

Meeting Minutes

A Backup Plan for Solos Task Force

Tuesday, July 17, 2018 – 7:30 to 9:30 AM
Wilder Center, St Paul, MN

Task Force Members Present: Joyce Edwards, James Falvey, Genevieve Gaboriault, Ellie Hands (co-chair), Susan Henry, Greg Owen, Peter Rothe,

Members Not Present: Kathleen Dempsey, Darla Kashian, Karen Peterson, Mark Peterson (co-chair), Sabina Sten, Martin Wera

Guest: Vic Rosenthal. Independent contractor working in aging field

Staff & Staff Support Present: Linda Camp, Julie Roles, Pahoua Yang Hoffman

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.

Expected Outcomes of the Project

- General profiles of solo older adults (situation, needs, perceived barriers)
- A description of the current Minnesota infrastructure to support solos health decision making
- Description of the core elements of a health decision “backup plan”
- A list of important resource gaps and potential solutions
- A list of recommended priorities for future action and preliminary work plan

Proposed Outcomes for This Meeting:

Complete discussion of issues, best practices, opportunities, gaps related to health decision making by and for solos with capacity to inform stakeholders and others. Develop a preliminary list of priority ideas.

Check-in and Updates

Co-chair, Ellie Hand, called the meeting to order. Asked for additions, deletions, changes to the minutes of the 6/12/18 meeting. Minutes were approved with one change. On second page correct “Return to Home” is “Return to Community”.

- Member followed up with Lutheran Social Services about their health care agent services. \$500 entry fee. \$105 per year for annual check-in conversation. Could be a barrier for many. Not good follow up. Now in conversation with First Fiduciary. They have been very responsive. Their entry fee is about the same.
- Pahoua introduced a guest: Vic Rosenthal. Worked for the Senior Federation and director of Jewish Community Action, a nonprofit that works on social justice issues. Working on a project on dialogues with multi-cultural elders for the last few months. Did 23 dialogue and working on a report to submit to the board on aging.
- Member is having knee replacement surgery. Had meeting with education care coordinator. Need a personal coach if you are a solo. Long list of responsibilities of a personal coach. Asked what happens if I don't have anyone to take me home. Medicare will only pay for a day in the hospital now and then you go home. Sending home helps to reduce risk of infection. Getting people out of hospital more quickly. Tasks of a personal coach are more

than you could ask any friend to do. I put together a care team. Four or five people. Shifting care out of medical system into the community.

- Ad hoc group will meet again on September 6 at the Minnesota Elder Justice Center from 11:00 to 1:00. We will share our preliminary recommendations with them prior to the meeting and will ask for their feedback.
- Linda noted that the agenda has information about our remaining meetings. She brought attention to a meeting scheduled for October 16 at Wilder to present the task force recommendations to the larger community. Hope task force members will attend and present at the session.

Review of Points for Snapshot of Solos

Linda presented a discussion summary document that she pulled from the task force meeting notes. Gave people an opportunity to review the document. She also noted that she sent out an initial draft of the solos chapter in the report. She invited people to email suggestions to Linda.

Barriers/gaps

- Should have something about people in poverty and generational poverty. Focusing on day to day crisis not planning. Poverty makes people stress out.
- Add cultural differences to personal barriers. Health care system is designed to serve the prominent culture. Intercultural issue.
- Project at an adult care center helping them do health care directives. Took a lot of education to get people to understand what it is. Some culture difference didn't trust, did know what could be put in the form.
- Unwillingness to ask for help is sometimes an inability to ask for help. Due to trust issues.
- Also think it is our independent nature. Dominant culture is geared toward independence. Cultural norm is to be independent.
- Lack of insight into the need to plan. Assumption that it will be okay. The doctor will decide. I don't need to worry about it. I don't need to plan.
- People are in denial.
- Under potential barriers, add mental health.
- Under personal barriers, add geographic isolation.
- Did know what old age would be like.

Information Related

- Add language. Different abilities, cultural backgrounds
- Literacy in general
- Too many resources to wade through. Overwhelming amount of information.
- Minnesota does not have one health care directive form. Everyone can make their own. Maybe that is a barrier. We could require a statutory form if we thought that would help.
- Poor design in MinnesotaHelp.info. Info about health care directive was under death and dying. If you didn't look there, you wouldn't find it.

