# A BACKUP PLAN FOR SOLOS



## Health Care Decision Making for People Aging Alone

Phase 2 Pilot Projects

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## I. Introduction

In July 2017 the Citizens League and the Minnesota Elder Justice, in partnership, commenced a project focusing on health decision making by and for solo older adults. The work was supported by a Community Innovations grant from the Bush Foundation. Solos were defined as "*…individuals who, by choice or circumstance, function without the support system traditionally provided by family.*"

In Phase 1 of the project, a 14-member Task Force spent a year gathering information, analyzing findings, and developing recommendations for future action. Task Force work was completed in November 2018. A complete description of Phase 1 is contained in a report released in February 2019 (Health Care Decision Making for People Aging Alone: Phase 1 Final Report.)<sup>1</sup>

A second phase of this solos project was launched in January 2019 in the form of five small "pilot" projects. These were not intended to be comprehensive efforts, but rather small and low-cost opportunities to test the soundness of several of the Task Force recommendations. The projects were developed around the following criteria:

- Core activities had to be completed within the Phase 2 window (January 1 to June 15).
- Pilot objectives had to be achievable with limited resources.
- Each pilot had to help build capacity and/or expand upon the ideas generated by the Task Force.
- Pilot activities had to be scalable and sustainable, and
- Pilots had to involve solos or incorporate ideas and information generated by solos.

#### **Overview of Proposed Pilot Projects**

#### Pilot 1: Information and Outreach

<u>Proposed Activities</u>: Conduct a variety of activities to inform stakeholders about solos and solo-ness. Complete and disseminate the *Phase I Final Report* in electronic and printed formats and distribute the Wilder Research *Solos in Minnesota and the United States* demographic analysis, and present key concepts to stakeholder organizations.

<sup>&</sup>lt;sup>1</sup> Report may be downloaded from <u>https://elderjusticemn.org/health-care-dicision-making-for-people-aging-alone</u> and also from <u>https://citizensleague.org/wp-content/uploads/2019/02/Solos-Project-Final-Report-2-2019.pdf</u>

#### Pilot 2: Community Building Around Personal Health Decision Making

<u>Proposed Activities:</u> Test the Meetup (social media) platform as a low-cost tool for identifying solos and facilitating connections. A goal for the solos who participate is to develop a personal health decision backup plan containing the *Minimum Element of a Health Decision Backup Plan* generated by the Task Force in Phase 1. Encourage participants to collaborate and engage in shared problem solving.

#### **Pilot 3: Community Building Among LGBT Solos**

<u>Proposed Activities</u>: Research and identify existing models for helping LGBT individuals develop personal connections and support to see how such models might apply to health decision support.

#### **Pilot 4: Incapacity Planning Clinic**

<u>Proposed Activities</u>: Create a mechanism to encourage solos who might not otherwise participate in health decision planning to do so. Implement the clinic as part of National Health Care Decisions Day in April 2019. Focus on practical skill development, with participants learning about the advocacy services at Minnesota Elder Justice Center (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.

#### Pilot 5: Serving Solos Through a Faith-Based Network

<u>Proposed Activities</u>: Initiate a faith-based network to help identify and offer help tailored to solos, starting at the Hennepin Avenue United Methodist Church (HAUMC) in Minneapolis.

Contact existing and recruit additional HAUMC caregivers; ask these caregivers to gather information from those they serve to learn their degree of "solo-ness;" develop and add a module to the caregiver training about the importance of personal health decision assistants (as defined by the Task Force). Market the training to other congregations as a first step toward building a broader network for solos.

#### **Proposed Outcomes:**

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

The section that follows summarizes each of the five projects, including objectives, participants, and results to date.

## **II. Results of the Pilot Projects**

#### **Pilot 1: Information and Outreach**

Project Manager: Linda J. Camp

Though the issues related to solos and solo-ness loom large, such issues are not yet well understood. Outdated and sometimes ageist concepts about solos are still embedded in systems, customs, and practices directed at older adults. Consequently, the Task Force felt it was important to widely disseminate its solos "framework," particularly to stakeholders who might be in a position to initiate actions and solutions. The *Phase 1 Final Report* was seen as an important educational tool, along with the *Solos in Minnesota and the United States* demographic analysis (prepared for the Task Force by Wilder Research, St. Paul, MN).

