

Meeting Minutes

A Backup Plan for Solos Task Force

Tuesday, June 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 (co-chair), Susan Henry, Darla Kashian, Greg Owen, Karen Peterson, Mark Peterson (co-chair), Peter Rothe, Sabina Sten, Martin Wera

Members Not Present: Kathleen Dempsey,

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

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:

Generate and analyze the issues, best practices, opportunities and gaps related to health decision by solo adults who have capacity.

Check-in and Updates

Co-chair, Mark Peterson, called the meeting to order. Asked for additions, deletions, changes to the minutes of the 5/15/18 meeting. Minutes were approved with one change on page 5, “We ~~should~~ **shouldn’t** try to take on all problems for all solos of all time.”

- Guest Diane Graham-Raff from ElderCare Development Partnership Coordinator at Metropolitan Area Agency on Aging. She is attending to listen to what the task force is working on and hopes to bring to the discussions ways to incorporate community partners into rolling out next level of solutions.
- Lutheran Social Services now offers a service where you can hire someone to be your healthcare agent (<http://lssmn.org/healthcareagent/>). \$105 to start and \$50 a year after that includes a check in each year with the agent. Once activated (in hospital or situation where needed) there is an hourly rate. They had lots of internal decisions about how to set it up and how to manage it. Can’t have an organization as the agent so need to list individuals. Identify a primary and secondary. Issue for insurance but LSS felt it was a gap and a needed service. *Member:* Is it really good that agencies and organizations aren’t allowed to be agents? Is that something we should think about recommending a change in? *Member:* What is the succession plan for the agency?

- Mark reported on the Ad Hoc Group meeting on May 22. Kristin Kinney, American Indian Family Center; Bee Vue, VOA Park Elders (Hmong community); Marsha Berry, Training to Serve were there. All had examples of solo individuals in their communities who experienced the issues we have talked about here. Very time consuming and laborious for organizations to deal with these issues. Asian communities have problems with translation and transportation. Seniors being kicked out their homes by younger westernize family members creates housing problems. In the Native American community, there is an elders lodge in east Saint Paul for elders without family. Elders are respected. Chemical dependency especially opioids is common. Grandparents caring for grandchildren is common. Lack of trust in government and western ways, particularly in medicine. Support system is mobile, family members go to reservations and back to urban areas. Accepting services from outside their community is resisted. Won't go to the doctor. LBGT community. Identifying people soon after diagnosis of dementia is important. People who don't have trusted connections struggle. Isolation is common. Fewer LBGT bars and gathering places. Becoming a younger phenomena. Suggestions: Look into Return to Home program. Metropolitan Area Agencies on Aging can help. They will review the materials we share as preliminary recommendations at the next meeting and provide feedback. Next meeting is scheduled for September 6 from 11:00 to 1:00 at Minnesota Elder Justice Center. Task force members are invited.

Snapshot of Solos

Linda brought attention to the solos snapshot summary she prepared. It captures the task force input from the last meeting with common assumptions about solos, what we now know about solos, insights/issues and possible solutions. Do you think the points capture what we know about solos?

Member: Will you expand on "solo-ness is on a continuum"?

Member: At Little Brothers we talk about social isolation is on a continuum. On one end you have rich and fulfilling set of relationship. Over time, with pressures they tend to deteriorate. We have a tendency to become more isolated as we grow older.

Member: How does that dovetail with solo-ness as a moving target?

Linda: I think that the point was sometimes people are fine and then a situation changes and solo-ness becomes an issue. Knee surgery for example.

Member: Assumption: "non-solos plan; solos don't plan". Are we saying that is a myth?

Linda: The list comes from our question to the group of "What were the assumptions that you had about solos when we started this project"? We are not saying these are valid assumptions to make about solos.

Question: What happens if you take someone who has no family but builds a complete support system. Are they still a solo?

Member: I think we need to separate the idea of living alone and solo-ness. I think of my friend Maggie who lives alone. She is so not a solo even though she is 58 or 59 never married, partnered. But not a solo. Are we saying that?

Member: Recently there has been a lot of discussion about social isolation vs. loneliness. Solo doesn't mean that person hasn't married or doesn't have kids. It is a condition.