Systems, Tools

- Advance directives are only a piece of the solution. Emphasis should include advance directives but it's a lot more than that. Many are working on them and we should be a part of that but it isn't our primary work. Back up plan is broader. We are also concerned about advocates and supports, etc.
- You're solo is you don't have anyone to identify on your advance directive.
- Advance directive needs to be updated regularly. As situations change, it needs to be updated.
- We should call health care directive not advance care directive to align with the statute.
- Need to unpack what we mean by resources not being well coordinated. Examples of someone going from transitional care to home and the transitional care wouldn't share information. Offer examples. Do you need the #4 bullet? The #2 bullet might cover it. List of wishes, who can find it? Maybe lack of coordination among resources. . .
- Are there gaps? – If I land in the ER how will they determine connections. Look in wallet. No standard for emergency contact info.
- Need for technology for making connections.
- "Effective communication and coordination of developed plan across all levels of care." You can have a plan but it is useless unless available.
- Add disability to list of biases. Also, sexual orientation, able/disable, religion.
- It is stronger than "bias". The system discriminates against particular groups. Not just what the system does. Because of the discriminatory practices people from certain cultures won't access the system. For example, many Native Americans will go to the reservation for the healthcare. Significant barrier.
- The term "bias" seems to be the politically correct term to use for discrimination now. It neutralizes it. It sugar coats it.
- Institutions agencies sometimes set boundaries. What does that mean? How far can I go when providing services. Can you do what is humanly called for or just follow policies. Examples at Ebenezer. Someone fell in shower someone who lives there went to help the person who fell but was told by the institution that he should not help because of liability. Family member at Capital View. Had health care directive put needed a power of attorney. Regions didn't want to notarize because they didn't want to get involved. Examples help. Hal made points about this. Just did things because he knew they needed to happen.

Resources

- Availability of health care advocates. Add the issues of cost. Available but the cost makes them unavailable for many.
- Health care directive is widely available and free. Could do it yourself.
- Multiple people may be available for care but they don't talk to each other. Provide competing ideas.
- How are volunteers regarded around the table among professionals. There are paid and unpaid resources.
- Few available health care agents that you can pay. Use the term "health care agent".

- Add bullet about durability of resource organizations. How are they maintained over years? Legal issue. Can't declare an organization as agent. Should we recommend change in statute?
- Resources need to be culturally sensitive.
- Fourth bullet. How is it specific to solos? Particularly challenging to solos. Remove "for solos." Should look at this throughout the report. What is general, what is about solos.

Other issues

- Social capital is big one in the room. How to build it is huge.
- Add at the end of the first bullet: interest and/or desire.
- How do you improve someone's personality or outgoingness? You have to get at the root causes of why someone lacks that interest and then see if there is a way to assuage those impediments. Who is the onus on?
- Years ago in the disability community they build a "circle of friends". It was kind of an artificial circle of friends around an individual. Don't know if that is possible around an unsupported older person.
- Could help to create groups of support. Village movement. Usually in a different socioeconomic group.
- Little brothers can form a club but don't have a lot of resources for support. LBFE seven chapters in US.
- Wellness 50+ in Ebenezer who we did the focus group with created community. They feel connected because they have build social capital.
- Some communities have historically had intergenerational household. Slipping away. For example Somali elders are living alone in high rises and have no support. Need a Little Brothers in every community to build those connections.
- There is a disconnect between the cost for those kinds of services and potential funding.
- Who pays for Little Brothers? Should we recommend Little Brothers as a model that could be replicated? What does robust support look like and where should it come from? Our society doesn't fund ongoing work of effective program. Foundations will fund start up but once successful you are out of luck. Large human services have found government and other sources but more volunteer based are out of luck. Should be a identified issue. Lack of reliable continuous funding to support these kind of programs.
- Does Little Brothers create a community among people who are participants? Working on that but it is difficult. About 20 percent participate in group activities. Does it create connections with people who they can depend upon? In some ways yes.
- Wellness 50+ by the Vital Aging Network is another model that should be considered. It is specifically about having older adults being leaders in creating community. Not just solos but everyone in the community. The result is ongoing connections where people can take actions for themselves and supporting other people in taking actions around health and wellbeing. They can start to depend on each other as they need each other.
- Point that is so important is that there is no regular stream of funding from the government. RSVP program, Senior Companion programs no longer funded. There are not enough models for this support.
- I have never gotten to the end of a report about this kind of stuff where funding issues are a significant issue. The argument is complex. Gets to the heart of political conservative and

