

# **Meeting Minutes**

## **A Backup Plan for Solos Task Force**

**Tuesday, November 7, 2017 – 7:30 to 9:30 AM**  
**Wilder Center, St Paul, MN**

**Task Force Members Present:** Kathleen Dempsey, Joyce Edwards, James Falvey, Genevieve Gaboriault, Susan Henry, Darla Kashian (acting chair), Greg Owen, Peter Rothe, Sabina Sten, Patty Thorsen, Martin Wera

**Members Not Present:** Ellie Hands, Karen Peterson, Mark Peterson

**Staff & Staff Support Present:** Linda Camp, Julie Roles, Pahoua Yang-Hoffman, Nicholas Bruno, Sean Kershaw

### **Overarching Goal**

Stimulate the development of a supportive infrastructure to help solo older 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 November 21 meeting:**

Develop a deeper understanding of the current infrastructure for health care decision making in Minnesota.

### **Welcome/Negotiate Agenda**

Acting chair, Darla Kashian, called the meeting to order at 7:30 AM. Asked for additions, deletions, changes to the minutes of the 11/7/17 meeting. Minutes were approved as submitted.

Darla reviewed overarching goal of the project and expected outcomes with the task force.

### **Updates and Check-in**

- A member talked about recent reports on elder abuse in nursing homes and assisted living. Solos are at greater risk because they don't have family members to protect them. Maybe we should focus on this kind of problem, at least address in our report
- Do people understand the regulatory agencies that are involved in regulating nursing homes? Genevieve said that maybe she and Marit could pull that information together.
- I am a medical director at two nursing homes. The nursing homes are so highly regulated. Part of the problem is sorting through all the minor complaints and focusing on the real problems.
- I receive calls from assisted living facilities about minor issues for my clients (scratch, bruise). Part of the problem is a lack of staffing at the regulatory agencies. Very serious issues with my mother and it took forever to get ombudsman's attention
- A thought related to the Dr.'s comment last month that if they had a 90 year old who was jogging and had a heart attack they would for sure resuscitate him/her. We don't want to assume anything. Might be the way I would want to go.

- To layers for the end product for the task force. Resources for the community at large and those that are available to solos. We never know who will out live who. Need to think about both personally and community wide.
- Member brought an example of a wallet card.
- Have a friend that was told that her healthcare directive is out of date (5 years old). Her children disagreed, so the medical community disregarded the directive.
- Could we recommend that on April 15 every year people revisit their healthcare directive?
- I encourage one person as healthcare agent. Joint decision-making is difficult in this stressful time.

## **Recapping where we have been**

Linda introduced exercise on thinking about infrastructure. Ground level piece of work that the task force is doing. Little has been done on helping people know how to take charge and be proactive in planning. Example of getting to Juneau in Alaska. There are no roads to Juneau. Can only get there by plane or boat. That's where we are in this project. We are trying to figure out how to get people to Juneau without any roads. We need to figure out how that road needs to look like and what are the pieces needed.

Three main objectives of the project: Shed light on solos, what resources exist to support solos, what does the planning process look like. Some of the information we need doesn't exist and we will need to create it.

We have talked about infrastructure already. We will build a map about what the infrastructure looks like. Not just tangible things. Think about it very broadly. For example, MN stature on health care directives, guardianship laws, Honoring Choices, POLST, practices and policies of individual hospitals. It is layered, with lots of pieces.

Today we are going to focus on solos "with capacity". Supportive decision-making.

*Member:* Might we look at this a quality of life rather than quality of death?

*Member:* So far we have looked legal and medical structures. What is the design problem? Difficult because it is different for every person. I am starting to think that a health care directive is a good tool to help an individual to start thinking about something but poor at communicating. The intent is not matching up with the practice.

Linda: We are still in discovery. When we get into analysis we will help define and narrow how we define the problem.

*Member:* Framing as a tension between individuals desire to make self-determined choices and their inability to do so as they have waning capability and people decline physically or mentally. So much of this is having surrogates in our place, usually family members, to help with that decision-making. Explore continuum of decision-making and how to perfect it for people who do not have a surrogate.

*Member:* Possible presenter – Krista Bosta, Senior Linkage Line. They might be a good source of achieving some of what we think should happen. State Fair survey every year. Maybe could add some questions to the survey about this topic.

*Member:* Dawn Simonson might also be a good person to present.

*Sean:* The brilliance of the Honoring Choices process is it is simple. We should keep that in mind as we produce outcomes.

*Member:* Mindset that is helpful after going on long-term disability is that none of us have a guarantee that we will wake up tomorrow with the same capacity as we have today.

