

# Meeting Minutes

## A Backup Plan for Solos Task Force

Tuesday, March 13, 2018 – 7:30 to 9:30 AM  
Wilder Center, St Paul, MN

**Task Force Members Present:** Kathleen Dempsey, Joyce Edwards, Greg Owen, Mark Peterson, Peter Rothe, Sabina Sten, Patty Thorsen, Martin Wera

**Members Not Present:** James Falvey, Genevieve Gaboriault, Ellie Hands (co-chair), Susan Henry, Darla Kashian, Karen Peterson

**Staff & Staff Support Present:** Matt Bryne, Linda Camp, Marit Peterson, Julie Roles

### 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:

Expand our understanding of solos—their situations, needs, and concerns related to health care decisions.

### Welcome/Negotiate Agenda

Co-chair, Mark Peterson, called the meeting to order. Asked for additions, deletions, changes to the minutes of the 2/13/17 meeting. Minutes were approved with submitted.

### Updates and Check-ins

- Marit and Linda are doing an ABA webinar coming up on April 24: “Building a Late-Life, Decision-Making Infrastructure For People Aging Alone” <https://shop.americanbar.org/ebus/ABAEventsCalendar/EventDetails.aspx?productId=304931709>. Also Marit and Linda had an article in February 2018 issue of ABA publication, Bifocal: “**Meeting the Challenge of a New Generation of Solo Agers**” [https://www.americanbar.org/groups/law\\_aging/publications/bifocal/vol--39/issue-3--february-2018-/agingsolo.html](https://www.americanbar.org/groups/law_aging/publications/bifocal/vol--39/issue-3--february-2018-/agingsolo.html).
- Member mentioned that she had a conversation with Julia Wolfe at Ramsey Public Health. One of big issues has been transportation. Linda mentioned that Brad, the volunteer from Citizens League is doing research on transportation for the task force.
- Mark told personal experience with his mother-in-law’s death. She came to live with he and his wife last December after pacemaker implant. Good buddies. In January, she fell and broke her pelvis. Talked about advance directory and what she wanted. Went to hospital. Diagnosis needed surgery. At crossroads. Had been talking about dying for about a year. She was 92. I told her that if she didn’t have surgery she would be in bed

the rest of her life. Had surgery. Pelvis needed to grow back together. Rehab. Transferred to transitional care. Week or so later oxygen stats were low. Found she had pneumonia. Said decided not to treat. Decision was very consistent with her advance directive. Nursing home staff were willing to overrule her and the family was inclined to overrule her. It is such an easy fix. A combination of things made us go along with her wishes. Did not want to be a burden. Wanted to preserve an estate. Uphill climb to heal to broken pelvis. Care felt degrading to her. Six days later she died. Very hard for us. When we honor people's wishes we are clearly doing the right thing. Even when it is sometimes hard. One wrinkle. Nursing home has a one-page advance directive that they asked us to complete. Three choices: Full resuscitation, comfort care and do nothing. She already had a directive. Nursing home policy. Interesting. What would it mean if someone chose on that piece of paper that contradicted what was on their full advance directive? Was it a POLST? No. Three choices don't cover the nuance of a true advance directive is. Example of compressed morbidity. Maybe such a thing as a good death.

- Member mentioned that her organization has an on call advocacy program. Recently one of my clients called me and told me she had just had hip replaced. The hospital called me about four days later and wanted her health care directive. They had her as full code. She insisted she was DNR/DNI but they would not go with it without the healthcare directive. Totally solo. Member asked why would they even care what the directive said if she is saying to them what she wants. Very inappropriate to take the paper over the individual's choice. Just have her sign a new one.
- Advisory Group update. We have been working with Pahoua trying to pull together have not been successful. Part of our way has been to make contact with organizations such as Centro Tyrone Guzman. We are continuing to work on it. Linda noted that Pahoua and she meet with contact at Bush Foundation a few months ago and talked about getting diverse voices in the mix. Feedback was everyone is struggling with it. Trying to find alternatives for getting that information.
- Definition of solo. Notion was to strike the word "older" from our definition of solos for our project. *Member:* I would vote to strike "older". *Member:* I second that. I can identify myself as a solo but I don't identify as "older." I'm 58. It's an invitation to think of it as about the "other." It encourages people to think about at all points of your life. *Member:* I have a concern about broaden too much. If it we remove "older" it brings to mind the almost 4000 people in MN who are homeless. I don't think the focus of this project is on homeless adults. Quite broad. *Member:* We should think about the ramification of broadening the definition. When we make our recommendations it will be good to have them tailored to as specific of an audience as we can. Does it diffuse the impact too much? *Member:* Can we wait to decide until we are at the point of making recommendations? *Member:* My connection to the group has to do with the homeless population. *Member:* I think the "solo" population does narrow it. Solo adults with an emphasis on seniors. That is what we have focused our research on. Mark asked for a motion to change or move on. *Member:* I think we should wait and see.

