

A BACKUP PLAN FOR SOLOS



Health Care Decision Making for People Aging Alone

Phase I Final Report

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“I do not have a plan but realize I need to do this. I do not have an advance directive nor have I spoken about these issues with others, including friends. I am an ostrich with my head in the sand.”

— Solos Task Force Personal Interview

Acknowledgments



Members of the Executive Team and Task Force wish to acknowledge the **Bush Foundation** for providing a Community Innovations grant to make this initiative possible.

We also acknowledge the excellent work of the **Wilder Research** staff who provided the demographic analysis discussed in Section IV of this report.

We thank the **guest speakers** who offered their insights and expertise to enable the rich conversations throughout the project.

We also thank the members of the **Ad Hoc Review Committee** for their feedback on our Findings and Recommendations.


We especially thank the **individual solos** who shared their views through personal interviews and focus groups.

Finally, we thank the many individuals who participated in our **Stakeholders Information Session**. The feedback, ideas, and support will help to make Minnesota a solo-friendly state.

“ ... I know how hard it is if you don’t plan.”

—Solos Task Force Personal Interview

Executive Summary



As people age, they often need assistance with health care decisions. Historically, family members have provided such assistance. It is not always clear who can and will be available to assist those aging alone or to serve as their health decision agents if they cannot speak for themselves. Without a plan or a supportive infrastructure, “solos” are at risk for lack of care, sub-optimal care, or care that goes against their wishes.

The Citizens League has recognized health care decision making by and for solos as an important public policy issue and a timely subject for study. To that end, in the fall of 2016, the Citizen League formed a partnership with the Minnesota Elder Justice Center to work on this issue. With financial support from a Bush Foundation Community Innovations grant, these Partners convened a 14-member, multi-disciplinary Task Force. They challenged the Task Force to discover, analyze, and make recommendations directed at the following overarching goal:

Stimulate the development of a supportive infrastructure to help solo adults, particularly older solo adults, successfully navigate health-related events and, therefore, be less likely to become vulnerable adults—with its accompanying loss of self-determination for the individual and high costs to society.

For purposes of this project, Task Force members employed the following working definition of solos: “Individuals who, by choice or circumstance, function without the support system traditionally provided by family.”

Over twelve-months, the group studied existing laws, policies, and practices. They also engaged in detailed discussions with individuals from legal, medical, social work, business, and volunteer sectors. In addition, Task Force members gathered information directly from solos through a series of personal interviews and two focus groups of solos from diverse communities.

Key Findings

A Snapshot

Overall, Task Force members found it impossible to point to a specific set of characteristics or demographic factors to define the “solo” segment of the population. While the term “solo” may be useful shorthand, it masks the variations in personal situation, income, culture, physical and mental abilities, personal attitudes, and choices that are present. What is more informative is not to talk about solos as a fixed category, but rather to use “solo-ness” as a descriptor. Solo-ness is not about the absence of friends and family but, as the working definition suggests, the availability and quality of support when needs arise related to health and functioning as well as end-of-life decisions.

In the context of health decision support, individuals may experience solo-ness temporarily, intermittently, for short or long periods. People without children may never be solo if they are able to craft a support network of health professionals and friends. People with children, who have completed end-of-life documents, may be “functionally” solo if none of these resources is

available to meet emergent needs. Hence, solo-ness can be viewed as a continuum, with those on one end having an effective plan and those on the other end having no plan at all.

The Numbers

Solos are a kind of moving target. This makes it difficult to document how many there are at any given place or point in time. One “risk factor” that often contributes to solo-ness is living alone. Such information is routinely captured in US Census data and provides some clues about people who are likely to be solos. Scrutiny of the three oldest generational cohorts (Generation X, Baby Boomers, Silent/Greatest) revealed that overall, Minnesota looks very much like the US as a whole:

- About **17%** of the cohort members live alone
- Boomers make up about **46%** of these solos
- Silent/Greatest about **30%**
- Gen X about **23%**
- About **56%** are female, **44%** male
- **88%** are white and **12%** non-white

On a positive note, about **96%** are covered by health insurance and nearly **73%** are without a disability. Of more concern is their economic situation; the median total personal income is just over **\$32,000**. About half of that is derived from Social Security. About **16%** are at or below poverty, and nearly **11%** receive food stamps. These facts raise questions about whether solos can pay for the services and support they may need in the absence of family.

Issues, Gaps, Opportunities

Through the Discovery process, Task Force members surfaced a series of issues that require further consideration:

1. Caregiving involves two distinct categories of activity: “hands-on” services such as help with medications and activities of daily living and “**decisional**” **elements** that include such things as researching and assessing resources, managing costs, and choosing among treatment options, among others. Historically, family members have functioned as both deciders and hands-on care providers. People often overlook decisional elements or lump them in with the more visible elements. Decisional elements must be unbundled from care to understand the needs of solos and craft effective solutions.
2. If people don’t have an underlying safety net in the form of family, then having a **health decision support backup plan** is critical. However, anecdotal evidence suggests that the percentage of solos who have such a plan is likely to be low. Better planning tools and incentives are needed.
3. There is little point in urging solos to create a plan if the building blocks to operationalize the plan are in short supply. Among the most critical building blocks are **committed and qualified people who can help**. Professional and volunteer decision supporters are lacking or difficult to locate.

4. Public policy makers, legal professionals, medical professionals, and professionals who work with older adults **do not see or understand solos or solo-ness**. It is easy to assume that available practices and offerings will serve solos and non-solos equally well.
5. Certain factors, such as **personal traits, habits, and values**, while not unique to solos, can have an impact on and sometimes exacerbate solo-ness.

Recommendations – Short-Term

1. Disseminate the Task Force Final Report to key stakeholders.
2. Develop and provide more extensive training about solos to professionals who interact with or serve solos.
3. Stakeholder organizations should examine current customs and practices to determine whether they are “solo friendly.”
4. Those who assist solo older adults with planning should recognize the importance of the Personal Health Decision Assistant (PHDA) and help solos to find/develop this personal resource.
5. Organizations who identify, train, and provide volunteers to support older adults should expand their scope of services to include health decision assistants.
6. Professionals who work with/serve older adults should identify or create and promote sustainable models for building “community” to help solos avoid isolation and craft a personal support system.
7. The Backup Plan Minimum Elements presented in the Final Report should be adopted by stakeholder organizations and shared widely and consistently with solos.
8. The planning resources available in Minnesota should be expanded to include a “self-assessment” tool to help solos identify gaps in their planning relative to health decisions and health events. Resources should also be added to help faith communities and other organizations educate solos about the risks associated with a lack of planning.
9. Minnesota should help address the information gap around solos and solo-ness by developing a detailed research agenda and plan for financing relevant research.
10. Key state of Minnesota Agencies, including the Department of Human Services, Department of Health, Workforce Development, and the Department of Employment and Economic Development, should collaborate to address the emerging and critical need for credentialed professional to serve in Personal Health Decision support and health care agent roles.

Other Recommendations

1. State of Minnesota agencies serving older adults should identify and implement policies, standards, and procedures to better address solos and solo-ness.
2. Key staff of medical providers, such as billing personnel, should receive more extensive training on Medicare billing codes to better document discussions related to development of health care directives or POLST (Physician's Order for Life-Sustaining Treatment) documents.
3. Minnesota Driver and Vehicle Services (DVS) should assess the current practice of requesting information about health care directives on MN driver's license application and look for ways to use that information more effectively.
4. Professional Guardian associations should work with members to learn about solos and determine whether guardians could also serve in the health decision assistant or health care agent roles for solos.
5. Organizations that train and recruit volunteers should identify and investigate perceived barriers for individuals who wish to volunteer as a health decision assistant or health care agent
6. Create a public awareness campaign to help solos understand the importance of having someone to serve in the health decision assistant role and potential sources of such support, including outreach strategies tailored to those whose first language is not English.
7. Medical service providers should ensure that the annual Medicare wellness exam includes a request to create or update a health care directive. Providers should consider modifying the annual Medicare questionnaire to include questions related to solo-ness.

I. Introduction



In 2014, Minnesota Compass described Minnesota’s aging population as “a jet airplane that has just lifted off.” By 2030, more than one in five Minnesotans will be 65 or older. As people age, they often need assistance with health care decisions.

Historically, family members have provided such assistance. It is not always clear who can and will be available to assist those aging alone or to serve as their health decision agents if they cannot speak for themselves. Without a plan or a supportive infrastructure, “solos” are at risk for lack of care, sub-optimal care, or care that goes against their wishes.

Advisors urge solos to “plan ahead” without offering guidance for how to do so or acknowledging a lack of resources. The American Geriatrics Society recently highlighted the need for proactive strategies to help solo older adults make medical decisions.¹ It is essential to understand needs better and address resource gaps before the potentially large number of solo older adults no longer have the capacity to manage health decisions for themselves.

Thus far, most work related to solos has focused on those who are the most vulnerable—solos who lack mental capacity. There is a need, however, to look more broadly, to focus on solos *with capacity* and identify needs, resource gaps, and possible solutions.

The Citizens League has recognized health care decision making by and for solos as an important public policy issue and a timely subject for study. To that end, in the fall of 2016, the Citizens League formed a partnership with the Minnesota Elder Justice Center to work on this issue. With financial support from a Bush Foundation Community Innovations grant, these Partners convened a 14-member, multi-disciplinary Task Force. They also retained two independent consultants (who are themselves “solos”) to manage the project (Appendix A). Because of the limited interdisciplinary work around health decision making by solos, the Task Force saw this initiative as foundational. The hope is that the findings will create a platform for key stakeholders to learn about solos and to develop the strategies, tools, and other resources to meet critical needs.