*Member:* My dad used to say “don’t think it can’t be you.”

*Member:* about defining the problem. Makes me think about another project I’ve worked on. Question was do we need hospice. We sent death certificates to a number of doctors and asked if there was a period of time when this person would have benefited from hospice. Then interviewed family members to understand the problems people actually faced. The solos issue is similarly complex. Solos present a number of problems for public systems. For example, we don't know what they want to do medically when they can't speak for themselves, when they die what to do if no clear directions to settle affairs, likelihood they will land in facility-based care before they need it because don't have support. Also problems for solo people. Don't have anyone to help me, no one to designate, Helpful to think of problem in two ways: personal impacts and public impacts

*Member:* Public problems might need legislation, money needed. Individual

*Member:* Are we squandering resources by having people move into facilities before they need to because we don't have the right resources to help people stay at home?

## **Exercise on Infrastructure**

Linda distributed a description of the exercise and provided instruction. What are the issues Pat faces? What does Pat need? What resources are available to Pat? Broke group into two groups to work on exercise. See attached diagram of what the groups produced.

*Sean:* Do the Accountable Care Organization get payment for coordinating nonmedical support?

*Member:* Very few extend beyond medical care. They might refer but they don't receive funding for other services like meals, etc. Need better referral mechanisms. Nate Garvis. Don't confuse needs with solutions. Needs are verbs; solutions are nouns. Need: to get to doctor; solution: transportation.

Humana did a pilot on private care coordinators found it didn't save enough money. MS society is doing a pilot. My organization is working with them to support people in person.

*Member:* What are the costs?

*Member:* Depends on organization. We charge \$120/hour for care coordination with no minimum. Can meet for one hour. Others have minimum number of hours (5 hours or so).

*Member:* If 10 people popped up tomorrow and wanted your service would you have the capacity to work with them?

*Member:* Not in the same day, but yes.

## **Assignments**

**Read article by Thaddeus Pope distributed earlier.**

**Do interviews with solos.** Everyone should do at least one interview with a solo. Do more if you can. We shared an electronic copy of the questions.

*Member:* Can we massage some of the questions to make them less directive? Yes.

*Member:* We should not ask people to record their names. You should put your name on them and somehow code them so you know who they are in case we need to go back for clarification.

*Member:* Who is our target audience? Are we looking for people who are currently self-sufficient, have everything worked out.

*Staff:* We want a mix. So yes, people who have it worked out are fine.

## **Evaluation**

Members rated the meeting: 4.5, 3, 4, 4, 4, 4, 3.5, 3, 2.5, 4, 3.5

- Really good conversation. Feel very good about it. Still a little bit of ambiguity and that I guess that is part of our process to create that clarity over time.
- I don't have deeper understanding of the infrastructure. I appreciate the conversation but it didn't help me get a deeper understanding.
- Felt frustrated for Pat. Lack of ability to reach out is the crux of these issues. Fuzzy about resources that exist today.
- Some things that fall on my responsibility. I am a little unclear about some things. Have a hard time hearing everyone. Would like it if everyone would speak up a little.
- Not a lot of new material today but introduced the ambiguity of these situations. Useful exercise. Puts us in the situation.
- I have a lot to go back to review and question. In addressing these questions it is important to have a balance in our approach including both clinicians and person-centered. Real people going through these things. How to address when situations change.
- Liked the exercise but don't think we got as much out as we could. Needed more time. Framing, etc.
- Swiss cheese analogy. We spend time with the cheese and not in the holes. Much of this we already knew.
- Overall goal. Who doesn't have people to write down on forms and how will they find those people. What we brought to the discussion today was mostly what we already know.
- Appreciated the ambiguity. Really appreciated your recap, Linda, at the beginning. Highlights how really difficult this topic is. Not just end of life. Stepping back is important. As uncomfortable as the ambiguity is I think it might help us in the end.
- Like the cheese and hole analogy. My big frustration is that we are not looking at the political dimension. We are primarily interested in the system problems that occur when they do not have resources and they do not have pre-planning. What's the role of a task force or the state in working with solos in nudging them, throwing resources in front of them, giving them guidebooks? Strong liberal/conservative political element. How much should you do for people who haven't developed friends, a support system, done any planning?

*Darla:* Next meeting is December 12 at Wilder Center, 451 Lexington Pkwy N. St Paul, MN, 7:30 to 9:30 AM. Thaddeus Pope, medical ethics from Mitchell Hamline will be a guest presenter. A meeting notice will be sent out. Thank you all.