

Meeting Minutes
A Backup Plan for Solos Task Force
Orientation Session
Wednesday, September 27, 2017 – 7:30 to 11:30 AM
Mount Zion Temple, 1300 Summit Ave, St Paul, MN 55105

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

Members Not Present: Bright (Dorn) Dornblaser, Greg Owen, Karen Peterson

Staff & Staff Support Present: Sean Kershaw, Pahoua Yang Hoffman, Linda Camp, Marit Peterson, 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 September 27 meeting:

- Get to know task force members and start to develop team capacity.
- Understand the Citizens League process, project goals and expected outcomes.
- Learn background information about solos, the current infrastructure for supportive decision making related to health care and demographic trends.
- Understand the mechanics of the task force moving forward

Welcome/Negotiate Agenda

Sean Kershaw called the meeting to order at 7:30 AM. Noted that Citizens League makes a practice of starting and ending meetings on time, honoring people’s time. This project is part of a larger effort that Citizens League is doing on aging. Sean noted that aging is a topic that matters enormously, is going to determine our future as a state and has all sorts of places where people can have an impact. There are a lot of hard topics to tackle but it is, on the whole, an optimistic policy topic.

Sean introduced co-chairs, Mark Peterson and Ellie Hands.

Co-chair, Ellie Hands, reviewed the agenda for the day and asked for additions, deletions, changes. Task force agreed to agenda.

Introductions

Co-chair, Mark Peterson, invited participants to introduce themselves, tell why they are participating and tell something of your own experience around solos.

(See bios in three-ring binder for basic information about each participant.)

Kathleen Dempsey

RN, founder and CEO, Pathfinder Care Management. I run into solo seniors all the time. Many of our clients are solo seniors who don't have any family. We get referrals from attorneys, trust officers and others to act as a medical advocate to avoid someone going into guardianship.

Joyce Edwards

Solo; small business owner. Completed VOA training to be a professional guardian/conservator. In that role, I can take on healthcare decision-making responsibilities for clients. Have two agents for myself but they don't live in Minnesota. Have concerns about having the right healthcare agent in my life

James Falvey

Executive director, Little Brothers - Friends of the Elderly. Social integration is the single biggest determinant to one's health. Little Brothers estimates that by 2020 there will be about 50,000 people in the Twin Cities who are 65+, live alone and lack support for optimal health. Big mandate to meet need. We need to foment a community-wide movement. Little Brothers can't do this alone. We need to inspire more and more people to engage elders in their own neighborhoods.

Genevieve Gaboriault

Managing Attorney, Mid-Minnesota Legal Aid. Serve seniors with government benefit problems, medical assistance problems, evictions, nursing home issues, light estate planning. Help do health care directives and power of attorneys. Many have guardians. There is a system for managing your money if you are a solo but no one to help with healthcare decisions. Even if you are living in senior housing there generally isn't someone to help with those issues. My interest here is to help figure out how to get this kind of help for people.

Ellie Hands

Solo, retired nonprofit executive director. I have children but they live far away and have young families and I know they can't come rushing to help me out. I developed a master aging plan for myself. The plan includes how to handle healthcare decisions and financial planning. There is a point in your life when you either have to make your own decisions or someone will make them for you. Very interested in planning. I think that is the key. We are looking at a "back-up" plan. I think it needs to be an "upfront" plan.

Susan Henry

Retired senior leader in airline industry; member, Minnesota Board on Aging. When my mother was going through end of life, I spent a lot of time with her. I got to know so many people in her facility that had no one and I wondered how they got through life. I took the VOA training for conservatory and guardianship. Everyone I work with is a solo and most are in very sad circumstances. I am a solo. Have a niece and nephew but don't expect them to be responsible. I have planned.

Darla Kashian

Senior advisor on the Nicollet Investment Group of RBC Wealth Management. My interest in this topic is a professional one. 60% of our clients are over 65. Have seen a lot of situations with parents, children and other interested parties. Firm has a program called Safe Guardian Assets for Elderly Clients. Hope to bring some knowledge back to them. Daughters often are the ones that step up. A whole separate issue, that of women stepping out of the workforce to care for elderly parents. Also Jewish, lesbian, a parent. Can bring some insights about issues of lesbian/gay people aging at home and being isolated from their families.

Mark Peterson

Lutheran pastor; retired pastoral care manager, interium pastor. In role as pastor at a trauma hospital have seen all sorts of healthcare decisions based on the thinnest of anecdotal evidence. Work with Dignity Center at Hennepin Avenue Methodist and in that role have done advance care planning with people who are homeless. Some homeless have said, "My living will says my family will have no say in what happens to me. They don't know me, why should they have a say?" Most are middle age or younger. My mother-in-law just moved in with us. She requires a lot of attention and it is intense. She has enormous needs that cannot be meant by any one person.