During the 6-month Phase 2 period, copies of the two publications were made available in both electronic and printed form. In addition, core ideas about solos and their needs relative to health decision making were shared in a series of presentations.

**Completed Presentations:** 

February:	Minnesota Leading Age 2019 Institute and Expo, Workshop (35 participants) ( <i>Leading Age is a professional and trade association of providers of services and facilities for older adults.</i> )
March:	MN Board on Aging (BOA), (Board and staff) (BOA has responsibilities for administering and overseeing Federal and State funds supporting older adults; promotes older adult policies to the MN legislature, governor, and state of MN agencies.)
	MN Department of Human Services, Aging and Adult Services Division Staff Meeting (40 staff)
April:	MN Elder Justice Center (MEJC) Partners Meetings - Solos Task Force Findings (18 participants)
May:	MN Elder Justice Center Partners Meeting-Pilot Projects (25 participants) ( <i>MEJC partners include staff from a range of public and nonprofit agencies, educators, and consultants who are interested in elder justice.</i> )

May Completed presentations continued...

Alliance of Professional Health Advocates (APHA) online training (15 participants) *(APHA is a professional association for independent health* 

advocates-- individuals who advocate for and assist older adults and others with health events and well-being.)

Hennepin Avenue United Methodist Church (UMC) Care Team Training (8 participants) *(See Pilot 5 description)* 

Copies of the Phase 1 report and demographic analysis were distributed as part of the presentations and also to other individuals and networks, including;

- Representatives of the 24 stakeholder organizations attending the October Task Force stakeholder meeting (**See Phase I Report for description**);
- Citizens League web site
- Minnesota Elder Justice Center web site
- Alliance of Professional Health Advocates web site
- ABA Commission on Law and Aging "Solos" online discussion forum
- Individuals who expressed an interest in the project

#### **Outcomes Thus Far**

Though it generally takes time for new information and ideas to percolate, some positive results from the educational efforts are beginning to emerge. Several stakeholders have already taken steps to incorporate the solos framework into their work.

- Members of the MN Board on Aging indicated that solos will be a subject for future Board discussions.
- MN Department of Human Services (DHS) staff have indicated a willingness to incorporate information about solos into training for those who staff the Senior Linkage Line. And, when DHS websites are updated, staff will look for opportunities to create greater visibility for solos, and to assure solos-related info is easier to locate.
- A round-table discussion about solos is being included on the agenda for the 2019 Aging and Disabilities Odyssey (July 2019, bi-annual conference, sponsored by the MN Department of Human Services).

The initial information and outreach generated the following additional requests for presentations.

#### Scheduled:

August: MN Department of Human Services Monthly Video Conference Training (Available to several hundred individuals and organizations throughout Minnesota.) Scheduled presentations continued...

- September: MN Living at Home Network Annual Meeting (Formerly known as Living at Home/Block Nurse programs.) Attendees will include staff and other representatives of 32 member programs in Minnesota.
- October: Honoring Choices Annual Conference (Twin Cities, MN)

#### Pilot 2: Community Building Around Personal Health Decision Making

Project Coordination Team: Linda J. Camp - Backup Plan Project Coordinator Susan Hawkins - Independent Consultant & Facilitator Marsha Berry - JustUs Health Nancy Maas - Volunteer, solo Elizabeth Delay – Volunteer, solo

#### Overview

Throughout their deliberations, the solos Task Force members came back to the subject of social capital—recognizing the importance of connections to health and well-being. A significant work product from their discussions was a list of "*Minimum Elements of a Health Decision Backup Plan*" (Appendix A). One of the recommended elements in the list is a "Personal Health Decision Assistant" or, more simply, at least one person who a solo can turn to for help with health-related decisions. Though solos may have friends and acquaintances, those individuals may not constitute an effective community of support when a health event or issue occurs. Thus, it may be necessary for solos to mobilize other support resources. This pilot project sought to explore one possible model for helping solos craft such a community of support using a widely available social network platform—the Meetup Group<sup>™</sup>.