*Member:* I make motion to amend wording of purpose to: "Stimulate the development of a supportive infrastructure to help **solo adults, particularly seniors**, 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." Friendly amendment: ". . . to help **solo adults, particularly older solo adults**, successfully . . ." Further discussion? All in favor of change? All opposed? Passed.

- Mark reiterated the interest in bringing a legislative voice into the conversation sooner rather than later. State or federal level? *Member:* Interested perspective to have. Middle of legislative session. Would we be able to have meeting with them. Suggested John Marty, Karen Housley (Chair of Long-Term Care Committee). If not them, staff. Interest is the current statutes and ideas about future. Make sense? Heads are nodding. We will invite staff to be in touch with Pahoua about this.

## Report of Results Focus Groups

Julie described the process for bringing the focus groups together. The group was recruited out of Julie's contacts at Centro Tyrone Guzman, a community center for Spanish-speaking people in south Minneapolis and a group of people involved in a project called Phillips Wellness 50+ led by the Vital Aging Network. We have distributed the transcripts of the focus groups.

### Centro Tyrone Guzman

Julie introduced, Claire Monesterio, who works for the Centro Wise Elders program. She led the focus group in Spanish and translated the comments.

Nine participants. All over 65. From Mexico, Puerto Rico and Ecuador. All low income. Highest income \$1,180/month. Six non-citizens and three citizens. Six insured and three non-insured. Two are proficient in English. One couple was married but feel very alone. Wife's health was declining

Claire's overview: Not used to being heard, given the floor. Pent up emotion is released. Fear of the future. Worry about being a burden. Hard for people to answer the question about what resources they want. What are the options? Many suffer from depression. They come to this group. We do exercises, we do field trips, we have medical professionals. They felt we were doing a support group. Had a hard time understanding that we were doing research. At the end they said, we need more support groups. Resource navigation came up frequently. How to find what you need. Who can I trust? Concern about elder abuse. Don't have a translator when I go to the hospital. Get overcharged. They don't hear what I need. Might have contact with good person, that person is limited. Disjointed resources and needed some full understanding about what is available. Workshoping, like what we did is good. Finding ways to bring the resources to them is very important. One person showing early signs of dementia. Need handholding. Doesn't remember appointments, etc. Very important. Without that guide, she is lost and has potential to become more lost. Transportation is big thing. Translation important so can communicate. Heard, "I'm afraid, I'm alone." Centro offers a lot but so much need.

*Member:* The emotional aspect comes through. We need to pay attention to that. I have had a lifetime of experience where trust has been broken. Why should I trust?

Claire: Watch a person in our group who had lost her son and grandchildren. So was beyond our reach. Severely depressed. She fell and broke a hip and died. Mental health plays such a huge roll in physical health. Finding an organization that we can trust. They trust Centro but it can't provide all they need.

"Solo" is a Spanish word. It means alone in Spanish but not in the same way that it means in English. It is tinted with sadness and an undercurrent of negativity surrounding solitude. Very different connotation. We used the word "independent."

One couple was married but feel very alone. Wife's health was declining and husband was very worried. One man had distant family. Don't associate. Woman has one child, won't help read mail. Other just had a stroke and understood no one will be there. Children have to work, don't have safety nets, can't take time off work. Others have family but not here. If I fell who would

help. Her friends are her age, could not lift her off the floor. When we build community for our elders it is just a bunch of elders getting together having their tea. Not an age integrated community.

*Member:* Do people understand concept of health care directive?

Claire: Four have been through Honoring Choices workshop. One of them started a health care directive. Has completed has to sign it. Not enough time to help. Barrier. Need to do every three or four months. Create a ritual with it. Lack in trust in the documents.

*Member:* Cultural is the advance directive more foreign?

Claire: Yes. Lot of confusion about why I need a document if I'm dead. How it comes into play when still alive?

*Member:* Do you know why the one person did a health directive?

Claire: Person is very organized. Has had a will. It made sense to her.

### **Phillips Wellness 50+ Group**

Julie described how it came together. A group of friends at Ebenezer Tower in Minneapolis. They know each other well and felt they would support each other. Focus on end of life and what will happen after they die. Looking for information. Themes of trust. Don't want to be a burden. Common things. Sense of I can't control this. If I die maybe I can say what I want. It feels overwhelming to people. They feel it will work its way out. No sense that making plans will mean it will work out better.

Six people. One woman had no family here. One who had family here but the sister had family, "I don't want to bother her." Man said family in another state. One son here, won't trust him. Women who everyone pointed would help said she had family here but didn't think they would help. She had a disabled son and was worried about him. Range of situations was pretty broad.

Demographics. HUD Section 8 building. All were low income.

*Member:* Did a focus group at Southwest Senior Center about preparation for events. Overwhelming sense that if I am alone, I need to be connected with my peeps, the people I trust. How do I not be alone? What can I change to make me less alone? If you had a major health crisis, what would you do? Very few had planned. They would turn to their main "fixer." If you are really alone, you try to identify people who you can trust. It is a big effort.