Overarching Goal & Questions

The project’s Executive Team challenged the Task Force to discover, analyze, and make recommendations directed at the following overarching goal.

Stimulate the development of a supportive infrastructure to help solo adults, particularly older solo adults, successfully navigate health-related events and, therefore, be less likely to become vulnerable adults—with its accompanying loss of self-determination for the individual and high costs to society.

Members were invited to explore these and other key questions to produce the outcomes below.

¹ Timothy W. Farrell et al. AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults. Journal of the American Geriatrics Society 2016 p. 2

1. What makes a person a “solo?”
2. How well equipped is Minnesota to address the need of solos for supported and surrogate health care decision making now and in the future?
3. What resources are available? What is working well and where are the gaps?
4. Is it possible for solos to be proactive and plan for these needs? If so, what would that planning process look like?

Proposed Project Outcomes

1. A general description of those who could be considered solos.
2. A description of the current Minnesota infrastructure to support solos health decision making.
3. Description of the core elements of a health decision “backup plan”.
4. Identification of important resource gaps and potential solutions.
5. Recommended priorities for future action and preliminary work plan.

This project was not intended to be a comprehensive look at all of the elements related to solos and health decision making. All of the topics covered in this report merit more in-depth scrutiny. The Task Force hopes that the material that follows will serve as a starting point for additional work and planning around this vital issue.

“What ifs have never been a part of my life.”

—Solos Task Force Personal Interview

II. Study Process



Health decision making by and for solos is a complex topic. There are social and behavioral dimensions as well as legal, ethical, and medical dimensions, among others. Compounding the situation are the underlying, often stereotyped assumptions about older adults. The medical and legal communities have been the most visible actors so far as they intersect with older adults who lack capacity. Research and thinking about solos who are still able to plan and decide is in its infancy. Because of the spottiness of information, Task Force members engaged in an eight-month Discovery process, first “zooming in” on specific content areas and then “zooming out” to better understand relationships and gaps.

Tapping into Existing Expertise

Task Force members began their journey by investigating existing laws, policies, practices, and data. They reviewed relevant Census information along with data on older adults generated by MN Compass and the 2015 Survey of Older Minnesotans. In addition, they grappled with terminology associated with end-of-life decision making such as health care directives, POLST (physician orders for life-sustaining treatment), and supported decision making

To enrich their understanding of the topic, Task Force members engaged in detailed discussions with professionals who are knowledgeable about solos. Presenters included individuals from legal, medical, social work, business, and volunteer sectors.

An important objective for these conversations was to gain a clearer understanding of real-world practices, successes, needs, and barriers. Table 1 summarizes the timeline and content for this portion of the Discovery process.

*It's hard to make decisions in a vacuum—
I don't really have support people to make sure an
advance directive is followed.*

— Solos Task Force Personal Interview

Table 1. Overview of Topics and Expert Resources

Date	Content
September - October	MN Compass, Census, Survey of Older Minnesotans Data MN Statutes 145C, POLST, HIPPA, Guardianship, Conservator, Supported Decision Making, Power of Attorney, Best Interest, Substitute Judgement
November	Dr. Carolyn McClain – Perspectives on Solos from an Emergency Room Physician
December	Dr. Thaddeus Pope – Health Law Institute – Work related to “unbefriended elders” in a hospital setting, default surrogate laws, medical ethics committees, lack of uniform policies among hospitals
February	Perspectives on supported ² & surrogate decision making: Hal Freshly , Volunteer, Unity Church, St. Paul, MN Anita Raymond , Center for Excellence in Supported Decision Making Eric Jonsgaard , First Fiduciary Corporation, Eagan, MN
February	Carl Hokanson A Social Worker’s Perspective on Solos – Capital View Transitional Care, Regions Hospital (HealthPartners)

Conversations with Solos

Personal Interviews

Task Force members felt it was essential to hear from another kind of expert—people who considered themselves to be solos. To accomplish this objective, the members conducted personal interviews with solos they identified through their networks. (See Appendix C for the list of questions.) At the January Task Force meeting, members shared the results of these conversations and the insights gained. Table 2 presents a demographic overview of the interviewees.

² Supported decision making allows individuals with disabilities to make choices about their own lives with support from a team of people. (<http://supporteddecisions.org/about-sdm/>)

Table 2. Overview of Personal Interview Participants

Category	Detail
Total # of Completed Interviews	20
Gender of Interviewees	Male = 6 Female = 14
Identification	Gay/Lesbian = 4 Straight = 8 Other or No Comment = 6
Ethnic/Cultural Identification	White/Caucasian (various descriptions) = 16 Black/African American/Mixed = 4
Qualify for Govt Funded Services	Yes = 3 No = 14 Don't Know = 1 Other Comment or No Response = 2

* Divulging personal details was voluntary; interviewees had the option not to respond.

Focus Groups

Project staff conducted two focus groups of solos from diverse communities to supplement the information from the personal interviews. Participants were asked the same questions as those who completed the personal interviews.

Centro Tyrone Guzman. This community center for Spanish-speaking people is in South Minneapolis. Center staff helped to recruit nine low-income participants, all of whom were age 65 or older and native to Mexico, Puerto Rico, or Ecuador (3 men, 6 women). All were in the US legally, though only three of the six individuals were citizens.

Because only two of these participants were proficient in English, project staff arranged for a Spanish-speaking interpreter to facilitate the focus group. After the focus group, the facilitator prepared a transcript of the discussion in English and distributed it to Task Force members. The facilitator presented a summary of the focus group content at the March Task Force meeting, so members had the opportunity to gain a more complete understanding of what this group of solos had to say.

Phillips Wellness 50+ Group. The second focus group consisted of six people (3 African American, 1 Asian, 2 Caucasian; 2 men, 4 women), all low income and age 65 or older. Staff conducted the group at Ebenezer Tower in Minneapolis where the Vital Aging Network has implemented a Wellness 50+ program over several years. This program helped the six participants, who were residents in the building, to form their own informal support network.

Responses to the focus group questions were recorded and shared with the Task Force members at the March Task Force meeting.

Analysis and Recommendations

After the Discovery phase, Task Force members reviewed all they had learned and synthesized the content to craft a framework around solos and health decision making. This framework and associated insights are contained in the Findings section that follows. Subsequently, the Task Force developed a list of Recommendations and Action Steps, directed at the overarching goal of engaging others to develop a more complete and effective infrastructure.

Ad Hoc Review Committee

At the outset of the project, Task Force members were concerned that any findings and recommendations be relevant to a broad range of solos. To that end, the Task Force established an Ad Hoc Review Committee composed of individuals who were knowledgeable about solos from the LGBT, Native American, Asian, and Hispanic communities. (See Appendix A for a list of members.) The committee met twice; the first time to learn about the purpose of the Solos project and to share their own experiences with solos. At the second meeting, the reviewers met with several Task Force members and project staff after they had reviewed a draft of the Final Report. The feedback was used to deepen the Final Report's content and to help identify possible future areas of work.

Stakeholders Information Session

Among the final activities of the Task Force was an informational meeting with a group of thirty invited representatives from various "stakeholder" organizations. Participants included staff from state and local government, culturally specific service entities, as well as financial, medical and social service organizations. The purpose of the meeting was to share the work of the Task Force more broadly, engage others in conversations about the issues identified by the Task Force, and identify action steps that might support the overarching goal of the Solos project. Appendix C contains more detailed information about this project step.

I would hope that my Long-Term Care insurance would cover care at a rehab facility or in my home. I would not involve my family as long as I am capable of making decisions. It is important to me that I am not a burden to anyone.

— Solos Task Force Personal Interview

Phase 2

When this project was conceived, the Executive Team envisioned that all of the grant funding would be used to support the work of the Task Force. As Task Force members wrapped up their work in early fall, it became clear that sufficient funds were available to support additional work. Consequently, the Executive Team created a plan to implement a series of small projects to begin implementing several of the Task Force Recommendations. Bush Foundation staff subsequently approved the plan and extended the grant period by six months.

As the Task Force issues this Final Report, the projects have been launched, with all scheduled to be completed by June 30, 2019. Section VI of this report contains more detailed information about these projects.

III. Solos: Who Are They? A Snapshot



One of the most basic, yet critical issues in this initiative, was what to call the target population. Medical and legal professionals frequently refer to the “unbefriended elderly,” while others prefer the terms “elder orphans,” or “solo seniors.” Each of these descriptors has some merit, but also limitations. Words such as “unbefriended” and “orphans” can be seen as pejorative and evoke notions about older adults that may or may not be true, contributing to stereotyping. Though the term “solos” also has drawbacks, the Executive Team felt it was more neutral than others in common use and so adopted it for the project.

To sharpen the focus of their work, Task Force members employed the following working definition of solos: *“Individuals who, by choice or circumstance, function without the support system traditionally provided by family.”* But Task Force members felt it was essential to develop a more complete picture of those considered as solos. This included untangling common assumptions and “charged” terminology.

Assumptions

According to recent research by the Frameworks Institute, “Many Americans think of aging as deterioration, decline, and dependency. This assumption is so deeply embedded in American social and cultural life that many people rarely notice it.”³ For older adults who may qualify as “solos,” there is a kind of double jeopardy. Layered on the ageist thinking are equally troublesome assumptions about people who live alone, who may have never married, or have no children. Research has shown the fallacy in such thinking.

Task Force members brought their own beliefs about solos into the project. A discussion about their starting assumptions yielded the following ideas.

