

# **Meeting Minutes**

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

**Tuesday, January 16, 2018 – 7:30 to 9:30 AM**  
**Wilder Center, St Paul, MN**

**Task Force Members Present:** Kathleen Dempsey, Joyce Edwards, James Falvey, Ellie Hands (co-chair), Susan Henry, Darla Kashian, Greg Owen, Mark Peterson, Peter Rothe, Patty Thorsen, Martin Wera

**Members Not Present:** Genevieve Gaboriault, Karen Peterson, Sabina Sten,

**Staff & Staff Support Present:** Linda Camp, Julie Roles

### **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 This Meeting:**

Report by task force members on the interviews they did with solos. Drawing insights, connections and meaning from information gathered from interviews. Continue discussion about what else we need to know and plan for upcoming sessions and how we will gather the information we need.

### **Welcome/Negotiate Agenda**

Co-chair, Ellie Hands, called the meeting to order at 7:35 AM. Asked for additions, deletions, changes to the minutes of the 12/12/17 meeting. Minutes were approved with submitted.

### **Updates and Check-ins**

- Brad Johnson, recently retired from United Health Group, was a visitor to the session. He is a Citizens League member. Interest comes from helping parents. Often wonder what do people do who don't have adult children? Interested in helping the task force in any way possible. Will work with Linda on plan.
- Member's brother-in-law is in hospital. Mid 90s. Daughter is a physician and is health agent. Her approach is very clinical. Going to be out of town and asked him to take over. Not the legal back up. His approach is very different. Waters can be murky as different players come on the field. Wife died recently. Aware of increased likelihood of death after a spouse.
- College friend called about mother. The mother has lots of support and still much uncertainty. One of my conclusions so far is that we can come up with an improved system but there is no perfect system. There is a lot of room for improvement.
- Pahoua is still working on bringing more diverse voices. We are working on focus groups with Centro Tyrone Guzman with people from the Latino community. We are also working with a contact in South Minneapolis who can bring together people from African-American, low income, possibly Somali groups.

- Member mentioned he has a contact with a Somali group. He will follow up. We have a budget for a \$25 gift certificate for people participating in focus groups.
- Might also reach out to Barbara Greene about reaching diverse populations.
- Know someone who has been active with the National Federation of the Blind. May be able to get their perspective.
- Might want to reach out to people with mental illness. NAMI might be a source for that.

## Reports on Solo Interviews

Task force members did interviews with solos. Each reported with brief description of the solo, key findings from the interview and insights they gathered about solos.

- Interviewed three people. One solo by choice, one divorced. Some have children. All very prepared with directives. All underestimating how needy they will be when time comes. Don't want to be a burden. Seem to have a false sense of security. Fiercely independent. Put myself in that category. But after observing my parents and others I work with on conservatorships it is not possible to do it all yourself.
- Interviewed two women – one gay with a new partner – other never married, no children. Fiercely independent. Inertia about completing health care directive – partner pushing – reluctance – not wanting to be a burden on family and friends. Both know I am going through guardianship training. One said, “Maybe I'll get a guardian.” I said I hope not. A lot of misinformation and ignorance about the process. Bright, well-educated women. Not fully appreciating what needs to be done.
- Interviewed one person and submitted my own. Woman is widowed in her mid-80s, lost son to heart trouble. Bought long-term care insurance. Very practical. She has financial resources and when asked, how would you meet your needs said she would hire people. Son travels all over the world, emotionally close but not physically available. She said the term “estate planning” is a daunting term. She prefers “succession planning.” Reminds me of my friend who has had health problems and the issue of listening to someone who wants to be independent but still needs help. Extremely important that we understand that even in a crisis a person may be able to hear what's going on even if you can't communicate.
- I interviewed a former board member for my organization. Rule follower – has plan based on best knowledge available to her. I got worried. She has two caregivers one is aging the other is nephew who lives a long way away. Reminded that the work of this task force is very important. People who are solo by choice are by nature very independent. We are talking about planning for dependence, contrary to their way of thinking. Adds to the challenge. It is becoming more apparent to me that all of us need to have strategies for expanding our social networks as we age. Just like we are attentive to healthy eating and exercise, we need to be attentive to social connection.
- Person I interviewed also wanted to not be a burden. Fiercely independent. Relied upon her doctor. Great faith in doctors. She has all the tools, health care directives, etc. Found ministers who are her health care agents. The interviewing process opened the door for her to realize that she *will* be a burden to someone and that she wasn't as prepared as she thought she was.
- Interviewed three people none of whom are prepared – 92 year old female, 59 year old African-American male, a 36 white female. 92 year old is my mother-in-law who lives with us. She has advanced directives. Her concern is logistical. Never lived more than 5 miles from where she was born. Not planning for dependency; she is already dependent. Asked, what happens if you die here? Wants to be cremated, buried where she grew up. Very clear

about not wanting to be in pain. "If I slump over in my chair, let me go." Second person, the Afro-American male and the third person are from the Dignity Center where I work. They are not worried about dependency, it is not on their radar. Just trying to get through their day. If they have an emergency they will go to Hennepin County Medical Center and know they will be looked after. Single mom with two teenager, 11 and 13. Had no contact with her parents or siblings in over a year. They are in Indiana. "I am a 'n-lover' they don't like that." Lives in a shelter but worries about losing that. Paranoid, suspicious of system. Doesn't plan on being sick. County assistance. Presence-tense people. Makes them different in an important way. This woman thinks that her 11 and 13 year old will take care of her in a shelter. Very different perspective. Transient people. Know where to get what they need in order to survive. But just to survive for today.

