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More Can Be Done:

Involvement of Older Consumers in the Design, Implementation and Oversight of Home and Community Based Services

NATIONAL ASSOCIATION OF STATE UNITS ON AGING

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Prepared for the National Program Office for the Cash & Counseling Demonstrations at Boston College by the:

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The Cash & Counseling programs in the original three Demonstration states and the 12 expansion states place high value on the importance of including program participants and their families in the design, implementation and monitoring of their programs.

To strengthen this involvement the NPO has created a National Participant Network comprised of participants, family members and advocates from all the Cash & Counseling states. The NPO also includes three participant and family members as an integral part of its Core Staff team. In spite of their efforts to include seniors in these endeavors virtually all states report difficulty in attracting and retaining senior members. In an effort to help states overcome this difficulty the NPO commissioned this report to identify promising practices on participant and family involvement of seniors across the country. The NPO turned to NASUA because of its strong ties to the State Units on Aging and its strong historic commitment to consumer-direction in programs for seniors.

The NPO wishes to thank NASUA for undertaking this work and completing this report. Many people from the State Units on Aging across the country took the time to complete a survey, share their experiences on teleconferences and, in some cases, donate still more time in follow-up interviews. A number of these individuals have been quoted in the report; we are unable to give specific attribution to each individual cited because it was not always possible to identify the speakers during the teleconferences. We nonetheless are grateful for extensive contributions from the State Units on Aging.

The shared experiences of field staff who work in senior programs every day and Aging Directors across the country provide valuable information to everyone interested in improving participant and family involvement in consumer-directed programs.

The NPO also wishes to thank the NASUA staff members who worked on this project. Virginia Dize, Associate Director for Home and Community Based Services, wrote the report. The contributions of time and insights of Sara Aravanis, Associate Director for Elder Rights, and James Whaley, Director of the Center for the Advancement of State Community Services Programs, have proven invaluable.

The full report will be posted to *www.nasua.org*; *www.cashandcounseling.org* and *www.HCBS.org*.

More Can Be Done:

Involvement of Older Consumers in the Design, Implementation and Oversight of Home and Community Based Services

"Too often when we are in community meetings, sitting around discussing what we are going to do for seniors, there are no seniors or persons with disabilities present. We need to include them. They are the ones who can tell us what they need."

Throughout the history of the aging network, older people have been at the forefront of numerous public policy debates at the local, state and national levels. Older people led the fight for Social Security in the 1920s and 1930s, advocated for Medicare, Medicaid and the Older Americans Act in the 1960s, and pushed for Nursing Home Reform in the 1980s. Whether working through groups such as AARP, Silver Haired Legislatures, or serving on Governor-appointed statewide advisory committees on aging, older people continue to be vigorous advocates, involved in numerous public policy activities. However, older adults who use home and community-based supports are largely an untapped resource for advocacy which ultimately could prove beneficial to the HCBS network.

The states offering Cash and Counseling[1] are expected to involve program participants and their families in the design, implementation and oversight of the program. Influenced by the Independent Living movement, younger people with disabilities are often outspoken advocates and enthusiastic about getting involved in public policy. The Cash and Counseling states, like the Real Choice Systems Change grantees funded by the Centers for Medicare and Medicaid Services (CMS), have not had any difficulty recruiting younger adults with disabilities to serve as policy advisers. However, efforts to engage older users of home and community-based services in these initiatives have not been nearly as successful.

Seemingly, the once powerful aging advocacy system does not appear to be as engaged as today's disability advocacy system. Disability advocates have successfully waged grassroot campaigns that get recipients of in-home services to the table for substantive work and contribution. This is surprising given older persons' strong preference for home and community services, as well as the expectation clearly stated in the Older Americans Act that "freedom, independence, and the free exercise of individual initiative" by older people includes not only "planning and managing their own lives" but also "participation in the planning and operation of community-based services and programs provided for their benefit…."[2]

Given the longstanding history of leadership by older people in public policy activities in the states, the difficulty in getting *older HCBS waiver partici-*

[1] *States offering Cash and Counseling include Alabama, Arkansas, Florida, Iowa, Illinois, Kentucky, Michigan, Minnesota, New Jersey, New Mexico, Pennsylvania, Rhode Island, Washington and West Virginia. Cash and Counseling programs are consumer-directed, give users the opportunity to control the budget and develop an individual spending plan, offer home and community supports to older persons with significant need for assistance with the activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and are supported by Medicaid waivers, State Plan Options and AoA grants.*

[2] *Older Americans Act of 1965 (Public Law 89-73) As Amended, Title I, Section 101 (10).*

pants to the table on these issues deserves exploration. Even within the aging network, misperceptions exist about the willingness or ability of older persons with long-term care needs to speak for themselves. While there is support for the value of involving older people in public policy, many in the network recognize the need for a more focused and deliberate effort. The SUA directors and staff who took part in teleconference discussions convened by the National Association of State Units on Aging expressed high interest in borrowing ideas from the disability community and learning about what has worked in other states to engage HCBS participants in public policy activities.

