

# Caregiving Policy Workshop Summary Report

*A partnership between AARP of Minnesota, Alzheimer's Association of Minnesota-North Dakota, Wilder Center for Communities*

AARP of Minnesota, the Alzheimer's Association of Minnesota-North Dakota, and the Amherst H. Wilder Foundation's Wilder Center for Communities partnered to conduct three workshops on public policy priorities for caregiving. The purpose of the workshops was to provide a forum for hearing the opinions of current and former caregivers, as well as individuals on the front-line of policy work on caregiving.

Topics covered in the information portion of the workshops included:

- The impact of caregiving in Minnesota
- Caregiving policy
- Potential policy changes
- The Caregiver Action Network

This report provides a summary of the workshops, including characteristics of the participants, top policy priorities they identified, and participants' summary thoughts on caregiving policy and the workshop sessions.



# Background

Three focus groups were held in June, 2013:

- June 4 at The Wilder Foundation, St. Paul, MN
- June 11 at Mall of America, Bloomington, MN
- June 17 at Fitger's Restaurant, Duluth, MN

The sessions were facilitated by Kirsten Johnson (Wilder Center for Communities) and Mary Jo George (AARP). Leonard Major (Wilder Research) took notes. The focus groups were attended by several observers, including Patrick Ness (Public Policy Manager, Wilder Foundation), Seth Boffeli (AARP Communications Director), Jay Haapala (AARP Outreach Coordinator), and Enzo Pasteur (AARP, Public Policy Institute).

Each workshop began with an introduction among participants and a chance to share background information about their caregiving experiences. Kirsten Johnson presented an overview of the purpose of the workshop, as well as background information on the impact of caregiving in Minnesota. Mary Jo George presented an overview of caregiving policy and potential policy changes according to four main topics:

- Legal supports for family caregivers
- Access and affordability of the long-term care system
- Coordination between long-term care and acute care systems
- Access to information resources

Workshop participants divided into pairs and were asked to discuss two questions before reporting back to the larger group:

- In what policy areas do you most want to see change happen?
- If you had to pick one potential policy change, what would be your #1 priority?

The workshop concluded with another paired discussion and report back to the larger group, based on two summary questions:

- How do you want to be involved?
- What will make it doable for you and other caregivers to be involved?

Participants were also asked for their final thoughts on the workshop session.

# Workshop summary

## Description of participants

A total of 42 people were recruited to participate in the Caregiving Policy Workshops. Six participants were men and 36 were women. Thirty-six participants reported some experience with caregiving. Twenty-six are currently involved with caregiving, and 10 said they were caregivers in the past. Most participants reported providing care at some time for a relative, with 28 mentioning experience with parents or parents-in-law, seven mentioning caregiving for a spouse, and four mentioning caring for another relative. Only four participants mentioned caregiving for a non-relative. Participants' current and past caregiving experience is presented in Table 1 below.

### 1. Current or past caregiving experience

	Caregiving for:			
	Parent/In-Law	Spouse	Other Relative	Non-Family Member
Group 1 (N=14)	11	2	0	1
Group 2 (N=18)	11	3	2	2
Group 3 (N=9)*	6	2	2	1
<b>Total (N=36)*</b>	<b>28</b>	<b>7</b>	<b>4</b>	<b>4</b>

*\*Numbers add up to more than the total number of participants, due to multiple caregiving roles for some participants.*

*Top priorities identified by the participants*

Based on the topics suggested by the facilitators, workshop participants discussed their main policy priorities for caregiving. Participants' unique personal and professional experiences with caregiving indicate priorities that can be expanded into five main topic areas:

- Education and information
- Legal concerns
- Coordination between systems
- Access to services and supports
- Financial concerns

**Education and information.** Twenty-two people mentioned education and information about caregiving as a top priority. Participants discussed the need for providing education about caregiving, in the workplace, and having materials about caregiving and resources in a variety of formats. Participants also noted the importance of one point-of-contact or source from which caregivers can get information. Finally, participants were clear about the need for people to have

access to information about a variety of issues before they are in crisis, in order to be proactive. Examples of their comments about the need for education and information include the following:

*We need to publicize Senior LinkAge Line® through Wilder, AARP, TV, radio, snail mail, health fairs, state fair, seniors, assisted living facilities, etc.*

*We need one source to go to for information.*

*I would like for there to be one resource where you can get all the information you need.*

*Many caregivers my age are computer illiterate and are often told to do things online that are beyond our competency level. Information for caregivers cannot only be online.*

*The educational component needs to happen in the workplace, but keeping in mind the problem of protecting caregivers from discrimination in the workplace.*

*...People are not interested in attending workshops or meetings on this subject [caregiving]...until they are in the midst of their own immediate crisis.*

*...when people are making last minute funeral plans, they are pressured to spend and are under duress. People are not informed about their options...They need to be able to plan ahead.*

**Legal concerns.** Seventeen people mentioned legal concerns associated with caregiving as a top priority. The conversations ranged from discussions about banking and protections against fraud, to the importance of legal documents that determine treatment options and guide advocacy for older people. Of particular concern and interest to participants were issues surrounding advanced care planning protocols and health care directives, Power of Attorney and Do Not Resuscitate documents, as well as health care directives and Providers' Orders for Life Sustaining Treatment (POLST). Examples of their comments include the following:

*We need better protections and laws around banking and finance.*

*It is important to do legal documents prior to a hospitalization.*

*How many people knew what a DNR was before they were faced with one?*

*The particular issue needing increased awareness is the necessity of getting power of attorney.*

*We need to extend the length of time Power of Attorney is valid after the death of the person being cared for (e.g. 30 days), so that the caregiver can pay immediate bills and funeral costs.*