The Meetup application has been widely available across the United States via the internet for more than a decade and is frequently used to bring people together around common interests and/or social activities. One or more organizers simply propose a new group to the Meetup site central administrators. If the proposal is accepted, a new group is created with its own Meetup page. A group may be open to anyone who is interested, or established as a "closed" group— available only to individuals who meet specified requirements. Each unique group page allows members to schedule and sign up for activities and to track participation.

In several places around the country "elder orphan" Meetup groups exist, with most having a general focus on topics relevant to individuals without partners or family, such as housing. Organizers of the solos pilot, however, wanted to see whether Meetup would be an effective tool for connecting people for a narrower purpose--creating and sustaining a health decision backup plan. Could the Meetup platform help build personal connections through shared research and problem solving? To find out, the *Solos Taking Charge* Meetup group (STC) was launched in mid-January as a "closed" group.

#### Process

Given the limited pilot period and the need to have a manageable number of participants, the organizers decided not to publicly advertise the availability of *Solos Taking Charge*, but rather to simply use the notification tool available within the Meetup application. In this way, individuals who signed up would already have a personal Meetup account (the first step in accessing any Meetup group) and be familiar with the site functionality; no new training would be needed. When STC was established, the organizers assigned it to the Health and Wellness category. So, any individuals with a personal Meetup account interested in new groups related to Health and Wellness received an email notifying them about the STC group. Interested individuals had to respond to the following three questions:

- 1. Why do you feel the term solo applies to you?
- 2. What do you hope to get out of the group?
- 3. Do you agree to be an active member-attending monthly meetings?

Approval for membership was contingent upon the answers provided.

Within 24 hours of the STC group launch, people began applying for membership and by the end of the first week, fifty **(50)** individuals had been approved for membership (none disapproved). By the end of the second week, an additional eleven **(11)** were approved. During the pilot period more people were added and some dropped off. As of this writing, the membership count is **72**.

An official kickoff/orientation session was held on February 26. Attendance was low due to snow and bad driving conditions, so a second session was held in St. Paul on March 16. On both days, organizers sought to clarify the purpose of Solos Taking Charge Meetup and to provide information on planning for health decision making and well-being. Participants received the Solos Task Force's *Minimum Elements of a Health Decision Backup Plan* (Appendix A) and had the opportunity to beta test a new planning tool.<sup>2</sup> Because an important goal of STC was to help participants connect with others for mutual support, at the March orientation session, time was allocated so participants could self-organize into two small groups—East Metro and West Metro. Participants received a handout with suggestions about how to work together going forward and were encouraged to share their reasons for joining STC. (Appendix B.)

These small group discussions proved to be lively, with good contributions from attendees. By the end of the meeting, both groups had started to plan for follow up meetings where the shared work would begin. Since then both the East and West metro groups have continued to hold monthly meetings (in St. Louis Park and Woodbury), each with specific agendas. Both have generated lists of topics or issues related to health decision making and planning and have divided up research responsibilities.

Because the times and locations of the two initial all-member meetings were problematic for some, a third "mini" orientation session was held in St. Paul on April 9, following the same format and content. At the end of that session, meeting participants opted to form a third small group that would meet in the Twin Cities suburb of Roseville. Since then, this Roseville group has also held additional meetings with good involvement from attendees.

The 72 individuals who have joined Solos Taking Charge reside throughout the 7-county Twin Cities metropolitan area. Many are retired, though some continue to work. Having such a dispersed membership with varying availability has made it difficult to find suitable times and locations to convene meetings of the entire organization. In response to this problem, STC organizers have experimented with online video meetings using the Zoom<sup>™</sup> conferencing platform. As of this writing, two different online meetings have been held with seven and fourteen participants, respectively. Those who participated appreciated the opportunity, but

<sup>&</sup>lt;sup>2</sup> This planning tool was developed outside of the Solos Task Force project and is not yet publicly available, so the beta version has not been included as an Appendix to this report.

indicated they saw such meetings supplementing rather than replacing the small group, face-to-face gatherings.