This paper explores the role of older participants in planning, developing and overseeing home and community based service (HCBS) programs. It seeks to help SUAs and others in the aging network identify concrete steps they can take to support the role of these older individuals as public policy advocates. The following questions are addressed:

- To what extent are older HCBS participants involved in such activities now?
- What are the barriers to success in this arena?
- What strategies are being used to attract, retain and support older persons as participants in HCBS policy-setting activities?

Methodology

This report is based on information gathered directly from the 56 State and Territorial Units on Aging (SUAs). Several methods were used to gather information: a web-based national survey; two teleconferences; and 8 interviews with SUA staff to follow-up on information provided during the teleconferences and obtain additional information on these states' initiatives.

Thirty-seven (37) states plus the District of Columbia and the Virgin Islands responded to the survey.[3] Thirty-four (34) individuals from 21 states participated in the two teleconferences and 8 follow-up interviews were completed to obtain additional information on specific state innovations.

[3] *A summary of the survey results is included in Appendix A.*

Older Participants' Current Involvement in Public Policy Activities

According to the survey, older people serve on SUA and AAA advisory committees, provide testimony at public meetings and hearings and participate in consumer surveys and focus groups in 97% of the responding states. In addition, 85% of respondents reported that older people also are Older people's involvement in public policy activities is generally viewed as effective. When asked whether or not older persons are a recognized voice on aging and long-term care issues, just over half (56%) of survey respondents agreed that they are, while 64% noted that positive policy and program decisions have resulted from older persons' advocacy and involvement in policy making.[4] Teleconference participants offered several examples as evidence of positive outcomes that have resulted from older persons' public policy advocacy, including the avoidance of budget cuts for home and community based services and passage of guardianship reform legislation in Washington State, and increases in the personal needs allowance in Ohio.

Service users are invited to participate in program design and development in fewer than half (43%) of the states responding to the survey. State Aging Directors and staff who participated in the teleconferences expressed dissatisfaction with the level of involvement and the extent to which actual users of services are involved in such activities. They expressed concerns about the perception of "tokenism" versus real power and authority of older persons who sit on advisory boards and what impact it has on their ability to significant contributions. Eighty-seven per cent (87%) of survey respondents indicated that efforts are underway in their states to engage, strengthen and support elders' advocacy in the long-term care arena. These activities include education and training of advocates (76% of respondents) and providing consultation to advocacy groups and individual advocates (56%) to support their development and advocacy work. Area agencies on aging are also involved in these efforts, according to 79% of respondents.

[4] *The percentages reported are based on the number of respondents who rated the statement 4 or 5 on a scale of 1-5, where 5 indicates strong agreement.*

Barriers and Challenges

"The challenges of getting older people to the table are always cost-related."

According to survey respondents, the principal barriers to increasing older HCBS participants' involvement in public policy and advocacy are lack of funding and resources to support such activities (according to 74% of respondents); the increasing complexity of the issues (66%); and the fact that older people with long-term care needs find traveling to meetings difficult (61% of respondents). Teleconference participants added to the list of barriers: lack of transportation, older persons' mobility limitations, and frequency of meetings.

The challenges of getting *older users of home and community-based services* involved in program and policy decision-making are daunting. Most SUAs reported that there are no funds designated to pay for transportation and stipends to support getting older HCBS participants to group meetings. Teleconference participants agreed that getting older participants to the table has received minimal attention or is considered too difficult to attempt by many in the aging network. The reasons given include that these individuals are too frail or unable to leave their homes to participate in groups, or the effort to involve them may not be worthwhile since they are not really interested in the issues and/or the issues are too complicated for them to grasp.

Older participants, unlike their younger counterparts with disabilities, are not likely to identify themselves as advocates. While there have been some noteworthy special efforts to reach out to this group, a one-time initiative is not sufficient to get older HCBS participants to the table and keep them involved in public policy. Even a mandate to require older participants' membership on state and local level advisory committees may be seen as mere "window-dressing" and does not alone assure that they will be able to impact the outcome of public policy deliberations.

In summary, the major types of barriers that impede older persons' involvement in public policy advocacy are:

1. Funding to support bringing older people to the table, including paying transportation and providing staff support;
2. A seeming lack of interest on the part of policy makers and older people themselves in being involved in HCBS public policy; and
3. A high level of difficulty in getting older people involved.

Promising Strategies for Getting Older HCBS Participants Involved

"The quality of the program benefits if people it is supposed to serve play a leadership role in the development of the program."

(1) Go to the Individual.

Outreach strategies are intended to obtain the views and participation of individuals whose physical condition and reluctance to travel from home make it difficult to get them involved in public policy activities. Such older people may be uneducated, isolated, uncomfortable in social settings or feel they have nothing to contribute. Nevertheless, their first-hand experiences can provide valuable and much-needed insights from the perspective of an individual recipient of services and supplement group recommendations on program design, policy development and oversight. Local agencies, including AAAs, may be able to identify individuals to participate.

Additional ideas generated by teleconference participants are not all tried and true methods, but offer some interesting possibilities for increasing older HCBS participants' opportunities to participate in public policy. Strategies include:

- Outreach/monitoring visits to individuals' homes;
- Targeted surveys;
- Focus groups; and
- Town hall meetings.