- Solos are people who are alone; they have no friends or family.
- Being a solo is a bad thing; it’s a problem for solos themselves and others.
- Solos are people who lack the skills to plan and manage their health.
- Partnered people aren’t solos.
- Institutions and social organizations have planned and are prepared for the needs of solos.
- Solos with money are ok—they can purchase the services and support they need.
- Non-solos plan, solos do not.
- Solos with the fewest resources (money) are the worst off.
- Once a solo, always a solo.

Over the course of the project, however, a more complete and nuanced view emerged.

³ Terry Fulmer & Drew Volmert. Reframing Aging: Growing “Old at Heart” *Stanford Social Innovation Review* June 12, 2018

Insights

Life Situations

The unique intersection of demographics, longer lifespans, shifts in culture and values has created a scenario unlike any in the past; a large number of solos have emerged for the first time in history. Recent articles have often suggested the solo population primarily consists of those born between 1946 and 1964 (“Baby Boomers”) without children or whose children live at a distance. However, the Task Force found this view to be an incomplete one. As the project working definition indicates, both circumstance and choice are operative factors. For example, not all children or family members are willing, available, or able to help with complex medical decisions. Consequently, solos may make a deliberate decision *not to* rely on the traditional family safety net.

“I have children, but I can’t depend on them. I was sick recently, and they were not there to help me. I don’t feel confident that I can count on them.”

—Solos Task Force Personal Interview

Equally relevant is the fact that life situations are fluid. Personal circumstances can and do change. Participation in the personal interviews and focus groups was voluntary, and there was no effort to pre-select individuals from particular life situations. At the start of these conversations, participants were asked if they felt the term solo applied to them and, if so, why. Interestingly, a wide range of personal situations emerged. Some had no children, some had children at a distance, while still others talked about “not getting along” or “not trusting” family members. From even this limited sample of solos, Task Force members could see that solo life situations are not unique to a particular demographic or cultural group. Solos can exist regardless of background or origins.

Values and Attitudes

Through the conversations with solos and observations from invited experts, it was clear that certain values and attitudes can be factors in whether an individual might be considered a solo. Independence and self-reliance are hallmarks of life in the United States today, and “going it alone” is often viewed as a virtue. In their presentations to the Task Force, the experts cited examples of how older adults highly prize independence. However, such an attitude can be a barrier to providing support. Conversations with solos reinforced this reality. It was not uncommon to hear comments about “not wanting to be a burden” to friends and family.

When these solos did seek assistance, trust was a critical element. Negative past experiences with medical, governmental, and financial institutions, as well as dealings with family and friends, caused some to shy away from the most obvious sources of support for health decisions. When options were lacking or unclear, they preferred to fend for themselves rather than to rely on someone unknown.

“So many people who are alone don’t ask for help and don’t get the medical care they need because they are afraid that if someone finds out they don’t have anyone, they won’t be able to continue to live at home.”

—Solos Task Force Personal Interview

Skills and Abilities

In addition to values, individual skills and abilities can dictate who becomes a solo. Discussions with solos around planning for and navigating health events reinforced how much difference these can make. Certain interviewees described internet research, conversations with doctors and financial advisors, while others did not know where to start. Both those with adequate financial resources and those that qualified for subsidized services, lacked taking action. Interviewees who seemed best equipped to address future health events demonstrated an ability to and a history of taking action on their own behalf.

The ability to build social capital⁴ also surfaced as a critical element from the interviews and focus groups. Again, those who seemed best equipped to manage their own well-being had developed connections, if only with one or two people. Articles about solos frequently advise them to join clubs, interact with younger generations, and get to know their neighbors. But it is clear that not everyone has the wherewithal to engage with others. Creating a personal network takes a certain amount of sociability, patience, and skill.

⁴ In his 2000 book, *Bowling Alone*, Robert D. Putnam describes social capital as “networks and connections; norms of reciprocity and trustworthiness.” P. 18, 19.

Diverse Communities

According to Minnesota Compass, about 6% of Minnesota’s older adults are people of color; 5% of them are foreign-born.⁵ Members of the Ad Hoc Review Committee described how various cultural structures and practice, such as clans, have traditionally created a safety net for solos. The “community” would reach out to solo elders in need of support. As new generations have become integrated into American culture, cracks in that support system are beginning to appear. The young adults of today do not always feel the same sense of commitment to older family members. In the words of one Ad Hoc Review Committee participant, “things are fine now, but I’m not sure where we’ll be in another ten years.” There is a need to plan for the diverse solos of the future.

“There are certain friends who I would not want making decisions for me. I’d want people who had a desire to help me live comfortably and follow through on what I requested.”

—Solos Task Force Personal Interview

A Snapshot

Overall, Task Force members found it impossible to point to a specific set of characteristics or demographic factors to define the “solo” segment of the population. While the term “solo” may be useful shorthand, it masks the variations in personal situation, income, culture, physical and mental abilities, personal attitudes, and choices that are present. What is more informative is not to talk about solos as a fixed category, but rather to use “solo-ness” as a descriptor. Solo-ness is not about the absence of friends and family but, as the working definition suggests, the availability and quality of support when needs arise related to health and functioning as well as end-of-life decisions.

In the context of health-decision support, individuals may experience solo-ness temporarily, intermittently, for short or long periods. People without children may never be solo if they can craft a support network of health professionals and friends. People with children, who have completed end-of-life documents, may be “functionally” solo if none of these resources is available to meet emergent needs. Hence, solo-ness can be viewed as a continuum, with those on one end having an effective plan and those on the other end having no plan at all.

⁵ Six Interesting Facts About Minnesota’s 65+ Population, May 2017. (<https://www.mncompass.org/trends/insights/2017-05-30-older-adults>)

Ageist thinking⁶ says that older adults without children, other family, or close friends are destined to lead lonely lives and to struggle with day-to-day activities, particularly when it comes to managing health events and decisions. The Task Force's discoveries suggest otherwise. A more useful frame is to understand solos as a group diverse in culture, abilities, values, physical and mental capabilities, as well as economic and personal resources, who sometimes need support with health decisions. Solos are not *them*; solos are likely to be all of *us* at one time or another.

“Having no relatives gives me less to worry about. I won’t be a burden to anyone – except (my power of attorney and health care agent).”

—Solos Task Force Personal Interview

⁶ The Merriam Webster Dictionary defines ageism as a “prejudice or discrimination against a particular age group, particularly the elderly.”

IV. Solos: What the Numbers Say



As the solos framework in the previous section suggests, solos are a moving target. This makes it difficult to document how many there are at any given place or point in time. It is possible, however, to identify “risk factors” that can contribute to solo-ness. These include:

- Having no children or stepchildren or having a disabled child.
- Living Alone.
- Having children or family members who live at a distance or are unavailable.
- Having children or family members who are unable or unwilling to provide support.
- Dysfunctional family relationships.
- Close friends or partner are same age or older.
- Extreme independence, lack of social skills, or reclusiveness.
- Lack of mental capacity (long-term, short-term, intermittent).
- Extreme poverty or homelessness.

Useful data showing the specific number of individuals who experience solo-ness as a result of any or all of these risk factors is scarce. As noted earlier, the large proportion of solo adults is a relatively new phenomenon; the impacts still emerging. Consequently, there are many questions for which little or no useful research is available. The one exception is the risk factor of living alone which is routinely tracked by the US Census Bureau.

To provide a more complete picture of individuals who may experience solo-ness, the project team retained research staff of Wilder Foundation (St. Paul, MN) to analyze recent Census data on people who live alone. Given the project focus on older adults, for this research, solos were defined as non-institutionalized individuals living alone without a spouse or partner present. Estimates were assembled separately for three generational cohorts:

- Generation X (born 1965 to 1982)
- Baby Boomers (born 1946 to 1964)
- Silent/Greatest Generation (1945 and earlier)

Of particular interest were the factors most relevant to health and health-related decision making. The sections that follow provide highlights from this analysis.

Solos: A Profile from the US Census⁷

Overall, Minnesota mirrors the United States in terms of the relative proportion of older adults (**52%**), with a slightly higher percentage of solos (**17%**) than in the US as a whole (**16%**) (Figure 1). It is important to emphasize that this number is just one yardstick by which to assess the total number of individuals who meet the solos definition offered in this report. Some people who live alone may be well supported, and so may not be solos. When the other risk factors are considered, however, the resulting percentage of people who experience solo-ness is very likely to exceed 17%.