Julie: How many people of the people in that community are connected? The group said less than 10%. Anything we can do to connect people would be very important. So many stories about people who fell and lay on the floor for three days and no one knew it. Whether they have a health care directive or not at least they have someone. VAN's Wellness 50+ program works to do that.

*Member:* MN VOA just got a federal grant to build on outreach program within high rises. You will reach the people who have overcome the barriers of connecting. Won't reach those that can't move beyond their isolation. Usually it is depression that is holding them down. Direct outreach model within the high rise.

Claire: Have done things that are in their homes. That helps a lot. I also did not mention earlier that many of the participants were worried about money and access to care. Many do not have insurance.

Member: I am assuming many do not have access to Medicare. Many are not citizens but legal. Have very little savings, maybe \$20,000, too much for medical assistance.

Claire: Yes.

Julie: Let's summarize what we have learned from the focus groups.

- If you are worried about being deported, having a health care directive is a pretty low priority.
- Poverty, lack of a "fixer", isolation, lack of transportation cause problems
- Mobility issues. What a difference it makes to go to where a person is
- Issues of trust. Your mother-in-law had trust in you. So many do not have the same. How do we address that?
- Danger of falling. Effects of falling can be devastating. I fell. Met in my home. Listening to what is under the surface for the individual
- Lots of emotion. Fear. How do we use the fear as a motivator?
- Wonder what percent of senior population is isolated? I would say at least 20 percent of the older population. Need to think about those that are isolated. Many are unreachable.
- Need for awareness raising about the need for social connection.

### **Brief Review of Data Related to Older Adults, Solos**

Distributed a sheet with more data that Linda brought together. We will get back to it when we get to analysis stage of the project.

### **Quick Preview of the Analysis & Recommendations Phases**

Project is meant to be foundational. Meant to have a multi-dimensional discussion to get the big picture. We are in the "starter dough" phase. We will come up with some things that we identify as really important. Identify who we should hand these things off to?

One more meeting allocated to discovery phase of project. Have had preliminary contact with Carl, the social worker, for April meeting. Then we would talk about the planning piece. In May we would start analysis and continue in June, July. In August and September we would make recommendations. (Linda, planning document is attached).

One idea is to convene a larger meeting with key stakeholders to present the recommendations and get their feedback.

*Member:* This is going to be the hardest work coming up. I wonder if it fits in a two-hour meeting. Should we consider a longer meeting?

*Member:* Sounds like a very good idea. We all have time constraints.

*Member:* Makes sense. Once we dig in we will see if it is realistic.

*Member:* Just because we have been in discovery mode it doesn't mean that our brains haven't been analyzing all the way along. We just have synthesis yet. But it may come together pretty quickly. Solutions will probably be in a few pockets where can we have impact. I have been

starting to think about what they might be. I keep thinking about what Hal said. "Money's a big problem but the people who don't have social capital are worse off." How far down the road can we go on building social capital? Probably not an area we will go deeply into. We need to cordon off the areas we think we can have an impact on. All that is to say that I am open to the schedule we've got. Not worried about it. Think we have done more analytic work than we think.

*Matt:* What assumptions will the group make about what is possible?

*Member:* Part of discussion has been focused on planning documents, which are limited. The whole issue of social isolation and need for social capital is very different? Do we address both? My dad fell the other day. 71 lives alone a few blocks from me. Very connected but he ended up spending a night on the floor. Didn't want to call anyone. All of a sudden needs 24-hour care. You can have plans, social capital and have every thing together and it still is a problem. Got up in the middle of the night, feet got tangled in bedding and fell. How do you plan for what can't be planned for?

*Marit:* On the dual focus question. Conversation on social capital is emerging as more prominent. Planning tools that concern you and me maybe can be set aside. Easy solutions. I am starting to focus on is the social capital piece. Primary question we have. The issues with advance directives are clear and we can create a pretty clear pathway to solve.

Planning assignment. Joyce and Peter will call Senior Linkage Line the rest do the other pieces.

## **Evaluation**

**5, 4, 5, 5, 4.5, 4.5, 5,**

- 5 - Something clicked for me today with Claire's comments. The people she talked about in the focus group are leaning on each other. Hal's words come back to me. How much he helped people create the social connection they needed when problems arose. I think a watershed here today.
- 4 - Discussion was robust but we spend too much time and had to hurry through other things.
- 5 – Really appreciate Claire and Julie and Linda bringing these voices in.
- 5 – Rich conversation, fleshed out the social capital issue.
- 4.5 – Very helpful. Dealing with oxymoron. How do you plan for the unplanable.
- 4.5 – struggle with professional vs human level. Concern that what we come up will be human. Useful to someone and not something we stick on the shelf.
- 4.5 – helpful – got to the emotion of how this come down to an individual. The .5 is that I continue to feel a little uncomfortable about what the outcome is going to be. Maybe discomfort is a positive thing.
- 5 – because of the aha moments. Hearing the stories. Got to tell your story. Maybe we won't fix but will understand what the barriers are and how we might help.