**Coordination between systems.** Fourteen people mentioned improving the coordination between systems as a top priority. Fragmented health care and insurance systems, for example, may not be focused on consumers' needs in a way that can benefit caregivers. Participants believe that improved communication between agencies and institutions could result in better supports for caregivers who may be overwhelmed and stressed. Examples of their comments include the following:

*Care providing systems and services need to improve in communicating and coordinating with each other.*

*There is a need for a uniform elder care facility evaluation system...*

*There needs to be a central place for caregivers to get the information they need. Everybody is doing their own little thing and nobody's talking to each other.*

*...There is this silo deal. They are not talking to each other. You've got to be the glue and nobody's talking to you....They really ought to take a good, hard look at their own rules and regulations, and figure out if something can't be simplified. This is crazy!*

*Electronic medical records need to talk across systems. If the military can figure it out and access it, why can't we?*

*There are administrative obstacles and a lack of coordination in the transitions from one caregiving setting (home) to another (hospice).*

*The people in all the specialties have their hands full, but there is no integration and it falls to the caregiver who is already stressed out.*

**Access to services and supports.** Twelve people mentioned the importance of caregivers' access to services and supports. They believe that services such as respite care in particular will keep caregivers functioning, and that the health care system could improve its focus on caregivers. Examples of participants' comments include the following:

*Doctors need education about the impact of being a caregiver.*

*We need to have more respite care available, as opposed to how it is currently more limited and siloed. This might require developing new eligibility requirements that better reflect caregiver needs in order to get them the right amount and right type of respite care.*

*I always wear my caregiver button when I go to the doctor with my dad. It's a constant reminder to him of my status.*

*Make it easier for people to get caregiving help.*

*Assure and teach caregivers that they have the right to speak up for their needs and insist on getting their questions answered.*

Three participants also had specific suggestions of ways to support caregivers, including a store for used medical equipment, a doula for the dying process, and adding a health care home standard to include a focus on caregivers.

**Financial concerns.** Ten people mentioned financial concerns connected to caregiving as a top priority. Participants believe it is important for caregivers to receive compensation for the time they spend caregiving. They also expressed concerns about depleting their financial resources, and confusion about the guidelines related to Medicaid coverage. Examples of participants' comments include the following:

*Medicaid is not accepted in most care facilities and after you have spent down all the money of the person you are caring for, you will be told you have to move her... to another home.*

*I would like to see social security fixed to give caregivers credit for the years they have put in that they have not gotten paid. Otherwise, the years they have not made anything while caregiving get counted along with the rest of their years...*

*We need paid family medical leave for adult caregiving.*

*I don't know what to do when I run out of money. It's private pay now. The information about the assets [and spousal impoverishment laws] is confusing.*

*We need a return of dollars on savings to MN to the caregivers, allowing them to have financial assets to do the job of caregiving, and a set of policies that protects them as much as the private and public entities that provide those services are protected. There needs to be some way to fund time, gas, money, other incidentals, and maybe post-traumatic syndrome after-care.*

Participants' priorities are presented in table form below.

## 2. Priority topics identified by participants

Priority topic mentioned	Number of people who mentioned this
Education and information	22
Legal concerns	17
Coordination of systems	14
Caregivers' access to services	12
Financial concerns	10

## Concluding thoughts shared by the participants

In addition to expressing their appreciation for being included in the workshop, many participants also mentioned the value in being able to share information with other people who understand the complex issues associated with caregiving. Participants also provided their thoughts and recommendations for valuable aspects of this policy work. Their comments can be summarized in three main categories:

- The importance of tapping resources of past caregivers for peer support
- The need for educating people and having materials to hand out
- Providing opportunities for involvement.

**Tap resources of past caregivers for peer support.** Participants discussed the difficult circumstances of caregiving and the need for on-ongoing support, even once the caregiving role has ended. They suggested that former caregivers could share their expertise with current caregivers, in more structured ways. Examples of their comments include the following:

*Past caregivers have information and expertise to share. You get thrust into the situation and then come out on the other side with all this wisdom.*

*People need support after the caregiving is done. There is emotional trauma after one is done with their caregiving role, and that is also a time when people really need to be supported.*

*Build a mentor program with people who offer support and ideas. It's wonderful to learn from others. You remember the face and the emotions and what you said better than what you read somewhere.*

*I think we've got a resource that you need to tap, and that is people like me who are no longer caregivers....I do things now because I have the time and I have the knowledge and experience that I know why it's important.*

*...processing could happen with ex-caregivers becoming involved in providing support for caregivers who were still in the midst of it.*

*I would like to see a way that people whose caregiving responsibilities are gone could provide some sort of incubator or support in getting independent initiatives started for people who need caregiving support, training or education.*

**Educate people and have materials to hand out.** Participants spoke about the need for continued efforts to educate people and reach potential caregivers. They suggested more seminars and education sessions, including at churches, along with materials that people can read. Examples of their comments include the following:

- Have something to hand out at Senior Expos.
- More things like that help.
- Children taking care of parents will be the future.

*Education is critically important. Information and the way things are done are both changing. Spreading information across the state is important. We need to reach the younger generations.*

*AARP should hold seminars and put out information in booklet form. Get information out to people who are about to become caregivers.*

*It's one thing for us to share our knowledge and experiences with caregivers, but the education also has to be given to the facilities and organizations that are caring for our family members. They need to address the issues of caregivers better...*

**Provide opportunities for involvement.** Several participants are currently involved with issues surrounding caregiving by volunteering with AARP or other local agencies. Several others mentioned their willingness to make presentations at future events, tie in with legislative activities, or assist with administrative tasks. Another participant expressed appreciation for an easy way to be involved, when she received an email from the Alzheimer's Association with instructions for sending a message to state legislators.

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