#### **Results & Observations Thus Far**

When Solos Taking Charge was initiated, the organizers had no idea whether the Meetup platform would be an effective tool for the specific purpose of helping solos with health decision planning and support. It wasn't clear what kind of structure and direction, if any, would be needed to accomplish the organization's purpose, and what participants could do on their own. And, equally important, it wasn't clear whether it would be possible to build sufficient momentum within the pilot period for the STC organization to be sustained into the future. Though Solos Taking Charge is still in a formative stage, this small pilot project has yielded a few important insights.

#### 1. Timeliness of Initiative

The rapid response to the initial posting of the STC group suggests that health decision planning and support is on the minds of many solos. Solos are beginning to recognize a need and are looking for assistance.

Sample Feedback from the March Orientation Session:

- I appreciate the information presented at this meeting.
- I'm impressed with the enthusiasm from everyone here this morning.
- I'm impressed by the conversation and the process.
- *I like the big and small ideas that my group shared.*
- It brought out the importance of community.
- I feel more empowered.
- *I'm inspired by the energy of the morning.*
- This is a trailblazing group!

Sample Feedback from the June 5 Online Meeting, Assessing Progress

- Our small group has made a lot of progress.
- People who have participated in our small group have been very engaged.
- I'm taking care of things I never would have done on my own.
- STC should definitely continue as a Meetup group.

#### 2. Balancing Structure and Individual Initiative

During the preliminary planning phase of this pilot, the organizer team debated how much to control the agenda and flow of activities and how much to leave to the discretion of the STC group members. Though it was essential to keep people focused on the overarching purpose, it is equally important for them to have a hand in the long-term shape and success of the organization. The decision to provide background information and guidelines (Appendix B) at the orientation session now appears to be a good one. This kind of foundation allowed participants to make early progress and not lose a lot of time floundering over direction. In fact, those who attended one of orientation sessions have been able to engage more quickly than those who were not present

That said, building a cohesive group takes time and skill, and some participants have more experience with group processes than others. Each group has moved forward in a different way and at a different pace. One of the small groups has lost several members and attendance has been low because of competition with other summer activities. The delegated, small group format seems best suited to "self-starters" and others who can function without a well-defined structure.

#### 3. Advantages and Disadvantages of the Meetup Platform

The Meetup group platform can be a useful and low-cost tool for helping people connect. It helped bring a group of solos together who probably would not have met otherwise and the format is beginning to facilitate collaboration. When active members were polled about future directions, there was a strong interest in continuing as a Meetup group rather than shifting to a different organizing mechanism.

While the decision to promote STC only to existing Meetup members allowed for a short "ramp up" period, it also had disadvantages. Individuals who have past experience with Meetup groups have formed certain "habits," such as signing up for a new group and then electing to observe it for a while rather than jumping in to the activities. Currently of the 72 approved members, only about a third are actively participating in the small groups and other offerings. It also seems likely that some of the individuals who joined did not read and/or fully comprehend the narrow purpose of STC and how it would work. Some such members have already left the group and others will probably do the same in the future when they realize their expectations may not be in line with the STC purpose.

#### 4. The Challenges of Creating Community in the Twin Cities

As noted earlier weather, schedules, driving distances, and workable meeting locations have proved problematic in mobilizing the people who have joined STC . Active members have expressed a preference for in-person gatherings, but it has been difficult to find suitable free locations for "all member" gatherings and meetings of smaller groups. Some individuals who have been inactive thus far have said it is largely because they are still working and prefer evening and/or weekend meeting times. None have stepped forward, however, to help organize small groups that accommodate such needs.

#### **Future Directions**

The active members of Solos Taking Charge would like to see the organization go forward and two the small groups have scheduled meetings during the summer. Some active members have suggested that the orientation session be packaged as a podcast or video to help stimulate wider participation. Similarly, members would like to see the orientation materials made more widely available via one or more web sites. There is also interest in continuing regular online conferences so people can check in with each other and also to serve as an avenue for presentations by guest speakers.