- Interviewed 73-year-old gay white man – no relatives except distance cousins. Recently had health issue and considered transition to assisted living. Independence more important than assisted living so pulled back. Trying to manage on own. Has advance directive and living will. No will, says he has nothing of value. Fits into group of people who thinks they are prepared but when things fall apart responsibilities fall on to others to respond to his crisis. In reading our interview results, I think we have a skewed sample of people who are better prepared than most. Homeless population is a good example. Just prepared for today. The burden on medical assistance will be immense.
- Interviewed two people. Interview process was helpful. Had a hard time finding people around me so asked others to help me find them. Did one interview by FaceTime. 66-year-old man, divorced many years ago. Has progressive pulmonary disease and had just started on oxygen. The recent event made him think about planning. Take away: we might be able to use these kinds of events to get wheels turning. This man has advanced directive, doesn't have long-term care insurance but has done a lot of planning. Had all these resources but still doesn't want to be a burden. It is kind of like retirement, you save all this money all your life but don't want to spend it when you need it because it wouldn't be there. He has people who want to help but doesn't want to burden them. A contradiction that needs to be dealt with. The other person was a 62-year-old nurse. Does not have a health care directive. Her plan is to "cross street carefully." Knows there is work to be done but is not prepared to do it. Has lots of friends but not "those kind of friends." Wouldn't ask them for help. Good reminder for self-reflection about how prepared we are as individuals. When asked about what resources would be helpful, said information about what is covered by insurance when you have a sudden need for home help. Man said he would go to the clinic he goes to cover that. Looking for a one-stop shop for information.
- I have observed that most of our interviews have been with women. Interviewed two people, a 72-year-old man who lives distance from one son. Retired physician with beginnings of dementia. As well prepared as he can be. Has financial means. How do you know where to go to get help when you don't know you need the help? Has a part-time PCA. You wouldn't understand that he has any capacity issues because his is still quite capable. Woman 67, long-term partner is in memory care. She thought step-children would help. Realize that they can't be counted on to help. In both cases, have health care directives, wills. The legal mechanics are in place but the emotional pieces are not in place. Like the "succession plan" term. Even wealthy people don't think they have estates.
- Interviewed someone from Little Brothers Friends of the Elderly. Had documents in place. When this actually happens, who will be there for the day-to-day needs? Technical in place, emotional aspects are not. Person had bipolar disease. For many years considered himself a solo now that his mental illness is better treated he is more connected. His sister is health care surrogate. Did that at suggestion of his doctor. Has high level of trust in her. Recently diagnosed as diabetic. Doesn't take it very seriously (nothing compared to the mental illness

he has dealt with). Who will be there? He said didn't know. Sister is 20 miles away. Doesn't have someone right at hand.

## **Discussion about Interviews**

When use the term "burden" we put a very negative spin on the idea of human beings helping each other. Maybe that is one of the things that could come out of our work, changing the terminology and the perspective of interdependency.

A member who is a geriatric care manager, a nurse and owns a care management company: One of the services we provide is on-call advocacy program. Available 24-7. Keep info on file, check in every three months. Solos use us as backup plan. Maybe not the health care agent but the person who can help coordinate. Preparing for dependence helps people preserve their independence. You have choices and know what they are and make clear your preferences. We often get referrals for people who are resistant to doing the planning.

Learned from an interview, that people don't get medical care because they are afraid that the doctor will say they can't continue to live independently. Member said, I have seen it go both ways. Situations where people should not continue to live independently and are not directed appropriately and those who are overprotected. That's why you need a health care advocate.

The term "interdependent" is very important. Have to persuade people to take advantage of services that are provided. Need to reinforce the need to interdependence.

Preserving their current state is usually what people want but it may not be reasonable. I liked the term "planning for dependence" because it is a reality check. But can't be all you talk about. I like interdependence to be used in relationship to the burden to counteract the heaviness of it. Our children are a burden but it is mostly a happy burden. When children take care of parents it is also usually a happy burden.

Societal messages. When I hear someone say "I don't want to be a burden." I heard people saying I'm not worthy, I don't count, I'm not important. We are all worthy of support. I like the term interdependent. Many of my friends are not prepared to be interdependent.

In our American society, independence is such a strong value and dependence is anathema. It gets at a self-worth. I am worthy of attention. A lot of people don't have that sense.