Member: Can we define who isn't a solo?

Member: A solo is a person with limited social connections.

Linda: We are not defining the universe. It is not fixed condition. It is a situation.

Member: At beginning we defined solo as someone who did not have traditional family support.

Linda: Are we good with thinking of solo-ness as a condition?

Member: I like that way of thinking about it. I am open to a different term. There is such fluidity in this. Shifts from time to time.

Member: The term that comes up for me is functionally solo. It is a status that shifts and varies. The conditions to be met to be solo would be 1.) limited social connections and support and 2.) no identifiable person to help with decision-making.

Member: When we use the word solo in that way we are creating a noun and a state of being should be an adjective. If someone is unsupported in the context of health care decision-making and we call him or her a solo it is can amount to “othering”. As soon as you create a noun you have to create a definition and whatever that definition is it will be too universal for what we are talking about.

Member: I don't know if we can do anything about that. The term “Solo” is out of the box. It has been made a noun.

Member: We don't have to accept the term. We can help to reset the conversation to make it right. Just as the Redskins need to work on with their team name. These are unsupported older adults.

Problem Description

De Bono: “A problem is simply the difference between what one has and what one wants.”

What do we have? What do we want?

What we have

- Trust is a big issue. Individuals who have limited social contact don't have someone they trust
- Many resources and solutions to problems but they are served up piecemeal
- Significant portion of people who are solo because of mental health issues or are just crabby
- Denial – people don't want to plan for eventualities
- Too many people becoming vulnerable adults with costs to individual and society.
- Lack of awareness on part of individuals and institutions about what people confront and what resources are available
- Inadequate legislation. Minnesota is law light in this area.
- A system that doesn't transfer information very well. Could have a health care directive but the system doesn't allow it to be pulled up in emergency.

What we want

- System that people can trust.
- A way to connect to resources in a way that is easy for people to understand and access.

- Everyone has a supportive people to help make decisions.
- Want fewer cases of vulnerable adults to occur

Member: We need to problem solve to the society we have. Lack of trust might be the problem not lack of people.

Member: Who in your network do you really trust to make important decisions for you? Have you had conversations about it? I feel the trust factor is very important. We don't trust the system to make those decisions for us. We are a very independent culture.

Member: Gets back to lack of trust. What we are solving for is tragically very American. My grandparents lived with my parents. My mother in law can't imagine living with us.

Member: Self-determination is one of the ideal for aging with dignity and grace. Often a loss of autonomous decision making as we age. Interdependence is the other side of the coin from our focus on independence. You hear about families being so proud that their 94-year-old mother is living on the family farm by herself without any social support and that is held up as a wonderful idea. But that really isn't ideal at all.

Member: I think what we want is a measured independence. We tend to go to absolutes. We don't want to be totally interdependence either.

Member: If I think about the problem we are trying to solve I might identify it this way: We are trying to identify and help individuals who are socially isolated and unsupported when challenged by serious health problems. We are trying to create a means of better support those individuals and identify strategies that service providers can use when serving those individuals. We need a set of solutions that individuals act on and a set of solutions that institutions act on.

Member: I agree. We could look at it as a dual set of issues/solutions. What do we have as far as individuals? What do we have as far as institutions?

Member: If I am a Fairview patient and I end up in the ER, would the doc have access to my healthcare directive?

Member: In the Twin Cities most systems use Epic and there is good interconnectivity. If it is in the system you could see it. I'm not saying that's everywhere in the state. But the connectivity expands beyond accessing a health care directive. I was on call last night. At 2:30 in the morning, an ER doc called me. Had the patient's advance directive. The patient was sent from nursing home for fractured leg and the doctor was trying to get a hold of the family. Couldn't so called me. I don't know the patient at all. Hard decisions. In this case it was a complicated situation. The ER doc was wise to call me rather than an ortho doc. I was able to give geriatric perspective but I couldn't give a personal perspective. A personal representative would have been better.

Linda: I interviewed a home care agency. The women who I talked to cited a solo who was in a rehab facility. She was unhappy and wanted to go home. She called the home care agency to arrange all services needed to go home. The rehab facility refused to share her information with the home care agency.

