then turn viewers' attention to two or three personal, documentary-style stories from constituents living in the legislator's voting area. The stories would consist of either video clips or audio with graphic stills. The constituents would speak about personal experiences and needs, stating their opinions in a manner that was straightforward and from the heart. The speakers would be identified (either on-screen as part of the video or, more legibly, outside the video frame) as a way to emphasize their importance as voting constituents or persons of recognized importance in the community.

The presentation would conclude with closing remarks from the advocacy group's president and, as separate files for easy downloading, include:

- key bullet points relating to the issue and the advocacy organization's position and rationale;
- an edited summary of the video narrative and key points;
- a well researched White Paper with bibliographical references;

- statistics/tables, possibly including a recent local constituent poll completed by the organization;
- links and instructions encouraging the viewer to e-mail the presentation to other congressional colleague and their staff (e.g., other congressional members on a specific committee);
- links to other websites dedicated to the issue; and
- link to the advocacy organization's own home website.

The segment would be located on the advocacy group's website. Lobbyists or the advocacy organization's members would notify members of Congress and their staff that this segment had been developed with them specifically in mind, and provide them with the URL for viewing. The organization also would notify its members from the specific congressional district, so it could see how its issue was being interpreted and presented to congressional policy makers. A mock-up graphic of this model appears at the end of this report (in Attachment A). This model, with an audio track, has been developed into a test CD-ROM to provide a better understanding of this strategy. A full demonstration of the model is available at the SPRY Foundation's website, www.spry.org.

CONCLUSION

Current practice and understanding of Internet use for advocacy is thin: practice is limited largely to sending e-mails. Yet the Internet holds the potential to play a major and unique role in advocacy, were its uses expanded. The SPRY-developed, video-segment prototype is a model that tests the expanded role in advocacy that the Internet is poised to take. The SPRY Foundation hopes that advocacy organizations across the United States will use this model and share their experiences, and that the model will inspire ever-newer innovations.

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ATTACHMENT A.

PERSONALIZED WEB-BASED ADVOCACY MODEL MOCK-UP

In order to illustrate personalized web-based advocacy, the SPRY Foundation has created a small mock-up. For the purposes of this demonstration, names, organizations, and issues have been fictionalized. None of the references in this demonstration are real. Statements made in this demonstration do not in any way represent the position of the SPRY Foundation on this or similar issues.

To set the context for this mock-up, imagine that a major piece of federal legislation (H.R. 9999) has been passed by the U.S. House of Representatives. This legislation amends previous legislation that provides 35 billion dollars over the next 10 years to support long-term care for Americans. The bill is currently in the Senate (S. 9999). Key Senators admit that the legislation is not very controversial, and should pass quite easily; however, it is being put onto the back burner due to other “higher priorities.” Congressional recess is fast approaching, as well as mid-term elections. Without swift action, the long-term care legislation risks being put off until the next Congressional session. If current polls reflect actual election results, the next Senate may not be as friendly to the long-term care legislation.

The Members of the Long-Term Care Association of America (LTC-America) have decided to aggressively pursue key Senators and convince them that the passage of S. 9999 is essential for the well being of older adults and caregivers across the United States. As part of their advocacy effort, LTC-America has developed a three-minute personalized, web-based presentation (the model was developed by the SPRY Foundation) aimed at Senator Marcy Buchanan of Florida, who is the Committee Chair overseeing this legislation. LTC-America feels that this technology will be an important element in persuading Senator Buchanan and her Committee that this “slam sunk” legislation must be passed immediately. The following seven slides (also available on CD-ROM) illustrate this personalized web-based appeal.

Instructions for viewing the personalized, web-based advocacy mock-up

In order to view the personalized, web-based advocacy model mock-up, please follow these instructions:

1. Make sure that your computer speakers are turned on in order to hear the audio segments of this mock-up.
2. Insert the SPRY Internet Advocacy CD-ROM into your computer's CD-ROM player.
3. On your computer desktop, double click on the "My Computer" icon.
4. Find the drive on your computer with the CD icon and titled "SPRY." Double click on this drive.
5. If you do not have PowerPoint:
 - a. Double click on the folder titled "Install_PowerPoint_Viewer."
 - b. Double click on the file titled "PPView97," and follow the instructions for installing the PowerPoint viewer.
6. If you already have PowerPoint:
 - a. Double click on the folder titled "Internet_Advocacy_Presentation."
 - b. Double click on the file titled "Start."
7. Once the application has been launched, go to "Slide Show" and pull down to "View Show." Follow the instructions on the screen.
8. When the show is on the last slide, left click the mouse to go to the Exit screen. Click again to exit the presentation.

Personalized Web-based Advocacy Model Mock-up

This is a mock-up of the personalized web-based advocacy model. This mock-up includes seven slides and will last approximately 3-1/2 minutes.

To begin this self-running presentation, simply click your mouse now.



Let the people tell you... why the Long-Term Care bill must be passed now

A personal message to

**Senator Marcy Buchanan of Florida
Chair of the Senate Subcommittee on Health**

From

**Dr. Phil Jones, President
Long-Term Care Association of America**



[Click here for a 56k download of my 3 minute presentation](#)

[Click here for a high-bandwidth download of my 3 minute presentation](#)



Dr. Phil Jones
President of LTC-America



Senator Buchanan, you and I have known one another for a long time. We both know how important Long-Term Care is to all Americans. The pending long-term care legislation simply must pass now - for everyone's sake. But you shouldn't be hearing this from me; please listen to what some of our LTC-America members, and constituents of yours, have to say.