The project organizers are exploring options for continuing the purpose and function of Solos Taking Charge. These options include:

- Polling the inactive members to find out their reasons for not participating and identifying ways to stimulate involvement.
- Advertising the availability of the STC Meetup more widely and recruiting additional members.
- Discontinuing using the Meetup platform and continuing the purpose and activities under the umbrella of a related organization.

If the function is to continue, regardless of form, based on the experiences thus far, one strategy seems likely to produce success. All new members should be required to attend an orientation meeting and to make a commitment to be part of a small group—whether one of the existing groups or any new ones that may be created. It also may be helpful to delineate the expectations for STC members more clearly up front —that members are responsible for ongoing operations and the ultimate success of each small group. Finally, each small group must be flexible and resilient enough to incorporate new people over time and to stay committed to the purpose of Solos Taking Charge and to each other.

#### Pilot 3: Community Building Among LGBT Solos

Project Manager: Marsha Berry, JustUs Health Megan Mueller, Community Education Supervisor, JustUs Health

#### Introduction

During the Discovery portion of the Solos project, Task Force members discussed the need to make sure all segments of the population are factored into conversations about solos. Among the groups who traditionally have been at risk for solo-ness are individuals who identify as LGBT. Because the Task Force did not have time to sufficiently explore LGBT solos, this topic was selected for additional investigation.

#### **Background Research**

The population in the US and in MN is aging and becoming more diverse. By 2020 Minnesota will have more individuals age 65 and older than students in K-12 education. <sup>3</sup> The Minnesota State Demographic Center predicts that Minnesota's population of people of color will increase by 50.3 percent between 2015 and 2035. The increase in diversity will also include growing numbers of LGBT older adults.

The estimate of LGBT older adults in the population ranges from three (3%) to eight percent (8%).<sup>4</sup> Using these estimates and those from other population surveys, there appear to be 10,500 to 28,000 people in the Twin Cities metropolitan area age 65 and older who are LGBT. <sup>5</sup>

The LGBT community in the Twin Cities metropolitan area is diverse and dispersed. There is no longer an easily identified LGBT neighborhood in either of the core cities of Minneapolis or St. Paul. As LGBT adults have moved out of the core cities to the suburbs many supports for the community have been lost. The lesbian identified and the gay identified bookstores have closed. The lesbian identified bar is no longer part of the community. Many of the gay identified bars are "trendy" and have become gathering places for people who do not identify as LGBT.

Not having an identified neighborhood makes it more difficult to find LGBT older adults and leaves many of them feeling isolated. Comments from LGBT older adults gathered by the MN Leadership Council on Aging (MNLCOA) in 2018 reflect this feeling.<sup>6</sup>

<sup>&</sup>lt;sup>3</sup> (Demographic Considerations for Long-Range and Strategic Planning. MN State Demographic Center, 2016)

<sup>&</sup>lt;sup>4</sup> (Institute of Medicine, 2011. *The Health of Lesbian, Gay, Bisexual and Transgender People: Building a Foundation For Better Understanding*. Washington, DC. The National Academies Press)

<sup>&</sup>lt;sup>5</sup> (2012 Twin Cities LGBT Aging Needs Assessment Survey Report. Pfund Foundation and the Greater Twin Cities United Way ) http://pfundfoundation.org/wp-content/uploads/2015/08/12046-PFund-LGBT-Aging-Report\_online.pdf)

<sup>&</sup>lt;sup>6</sup> (In 2018 MNLCOA worked with Hayley McCarron, a Masters in Public Health student at the University of Minnesota to prepare a report focused on diverse older adults. The report, *Needs Assessment of Older Adults in Minnesota's Diverse Communities*, was released in early 2019.)

One finding showed that LGBT older adults "in need of temporary care, such as after a surgery do not have anyone to rely on due to their thinning social networks."

The *2012 Twin Cities LGBT Aging Needs Assessment Survey* also highlighted this isolation. Compared to other older adults, LGBT older adults were more likely to live alone and less likely to have a caregiver or children.