Not surprisingly, Baby Boomers make up the largest share of the of the group under study. (Figure 2) This allocation is

Figure 2. Distribution of MN Solos

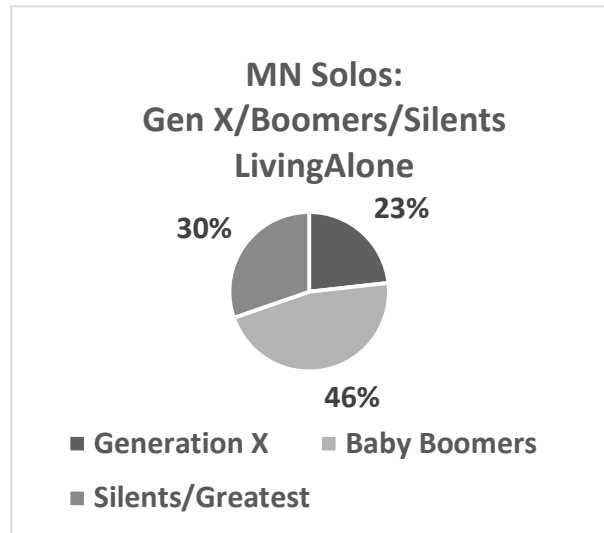
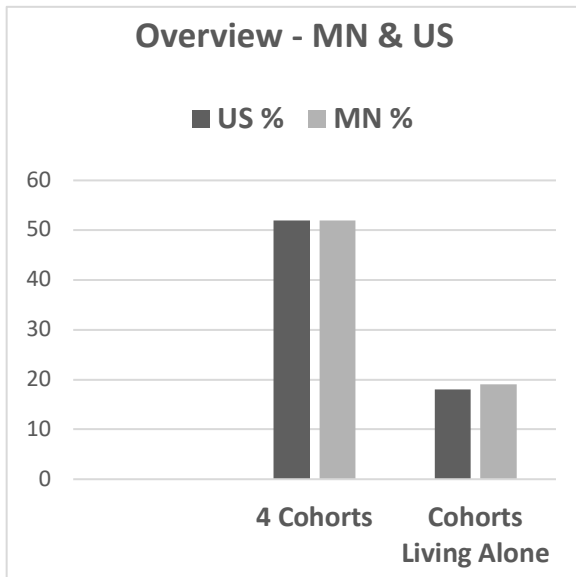


Figure 1. Proportion of Older Adults



particularly relevant because it helps to underscore the fact that solo-ness is not just a blip on the radar screen. The youngest members of the largest cohort—Baby Boomers—will turn 55 during 2019; the youngest Generation Xers will be just 37. Thus, these data show a long-term trend; solos are likely to have a significant presence for the next two to three decades, maybe longer.

About **88%** of Minnesota solos are white; **12%** non-white. In the entire US, about **72.5 %** are white, **27.5 %** non-white.

Females tend to outnumber male solos in Minnesota, though there is a marked difference by cohort. Figure 3 shows that male Gen Xers

⁷ Solos are defined as individuals who are living alone, without other family members or unrelated individuals present in the household. Estimates used in the analysis are limited to individuals born in 1982 or earlier. Source: Integrated Public Use Microdata Series from the US Census Bureau's American Community Survey 2012-2016.

outnumber females while the balance is flipped with the Silent/Greatest Generation cohort. The percentages are nearly equal with Baby Boomers.

Minnesota solos are generally well educated. About **63%** have some college, an associate’s degree or higher level of schooling. This represents a slight edge over the US as a whole, with **59%** of solos reporting the same level.

Figure 4 summarizes how the educational levels compare among the generational groups. The figures are consistent with the general pattern of an increasingly educated population.

Figure 3. MN Solos by Age and Gender

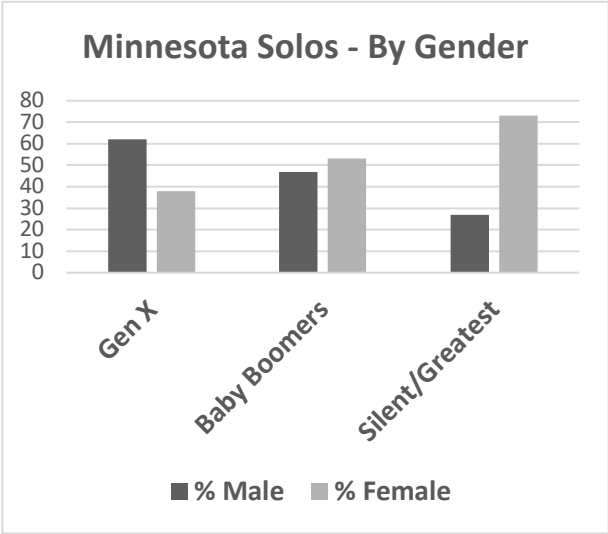
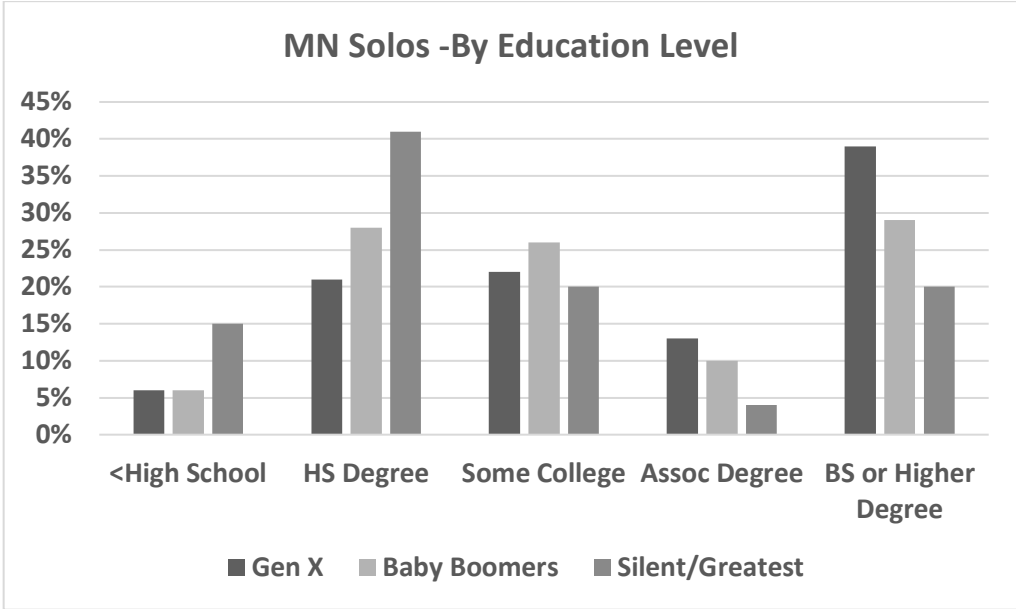


Figure 4. MN Solos Educational Attainment



An Economic and Health Profile

Because the central framework for the Solos Task Force was health and health decision making, several categories of the Census data were of interest. These included details about physical and mental well-being along with information about solo’s ability to pay for medical and other health-related services.

Minnesota solos appear to be a sturdy bunch. Only one in four solos in Minnesota has a disability (**27%**) but this differs across Minnesota’s generations of solos. (Figure 5) The share of Minnesota solos with a disability increases with age. The most common disability types are

cognitive limitations among Generation X solos (**7%**) and ambulatory limitations among Boomer and Silent/Greatest solos (**13%** and **27%** respectively). Silent/Greatest generation solos also have a high prevalence of independent living limitations and hearing limitations (**19%** and **18%** respectively).

Figure 5. MN Solos – Disabilities

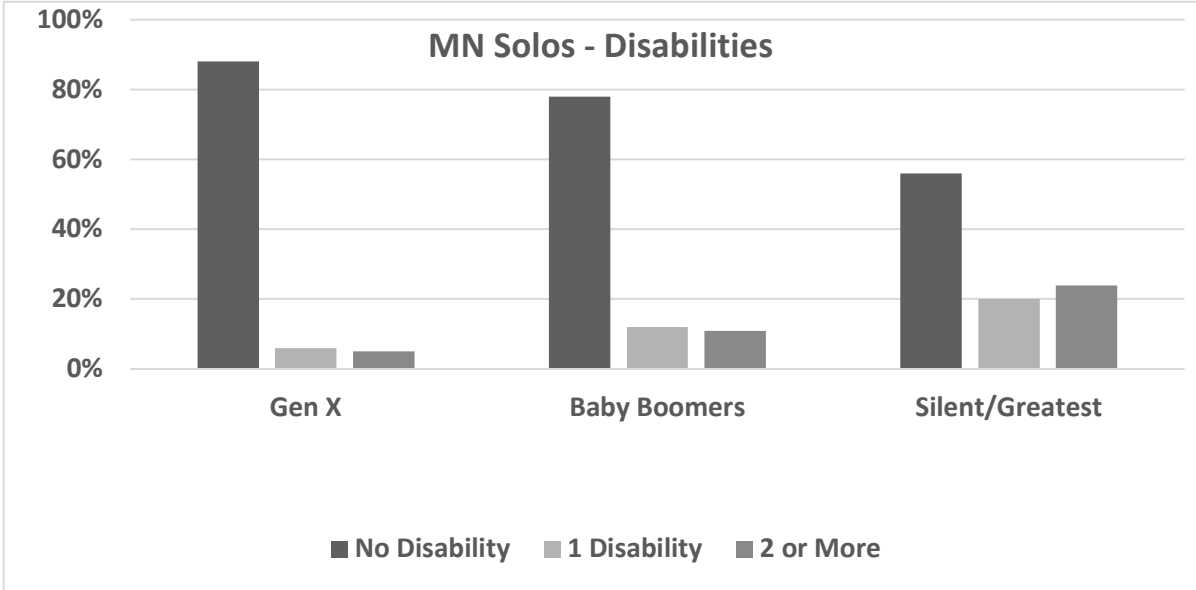
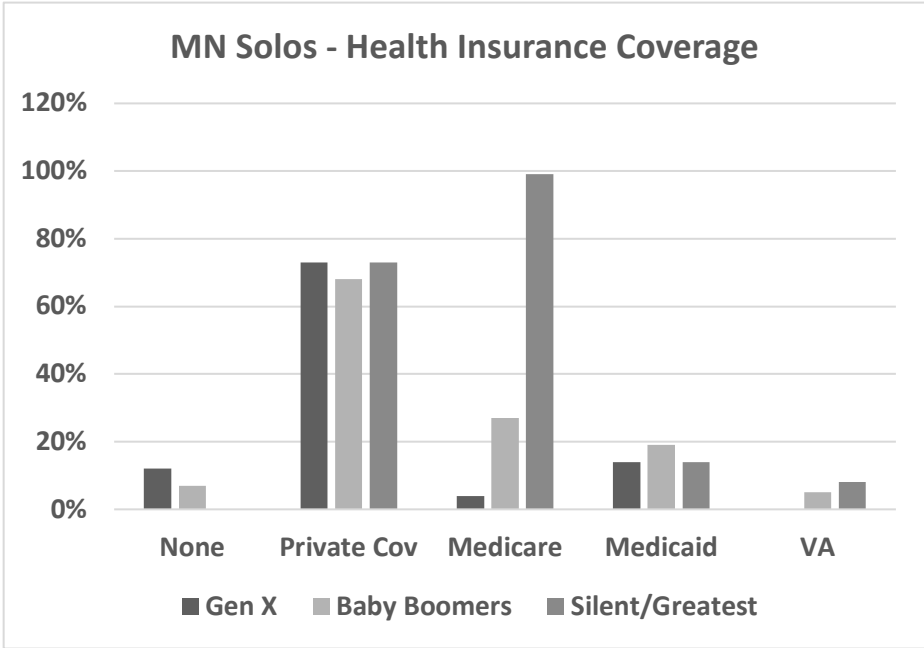