NOTE: *This introductory page would be a personal message from the organization president to the Congressional representative describing the issue, its general importance, and its significance to their constituency.*



Steven Park
Dade County, Florida



Senator Buchanan, I currently pay for home health care services for my mother, and I oversee the care she receives. The other day I read an article in the *Miami Herald*, which said that an important long-term care bill may not pass the Senate. If this happens, I may have to pay for my mother's skilled nursing care out-of-pocket. I don't know how I can afford this.

NOTE: At this point, the first of three documentary-style "stories" would be presented by constituents that had particular interest in the issue at hand. In this case, a son expresses his concern about the long-term care legislation.



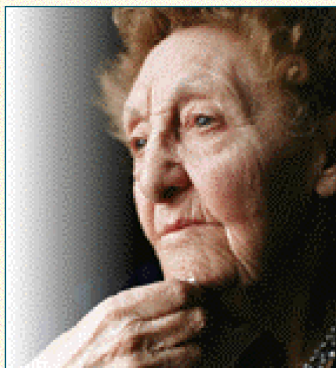
Dr. Jenny Chen
Geriatrician, Miller's
Crossing
Coral Gables, Florida



Senator Buchanan, at Miller's Crossing, a large number of our patients need day-to-day care, which require highly trained professionals and the most current equipment. We depend upon federal subsidies in order to provide high quality services to our residents.



NOTE: In this example, a video image of a geriatrician expresses her concern on the left, while still images of long-term care residents and staff rotate on the right.



Helen Bishop
*Resident of Misty Knoll
Orlando, Florida*

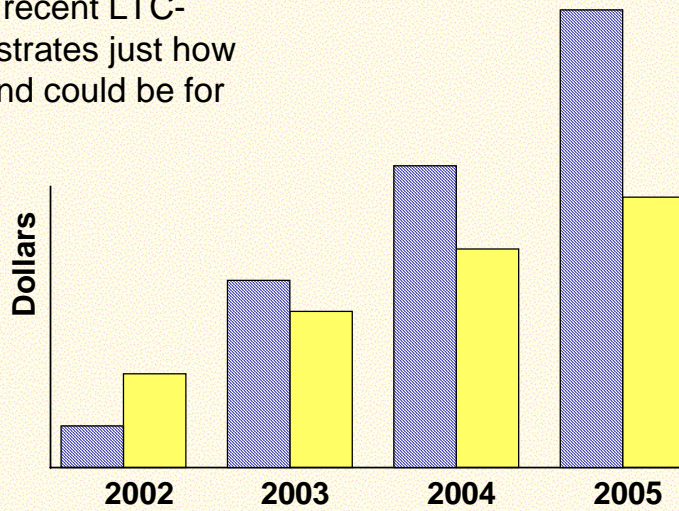
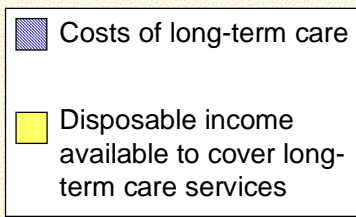


I don't have any children, and I am pretty much on my own now. I was a teacher and have worked all of my life, and I've paid my taxes and social security. Senator Buchanan, I have always voted for you because, as you've always said, you care for your constituents. I depend on the government to help me stay at Misty Knoll, and I like it here with my friends. I don't know where I would go if the government couldn't help me pay my bills.

NOTE: *In this example, a senior explains the importance of the long-term care subsidy to her.*

NOTE: At this point, the voice of the organization president would return and narrate the viewer through a rotation of important facts and statistics.

Senator, did you know that the costs of long-term care in Florida are projected to outpace a senior's ability to pay for these services by a rate of 40% a year? I was shocked, too. This graph, which is the result of a recent LTC-America Internet poll, also illustrates just how financially devastating this trend could be for future generations as well.



NOTE: In the final remarks, the organization president would extend his/her gratitude to the legislator and offer to provide additional information.



Dr. Phil Jones
President of LTC-America



Senator Buchanan, thanks again for your time.

I've attached some information for you and your staff. I think you will find this helpful.

And, please feel free to pass this message to your other colleagues. Click [here](#) .

Senator Buchanan, LTC-America and its millions of members are here to work with you and your colleagues in supporting the passage of S.9999 now.

Click on the icon below to download these PDF files:

*Bulleted
Summary*

*White
Paper*

*Research
Report and
Critical
Statistics/
Recent Poll*

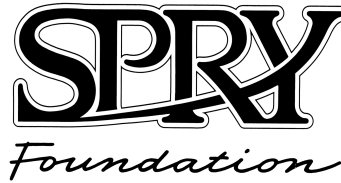


This personalized web-based advocacy mock-up was developed to accompany *Innovations in Health Advocacy*. For more information, please contact the SPRY Foundation at info@spry.org.

The SPRY Foundation

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ABOUT THE SPRY FOUNDATION

The SPRY (Setting Priorities for Retirement Years) Foundation (www.spry.org) is a 501(c)(3) nonprofit research and education organization that helps people prepare for successful aging. We believe *all* people have the basic right to achieve the highest quality of life as they age. As such, SPRY's work focuses on four core areas:

- Physical health and wellness;
- Mental health;
- Financial security; and
- Intellectual fulfillment.

SPRY works with government agencies, non-profit organizations, foundations, and corporations to develop collaborative programs that help people age successfully. SPRY uses its in-depth research in adult learning and communication as an underlying strategy to create:

- Community-based models;
- Hands-on training programs;
- User-friendly guides, CDs and web sites;
- National conferences and workshops; and
- Reports, journal articles and issue papers.

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