An interesting and important finding of this survey may have implications for the Solos Task Force work. Survey respondents were asked about LGBT specific services or health care and aging programs that serve everyone in the community in nine categories (adult day services, support group, senior center, retirement housing, housing, nursing home, home health care, health care clinic, home services). For eight of these categories respondents indicated they preferred to access services that served the entire community, but were LGBT welcoming. The only service respondents preferred to be LGBT specific were support groups.

Also related to the Solos project, over half of the survey respondents stated they have a healthcare directive. Some 90% of the respondents older than age 75 reported having a health-care directive. These rates are higher than those found in the general population of older adults. This finding also matched rates found in other national studies.

As part of the research for this pilot project, JustUS Health staff searched the Pub Med databases to look for other research related to the LGBT community and health care directives. Utilizing a variety of search criteria, words, and phrases, however, generated no additional studies specifically related to health-care directives and LGBT older adults. There are specific LGBT aging services and support organizations, but none seem to be focused on health-care directives particularly or utilize the definitions of solo generated by the solos Task Force.

#### Connecting with Pilot Project #2 - Community Building

To add another dimension to the LGBT solos pilot project, the Project Leader was added to the Coordination Team for the Solos Taking Charge pilot described previously. The Meetup format seemed to offer a way to reach out to LGBT older adults and include them in the work of developing plans and resources for solos. During the February Kickoff meeting, one of the coordinators identified herself as a lesbian older adult and offered to talk with anyone who had questions about how the Solos Taking Charge Meetup would proceed. After the meeting one woman approached the coordinator and said she wanted to share information about STC with her friends.

At the March Orientation session, the same coordinator made a similar presentation. Since one of the agenda items was for those present to begin forming smaller subgroups, the coordinator let participants know it was possible to form one or more small groups that would be LGBT specific. Though the organizers had indications that some of the attendees likely identified as LGBT, no one indicated an interest in forming an LGBT small group. This occurrence was consistent with the findings of the *2012 Twin Cities LGBT Aging Needs Assessment Survey* that LGBT older adults preferred to access services that are LGBT welcoming, not LGBT specific.

#### Recommendations

The research described herein, though limited, offers additional insights into how to help solo LGBT older adults plan for and manage health decisions and health events.

#### Recommendations continued...

- Continue to ensure that any Meetup or other group gatherings and associated print and outreach materials are LGBT welcoming. Developers of such resources should use inclusive language such as; "Whether you identify as straight or LGBT it is important to have a Backup Plan."
- Those who provide services and support to older adults should make participants/clients aware of resources specific to the LGBT community such as the MNLGBTQ Directory managed by JustUs Health.
- Include members of LGBT community and organizations on committees or task force groups. Ask them to openly identify to help make the space feel safe for all.
- Educate professionals who serve older adults about the Pilot 3 research, and encourage them to incorporate the key ideas into their work.

#### **Pilot 4: Incapacity Planning Clinic**

Project Managers: Chris Courtney, MN Elder Justice Center Nora Huxtable, Extern (University of St. Thomas Law School)

#### Overview

In conjunction with National Healthcare Decisions Day (April 16, 2019), MN Elder Justice Center (MEJC) worked with the MN State Bar Association and Northwest Legal Aid to offer incapacity planning clinics in two locations—St. Paul and Perham, MN. Participants each had the opportunity to schedule a 45-minute session with a professional volunteer to work on health care directive and power of attorney documents. The emphasis was on practical skill development with participants learning the advocacy services of MEJC, along with how to craft essential documents and locate resources. The clinic also offered the opportunity for MEJC to gather information about needs and experiences relevant to the planning needs and concerns of the solos who participated. All of the volunteer professionals received information and training about solos prior to the clinic.

MEJC staff transmitted information about the availability of the clinic to its list of partner organizations. In addition, the members of the Solos Taking Charge Meetup group (Pilot 3) were informed of the opportunity and encouraged to attend. The St. Paul clinic was held at an Episcopal Homes residence in St. Paul, and so flyers were distributed at that location prior to the event.

