

Meeting Minutes

A Backup Plan for Solos Task Force

Tuesday, September 12, 2018 – 7:30 to 9:30 AM
Wilder Center, St Paul, MN

Task Force Members Present: Joyce Edwards, James Falvey, Genevieve Gaboriault, Ellie Hands, Darla Kashian, Greg Owen, Mark Peterson (co-chair), Peter Rothe, Sabina Sten, Martin Wera

Members Not Present: Kathleen Dempsey, Susan Henry, Karen Peterson

Guest: Diane Graham-Raff, Metropolitan Area Agency on Aging

Staff & Staff Support Present: Linda Camp, Marit Peterson,

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:

Finalize the list of recommendations for the Final Report.

Plan agenda for October 16 Stakeholders meeting

Reflect on our journey

Check-in and Updates

Co-chair, Mark Peterson, called the meeting to order. Asked for additions, deletions, changes to the minutes of the 8/14/18 meeting. Minutes were approved as submitted.

- Linda noted a website by the Minnesota Department of Human Services called Direct Service Connect. It is a “job board for direct support workers and the people who hire them.” <https://directsupportconnect.com>. It helps people find personal care attendants (PCAs) To sign up as a worker you need a Unique Minnesota Provider Number assigned by the Department of Human Services.
- Linda has a meeting set up with Kari Benson, director of Minnesota Department of Human Services (DHS) Aging and Adult Services Division and executive director of the Minnesota Board on Aging.

Report on Ad Hoc Review Committee

The Ad Hoc Review Committee intended to include more diverse voices in the task force’s work met on September 6. Bee Vue, VOA Park Elders; Kristin Kinney, American Indian Family Center; Wendy Moreno, Centro Tyrone Guzman; Marsha Berry, Training to Serve were present. Ellie, Greg, Martin and Linda participated.

One member said one take away was that there are so many other issues that this is not a high priority. Overall feeling is that we haven't reached deeply enough into these groups.

A member said that he felt the participants could see the value of this work to their communities even if it hasn't been a high priority. Two specific recommendations: Do a printed piece in multiple languages and aimed at multiple cultures with a simple message that could be used by a number of organizations to get the word out and direct people to resources. The other suggestion was to connect with ECHO, which does video productions in multiple languages and that are culturally sensitive. They are a 501(c)(3) entity. Lillian McDonald runs the organization.

Some of these cultures do a better job of caring for each other than the majority culture. Bee Vue said that he thought they would be okay for the next ten years but after that he didn't know because greater generational divides are starting to show up.

Member said he heard them say that it happens, but they have ways to take care of it. People wanted information about solos. Changing practice is more difficult.

Member asked if there was a baseline understanding of health care directives and other resources among the groups? Linda said that Karen Peterson has some recent experience with the Native American community and is finding that the approaches need to be modified. People in this meeting didn't provide insights on that.

Member noted that if you are not middle class, not part of a close family, you are more likely to have issues. It is hard to reach that population.

As a task force, we have talked about homelessness several times and decided that it is a bigger issue. Should show up on our recommendations to acknowledge the difficulties.

Member suggested that some of our recommendations should be pointed at the institutions that have to respond to these issues. Others should be focused on what the individual can do. The ER doc who came here raised those issues. Going through wallets, trying to find connections, etc. The burden of this problem isn't just on individuals needing to plan. It is also on systems, institutions that need to respond to circumstances that are really difficult to respond to.

Member suggested that there is also a generational aspect to this. Younger generations seem to be less interested in having an institutional infrastructure. Families are not as connected as we would hope. Institutions are not valued. We are left with problems such as homelessness. We can't look at this without recognizing the gaps in the stories we tell. What has been so fantastic about this task force has been hearing from all of you. People I would not have heard from otherwise. And it raises the question again about the voices that are not at the table. One voice that I think is missing are the libertarians. People who believe that people need to take care of themselves. They might say, this isn't my problem, this isn't a societal problem. Lots of voices are missing.

This is a pioneering effort. Linda noted that everywhere she has gone, people have responded in a similar way. Light bulbs going off. Saying they haven't really thought about it.

Recommendations

Linda directed attention to the "Summary of Recommendations" document, which she emailed to task force members prior to the meeting.

Member asked what the final report will look like. Linda shared a preliminary draft of the report.

Member suggested that we think about this as developing a different cultural competency around solos. Some of recommendations should be in the arena of cultural competencies. For individuals, we might think of it as the technical competencies that one needs as they move through life. We have many different groups and we need to think about different methods for learning competencies.