Figure 6. MN Solos – Health Insurance Coverage



Only a small share of Minnesotans lacks some form of health insurance (**4%**) compared with about **6%** in the entire US. Medicare and Medicaid coverage are important to MN solos, but nearly **70%** had private coverage as well, provided either by an employer/union or purchased directly. (Figure 6)

Solos who cannot or choose not to rely on family for health care support and decision making may have to look to paid resources to meet certain needs. Table 3 offers some clues about whether MN solos are equipped to meet expenses not covered by insurance. The median income for the large bulge of solo Baby Boomers is just over **\$35,000** with about one-third of that income generated through Social Security.

Table 3. MN Solos Economic Characteristics

Category	Gen X	Baby Boomers	Silent/Greatest
Employed	86%	61%	9%
• Full-time worker	69%	45%	,3%
• Part-time worker	17%	17%	6%
Total Personal Income (median 2017 \$)	\$44,307	\$35,463	\$23,291
• Wage & Salary	\$46,368	\$40,769	\$11,152
• Social Security	\$10,936	\$13,500	\$14,582
• Retirement Income	\$8,000	\$13,164	\$11,499
• Other Personal Income	\$4,913	\$6,590	\$9,826
Percent Receiving Type of Income			
• Wage & Salary	86%	63%	10%
• Social Security	4%	29%	93%
• Retirement Income	2%	17%	44%
• Other Personal Income	5%	9%	10%
At or Below 100% of Poverty	13%	18%	16%
At or Below 200% of Poverty (low income)	25%	37%	50%
Household Receives Food Stamps	9%	13%	7%
Housing			
• Own	51%	65%	62%
• Monthly mortgage, tax, insurance, utility, & fuel (median)	\$1,153	\$818	\$493
• Rent	49%	35%	38%
• Monthly contract rent, utility, fuel costs (median)	\$773	\$690	\$777
• Pay 30% or more of monthly gross income on housing (cost burdened)	37%	41%	48%
Length of Time in Current Residence			
• Less than 1 year	1%	10%	8%
• 10 to 19 years	21%	24%	19%
• 20 to 29 years	3%	18%	12%
• 30 Years or longer	<1%	12%	30%

Measures of poverty status help supplement our understanding of Minnesota solos’ economic well-being. In 2017, the federal poverty threshold was roughly \$12,500 for an adult under 65

living alone and \$11,500 for an adult age 65 years and older living alone. Poverty is used to describe individuals with incomes at or below these thresholds; low income is used to describe individuals with incomes at or below 200 percent of these thresholds.

Overall about one in six solos in Minnesota lives at or below the poverty threshold. Poverty rates vary slightly across generations of solos, as depicted in Table 3. There is an upward trend in the share of Minnesota's solos who are low income for older generations. While **25%** of Generation Z solos are low income, double the share of Silent/Greatest generation solos are low income.

About half of Minnesota's Generation X solos own their homes (**51%**), while homeownership rates among Boomer and Silent/Greatest solos are higher (**65%** and **62%**, respectively). The slight decline in homeownership among Silent/Greatest solos, compared to Boomer solos, may signal a slight shift toward renting at older ages. The larger difference between homeownership rates of Generation X solos, compared to Boomer and Silent/Greatest solos, may point to differences in life course stages. But these differences may also signal barriers to homeownership for younger solos, especially related to housing affordability.

Indeed, monthly owner costs tend to be much lower for solos in older generations. While average monthly owner costs are \$1,150 for Generation X solos, owner costs average around \$820 for Boomer solos and \$490 for Silent/Greatest solos. For solos who rent their home, costs are approximately even across the three generations:

Aspects of social connectedness and personal safety can be captured, to a partial extent, through measures of access to a variety of household technologies. More than half of Minnesota's solos have access to the following household technologies:

- Telephone (97%)
- Internet (72%)
- Laptop, desktop, or notebook computer (60%)
- Smartphone (57%)

For this analysis, estimates of access to household technology are not available by generation because most of these questions have only recently been added to the American Community Survey.

V. Issues, Gaps, Opportunities

Defining Health Decision Making



While Task Force members sought to avoid the “aging as decline” stereotype, they also recognized that managing health is a central issue for many from mid-life onward. As Barbara Ehrenreich noted in her 2018 book, *Natural Causes*, “No matter how much effort we expend, not everything is potentially within our control, not even our own bodies and minds.”⁸ Notably, over the past decade, the care needs of older adults have received considerable attention from many quarters. AARP has sponsored a series of studies about elder care as has the American Geriatrics Society, and the Administration on Aging has provided funding related to caregiving to states and tribal organizations, to cite a few examples.

Aside from the strong focus on *family caregiving* in these endeavors, it is important to point out the emphasis on the *delivery of “hands-on” services* such as help with medications and activities of daily living (ADL). The **decisional elements** of care are often overlooked or lumped in with the more visible activities. Decisional elements include such things as researching and assessing resources, managing costs, choosing between treatment options, navigating complex health system practices, and making decisions related to quality of life, among others. Data on the allocation of time spent on decision making was difficult to locate, but the Family Caregiver Alliance website (www.caregiver.org) provided some insights.

- According to the 2011 Gallup-Healthways Well-Being Index, caregivers spend an average of 13 hours per month researching care services or information on diseases, coordinating physician visits, and managing financial matters.
- The National Alliance for Caregiving and AARP 2015 report, *Caregiving in the U.S.* said caregivers hold decision-making authority. Specifically mentioned was monitoring the care recipient’s condition and adjusting care, communicating with health care professionals on behalf of the care recipient, and acting as an advocate for the care recipient with care providers, community services, or government agencies.

Historically, family members have functioned as both deciders and hands-on care providers, particularly in situations where older adults lack the capacity to make decisions for themselves.

Planning

If people don’t have an underlying safety net in the form of family, then having a health-decision support backup plan is critical. Ideally, this plan would envision and address the likelihood of health changes and events across mid-life as well as what might happen at the end of life. The scope of the Solos project did not include formal research to document what percentage

⁸ Barbara Ehrenreich, *Natural Causes: An Epidemic of Wellness, the Certainty of Dying, and Killing Ourselves to Live Longer* 2018 New York: Twelve- Hachette Book Group

of solos have long-term care/health decision plans. However, anecdotal evidence and personal experience suggested to Task Force members that the percentage is likely to be low. For participants in the interviews and focus groups, when planning had occurred, the plan was generally in the form of a will or health care directive.

With solos in mind, the Task Force spent time investigating and discussing existing models and tools to help older adults address and prepare for health events. Among the resources assessed were several developed by the state of Minnesota:

- *The Senior Linkage Line* – a call-in line staffed by individuals who can answer questions and direct callers to appropriate resources
- *Own Your Future: Long-term Care Planning Guide* (mn.gov/ownyourfuture) – a workbook that guides users through a planning process, looking at financial and support needs
- *MinnesotaHelp.info* - a searchable database of resources related to older adults throughout Minnesota
- *Minnesota Statutes 145C.16* (Suggested health care directive form) – policies and requirements governing health care directives in Minnesota

“I’ve been so focused on estate planning stuff that I didn’t think about health-care planning...”

—Solos Task Force Personal Interview

Overall, Task Force members felt these were valuable components of Minnesota’s health decision infrastructure, serving solos and non-solos alike. In particular, the Task Force liked the Senior Linkage Line because it allowed callers to talk directly with knowledgeable people and obtain personalized assistance. Task Force members did not view LTC Planning Guide and MinnesotaHelp.info quite as favorably. Both appeared to be best suited for users who were “self-starters” with the ability to work through the material independently and who had facility with the English language. These resources did not appear to be designed for individuals of different educational levels and levels of willingness and ability to think through the relevant issues. Also important, such resources did not appear to be well targeted to older adults from different cultures. It is not merely a matter of translating the materials into different languages; entirely different approaches may be needed to accommodate underlying health-related values and traditions.

The subject of health care directives came up throughout the Task Force Discovery process. This element of planning has received much attention since Congress passed the Patient Self Determination Act in 1990. Many attorneys and financial planners routinely encourage clients to document their end-of-life treatment preferences and name a health care agent in the event they are unable to speak for themselves. Task Force members found many tools and programs available, free of charge, to help people complete directives—a positive element in Minnesota’s health-decision infrastructure.