liberalism. We have lots of programs that are paid for universally such as Medicare. We are reluctant to replace family institutional roles. Some people don't want to have government surrogates to replace family roles for people who are lonely or on their own. This tussle is forever. The listing of stuff is very helpful of all the stuff we have talked about. What's missing for me is the organizing principles for representing this. What's the framework? Have identified three basic frames: absence of planning, absence of person, support when experiencing difficulties.

Proposed structure for organizing our results:

What is the population we are talking about?

Is it a person or a circumstance? Proposed definition: "People who for any reason find themselves without social and functional support during major life changes or in the face of health difficulties." (Doesn't point to a person and say you are a "solo." Instead, these are the circumstances that we are talking about. Can happen to virtually anyone.

Framing issues (problems we are trying to find solutions for)

- Absence of planning for a time when a individuals can't make decisions or carry out needed tasks on their own. (Universal. Happens for all of us.)
- Absence of a backup person or plan for healthcare decision making when health is compromised or impaired
- Absence of support—could be social, physical, emotional, functional support—when facing health challenges.

What aspects complicate the issue?

- Cultural differences
- Mental health problems
- Denial
- Continuity over time
- Durability of plans
- Other . . .

What are the potential solutions for individuals?

What are the potential solutions for institutions?

What are our policy and practice recommendations?

Elements of an individual backup plan

Refer to the first page of the discussion summary.

- Curious about the watchdog. Who would it be? Would it potentially be the same as the trusted individual? I agree with the need. How do you know when you can no longer make decisions for yourself? So hard to find a trusted individual to be health care agent. Might be too hard to also recommend a watchdog in addition.
- I am 59. In five or six years I am going to contract with someone to keep an eye on me. I'm looking for professional backup. In a family you have that with adult children who say mom

or dad you are kind of losing it. Watch dog person might be important. The decisions are not clean.

- In written instructions, is that just health care directive or is there also something else? If there is more, what is it? Master Aging Plan.
- Minimum is the health care directive. Where is it housed? What should we add to define that?
- If we agree that every solo out to have these things, what would be the next steps to get us in that direction.
- What do I want? Who needs to know? Where is it kept? How often refreshed? Those things aren't out there.
- Something in writing but also needs to be accessible. Need a flow chart. How to avoid these things living independently and not being connected?
- There is no model for what to do as you grow old. How to anticipate what you will need?
- Recommend site called Everplans (<https://www.everplans.com>).
- We can separate what we recommend for the elements of the backup plan from what we need to do to make it happen. What gets in the way is another question that we are addressing in other ways. When we get into solving why people don't do it, it is very difficult. We are talking basic culture change. Can't force people to make plans. Change in our normative expectations about what we should do. We don't plan for anything bad until something bad happens. Are we going to encourage people to strengthen their relationships with others so they have better functional social support? Are we going to make knowledge and ease of access to advance planning strategies and documents a priority. Are we going to give people access to their own portable health care records?
- Do you feel we have done a good enough job of describing the complete backup plan? I think we are close but not yet complete. The plan would be as much as you can document then how widely make that document available. A set of people who are aware of the plan. The support is . . .
- That gets closer to what I was thinking. More fleshed out.

Evaluation

- Ellie reviewed the purpose of the meeting.
- 4 - Came to grips today with the sprawling nature of the problem. Heartened that we know the pieces. Not well organized yet but we know what the pieces are. Need to help people to others know.
- 4 - Frustration on how to pull all together.
- 4.5 - Discussion summary is a good work produce. Now just need to move forward to next step.
- 5 - For effort. We are all working really hard to get our arms around. We might end up helping people who are inclined to help selves but maybe will help some others too.
- 4 - Got lost in bullet points but can see a path forward. We need a structure for housing data. Know that's where we are heading.

- 4.5 – Don't think we are ready for recommendation. Think we need to finish this discussion first and then we will be ready to move on to recommendations.

5 - Everyone participated. Passion and enthusiasm came out. Think we are on the right track.

The draft findings document is well written and helpful. Thank you for that.

Next meeting August 14.