A member said he appreciate that way of thinking about it. There is clearly more for us to understand. I wouldn't use the language of "information gathering and research." For many in communities of color, those words are triggers. Frame in terms of engaging, fostering conversations. Make us a part of the conversation.

It can be as simple as a reluctance to put something on paper. Member talked about experience working with Hmong community members. People had a name to put down, but many didn't have an interest in participating in the health care directive system. Think we should consider reframing this whole document to be more focused on engagement.

Seems like we had a conversation last time about needing more data. Maybe that is one recommendation, and your point about engaging communities might be another recommendation.

We talked about a process for collecting data on number of solos. How do we make this data-driven? We need the numbers to drive public policy. We also need a way of understanding how many people are "transient" solo. And we need to consider how to project numbers given the changing age demographics.

Could collect that info through a survey of institutions who deal with solos. Not suggesting we do that but may be the only way to do it. My wife used to work at Hennepin County Medical Center. She would give instructions to people saying that they needed someone to drive them and they would say they don't have anyone, and she would say you have to have someone. This presents itself in different ways, but I think it is a pretty common experience.

Member suggested that the social worker who presented said about 5% presented without someone who was unconnected. That may not translate to all situations. Linda noted research done by Maria Carney at Hofstra Northwell School of Medicine in New York estimates that 23 to 24% of the older population is at risk for being elder orphans. Do we want to do more with understanding the data? MN Compass might be able to help with looking at the data.

One of my providers always asks me if I have mental health issues and if I am in an abusive relationship. How do we get that to happen in health systems for soleness? Can we have a small research study to do this?

Include federal level officials as stakeholders (Betty McCollum's office, etc.)

Editing suggestions: move "trusted" so it refers to all the people who can help. In #2, it is a little unclear who you are referring to in the use of "people." Maybe use "supportive people".

We need to separate recommendations for institutions and for individuals. It should be the framework for all the recommendations. Separate lists. Then, each of these primary audiences will have sub-audiences. They are so mixed now it is hard to evaluate.

I agree. Could be separated as 1.) Assemble resources that would be useful to solos in connecting and planning and 2.) Build institution capacity to respond to solos. Two very different sets of activities.

I find the recommendations very unsatisfying. They don't say anything about what we are going to do. For example, we say we want to build awareness but not how we will build awareness (2 or 3 bullet points). We could rework the main recommendations to say something like:

1. Build knowledge about soloness including consequences that result from not planning and benefits of planning and building resources.
2. Assemble resources that can be useful to solos and solos' planning.
3. Engage cultural groups . . .
4. Build institutional capacity to respond . . .
5. Work with state agency and . . .
6. Do research to estimate the extent of the problem.

Then under each one of those there would two or three specific actions that we recommend. So, for example, under the assemble resources item we might say develop a multi-language brochure that engages people and directs them to resources, partner with ECHO to produce videos, do a PSA in multiple languages. We need to be pretty concrete to make our work worthwhile.

Linda said she hopes that some of that will come out in the stakeholders meeting.

Linda asked what people think of the no. 4 item: Modify existing tools. . . What tools are we talking about? Planning tools, health care directives, etc.

Member said he was thinking about what we talked about in the past about what motivates people to do things or discourages people to do things. Ran a social service agency in Minneapolis for a while. Was very hard to get Somali women to get groceries because the men in the community often discouraged them. We had to work with the leaders in the community to get them to say, "You need to do this." I have seen that over and over in faith communities. If you can get the leader to say to do something it carries authority that we don't have. Now only 30% of people are part of faith community these days but that is still substantial.

I compare it to getting people to accept immunizations. Some communities resist. Started to do work with Imams in Somali community to incorporate into communities and that started to make a difference. We will need a range of solutions. Need to think of this as a public health problem and then what might be solutions to the problem.

Linda suggested we get to some immediate next steps that would keep us move down the path.

Get the information out can be very general. Getting to individual audiences is very complex and specific. What is our message? First, that solos exist. And then what?

Part of engaging people, is getting all the stakeholders to think about next steps.

I am coming to terms with that we just scratched the surface. We aren't at a point where we can say exactly what needs to happen. We need to do more talking about it.

People will say that they don't know anyone who is a solo. Linda said that is not her experience in talking with people. Everyone has a story about a solo.