#### Results

MEJC was able to serve **19** clients through the two clinics. Professionals who volunteered to work with the participants included **7** attorneys, **4** law students, and **5** social work students/other professionals. Eight participants filled out a written evaluation, seven of them solos.

#### Written Evaluation Responses

- All agreed or strongly agreed their attorney answered their questions
- All agreed or strongly agreed they "understand health care directives and powers of attorney better than when I walked in"
- All strongly agreed they would recommend the clinic to a friend

#### **Comments**

"This is very helpful for the community"

"Like the resource people and the documents

"I didn't know before this that professional resources are available to deal with these end-of-life issues"

"Great service-Thank you!"

*Comments continued...* 

The professional volunteers who participated in the clinic gave the initiative high marks. Sample comments:

"Wonderful group of attorneys, social workers. Great client base.

"Do this again. Great event."

"This was a fantastic learning experience for students! A great way to get involved."

Minnesota Elder Justice staff are now reviewing the results and assessing whether and how this kind of clinic might be replicated .

#### Pilot 5: Serving Solos Through a Faith-Based Network

Project Manager: Mark Peterson, Hennepin Avenue United Methodist Church (Co-Chair of the Solos Task Force)

#### Overview

For a number of years Hennepin Avenue United Methodist Church in Minneapolis (HAUMC) has implemented a Care Team—lay volunteers who visit other congregation members who are "shut-ins" or in nursing homes. Stimulated by the solos Task Force work, HAUMC decided to expand the Care Team efforts to include a focus on solos.

HAUMC has developed a detailed curriculum to train Care Team members, consisting of six modules related to care and support. For this pilot, a seventh module was added to offer information and guidance about solos and their needs about mid-way in the overall training. Content included the solos definition and framework, along with a delineation of ways the Care Team might support solos. Copies of the Wilder demographic analysis were distributed attendees.

#### Results

Those who attended the training were very interested in the material and contributed their own insights and examples related to solos. All agreed that the session had been helpful. The next day, one participant sent the following feedback:

"The presentation on solos was remarkable in that it has opened a dialogue between my wife and myself regarding many of our friends who are living 'solo" and what conversations we might want to have with them going forward."

Care team members have been asked to collect some new information from those they visit:

Does the individual

- Qualify as a solo per the Task Force definition?
- Have a Health Care Directive?
- Have a health care agent, and if yes, who?
- Have a family member or friend who helps them navigate the health care system, and if yes, who?

This information will help the Care Team better understand and identify people who may meet the definition of "solo."

#### Next steps

The training was just a first step for HAUMC; several other activities are planned to achieve the overall pilot project goals.

- HAUMC will offer a Sunday morning adult education session on identifying and supporting solos to congregation members. It is tentatively scheduled for mid-October.
- After holding the adult education session, HAUMC hopes to create and facilitate a "solos peer support group" similar to the "Community as Family" initiative by several faith communities in the Greater New York City area. The purpose of the group will be to provide solos with a mechanism for mutual aid, support, and shared problem solving.

### Appendix A: Minimum Elements of a Health Decision Backup Plan

(Developed by the Citizens League/MN Elder Justice Solos Task Force. February 2019)

#### 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.

Appendix B: Solos Taking Charge Meetup Group Handout

## Developing Your Backup Plan

#### Just In Time/Just Enough

The second half of life differs from the first half in several important ways:

- There is more emphasis on using up resources rather than accumulating resources;
- The time perspective generally changes from unlimited to limited.

Consequently, a different approach to planning is warranted—one that focuses more on the present than the future. In the manufacturing world, "just in time" acquisition of materials is considered a best practice. This may be a useful model for planning around managing well being and health decisions.

Think of the rest your life as a series of increments (3-5 years each).

As you start each increment, ask yourself:

- What is important to me right now? (lifestyle)
- What do I know about my own health right now?
- Is my Backup Plan adequate for the next 3-5 years?
- If not, what should be added or changed?