Quality assurance and improvement activities, such as **outreach and monitoring visits to the homes of participants** in specific programs, typically collect information directly from program participants. The feedback from older individuals using home and community-based supports based on their personal experiences can also be used to pre-test forms and procedures, as well as to identify needed improvements and recommended changes in HCBS programs and policies. While no substitute for participation in stakeholder groups and other public policy processes, quality assurance information collected from actual users of home and community services provides input from a broader and more diverse group of individuals whose unique perspectives add valuable information to the overall picture of the home and community based service system. Involving citizens whose voices have never been heard before or offering former activists a chance to stay involved expands and enriches the public policy dialogue and will result in HCBS systems that are more responsive to individual needs.

Reaching out to older people also means interacting with family caregivers. Family caregivers can play a strong advocacy role on behalf of, or in conjunction with, older people. In certain situations where an older user of home and community-based services is unable to speak for her/himself, the caregiver's perspective can add important information to the overall picture of HCBS.

The **Oklahoma** SUA sends case managers from the state office to visit HCBS program participants for the purpose of finding out whether or not the services they receive are meeting their needs, the degree to which they are satisfied with the services, and their recommendations for service improvement.

In **Idaho**, case managers will soon be equipped with laptops for home visits, another approach for getting older participants' feedback on their services.

Written and telephone surveys conducted annually or less frequently by states or area agencies on aging is another approach for getting input from program users, and may also be used to reach out to persons who are not current participants but who may have unmet needs for services.

In **Washington** State, the Aging and Disability Services Administration and the Home Care Quality Authority recognize the value of getting information directly from service recipients. These agencies conduct targeted surveys via telephone and home visits two times each year to find out:

- Whether the services are meeting participants' needs; and
- If services have resulted in improved participant outcomes.

Focus groups, which typically are small and conducted by a neutral facilitator, are a useful approach for getting participant input on a specific set of issues. Focus groups may be held in several different locations and offer the added benefit of new ideas emerging from conversation among participants. The Ohio SUA, for example, held a series of focus groups around the state to seek input on the renewal of the state's aging and disability Medicaid waiver program.

Town hall meetings have been convened by a number of states to garner participants' input and/or inform participants and the general public about the state plan, proposed regulations or other public policy developments. Town hall meetings may be convened by the SUA, another state agency, the governor's office, legislature or by area agencies on aging.

In **Arizona**, town hall meetings were held in locations around the state by the Governor's Council on Aging. Transportation was provided by area agencies on aging or senior centers and considerable work was done to get the word out. Accessible, centrally located meeting sites were selected to maximize the number of participants. Council members, the majority of whom are 60 and older, passed out flyers, talked with the media and promoted the meetings through word of mouth. The presence of legislators at each meeting also increased interest and attendance.

(2) Make it easy to participate.

Participants in the teleconferences agreed that getting older individuals to the table is "good aging policy" not only because it is important to hear their voices, but because such activities counter isolation and help to keep older people with long-term care needs connected to their communities. The approaches identified to address the barriers to HCBS users' participation in advisory and stakeholder groups include:

- Provide transportation;
- Pay stipends;
- Ensure meeting accessibility; and
- Use technology.

Teleconference participants pointed out that younger people with disabilities who participate in stakeholder groups in their states sometimes bring personal attendants with them and are provided with transportation to get to the meeting. Although it was agreed that older people who participate in such groups should not be expected to pay their own transportation costs, providing transportation to support meeting attendance is not currently standard practice in much of the aging network. If older people are to participate in stakeholder groups to the same extent that younger persons with disabilities now do, providing transportation is key. Currently, only limited resources are available to pay transportation costs, with older people frequently having to pay out-of-pocket or rely on volunteers to transport them. Approaches for addressing this issue include:

- *Mileage reimbursement and gas cards.* The Arizona and Ohio Long-Term Care Ombudsman Programs (LTCOPs) reimburse ombudsman volunteers for mileage, both to make facility visits and to attend training offered by the program. The Ohio LTCOP has also provided pre-paid gas cards to volunteers.
- *Offering rides in vans, buses or private cars.* This approach requires local coordination with Area Agencies on Aging and/or transportation providers, to identify potential participants who need rides and resources for providing rides, including volunteer drivers.
- *Public transportation and specialized transportation programs* targeted to elders and persons with disabilities could possibly be used to transport older consumers to meetings. However, these programs typically have restrictions regarding how transportation services may be used, such as limiting rides to medical appointments. Since in some cases, similar transportation programs have been used to transport younger adults with disabilities to meetings, SUAs and AAAs are advised to examine the policies and practices of transportation programs that serve older people to identify opportunities to use these programs to support older consumers' involvement in public policy activities.

Ideas for addressing transportation include: using Medicaid administrative funds to pay for transportation to group meetings; utilizing the Senior Companion Program under the Older Americans Act to assist with transporting participants to public meetings; convening meetings near public transportation; and holding meetings at sites, such as senior centers, where transportation services are available.

In **Rhode Island**, the ADA (Americans with Disabilities Act) Transportation Network is available to persons who meet threshold disability criteria. The cost is $3 per round trip, but rides are only available to go to medical appointments or nutrition sites.