But Task Force members were also concerned that the health care directive is an imperfect tool and not a complete solution for addressing health decisions over time. Plans should attend to needs across mid-life, not just the very end. And, while attorneys and others may advise people to review and update their directives periodically, in reality, the step often does not happen. Consequently, at a critical decision point, the directive may have limited value. The older adult’s stated preferences may not reflect the current situation, and designated health care agents may no longer be willing or available to step in.

Unfortunately, health care directives may wind up in file cabinets, safety deposit boxes, and other locations unknown and inaccessible when circumstances create a need. Both of the above realities can cause problems for everyone, but they are particularly troublesome for people who lack a family safety net. There needs to be a clear set of guidelines about what to do with a completed health care directive so it is readily accessible. One guest speaker indicated that when health care directives are scanned into electronic medical records, they are generally more accessible to physicians. Hence, this step could be included in such guidelines. Not all medical providers and facilities have fully adopted electronic medical records, though. A number of online or cloud-based Advance Directories have been developed, including the American Living Will Registry (www.alwr.com) and US Living Will Registry (www.uslwr.com). These might be an alternative.

People – A Key Resource

There is little point in urging solos to create a plan if the building blocks to operationalize the plan are in short supply. And probably the most critical building blocks are committed and qualified people. When solos wind up in emergency rooms or short-term care facilities for rehab services, health care professionals first look for a person who is authorized to speak on behalf of the solo or provide decision support. Health care directives or other kinds of written instructions are not the first places people look.

Similarly, solos themselves cite the importance of having one or more people to consult and assist them, rather than informational materials or technology. Participants in both the individual interviews and the focus groups talked about seeking out friends or professionals when faced with various health situations and events. Only a few said Internet and other research would be a first or primary step.

If a solo lacks a friend who is willing and able to help, what other options exist? Sadly, Task Force members discovered there aren’t many. While some faith-based organizations have stepped in to meet the needs, many more have not. Concerns over liability and difficulty in recruiting volunteers who are willing to make a multi-year commitment to help often stand in

the way. A few nonprofit and volunteer-based organizations, such as Minnesota’s Living at Home Network and Little Brothers – Friends of the Elderly, provide rides to medical appointments and help with social isolation, but historically have not helped solos locate individuals who might serve as health care agents. Overall, there are few “pools” of willing, knowledgeable volunteer health-decision supporters and surrogates to be tapped.

Building Social Capital

A continuing theme running through the Task Force’s Discovery process was the importance of solos building social capital. But, as noted in the “Solos Snapshot,” the ability and willingness to do this varies substantially among solos. Good models and incentives to act are needed. Building support is not an impossible task, however. The participants in the Ebenezer focus group are a good example of how people can and do come together for mutual assistance—even those who qualify as low income. When asked about how they would handle health emergencies and who they would rely on, the participants consistently pointed to each other. Trust was the most essential ingredient, though they felt clearer information about available resources and health care directives would be helpful.

“I would really like a public effort to inform people about the idea of forming communities for aging... to get a group of friends to invest in a property where they would live and share a live-in caregiver.”

—Solos Task Force Personal Interview

Professional Supporters and Surrogates

Some solos are interested in retaining professionals to be decision supporters and health care agents and have the financial resources to make this possible. But again, credentialed professionals who can perform the desired roles are relatively few in Minnesota—and elsewhere—and often difficult to locate. Those roles include care managers, advocates, navigators, and health care agents. Medical facilities and service providers may have staff who perform some of these functions, but usually it is on a limited basis, such as during treatment or a rehabilitation period. Once discharged, solos then have to look elsewhere for ongoing professional decisional support. The need for independent paid health decision “supporters” and surrogates will only increase in the future.

Laws and Policies

As part of the project orientation session, Task Force members received an overview of the kinds of laws and policies that apply to supported and surrogate decision making. The project work plan did not allow for in-depth research and discussion of the legal underpinnings of health decision making. However, several issues emerged that seemed especially relevant to solos.

- An increasing number of states have adopted *default surrogate laws*. These are policies which establish a hierarchy of individuals who physicians may consult about treatment when the patient lacks decisional capacity, has not designated a health-decision surrogate, or where a health care directive is unclear or likely non-existent. Such hierarchies most often give priority to family members, but some states, including Arkansas, Colorado, and Delaware, have identified “close friend” in the list. Minnesota does not currently have a default surrogate law.
- Interest in retaining a paid, professional health care agent is increasing among solos and businesses are beginning to respond to this emerging need. With the expansion of private sector alternatives, new legal questions are beginning to appear, including whether and how to designate an organization as a health care agent. Also notable is the matter of how to assure effective oversight of professionals to prevent and address potential fraud and exploitation. More thinking and work is needed.
- Solos are not yet on the radar screen for policymakers, including Minnesota legislators. The growing number of people who could potentially meet the definition of a solo portends significant public policy issues if no steps are taken to help address decision support needs and gaps. How can solos be factored into future discussions about Minnesota’s older adults?

Education and Awareness

Public policymakers are not the only ones who lack an understanding of solos or solo-ness. For example, the view of some legal professionals is likely to be shaped by the context in which they come into contact with solos. Often this means acting on behalf of individuals who already lack capacity or who have been the victims of abuse or exploitation. Even professionals who deliver services to older adults aren’t always fully tuned in to the “continuum of solos” described earlier in this report. Organizational policies give priority to the most vulnerable adults or rely on a family member to be involved.

For professionals experienced in working with older adults, it is easy to assume that available practices and offerings will serve solos and non-solos equally well. When it comes to the “hands-on” portion of care, the assumption may be valid; for the health decision making element, maybe not. Consider the situation where a care provider notices a change in the client that calls for a different strategy and the client is not sure of what to do. For a non-solo, the provider would likely call upon a designated family member for help with a decision. However, if the same situation occurs for a solo, how would the provider respond? Given their independent tendencies, many solos are likely to be making their own care and support arrangements in the future. Do current policies and practices consider this?

Equally important and consistent with the framework offered earlier, people who are “a little bit solo,” or “occasionally solo” often are invisible. While they may not require regular personal care, they may need some resources to plug into their backup plan. Two examples came up in Task Force discussions.

- A standard practice of medical providers is to require patients to have a personal escort for certain procedures, such as colonoscopies and cataract surgery. This can be a particular obstacle for solos, particularly those where low cost or volunteer options are limited. A decision to forego or delay a procedure because of the resource gap could potentially lead to serious and costly health consequences later on.
- A common practice for organizations of all kinds (health clubs, rental units, nonprofits that recruit volunteers, employers, etc.) is to ask for an emergency contact. The underlying assumption seems to be that everyone has someone who can be reached 24/7 and who is capable of handling whatever the situation requires. Again, this can be a particular obstacle for solos.

With a better understanding of solo situations, organizations and professionals may be able to tweak practices or expand services to meet the needs of solos better.

“A few weeks ago, I didn’t have anyone to give me a ride to my colonoscopy appointment, so I finally ended up asking a couple from church to take me. It bothers me because I inconvenienced them.”

—Solos Task Force Personal Interview

Complex Systems and Personal Situations

Throughout the Discovery process, Task Force members encountered factors that, while not unique to solos, had an impact on and sometimes exacerbated solo-ness. A few examples:

- The absence or presence of medical providers and health care facilities is a critical factor in health and well-being. Solos may live in rural or underserved locations with few resources and so have difficulty in making optimal choices for themselves. Available providers may lack the cultural competency to serve diverse clients or have customs and practices that prove to be barriers.

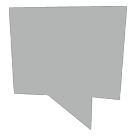
- The scope and affordability of health insurance is currently a major public policy issue—one that impacts health decisions by all, not just solos. Medicare, Medicaid, and long-term care insurance currently do not cover some of the services that solos need most (e.g. professional, independent care managers and advocates), though recent changes in policies provide coverage for some non-medical services.
- Personal financial situations are obvious potential contributors to solo-ness. For those who live in poverty or who lack financial resources, advance planning for possible health events is a theory at best. It is impossible to think ahead when all attention is on how to pay the rent or from where the next meal will come.
- Personal traits, habits, and values (e.g., fierce independence, anger, depression, procrastination, etc.) can and do influence solo-ness. Additionally, loss of physical capacity can impact the ability of older adults to perform self-management tasks such as using a computer to do research, getting to medical appointments, etc. Solos with disabilities may be subject to bias and stereotypical thinking from others
- Overall mental health and cognitive functioning can be an important factor. While there has been attention to those with declining or limited cognitive capacity, the temporary or intermittent loss of mental capacity is also an issue. Instances of depression, grief over a personal loss, addictions, and loneliness can influence the ability to make effective health decisions or ask for help.

Untapped Opportunities

During the Discovery process, Task Force members discussed several untapped opportunities, including the following two examples.

- As part of Medicare annual exams, patients are asked to complete a brief questionnaire exploring various elements of well-being, such as feelings about personal safety. Task Force members wondered if this might afford an opportunity to ask questions that might reveal the patient's degree of solo-ness and also point solos toward supportive resources.
- The application for a new or renewed Minnesota Driver's License provides a place for individuals to indicate whether they have completed a health care directive. Prior to the commencement of the Solos project, investigations by a Task Force member revealed that it was unclear whether and how anyone was using the captured data. Given the importance of knowing who has completed a health care directive, this practice merits more attention to assure agencies are putting this information to good use.