Gaps, Issues, Opportunities

Member: I've been thinking about the ER doctor we heard from and the problem from her perspective. If people come in and don't have a decision maker she has needs fallback plans. One of the gaps is that she has to go through people's wallets and phones to find a contact. If there is access to information, that's a big help. When people come in in a state where they

can't communicate for themselves, the institution needs to find someone. How do they identify the social connectedness of people? There is a gap in how to do that.

Member: Everyone a valid representative. That is a universal need at all ages in the event of someone not being able to make a decision for self.

Member: In the absence of a valid representative, my experience is that just any old body is better than no one.

Member: That's not ideal. That's a band aid. An ER physician is reluctant to show restraint. With the patient that I was dealing with last night the default should be palliative care unless you know something else. But in general historically the default has been full care. I don't think that's kind much of the time.

Member: Gap is the inadequacies of health care directives and POLSTs. There isn't a single document that takes the place of a person to interpret the intentions of what a person wants.

Member: If a decision maker lives out of state they won't be accessible.

Member: Everyone needs a valid and accessible representative. That's the ideal. We might not obtain it but it is the ideal.

Member: Every situation is different and you need people who can think. That's one of the skills that the representative needs.

Member: Before you have an agent you need a planning process. Unless you say call my sister and the sister has knowledge of my desires. A solution might be at every touch point in the health care system nudges people to create a health care directive with an agent.

Member: Great point. People with money are nudged towards this much more so than for people without money. Financial rep will ask about will. Go to an attorney and they will ask about a health care directive. Having money is an on ramp to planning.

Member: Most people still ignore it. You can't be a client in my financial firm without a health care directive.

Member: Some people have barriers and can't be reached. Had a client call me because she wanted to make a donation when she dies. Had no one. Didn't want to use people she had. She is the barrier.

Member: Every client in my financial firm has to name a trusted contact. (Short story about this: <https://www.cnbc.com/2018/05/15/advisors-are-asking-their-clients-for-a-trusted-contact-choose-wisely.html>) We require that but I can't imagine that my physician would require that. Maybe they should.

Linda: My financial advisor said he needed a trusted person on your record. I think people are making the assumption that everyone has someone who knows their everyday doings.

Member: Our purpose for the trusted contact is related to capacity. If I start to observe that a person is not taking care of self, calling frequently, radical change in personality that is when we will reach out to the trusted person.

Linda: I challenge the underlying assumption that everybody has someone like that. That's a gap.

Member: If you are flying internationally you need an emergency contact. What are all these roles and what are the expectations of them.

Member: I think one of the assumptions we are making is that the advance directive is going to be a part of the solution. I don't see it that way. How many years have we been working on getting people to do them and most people don't do them.

Member: Even in 1976 the idea of an advance directive came up and people were saying that everyone needed one.

Member: It just hasn't caught on. I worked many years on getting people to do it. It is a tool to help you have the conversation with your family and the person who will be your agent. Don't expect it to be an end all in a medical situation.

Member: If you had a choice between an advance directive and an agent you would want the agent.

Member: If you see them, many are not well done and they are outdated almost immediately. If we are making the assumption that that is the most important thing, I think we are making a mistake.

Member: We won't have a solution for everyone. There are barriers in having a trusted person. Gap is that there are people who don't trust. Can we help people get over that barrier? Can we help provide tools that will help people reconcile with the people in their lives?

Member: I think we want to avoid thinking about advance directives as a decision document. The issue isn't advance directives. People need help with decision-making all along the path of life. Need representative (partner, advocate, etc.)

Member: (Looking up statistics) About a third of adults have a health care directive or agent. That number goes up to 46 percent if you are over 65.

Member: Default is to over-treat. Is there an assumption that if people don't do the planning that they are happy with the default? For me right now if you ask me, I would say that I want everything that can be done for a full recovery. That may change over time as a function of my age and other things. What is the right number of people to have an advance directive? For a lot of people the default is good. They assume someone will figure it out.

Member: Anyone can run into things that would trigger a need for an outside decision maker. Now they are on a ventilator. They are brain dead. Probably not what they were thinking when they did the health care directive or that someone would just take care of it.