Stipends may be provided to pay for transportation, personal care attendants, meals, overnight stays or other supports needed to help older HCBS participants attend meetings. This is a common practice in the disability arena, in recognition of the value of getting service users to the table. Within the aging network, only a handful of states reported that they routinely provide transportation and other supports to individuals who participate in advisory groups.

To support older consumers' involvement in public policy activities in the States of Oregon and Washington, the following supports are routinely provided:

Washington

- Transportation
- Per diem to pay personal attendant or other costs

Oregon

- Transportation
- Attendant svcs.
- Lodging

Meeting accessibility, including choosing sites that are convenient as well as physically accessible, is also an important consideration. Convening town hall meetings in several locations instead of one central location or holding meetings of groups that meet monthly at different locations each month are options for making sure that meetings are accessible to a broad audience.

Accessibility goes beyond physical location and includes practices that are common in the disability field. The availability of accommodations to meet the needs of persons with different disabilities sends a message to all participants that they are welcome, and that meeting planners considered their needs in planning the meeting and want them to participate fully in discussions. For example, to accommodate persons who are deaf or hard of hearing, it is advisable to provide interpreter services, readers, hearing devices and/or closed captioning.

Technology may enable older HCBS participants who are unable to leave their homes or travel long distances to participate in meetings and become members of advisory or other groups. While not a substitute for being able to engage in face-to-face discussions, technological adaptations may help keep some individuals engaged in the public policy process and bring to the table other individuals who are typically excluded. Simply thinking through these issues as part of meeting planning may result in the identification of affordable, easy-to-use technological accommodations. For example, using a speaker phone and call-in number will allow interested homebound older consumers unable to attend meetings in-person to participate in discussions.

Teleconferencing can be used instead of, or in addition to, face-to-face meetings of different groups. Using satellite videoconference sites, available at many state universities, to bring together a large group of diverse participants from throughout the state may be a viable substitute for holding a series of meetings at different sites. The use of such technology can further extend the reach of an advisory group to stakeholders throughout the state and serve as a vehicle for engaging more and more diverse consumers in public policy activities. In its efforts to involve older people in the public policy process, the state of Delaware is starting to allow seniors who are unable to attend meetings in-person to call in to the meeting, and sees more opportunities to use teleconferencing and videoconferencing. Wisconsin has also used speaker-phones at meetings and teleconferences.

The Idaho State Aging Director, an attorney, discussed video-taped depositions used by the court system to obtain testimony from persons unable to attend court, as an approach that might be used to hear about the real-life experiences of homebound seniors. Although videotaping equipment may not be readily available, low-tech options, such as cameraphones or small hand-held camcorders, could be used. No examples emerged of states that have tried this approach, but teleconference participants credited the call for raising their awareness of possible methods to encourage HCBS participants to become involved in public policy.

(3) Support older individuals' meaningful participation.

> "If you are serious about getting older people involved in these processes and ensure that they feel effective as advocates, you can't do it as a one-shot deal. It's a continuing and ongoing effort."

Within the aging network, nursing home resident councils provide a positive example of the impact even very frail elders engaged in advocacy can have. Resident councils typically respond to individual resident concerns and serve as advisers to the nursing home administration on resident issues. While it is true that all resident councils are not equally effective, these bodies, nevertheless, illustrate the commitment and effectiveness of frail elders as advocates. The experience of resident councils surely bolsters the argument that older HCBS participants can be effective policy advocates and may offer a model adaptable to HCBS.

The interest of older people transitioned from nursing facilities in North Carolina illustrates that older HCBS participants may be more interested in becoming involved in public policy activities than is generally assumed. The Centers for Independent Living were a rallying point for this project in the areas of the state where it operated, providing education to former nursing home residents about their rights as users of home care services. Many of the older and younger adults with disabilities were empowered to speak for themselves through the transition process and became active participants in the work group that guided the transition project. Some also became mentors to other nursing home residents

who were being transitioned back to the community. In addition, a number of these individuals became "invested" in doing advocacy work and have continued their active participation in public policy activities.

> "Seniors may be sitting at the table but they don't feel like they have a voice, or that what's being said even matters."

Teleconference participants focused a lot of attention on the challenge of making sure that older participants' involvement in public policy goes beyond lip service. It is recognized that these older individuals may need support to speak up, training on advocacy techniques and education about the issues. Identified strategies include:

- Support older people's involvement in public policy from the top;
- Mandate older participants' involvement in HCBS public policy; and
- Provide education and ongoing support to older HCBS participants who are involved in public policy activities.

Commitment from federal, state and local leaders may help to get older participants to the table and keep them there. CMS' insistence that system users themselves play a leadership role in oversight of Real Choice Systems Change grants has made it difficult, if not impossible, for policy makers to justify developing long-term care reform plans without seeking input from those who will be affected by the reform. The governor and legislators have stepped forward on this issue in a number of states by reaching out to individuals to seek their input and recommendations on public policies and appointing older individuals to advisory boards and task forces.