#### **Planning/Action Steps**

#### Things to Do on Your Own

- 1. Complete or revisit the Backup Plan Personal Inventory
- 2. Review the questions at the end of the Inventory
- 3. Determine whether you have met the Minimum Requirements for Health Decision Backup Plan

If you haven't met the minimum requirements, try to fill in the missing pieces as soon as possible. You may find it helpful to collaborate with others here.

#### **Collaborating With Others**

## <u>Personal Discovery</u> – (With an emphasis on sharing ideas, surfacing concerns rather than asking for commitments from others)

- 1. Share your "solo" situation (What factors cause you to identify as a solo when it comes to health decision making and well-being?)
- 2. Share the results of your Backup Plan Inventory (Where are you best prepared? What are your biggest gaps?)
- 3. Thinking about your current situation, what gaps do you want to address first?
- 4. What are the priority gaps for others in your group? Do you see common themes/concerns?
- 5. What kind of expertise/support might you offer to others in your group? What kinds of help/support might you like from others? [Examples: Sometimes need a person to accompany you to a medical appointment/would be willing to accompany someone; Need help in organizing records/would be willing to offer help in organizing records]
- 6. What kinds of community and/or professional resources do you know about? What kinds of resources would you like to learn about?

#### **Discovery Through Research**

- Based on your discussions of the above, create a list of topics/resources, etc. for investigation. Talk about approaches (i.e. phone interviews, internet research, experiences of others) (Note: the resource list on page 4 is a possible starting place)
- 2. Identify some of the key questions to pursue as part of these investigations.
- 3. Have group members volunteer to handle each item.
- 4. Agree on a timeline and format for reporting back to the group (i.e. oral report, notes to be shared with others, etc.

#### <u>Analysis</u>

- 1. Talk about what you have learned from your Discovery process.
- 2. Do you see possibilities for crafting your own solutions to address gaps?
- 3. What can you do together?
- 4. What kind of support/assistance do you need?
- 5. What barriers/issues did you identify?

#### Important Roles in a Backup Plan

Your people resources play different kinds of decision support roles. Consider these as you collaborate with others.

Decision Role	I need this	I Could Do This For Others	Not Sure
Advocate			
Researcher			
Planner			
Navigator			
Evaluator			
Coordinator			
Helper/coach			
Listener			
Decision Enforcer			
Decision Maker			

#### **Development of Solutions**

(Further guidance will be available as needed if/when you reach this point.)

#### Logistical Elements for Group

Where to meet
Meeting agenda
Meeting Time/length
Discussion Ground Rules (if any)
How often to meet
Documenting discussion
Meeting Manager
Posting notice of meeting on STC Site

#### Resources

Minnesota is fortunate to have many good resources to assist older adults, however, long lists of web sites, publications, and providers can be confusing and overwhelming. Below is a list of what can be considered "gateway" sources; these are a good starting point and can lead you to additional information.

#### Minnesota Board on Aging Website <u>http://www.mnaging.org/</u>

Sponsored by the State of Minnesota, this site provides information for individuals, advocates and service providers.

#### Senior Linkage Line <u>http://seniorlinkageline.com/</u>

1-800-333-2433

A phone line where callers have the opportunity to talk directly with trained staff who can provide assistance in locating resources, and will answer questions about topics of concern, such as Medicare.

#### Honoring Choices <u>https://honoringchoices.org/</u>

Honoring Choices helps individuals develop Advance Care Directives (ACD) that meet MN legal requirements. Includes links to both the MN Short and Long ACD forms

#### American Bar Association/Commission on Law and Aging

https://www.americanbar.org/groups/law\_aging/resources/health\_care\_decision\_making/ The above link will take you to a page of excellent tools and articles directed at consumers (scroll down to the "Consumer Resources" section.

#### Minnesota Elder Justice Center https://elderjusticemn.org/

Local experts on elder abuse, exploitation. Offer a call-in line to assist individuals

#### MNLGBTQ Directory MNLGBTQDIRECTORY. org

This is an online space for LGBTQ people who are seeking health-related resources in MN. It is managed by JustUs Health.