Peter Rothe

MD, Geriatrics. Have had rich experiences in working with older adults. Everyone is a solo at some point in his or her life, by choice or circumstances. There is so much diversity in solos it will be interesting to see how we deal with that. The medical component is important but as we all know the social components are far more important. I keep thinking about technology helping me as I get older. I look forward to autonomous vehicles.

Sabina Sten

Solo, co-founder Mill City Commons. Three children, two live outside the US. One in California so I am a solo. I took care of husband who had Parkinson's Disease until the last eight months of his life. I am 81. I have learned so much as a solo and am pleased to be a part of the task force.

Martin Wera

Bush Fellow and a Director in the Community Relations department of Ameriprise Financial. Focus in Bush Fellowship is on aging, issues related to the social determinants of health. Particularly interested in food and how it contributes to health and well-being. My personal connection is through my own family. My dad passed away

about five years ago and shortly after that my mother fell and broke her hip. We don't live in the town that she lives in. We can't be right there for her. Made me aware of the need for better planning. We need ways that build on the social connections that people have.

STAFF

Linda Camp

A solo. Julie and I are a tag team in providing support to the task force. Started getting interested in this topic when I was reviewing my documents. I realized that the woman who was my backup has health issues of her own. I couldn't figure out what to do. I started interviewing people and everyone agreed it was an important issue and there was lots of interest in the findings. We are not in crisis mode yet but probably will be if we don't find solutions. People seem to think that government is going to solve the problem. There isn't the money to do that now, what makes us think there will be as the number of older adults grows? I have many solo stories. For example, a woman I will call Lucy in her early 70s. She had no children, no siblings but has a cousin who was named on all her papers but she said she hasn't spoken to in more than 10 years. She didn't know what to do. Looking forward to learning from all of your experiences and knowledge.

Pahoua Yang Hoffman

Policy director for Citizens League. Have been at Citizens League for 3 years. Prior to Citizens League worked with Twin Cities Public Television for 7 years. Worked on project with question: What is the Sesame Street model for older adults? Next Avenue was the result. Also worked on Honoring Choices programming with Karen Peterson. Am a caregiver for two moms, my own and my Jewish mother-in-law. 42, don't have kids. My husband is 10 years older than me so I am interested in this topic even at a younger age.

Sean Kershaw

Executive director of Citizens League. I have the opposite of a solos problem. I have a huge family. I got all revved up about the topic of aging when I heard the demographer's data five or six years ago. The data is important but as soon as you move away from the numbers to people's stories the energy starts to change. I worked for the city of Saint Paul for years. What strikes me is how limited government is in so many ways. All the things that happen about aging happen in people's homes, in their lives, in their communities.

Marit Peterson

(Marit, pronounced like "Mar(k)"). Program director at the Minnesota Elder Justice Center. Focused on preventing and alleviating abuse, neglect and financial exploitation for older and vulnerable adults. Work is primarily education and training with criminal justice, health professionals, etc. Do some direct service, helping people respond to situations and know how to impact systems. My interest in this project is related to my belief that community is a protective factor in preventing abuse. Isolation is a risk factor. The notion that we can come up with ideas that would help older adults be participants in their communities is significant. Before joining the Elder Justice Center I was an

attorney in private practice and did estate planning and incapacity planning for older adults and I can help shed light on tools and supports that currently exist in this area.

Julie Roles

Background is in business and nonprofits. For the past 25 years as an independent consultant as a program developer and program manager. I have working in the aging field for the past 10 years, much of that with the Vital Aging Network. VAN focuses on building the capacity of people as they age to be engaged and contributors in their communities. I am a solo without much of a plan. Expect I will benefit from some of what we learn. Experience with VAN's Wellness 50+ program, a grassroots effort to engage people in self-care and supporting each other in their communities. Work in the very diverse Phillips neighborhood. Last night that group had a discussion with an attorney about these topics. Several of the people were solos and each had a unique story and did not know where to turn. The attorney's only answer was "find a family member." There is a great need to find solutions and I am happy to be a part of the process.

Co-chair Mark: Thanks to all. A pastor at my church was fond of saying "Everything we need in this church is here in this room." Not exactly the case for us but we know people that we can call in to help us understand the issues. Be thinking about that. These issues transcend death (what happens with our bodies). Others will make the decisions if you don't. It would just be better if you did.

About a Citizens League Task Force

Pahoua drew members' attention to the Citizens League Handbook in the Basics tab of the three-ring binder. Recommended that members read through the handbook. She noted that the executive team worked hard to bring diverse viewpoints to the table and were not successful in terms of the task force, mostly because of the time commitment required. We are working to pull together an advisory group with diverse voices that can help to inform the task force. Pahoua covered these points:

- Citizens League uses of study committees and principles. (Pages 2–3).
- How Study Committees Work. (Page 3). Three phases. Discovery – we all learn together and by some point makes it difficult to pretend we don't know something. Phase two is Consensus on Key Findings and Conclusions. Phase three is Making Recommendations.
- Responsibility as task force member and standards. (Pages 3–4). Standards help to engage the right people, encourage civil conversation, contribute resources and sustain the solutions.
- Meeting style. (Page 5). Start and end on time. Recorded in order to produce detailed notes. Task force members are not identified in the notes to encourage free exchange of ideas. Minutes will be put on the Citizens League website for public access.