- In Arizona, the Governor's Council on Aging held town hall meetings with legislators throughout the state, as well as more intimate "coffee talks" with representatives of the governor's office. More than half of the members of the Council are required to be 60 or older.
- In Oregon, a state with a long history of citizen involvement in the policy-making process, the governor and the legislature have longstanding commitments to involving older citizens and advocates in public policy, and are responsive, through legislation and public policy directives, to their recommendations and suggestions. However, the state is not content to rest on its laurels, but sees opportunities for more direct involvement in public policy activities by actual users of HCBS. Much of this effort is directed to the local level and includes involving area agencies in aging in identifying older HCBS recipients to participate in public forums recently held by the Senior Commission around the state, as well as asking HCBS users to provide feedback on the services they receive.

Mandating participant involvement in committees and public policy deliberations is one way to assure that the older individual's voice is heard. However, a prescriptive requirement will not, by itself, enable older HCBS participants to impact the public policy process in meaningful ways. The involvement of local leaders, whether advocacy groups, area agencies on aging or independent living centers, is also a crucial element for identifying, and getting to the table, the actual users of services.

Education and ongoing support. If older individuals are to be more involved in public policy activities, attention needs to be paid to providing the kind of support they need to participate as equal partners in the policy making process. The Ohio ombudsman program, for instance, publishes a newsletter to keep the program's volunteers, many of whom are elders, current on public policy issues.

> "Be patient, educate people…provide orientations, provide job descriptions… so consumers know what their role is and how important it is. Put time in on the front end."

In Oregon, the SUA is committed to empowering older individuals to express their opinions. They try to tap into people's passions and personal interests. Education for participant advisers is focused on helping participants articulate the impact of program policies on their individual situations. It is important not to talk down to participants and avoid using "officious" language and jargon. As the users of the program services, these are the real experts.

The State of Wisconsin has made a focused commitment to build support for the role of older participant-advocates at all levels of the aging network by better preparing individuals to be effective policy

advisers. The initiative, which aims to get more older individuals involved in public policy, employs a number of methods that could work in other states. At the conclusion of advisory council meetings, a "common message," reflecting the group's discussion of the issues, is developed. Council members are assigned "homework" between meetings to go back home and share the message with other individuals to get their reactions and recommendations. Individual council members then bring the feedback they got to the next meeting for consideration by the group. This approach not only gives more individuals a voice in the council's deliberations, it also builds a broader constituency for the work of the council.

Importantly, the state is also paying attention to the need to train professionals in the aging network on approaches and techniques for involving program participants in public policy. The training is also a way to build support among aging professionals and getting them involved in identifying older HCBS users who have something to contribute in this area. This effort underscores the importance of not overlooking the crucial role of staff in building a strong older voice in HCBS public policy and ensuring that staff have the tools and knowledge to be effective in this role.

Next Steps

"It is naïve to assume that older advocates are going to have the power, influence and knowledge of the billion dollar industries invested in long-term care. What we're trying to do is make the table as level as possible."

Getting older users of home and community-based services involved in public policy presents an exciting, albeit challenging, opportunity for the aging network. The SUA directors and staff who responded to the survey and joined the teleconference discussions were clear that they see this as a difficult task, but were also eager to learn more and find out what other states are doing. As one State Aging Director put it, "there is more that can be done."

However, it will take more than willingness on the part of the aging network to assure that older program participants have the opportunity to impact HCBS public policy. The costs involved in many of the approaches discussed in the paper cannot be ignored. The cost of getting older HCBS participants to meetings will vary somewhat, depending on the care needs of the individuals involved.

The use of available resources, such as transportation programs for the elderly, to support older HCBS participants attendance at advisory meetings and other public policy events should be explored. One example of creative use of resources is the Ohio Ombudsman Program's use of civil money penalty (CMP) funds, collected by each state from nursing facilities that commit regulatory infractions, to support the development of resident councils. Other "outside the box" funding ideas should be explored, and adopting ideas from the disability community also holds promise.

However, it is important that the lack of designated funding to support the activities discussed in this paper not be seen as an insurmountable stumbling block. Some of the ideas discussed here can be attempted without first securing funding. One might even argue that getting older users to the table is the first step necessary for securing funding to support more extensive participation.

The active involvement of many nursing home residents in advocating for their rights and the rights of their fellow residents around the country should serve as a reminder that the frail, often isolated older people who receive home and community-based services in the U.S have something to say too. They just need someone to help them raise their voices.

One teleconference participant noted the value of the conversation on this topic in raising her awareness and determination to be more pro-active in reaching out to older program participants. This issue needs more focused attention and effort should be made to keep it on the radar screen of the aging network.

APPENDIX A:
Results of the Survey of State Units on Aging

The electronic survey was conducted in August-September 2007. Responses were received from 37 states, the District of Columbia and the Virgin Islands. The 37 states that responded include: Alabama, Arizona Arkansas, California, Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Maine, Michigan, Minnesota, Mississippi, Missouri, Montana, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Rhode Island, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin. and Wyoming. The results of the survey are provided below.