We all live inter-dependently. The idea of independence is not reality.

Someone will make the decision. Who do you want to make the decisions? Do you want to leave to chance? That's what I think this is about.

Lots of people have POLST, health care directives but is that enough? What does preparedness look like? That's one of the intended outcomes of this project.

People felt a sense of accomplishment in having a health care directive. Many are not confident that it will kick in. On the road, have an accident. No one knows about it. Can have the mechanics in place but who reminds you to eat? So many people have health care agents that are remote. How do they deal with activities of daily living? Even when families are close many cannot provide daily supports. Need to be clear about what is part of the role of the health care agent.

Health care directive is about starting to think about the decisions. Read Barbara Blumer's comments about surrogacy (shared by email last month) and why MN doesn't name them in the law. Health care agent is not a caregiver. It is a very limited role by law.

A health crisis is an opportunity for raising awareness about need for planning. Planning for someone else is not the same as someone planning for themselves. Take advantage of places where there are critical changes in life. Solo problem is compounded because you might not have a second set of ears.

When I go to a clinic, there are translators for language. Do we need someone who is like that to help solos.

Hospitals have care coordination for some patients that helps them as they go home. Need to fit a set of qualifying events. Could qualified for weekly visits and telephone follow up. Funded for short time of support. Who will pay for this?

### **Key Themes**

- Advance directive is too limited. Focused on acute end of life events. Bundles decision maker to also be the caregiver but that isn't always the case. Often one person financial, one decision maker, one lives locally to provide hands on support. Need a more refined advance-care planning tool.
- Natural tendency is to not plan for this stuff. Need a range of incentives and strategies for encouraging planning. Current culture creates barriers to doing the planning. For people living day-to-day even more barriers.
- Cultural barriers. We have a negative language frame about how we think about dependency.
- Younger people family members or supporters don't want to have the discussion.
- Emotional barriers. "My mother-in-law says she doesn't want to be trouble. I say 'you are a little trouble but it is manageable.'" Fears running out of money and that her family will disappoint her and not take care of her.
- Lack of awareness and knowledge.
- Theme of independence. Can't be independent forever.
- We all need to be needed. Would turn around the burden issue. We fail to communicate that idea.

### **What More Do We Need to Know**

Linda handed out a document (attached) that summarizes where have we been, where we are, where we want to go. We are about a third of the way through the process about half way through the discovery period.

We are adding meeting dates (see attached).

We have focused on the substitute decision making quite a lot. We have a unique opportunity to focus on the supported decision making part of the scale.

Putting together a panel for the February meeting. Anita Raymond, Volunteers of America, setting up supportive decision making system. Hal Freshley, former executive director of the Minnesota Board of Aging serves as a volunteer advocate and health care agent for people in

his church. Third person from First Fiduciary, a for-profit that provides guardians and health care agents.

We have two more discovery meetings. One might be around planning. Possibly a homework assignment. Who is going to be available to support? Another might be around workforce issues – direct care – helpers in decision makers – navigators – hire for personal care. And how will people pay for it? What does it cost to get the support a solo needs? What is the cost of unplanned dependency? Personal costs and public costs. There are no free alternatives. What's the best use of the resources we have? What are the priority needs to address? Might be a motivator to spend money to save money.

Social networks. The single most important planning thing that a person can do to protect themselves is to build out their social network. How do we encourage that? Can be a contradiction between encouraging people to “live well at home” and social connection especially for people in rural areas.

Potential homework assignment: reviewing planning tools and accessing their usefulness. Linda will write up the exercise and share at a later meeting.

## Evaluation

Ellie repeated the purpose of the meeting and asked for people's evaluation.

Ratings: 5, 5, 4.5, 5, 5, 5, 5, 4, 5, 4, 4

- 5 - Partly based on assignment. Very good to rub our noses in material. Think less intellectually and more practically. Good discussion.
- 5 - First hand experience this forced us into was very good.
- 4.5 - Wonderful conversation. Only interviewed one person. Need to talk to more. Well facilitated.
- 5 – Can't improve upon what Peter said
- 5 - Very productive conversation. Feel we need to put our arms around the problem before getting into the solution.
- 5 - Got pass some of the initial definitions and getting into the meat. Seeing some possible solutions.
- 5 - Fun to get into the meat. Good sign that we are enthusiastic enough to be articulating possible solutions.
- 4 - Haven't framed the problem well enough.
- 5 - Level of enthusiasm for the work. Feel like we are moving forward.
- 4 – Stories are wonderful. Concerned that the way we collected data doesn't let us look for pattern.
- 4 – Just scratched the surface of the problem. Good experience. Most discomforted that we are a bunch of white people from an urban experience from with means planning for well enough people.

Next Meeting: February 13 at Wilder Center, 451 Lexington Pkwy N. St Paul, MN, 7:30 to 9:30 AM. If you haven't sent interview summaries, please do to [solos@citizensleague.org](mailto:solos@citizensleague.org).

Thank you all.