Member: If the default was no treatment, I would suddenly become very interested in advance planning.

Member: Do we have statistics on percent of people who choose less aggressive treatment in advance directives? Most people I have seen scale back on treatment.

Member: Two themes that we have been talking about. One is health directives for people who don't have capacity and the other is addressing situations where people don't have people to get to them to the hospital when they have knee surgery or a care provider doesn't show up. Need emergency pool. Peace corps for these needs. One-offs. Need a system for that like calling the Senior LinkAge line to arrange. Block nurse programs so something like that.

Member: How do you foster relationships so you have that person you can trust?

Member: 90 percent of support happens because people form connections with individuals and they provide support and take an interest in people lives. If you don't foster relationships and occasionally pay it forward for other people you can't call those chits in. We are trying to create a social fabric. Very, very difficult to create. Need to establish reciprocity. Getting people to go to a volunteer corps without the reciprocity is difficult.

Member: I agree that it is very hard. Tactics can make some impact but an ongoing social fabric is hard to maintain.

Member: Many communities have volunteer drivers. Much of this is going on under Older Americans Act funding from federal government and funneled through the Area Agencies on Aging. Escorted transportation.

Member: There are door-to-door transportation services that and health care advocates. Most are volunteer based. By nature they are community based and spotty in location.

Member: In my condo, we have a group that provides airport transportation. Could be expanded to driving to cataracts appointment. Building neighborhood-based support systems. Babysit coops. Can an app be created? Nextdoor.com an option?

Member: Neighborhood based solutions could be part of the recommendation. Has anyone looked at best practices?

Member: Blue Zones is an example.

Member: Need to research the apps that are out there already.

Member: I just set up in my phone access to emergency contact. It's an iPhone app.

Member: Faith communities are a good source for potential volunteer drivers. Might offer a workforce. Minnesota Council of Churches could be a good partner.

Linda: I am working with a church that has shied away from offering transportation because of legal issues. Gap: issues around liability.

Member: Does the American Cancer Association still transport patients for appointments?

Diane: They do. They often reach out to other organizations for help. The state convened a huge volunteer transportation forum a few weeks ago to address issues. If organizations reimburse volunteer above a certain level it is taxable income and if you have low-income drivers it can kick them off supports. Legal issues around how drivers are defined. The religious organizations are backing away. The group is working on legislative correctives.

Member: Sounds like we are coming to a consensus that health care directives are necessary but not sufficient.

Member: When doing the health care directive, part of the process is identifying person who is the health care agent. That's a valuable part of the process.

Member: Planning process should be defined as broader than the health care directive.

Member: I keep thinking about the incentives for people to do planning. For life insurance, the incentive is planning for children. If you meet the qualifications for being at risk for solo-ness, what are the incentives for doing planning? Not obvious to me what they are.

Member: Not sure that the incentive need to be financial. Emotions can help drive actions. Trying to get people not to do something, use fear. When you want people to do something, hope is most effective.

Member: When people become eligible for Medicare they get a welcome to Medicare packet maybe planning tools can be a part of it.

Member: Solutions need to be multi-pronged.

Report of Results Focus Groups Evaluation

45, 5, 4.5, 5, 5, 5, 5, 5

Purpose of meeting

Generate and analyze the issues, best practices, opportunities and gaps related to health decision by solo adults who have capacity.

4.5 – Farther ranging conversation than the purpose. I was good with that.

5 – We are in the phase where it is a lot of work. Trying to condense everything we have learned doesn't feel particularly gratifying at the moment but needs to be done.

4.5 – Discussion was all over the map and a little vague but I think we are making progress.

5 – Getting a better grasp

5 – Like the wide-ranging discussion

5 – I have a building appreciation for what staff does with all the info to make it useful for us

5 – Staff has done a lot of synthesis of all that we have surfaced and it comes out on these papers.

5 – In reading the notes and the summaries, it seems like we are more coherent then it feels in the moment.

5 – Distilling a lot of info.

5 – So many wonderful things came out of our discussion. Linda will take it back and pull it all together for us. Functional solo concept is important. Need for incentives also important.

Next meeting July 17.