Percent of states in which older people are involved in specific consumer advocacy/policy making activities related to long-term care at the state or local levels:

97%	Organize or participate in political actions (e.g., "Senior Day at the Legislature", marches, letter writing campaigns, boycotts, protests, etc.) around specific issues related to aging and/or long-term care
97%	Serve on SUA or AAA advisory committees
97%	Provide consumer feedback on quality of services via consumer surveys and/or focus groups
97%	Participate/provide testimony at public meetings/hearings
92%	Individual advocacy with legislators
85%	Involved in developing policies for aging /long-term care programs
85%	Provide testimony before the legislature/other governing body
85%	Lead and/or participate in consumer advocacy organizations
79%	Serve on ad hoc groups that provide advice/guidance on specific issues (e.g., regulation development; oversight/development of a specific program)
72%	Serve on Olmstead or Real Choice Systems Change advisory group
62%	Participate in Medicare partnership/advisory group
54%	Participate in political parties as an advocate for aging/long-term care reform
46%	Participate in Silver Haired Legislature
26%	Serve on minority task forces
1%	Other

Percent of states where the following Citizen Advocacy Groups advocate on long-term care:

97%	AARP
90%	Developmental disabilities council
87%	Citizens with disabilities group
85%	Mental health consumer group
82%	Nursing home advocacy group
67%	League of Women Voters
64%	Older citizens advocacy group
54%	Elder rights coalition
54%	Hispanic advocacy group
46%	NAACP
44%	Native American advocacy group
41%	Silver Haired Legislature
38%	ADAPT
33%	Older Women's League
28%	Urban League
26%	Common Cause
23%	Asian advocacy group
18%	Gray Panthers

The percentages below represent extent to which older people are involved in the states where the groups are active:

100%	Silver Haired Legislature
100%	Gray Panthers
95%	Elder rights coalition
92%	Older citizens advocacy group
92%	Older Women's League
87%	AARP
73%	League of Women Voters
67%	Asian advocacy group
58%	Mental health consumer group
55%	Urban League
54%	Nursing home advocacy group
53%	Citizens with disabilities group
44%	NAACP
43%	Hispanic advocacy group
41%	Native American advocacy group
40%	Developmental disability council
40%	Common Cause
33%	ADAPT

The numbers of older people who participate in the activities/groups identified above indicate that older people in the state are sufficiently involved in advocacy/policy making on aging and/or long-term care issues.

DISAGREE					AGREE
	1	2	3	4	5
	3%	*21%*	*41%*	*26%*	*10%*

Older people are a recognized voice within the state on the aging and/or long-term care issues that impact older people's lives.

DISAGREE					AGREE
	1	2	3	4	5
	3%	*15%*	*26%*	*28%*	*28%*

Positive policy and program decisions that affect all older people and/or people with long-term care needs have resulted from the involvement of older people in advocacy/policy making on aging and/or long-term care issues in the state.

DISAGREE					AGREE
	1	2	3	4	5
	0%	*18%*	*18%*	*36%*	*28%*

Persons who are expected to use the services/programs are invited to the table from the beginning as programs are being designed/developed for older people.

DISAGREE					AGREE
	1	2	3	4	5
	5%	*13%*	*38%*	*33%*	*10%*

**Percentages have been rounded.*

87% of states reported new and/or ongoing efforts to engage, strengthen and/or support the involvement of older people in long-term care advocacy or policy making. These efforts include:

74% (25 states):	special initiatives
76% (26 states):	education/training
35% (12 states):	web-based updates/communications on public policy
44% (15 states):	technical assistance
56% (17 states):	consultation
26% (9 states):	mentoring/peer mentoring
41% (14) states:	funding to support advocacy/public policy activities
44% (15 states):	annual conference on advocacy
29% (10 states):	other annual event
50% (17 states):	developing a coordinated advocacy approach
50% (17 states):	developing an advocacy agenda
24% (8 states):	other

* *The state agency on aging is involved in these efforts in 34 states (87% of respondents to this question).*

** *Area agencies on aging are involved in these efforts in 31 states (79% of respondents to this question).*

Barriers SUAs have encountered in efforts to support older people's involvement in public policy and advocacy:

53%	The traditional aging advocacy network has not been successful in attracting the younger generation of older people (the "young old")
47%	The traditional aging advocacy network has not attracted new potential advocates from different cultural and ethnic groups
3%	Older people are no longer willing to volunteer their time to public policy activities
61%	Older people with long-term care needs are not able to travel or participate in meetings
20%	Decline in strong leadership among older people
66%	Increasing complexity of the policies and programs that impact older people
24%	Older people are put off by the aggressive tactics of some advocacy groups
37%	Older people are often overlooked when programs or agencies reach out to consumer groups on long-term care issues
47%	Lack of effective outreach to engage/recruit older people in advocacy activities
58%	Insufficient staff to support advocacy efforts
74%	Lack of funding/resources to support advocacy
37%	Difficulty getting everyone on the same page
45%	Keeping advocates informed and up-to-date
42%	Teaching people to advocate
29%	Other: aging advocacy is not centralized; federal focus on disability in CMS initiatives; large gap between seniors and boomers; paying for travel/attendant care for needy advocates; high cost of gas; older people don't want to advocate for themselves; intimidation by provider trade groups

Tools/supports needed to enhance existing/new efforts to engage, strengthen and/or support advocates:

87% (34 states):	Funding
82% (32 states):	Training
72% (28 states):	Tool kit
74% (29 states):	Models/best practices
72% (28 states):	Modernized conceptual framework for advocacy
5% (2 states):	Other: federal attention to desire for reforms by states; on-site technical assistance

APPENDIX B:

Teleconference Participants

Two teleconferences were held with State Unit on Aging representatives on September 20 and September 25, 2007. The following states and individuals participated in one or both calls.