There is a parallel with the caregiver situation. In caregiving, Wilder identified this as a significant issue. People didn't identify themselves as a caregiver. Wilder did a big campaign raising awareness about what a caregiver is with ads, bus covers, etc. "You may call it getting groceries for mom. We call it caregiving." The state picked it up and made it a statewide campaign. Then they created planning tools to help people. Is this the same kind of problem?

As a caregiver, I have not found those sites helpful. We need to be sure there is something to offer before we do a public awareness campaign.

The state has the site for personal care assistants PCAs. We need a PDA – personal decision assistant. Think about advocates for children when in difficult situations. Could do the same for solos. Second half of the message is where to go for help.

Wilder created a self-assessment. Are you a caregiver? Do we need a self-assessment about are you a solo or at risk of being a solo? In the tobacco cessation issue. A lot of time went into how to make it work. Would an assessment stimulate someone to do something? If we had tobacco money we could go into depth about what needs to be in place for people to plan. Big elephant in the room is moving people to action after they have awareness.

My frustration is that there are no specific steps in the recommendations. We need to get to those steps. Maybe a smaller group should work on this? Works better in group with the discussion otherwise we spin with our own ideas. Linda said that everything needs to be done by December 1.

Member said he liked the idea of an ad hoc group. Maybe someone from department of public health, aging in DHS. Who do you need in the room to get to the specific steps?

Discussion about whether the task force is ready for the meeting on the 16th with stakeholders. Conclusion was to go ahead with the meeting.

What are your hopes about what should happen after this group quits meeting? Hoping that we are presenting enough at the meeting on the 16 so people can contribute to hope to move to action. Could we do another meeting of the task force the first week in November.

Have we already created a list of potential action steps? People have generated ideas and Linda collected them from the notes and shared with task force earlier. Linda will send out some potential dates. Wednesday, Nov. 7 is a possible date. Linda will look for room and schedule the meeting.

Genevieve announced that she is going to work for the state as deputy officer for long term care.

October 16 Stakeholders Meeting

Linda brought attention to the draft agenda for the meeting and suggested that task force members lead various aspects of the work. Provide executive summary and proposed recommendations to the participants prior to the meeting.

Ellie and Mark would do the "Who are the solos?" 10 minutes

Martin and James will do: What journey have we taken; what have we learned? 15 minutes

Linda will share the recommendations of the task force – 15 minutes

Members suggested getting participants involved in dialogue as early as possible. Suggested opening the meeting with individual introductions responding to question: "What does your organization do to/how does your organization support solos?" This might show a higher level of

knowledge than we know and could allow the task force presentation piece to be even shorter, briefer.

After Linda briefly presents four or five recommendations, invite participants to go to the group that they have an affinity toward. Each table will have a facilitator (a task force member). Provide two or so questions for each group that encourages discussion about their suggestions for how to act to achieve the recommendations.

Half hour 8:00 to 8:30 set the stage and summarize. The journey and what we have learned. Martin and James. Ellie and Mark with do the who solos are. Linda will do potential action items. Question and answer time should be there. If no questions, move into the next piece. 9:00 to 9:15. Don't want to lose what individuals can do in their role. Executive summary, agenda, what could your organization do. Need questions for the table discussion.

Invite list: Add Rajean Moone, Vic Rosenthal; Larry Penbrock, LSS; Jewish Family and Children Services Mpls and St. Paul (two organizations), Stevens Square Foundation, MN hospital association, health care system people are missing. Someone at the DMV. Ross Owns, Hennepin Health. Ethics Lead at Hennepin County.

Maybe we need to change the definition in the executive summary to "health care support and decision making." Recommendations maybe should also be divided for support and decision making.

Evaluation

Evaluate the meeting on scale of 1 to 5.

4 – Lot of thrashing around. Not in a bad way – feel like we accomplished a plan for how to carry on

4 – Linda, you have done an incredible job of wrangling us.

4 – We did a lot – Good meeting

5 – The thrashing was good – need the space for doing that.

5 – For earnestness and effort – took a lot of time talking about soloness – if we had more time we could be more refined with our recommendations.

4.5 – Want to get to doing – huge topic – feel a little stressed because of lack of time

4 – thrashing piece – lots of loose ends

5 – good work – hard work

5 – Still tension but can see the end point

4 – Ambiguity around the recommendations – don't see the action steps

4 – Our time together have scratching the surface but need to go deeper – not worried about running out of time – will do the intense work now – thankful for your work, Linda.

Next meeting Task Force meeting is stakeholders meeting on October 16.