VI. Recommendations and Future Actions



After more than a year of exploration and discussion, the Citizens League Solos Task Force sees both the possibilities and the challenges of better supporting solos. Though creating infrastructure is not a simple matter, it is possible to start taking small steps toward the overarching project goal. There are many excellent resources in Minnesota for older adults that can be part of the long-term solution. Among the most critical first steps is developing a kind of “cultural competency” around solos and solo-ness as defined in this report. Organizations and policymakers alike must embrace this more nuanced view of those who function without the traditional safety net. And, solos themselves must acknowledge personal realities and master the technical and social self-help skills to stay in the driver’s seat of their lives.

As noted in the Introduction, the Task Force saw its work as a starting point, not a final destination. The ideas that follow will start to build understanding and momentum, including Short Term Actions (ideally to be commenced within the next one to two years) and Other Actions (to be implemented later or over a more extended period).

Recommendations

The Backup Plan

If an individual cannot rely on a family member or close friend to be a health-decision supporter or decision surrogate, then having a health decision “backup plan” is essential. But what exactly does that mean? Descriptions of what constitutes an effective plan abound—ranging from having a few legal documents to crafting more detailed documentation of personal preferences around care and end-of-life issues. While having many options is good, it can also be a source of confusion, particularly to those who don’t want to think about what might lie ahead.

Task Force members believe that the best strategy for helping solos is to establish a set of *minimum* plan elements and then to communicate that message clearly and consistently to all kinds of solos. The chart that follows contains what the Task Force recommends for **a basic health decision backup plan**. (Individuals may wish to do more but should work towards at least these items.) It is important to note, however, that organizations and policymakers must work to assure that these minimum components are available to solos who are endeavoring to create a plan.

Minimum Elements of a Health Decision Backup Plan

- **A Personal Health Decision Assistant (PHDA)** – *At least one individual who has the appropriate skills and is available to whom a solo can turn for help in the face of a health care change or health event. (Person may be a paid professional or volunteer.)*
- **An Emergency Contact** – *Someone who is very likely to be reachable 24/7. (This may not be the same person who serves as the PHDA or health care agent.)*
- **An Executed HIPAA Release Form** for each person with whom the solo wishes to share personal medical information if such form is required by a physician, facility, or clinic.
- **“Short Form” Health Care Directive**, completed in accordance with Minnesota law and reviewed at least every 3-5 years to make sure all information and preferences remain the same. (Both the “long” and “short” forms are available at Honoringchoices.org). If feasible, the health care directive will name one individual who is authorized to speak for the solo in the event the solo cannot speak for him/herself. [moved here]
- **Scan Any New or Modified Health Care Directive into Personal Electronic Medical Record**, if this option is available. The designated emergency contact should know who has a copy of the health care directive.

Short Term Actions

1. **Disseminate the Task Force Final Report to key stakeholders.** This will help organizations and others who serve and interact with older adults to better understand solos, solo-ness, and associated needs and issues.
1. **Develop and provide more extensive training about solos to professionals who interact with or serve solos.** Examples include elder law attorneys, non-profit agency staff, Senior Linkage Line staff, county human services staff.
2. **Stakeholder organizations should examine current customs and practices to determine whether they are “solo friendly.”** There is a need to identify whether and how stakeholder staff intersect with solos and whether those interactions support solos in managing personal health and well-being. Do standard practices (such as assuming a family member is available to act as a decision surrogate) present barriers? Organizations should look for opportunities to provide information to or gather information from solos relevant to health decisions and planning.

3. **Those who assist solo older adults with planning should recognize the importance of the Personal Health Decision Assistant (PHDA) and help solos to find/develop this personal resource.** Task Force members view this role as one of help and support and is separate and distinct from the decision surrogate role of the health care agent. It could be in the form of a single individual or a group of individuals who each support the solo in different ways. For solos with capacity and potentially many years of life ahead, finding this kind of support may be a higher priority than locating a health care agent.
4. **Organizations who identify, train, and provide volunteers to support older adults should expand their scope of services to include health decision assistants.** Many solos cannot afford to pay for support services, such as navigation, and need of free or low-cost options.
5. **Professionals who work with/serve older adults should identify or create and promote sustainable models for building “community” to help solos avoid isolation and craft a personal support system.**
6. **The Backup Plan Minimum Elements presented earlier in this section should be adopted by stakeholder organizations and shared widely and consistently with solos.**
7. **The planning resources available in Minnesota should be expanded to include a “self-assessment” tool to help solos identify gaps in their own planning relative to health decisions and health events. Resources should also be added to help faith communities and other organizations educate solos about the risks associated with a lack of planning.** Any tools should reflect a range of learning styles, educational levels, and cultural preferences.
8. **Minnesota should help address the information gap around solos and solo-ness by developing a detailed research agenda and plan for financing relevant research. This will facilitate the development of evidence-based solutions for the many issues delineated in this report.** Potential research could include collecting data about solos outside of the metro area, an assessment of institutional responses to solos in health care and service delivery settings, and factors that motivate planning among solos.
9. **Key state of Minnesota agencies, including the Department of Human Services, Department of Health, Workforce Development, and the Department of Employment and Economic Development, should collaborate to address the emerging and critical need for credentialed professional to serve in personal health decision assistant and health care agent roles.**

Other Recommendations

1. **State of Minnesota agencies serving older adults should identify and implement policies, standards, and procedures to better address solos and solo-ness.**
Example: Consider changes to Minnesota's Health Care Home standards so clinics could help solos identify sources of support for physical care needs, health decisions, and planning.
2. **Key staff of medical providers, such as billing personnel, should receive more extensive training on Medicare billing codes to better document discussions related to development of health care directives or POLST (Physician's Order for Life-Sustaining Treatment) documents.**
3. **Minnesota Driver and Vehicle Services (DVS) should assess the current practice of requesting information about health care directives on MN driver's license applications.** DVS should modify practices to assure that such information is available to medical professionals and others who can best use it.
4. **Professional Guardian associations should work with members to learn about solos and determine whether guardians could also serve in the health decision assistant or health care agent roles for solos.** Guardians who are willing to serve in these capacities should indicate this in any membership directories.
5. **Organizations that train and recruit volunteers should identify and investigate perceived barriers for individuals who wish to volunteer as a health decision assistant or health care agent.** Examples of barriers include concerns over personal or professional liability and conflict of interest.
6. **Create a public awareness campaign to help solos understand the importance of having someone to serve in the health decision assistant role** and potential sources of such sources of support, including outreach strategies tailored to those whose first language is not English.
7. **Medical service providers should ensure that the annual Medicare wellness exam includes a request to create or update a health care directive.** Providers should consider modifying the annual Medicare questionnaire to include questions related to solo-ness.

Work Plan

Phase 2 - Capacity Building Pilot Projects

The purpose of Phase 2 is to begin implementing several Task Force recommendations and develop individual and organizational capacity to achieve the overarching project goal.

Work to be completed between January 1 and June 30, 2019.

Project Key Activities

- *Analyze current Census data* to understand solos better and create evidence-based solutions. Disseminate the resulting information to stakeholders. (Task Force recommendation to address the information gap around solos through research.)

Work performed by Wilder Research. (Find a summary of these data in Section IV.)

- *Conduct a variety of informational and outreach activities* to inform stakeholders about solos and solo-ness. Includes completion and dissemination of Phase I Final Report in electronic and printed formats; creation and distribution of a solos Fact Sheet based on the data gathered in Activity 1; presentations to 2019 MN Leading Age Conference, Living at Home Network Annual Conference, MN Board on Aging, and MN Elder Justice Center Partners. (Task Force recommendations about educating stakeholders about solos.)
- *Community Building Among Solos Around Personal Health Decision Making.* This project will involve researching and identifying existing models for helping individuals develop personal connections and support to see how such models might apply to health decision support. In addition, the project will test out the Meetup platform as a low-cost tool for identifying solos and facilitating connections. Solos who participate will receive copies of the “Minimum Element of a Health Decision Backup Plan” generated by the Task Force in Phase 1.

A particular focus of this capacity building activity will be *LGBT solos*. Marcia Berry of Just Us Health will conduct research specifically about community building in the LGBT community and will coordinate a Meetup group, with initial activities related to creating a Backup Plan that addresses specific needs, concerns faced by older adults who identify as LGBT. Project leaders will document the process and learning so others can benefit from this initiative.

The Meetup platform will be used to offer a separate and more general group of solo older adults. The content and discussions will also be around creating a Backup Plan, locating resources, etc. A team of solos will be selected to lead and coordinate the activities. (Task Force recommendation about the need to identify, create, and promote sustainable models for building community.)

- *The Minnesota Elder Justice Center (MEJC) will develop an incapacity planning clinic to encourage solos who might not otherwise participate in health decision planning to do so. The clinic will be offered as part of National Health Care Decisions Day in April 2019. The focus will be on practical skill development, with participants learning about the advocacy services at MEJC, along with how to craft essential documents and locate resources. MEJC will use this as an opportunity to gather information about needs and experiences relevant to health care decisions of the solos who participate. The funds allocated will be used to compensate an intern and MEJC staff for supervising the project, marketing the event to solos, copying, etc.*

(Project addresses Task Force findings that more tools/resources are needed to help solos plan and offers an alternative model to the “community building” idea identified in 3 above.)