ARIZONA

Arizona Aging & Adult Administration
Greta Mang, Legal Services Assistance

DELAWARE

Delaware Division of Services for Aging & Adults W/ Physical Disabilities
Andrea Wasney, Adminstrator of Journeys
Guy Perrotti, Deputy Director DHSS-Child Support Enforcement
Victor Reggia, Passport

HAWAII

Hawaii Executive Office on Aging
Nancy Moser, Grants Manager

IDAHO

Idaho Commission on Aging
Melinda Adams, State Older Worker Coordinator
Pam Catt-Oliason, Program Planning and De elopement Specialist
Kim Toryanski, Administrator

ILLINOIS

Illinois Department on Aging
Shelly Ebbert, Manager, Division of Planning, Research & Development

INDIANA

Indiana Division of Aging
Celeste Stinson, Home and Community Service Based Specialist

MAINE

Maine Office of Elder Services
Derrick Grant, Analyst, Policy, Planning and Resource Development

MISSISSIPPI

Mississippi Council on Aging
Tish Kelley, ADRC Coordinator
Shirley Rainey, HCBS Coordinator
Melinda Smalley, Title V SCSEP Program Manager

MISSOURI

Missouri Division of Senior & Disability Services
Kevin Fosse, Special Projects

NEVADA

Nevada Division for Aging Services
Linda Slattery, Elder Rights Advocate
Russ Schoenbeck, Elder Rights Advocate

NEW YORK

New York State Office for the Aging
Sandy Longworth, Director of Federal Relations

NORTH CAROLINA

North Carolina Division of Aging and Adult Services
Heather Burkhardt, Information and Assistance Program Specialist

OHIO

Ohio Department of Aging
Beverley Laubert, State Ombudsman
Barbara Riley, Director

OKLAHOMA

Oklahoma Aging Services Division
Beth Batman, Policy and Strategic Planning
Diana Garland, Respite Program
Lance Robertson, Director

OREGON

Oregon Seniors & People w/ Disabilities
Debbie Bowers, Intergovernmental Affairs Liaison
Marc Overbeck, Advocacy Coordinator for the Governor's Commission on Senior Services

RHODE ISLAND

Rhode Island Department of Elderly Affairs
Corinne Russo, Director

WASHINGTON

Washington Aging & Disability Services
Bill Moss, Director

WISCONSIN

Wisconsin Bureau of Aging & Disability Resources
Jim Schmidlkofer, Aging Services, Older Americans Act
Chris Felton, President, Hospital Bed and Patient Tracking Systems
EMSystem

WYOMING

Wyoming Aging Division
Tina Carroll, Deputy Administrator
Joan Franklin, Nutrition Programs

CONSUMER PARTICIPANTS

Glenna Taylor, Kentucky
Christine Battista, Rhode Island

APPENDIX C:
State Interviews

Interviews were held with State Unit on Aging staff to follow-up on issues raised during the teleconferences. Interviews were conducted between October 30 and November 8, 2007. Each interview lasted about one hour.

ARIZONA AGING & ADULT ADMINISTRATION
Greta Mang, Legal Services Assistance
Lynn Larson, Home and Community Based Services

IDAHO COMMISSION ON AGING
Kim Toryanski, Administrator

NORTH CAROLINA DEPARTMENT OF MEDICAL ASISTANCE SERVICES
Michael Howard, Transitions Services Manager

OHIO DEPARTMENT OF AGING
Beverley Laubert, State Ombudsman

OREGON SENIORS & PEOPLE WITH DISABILITIES
Marc Overbeck, Advocacy Coordinator for the Governor's Commission on Senior Services

RHODE ISLAND DEPARTMENT OF ELDERLY AFFAIRS
Corinne Russo, Director

WASHINGTON AGING & DISABILITY SERVICES
Bill Moss, Director

WISCONSIN BUREAU OF AGING & DISABILITY RESOURCES
Jim Schmidlkofer, Aging Services, Older Americans Act

APPENDIX D:
Survey Questionnaire & Teleconference Discussion Guide

ELECTRONIC SURVEY QUESTIONNAIRE

1. How are older people involved in consumer advocacy and policy making related to long-term care at the state or local levels in your state? (Check all that apply)

- ☐ Serve on SUA or AAA advisory committees
- ☐ Participate in Silver Haired Legislature
- ☐ Serve on Olmstead or Real Choice Systems Change advisory group
- ☐ Lead and/or participate in consumer advocacy organizations
- ☐ Serve on ad hoc groups that provide advice/guidance on specific issues (e.g., regulation development; oversight/development of specific program)
- ☐ Involved in developing policies for aging/long-term care programs
- ☐ Provide testimony before the legislature/other governing body
- ☐ Organize or participate in political actions (e.g., "Senior Day at the Legislature," marches, letter writing campaigns, boycotts, protests, etc.) around specific issues related to aging and/or long-term care
- ☐ Participate in Medicare partnership/advisory group
- ☐ Provide consumer feedback n quality of services via consumer surveys and/or focus groups
- ☐ Participate/provide testimony at public meetings/hearings
- ☐ Participate in political parties as an advocate for aging/long-term care reform
- ☐ Serve on minority task forces
- ☐ Individual advocacy with legislators
- ☐ Other, please specify: ______________________________

2. Please identify the citizen advocacy groups that advocate on long-term care in your state and specify whether older people are actively involved in each group.