- *Mark Peterson, Pastor at Hennepin Avenue United Methodist Church (UMC) (and one of the Task Force Co-Chairs) will take steps to launch a faith-based network to help identify and offer help tailored to solos. Activities will include contacting existing and recruiting additional UMC caregivers; asking these caregivers to gather information from those they serve to learn their degree of “solo-ness,” and developing and adding a module to the caregiver training about the importance of personal health decision assistants (as defined by the Task Force). The plan is to market the training to other congregations as a first step toward building the broader network. (Task Force recommendation related to training those who help solos plan.)*
- *Phase 2 Capacity project coordination, oversight, and reporting will be provided by Linda Camp. Activities will also include preparation and dissemination of Phase 1 Final Report and preparation and dissemination of the materials and presentations described in 2 above.*

Project Outcomes

- Documented process and outcomes of new planning, training models.
- Evidence of viability and sustainability of these potential elements of the health decision infrastructure for solos;
- Credible data to expand understanding of solos and develop additional solutions.
- Professionals from stakeholder organizations will have a greater understanding of solos and solo-ness.

APPENDIX A

Project Teams

Executive Team

Pahoua Hoffman, Executive Director
Citizens League

Marit Peterson, Program Director
MN Elder Justice Center

Linda J. Camp, Solos Project Co-coordinator
Owner, Turning Point Consulting

Julie Roles, Solos Project Co-coordinator
Owner, J. Roles & Associates

[**Sean Kershaw**, former Executive Director of the Citizens League, served on the Executive Team through December 2017)

Task Force Members

Ellie Hands, Solos Task Force Co-Chair
(Solo, retired nonprofit executive director)

Mark Peterson, Solos Task Force Co-Chair
(Lutheran pastor)

Kathleen Dempsey
(Pathfinder Care Management)

Joyce Edwards
(Solo, small business owner)

James Falvey
(Executive Director, Little Brothers/Friends of the Elderly)

Genevieve Gaboriault
(Managing Attorney, Senior Law Project, Mid-Minnesota Legal Aid)

Susan Henry
(Member, MN Board on Aging)

Darla Kashian
(RBC Wealth Management)

Greg Owen
(Consulting Scientist, Amherst Wilder Foundation)

Task Force Members (continued)

Karen Peterson

(Executive Director, Honoring Choices MN)

Peter Rothe

(MD, Geriatrics, Health Partners)

Sabina Sten

(Solo, co-founder of Mill City Commons)

Patty Thorsen

(Solo, chair Met Council Transportation Accessibility Advisory Committee)

Martin Wera

(2016 Bush Fellow, Ameriprise Financial)

Ad Hoc Review Committee

Marsha Berry, Education Director, Training to Serve

Kristin Kinney, Executive Director, American Indian Family Center

Wendy Moreno, Wise Elders Coordinator, Centro Tyrone Guzman

Bee Vue, Service Director, Park Elder Center, Volunteers of America

APPENDIX B:

Questions (Interviews & Focus Groups)

Introduction:

Thanks for taking the time to talk with me today. I am part of a Citizens League Task Force investigating how solo older adults deal with decisions related to their health and future care needs. We define “solo” as an individual who, by choice or circumstance, is without the support traditionally provided by other family members.

1. Do you think that definition might fit in some way for you?

Yes _____ No _____

Why? {Record pertinent details}

Opening Questions

2. I'd like to begin by simply asking if you have had any experiences in the recent past that raised concerns for you about what would happen in the event of a significant change in your health or circumstances. If so, what kind of concerns did it raise?
3. Have you taken any steps to plan for your future health care needs, including both in the near future and at the end of life? [Probes: For example, do you have a Will or Health Care Directive? Some other kind of planning?] Describe. If not, why not?

Managing Health Events

4. Consider the following potential situations. How would you handle them? Describe.
 - Your doctor has diagnosed a medical condition that is not life threatening, but should not be ignored. There are several options to consider but you are unsure of what to do.
 - You are temporarily sick or disabled. Though you are not hospitalized you need medical/supportive care to recover.
5. If you needed help because of a significant change in your health or circumstances, do you have someone that you know you could count on to help you?
Yes _____ No _____ Not Sure _____

Decision Surrogate

6. You have a major health event and are suddenly unable to speak for yourself or make decisions about a treatment plan or action. Have you planned for such an event? Have you spoken with anyone about acting on your behalf? If not, why not?
7. What concerns do you have, if any, about having someone make health decisions for you?

Potential Solutions


8. What solutions/resources would you like to have available to help address some of the issues we have talked about in this interview

Background Questions

9. First, will you share your age? ____
10. Gender [***don't ask unless unsure***] ____ Male ___ Female
11. Do you identify as straight, gay, transgender or something else? (circle one or write in response)
12. How do you describe your ethnic or cultural background:
13. Do you currently qualify for any county or state funded services that you are aware of?
Yes____ No____ Don't Know____
14. Do you currently have a long-term care insurance policy of any type?
Yes____ No____
15. Are you part of any religious or spiritual community?
Yes____ No____

Appendix C:

The View from Stakeholders



Minnesota is rich in the number and kind of existing resources available to support people as they age. Task Force members felt that to move forward it will be important to tap into the expertise of these resources to build solutions for solos. As a first step, stakeholders were invited to a half-day informational gathering on October 16, 2018. Several Task Force members discussed the project's Discovery process and what they had learned. Following that, participants were invited to share their own experiences and ideas related to solos through both small group and large group discussions.

Thirty individuals representing 24 different organizations/agencies attended the gathering, giving a clear indication of the interest and timeliness of the issue. (See list at the end of this section.) Some participants shared information about their organization's current work related to solos; others identified steps they could take to become better informed about solos or better serve them. At the end of the session, sixteen individuals indicated an interest in being part of a work group that would continue to focus on solos in Minnesota.

Examples of Comments and Feedback

- *There can be fear from solos when seeking help that they aren't "good enough." Faith communities can be helpful in reaching home-bound and isolated older adults.*
- *Age friendly communities (World Health Organization initiative) is addressing social isolation and social participation. Pairing efforts would make sense. Curriculum, resources that can be built upon.*
- *Greatest need is raising overall awareness about what is needed to be prepared for making health care decisions.*
- *Elder waiver program may have data that can help to illuminate characteristics of solos.*
- *There is a lack of coordination of resources.*
- *ACT on Alzheimer's is a good model for making this kind of change.*
- *Health care has changed so that so much of it depends on active engagement of the family (even changing dressings in a hospital).*
- *Intervention point. We can use hip surgeries and similar as an entry point to talk about these kinds of issues. Need somewhere to refer them to.*
- *A lot of people are seeking neutral parties to help.*

- *Who pays for all of this? If people have support systems, health care costs are much less. Health care systems may see it in their interest to pay for some of the interventions.*
- *In the metro, Senior LinkAge Line serves about 89,000 people. We don't know how many of those folks are solos. Could be a place to gather some data. Also, the Board on Aging's survey of older Minnesotans, if they decide to repeat it might be a source of information.*
- *Senior LinkAge Line just name a new director and they are working on a strategic plan for where the Senior LinkAge Line needs to go for the future. Maybe someone from the task force could meet with them on topics of solos.*
- *Brochures in health care could be tweaked to be inclusive of solos.*
- *Consider a modification of intake system so people are asked if they have a support system rather than assuming they do.*
- *Concerns about making information available at the right place and right time. Privacy issues limit availability of information.*
- *Caregivers are often coming into solos lives in times of crisis.*
- *Fear of asking for help because if people realize you are struggling you will be put in an institution.*
- *Lack of trust in medical systems.*
- *Empowering. Experiencing solo-ness they are not solos.*
- *How can we create a framework that is all inclusive, includes solos but also includes others?*
- *In Minnesota in care facilitates, the patient's determination act says we need to ask people if they have a health care directive but that's all they do. How can we get them to take it a step further?*
- *We need to help people understand that solo-ness is fluid; it isn't unchangeable.*
- *We can add solo-ness to our web site to raise awareness of opportunities.*
- *We are developing a program/service to provide an on-call "trusted person" to support solos (who lack an emergency contact).*
- *Solos need better awareness of what health care planning means.*
- *I will take the solo information to our committees to start the conversation*
- *Should add language to the Board on Aging diversity guidelines to include solos and expand topics discussed in senior forums.*
- *Solos may not have the skills to plan and may not have the choice to pick someone with skills.*
- *I will talk with provider groups and challenge them to look at this issue.*
- *We most likely interact with solos but have not teased them out.*

- *Lack of knowledge of existing resources is a barrier.*
- *I am interested in exploring how Hennepin Public Health can inform/influence/connect Hennepin County Medical Center to address system barriers that exist for solos.*
- *Will take explanation to organizations to assess how focusing on this topic aligns with strategic plans for various communities.*
- *I can bring the “solo-ness” lens to partnerships to work with organizations to create systems change.*
- *We should look for “teachable moments” in our medical system (such as when someone schedules a colonoscopy).*
- *To help educate people about solos, we should mimic what works (e.g. Act on Alzheimer’s).*
- *The Faith Community Nurses Network nurses directly serve solos throughout the metro area in 250 congregations.*

Organizations Represented at the Stakeholders Meeting

- American Indian Family Center
- Apparent Plan (Faith Community)
- Carver County
- Center for Excellence in Supported Decision Making
- City of St. Paul, Advisory Committee on Aging
- Faith Community Nurse Network
- First Fiduciary
- Greater Twin Cities YMCA
- Hallie Q Brown Community Center
- Hennepin County
- Highland Park Living at Home Network
- Jewish Family and Children’s Service
- Living at Home Network
- Lutheran Social Services
- Massachusetts Health Decisions
- Metropolitan Area Agency on Aging
- Minnesota Gerontological Society
- Ramsey County
- Southview Acres Healthcare Center
- State of Minnesota, Department of Human Services/Board on Aging
- Stratis Health
- Unity Church Pastoral Care Committee
- Volunteers of America - Park Elders
- Washington County Public Health