- ☐ AARP
- ☐ Silver Haired Legislature
- ☐ Nursing home advocacy group
- ☐ ADAPT
- ☐ Mental health consumer group
- ☐ Developmental Disabilities Council
- ☐ Older citizens advocacy group
- ☐ Common Cause

- ☐ Citizens with disabilities group
- ☐ Urban League
- ☐ Elder rights coalition
- ☐ Older Women's League
- ☐ Gray Panthers
- ☐ NAACP
- ☐ Hispanic advocacy group
- ☐ Native American advocacy group
- ☐ Asian advocacy group
- ☐ League of Women Voters

3. From the SUA's perspective, how satisfied are you with the level of older persons' involvement in advocacy and policy making on long-term care issues in your state? (Please respond to each statement on a scale of 1-5, where 5 indicates total agreement and 1 means total disagreement.

The numbers of older people who participate in the activities/groups identified above indicate that older people in the state are sufficiently involved in advocacy/policy making on aging and/or long-term care issues.

DISAGREE				AGREE
1	2	3	4	5

Older people are a recognized voice in the state on the long-term care issues that impact older people's lives.

DISAGREE				AGREE
1	2	3	4	5

Positive policy and program decisions that affect all older people and/or people with long-term care needs have resulted from the involvement of older persons in advocacy and policy making.

DISAGREE				AGREE
1	2	3	4	5

Persons who are expected to use the services/programs are invited to the table from the beginning as programs are being designed/developed for other people.

DISAGREE				AGREE
1	2	3	4	5

4.A. Are there ay new efforts in your state designed to engage, strengthen and/or support the involvement of older people in long-term care advocacy and policy making?

____

____

4.B. Efforts to engage, strengthen and/or support the involvement of older people in long-term care advocacy and policy making include: (Check all that apply.)

- ☐ Special initiatives
- ☐ Education/training
- ☐ Web based updates/communications on public policy issues
- ☐ Technical assistance
- ☐ Consultation
- ☐ Mentoring/peer mentoring
- ☐ Funding to support advocacy/public policy activities
- ☐ Annual conference on advocacy
- ☐ Other annual event
- ☐ Developing a coordinated approach to advocacy
- ☐ Developing an advocacy agenda
- ☐ Other, please specify: ______________________________

4.C. Is the state agency on aging involved in these efforts?

____

____

4.D. Are area agencies on aging involved in these efforts?

____

____

5. What barriers have you encountered in your efforts to support older people's involvement in public policy and advocacy? (Check all that apply.)

- ☐ The traditional aging advocacy network has not been successful in attracting the younger generation of older people (the "young old").
- ☐ The traditional aging advocacy network has not attracted new potential advocates from different cultural and ethnic groups.
- ☐ Older people are no longer willing to volunteer their time to public policy activities.
- ☐ Older people with long-term care needs are not able to travel or participate in public meetings.
- ☐ There is a decline in strong leadership among older people.
- ☐ The policies and programs that impact older people are increasingly complex.
- ☐ Older people are put off by the aggressive tactics of some advocacy groups.
- ☐ Older people are often overlooked when programs/agencies reach out to consumer groups on long-term care issues.
- ☐ There has been a lack of effective outreach to engage/recruit older people in advocacy activities.
- ☐ There is insufficient staff available to support advocacy efforts.
- ☐ Funding/resources are lacking to support advocacy.
- ☐ It is difficult to get everyone on the same page.
- ☐ It is difficult to keep advocate involved, informed and up to date.
- ☐ There is a need to teach people to advocate.
- ☐ Other, please specify: ______________________________

6. What tools/supports could you use to enhance existing/new efforts to engage, strengthen and/or support advocates? (Check all that apply.)

- ☐ Funding
- ☐ Training
- ☐ Tool kit
- ☐ Models/best practices
- ☐ Modernized conceptual framework for advocacy
- ☐ Other, please specify: ______________________________

Teleconference Discussion Guide

1. Historically, some participant/caregiver involvement in long-term care policy has been described as "token." Have you been successful in getting older people involved in a truly meaningful way in long-term care advocacy/policy making? If so, how did you do it and what makes the difference.

   ____

   ____

2. What strategies have you used/plan to use in your state to address barriers to older persons' involvement in long-term care advocacy?

   ____

   ____

3. What have you done/plan to do to engage older people in long-term care advocacy? What approaches/practices would you recommend to others?

   ____

   ____

4. What funding sources have been tapped to support older people's advocacy activities in long-term care? How is the funding used?

   ____

   ____

5. Are older people involved in Real Choice Systems Change efforts in your state? Why/why not?

   ____

   ____

6. Have you borrowed successful ideas from other groups, such as the disability community? Have you conducted any joint activities with other groups to support older persons' involvement in advocacy?

   ____

   ____

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