Sean suggested that people trust the process. Often at some point there is a switch, even when it feels like things aren't on track. What makes the Citizens League unique is its open and transparent approach, one that is rarely used in policy development. It is

really helpful for you to talk with others about what we are doing. We don't expect everyone to agree on everything. And we will even occasionally do a minority report if there is a strong difference in opinion. The breakthroughs happen when someone says, "I don't get this but . . ."

An example, in our long-term care project at one point a person, who was a solo, said "What I need is an available daughter." It says so much about the topic. We couldn't take on that topic at that time. It is nice that we can now come back and take on that question.

Member: There was an organization, Rent a Daughter. Kathleen Dempsey wrapped that organization into her organization, Pathfinder Care Management.

About the Project: Key Ideas

Linda Camp presented key concepts. (See notes in the Background tab of three-ring binder). This is a foundational project. We don't expect to come up with one single answer but a body of work that will spawn much more work.

Working definition of solos: Older adults who, by choice or circumstance, function without the support system traditionally provided by family. (See page 19 in handbook for more detail).

Member: How do we define "older adult"?

Member: It varies so much, personal thing. Much of what we are dealing with won't fit in a nice box.

Member: You could almost remove the word "older". A lot of adults of all ages could have the needs that we are talking about.

Member: That's a foundational point. The homeless people I talked about are not old. We might consider striking that word. Eighteen is the pivot point.

(We put the idea of striking "older" on a Parking Lot sheet).

Terminology. We are using the term "solo". Other terms that are out there include: unbefriended elderly, elder orphan, solo senior.

Our focus is on solos with capacity. Others are working on people without capacity. Few are working on this group of capable people who can make decisions. They are hard to count. They are not a distinct group. Choice and circumstances are key factors. The culture has shifted and people are living their lives differently.

Member: Are you familiar with the DHS survey that is done each year at the State Fair? Questions relate to how prepared you are for the next phase of your life. The results should be out soon and we should take a look at them.

Not much available about solos so the pool of knowledge that we will develop as part of this project will be an important contribution. How many are there? Could be 30 to 40 percent of the older population.

We need to look at solo population from different angles. Diffusion of Innovations model identifies different abilities/willingness to make change. (See page 20). Self starters, good followers, at risk, unbefriended elderly.

Our focus is on the self-starters, good followers and at risk. Not so much the unbefriended elderly.

Member: Do you feel that solos work their way through the continuum? My experience is that while people are physically and mentally active they do quite well. But when you lose ability you become at risk. You are identifying people who are self-starters and that they will always be that. I don't see that in my work. People move through different levels of ability as their situation changes.

People might be at different points at different times. Where people are will drive what approaches might be successful in helping them.

Member: If you get support to self-starters early they are less likely to become at risk.

The widespread assumptions are that family members will fill supportive roles. The usual pyramid for support shows a single person at the top. One person is the decision maker but also fills all the other roles. It is usually a struggle to find one person. Does it have to be one person? A team approach might be an interesting model to explore.

Who are the people who will support? Possible avenues: personal relationships, constructed relationships, professional relationships, relationships by policy or law. (Page 23).

Member: There are some organizations that will provide health care agents. Also association of guardianship and conservators. Some of those people will do less restrictive services.

Co-chair Ellie: An assignment for everyone: Read the Background section in the binder.

The Demographics

Guest presenter: Allison Liuzzi, MN Compass. See PowerPoint presentation at <http://citizensleague.org/solos>. Other demographic info at mncompass.org.

Member: Does "working age" include people 65+?

Allison: No. I am using working age as a label for the particular age group of 18 to 64 year olds.

Member: How are you defining "work" in this case?

Allison: Any engagement in the workforce for pay.

Member: What about other population shifts in other age groups?

Allison: Depends on the region of the state. Seeing declining working population in west central and southwest Minnesota. Staying put more in the northern part of the state. In the southeast not so much out migration. Most dire situation in terms of losing workers is in southwest Minnesota.

Member: Is there data about how a working age person supports the whole population not just older adults? Young people, older people, people with disabilities. Maybe it is not as extreme a change just focused on a different population.

Allison: I don't have info on that. Good suggestion for further study.

Member: Does your data take into account policy changes that might impact immigration?

Allison: It does not. Everything from the state demographer's office shows a increasing need for bringing immigrants into the state.

Sean: If it weren't for immigrants from other countries, Minnesota would be losing population.

Member: What is the poverty level for older adults?

Allison: About \$11,000.

Member: What's the ballpark cost of paid caregivers?

Member: \$27 to 30/hour for a companion – \$31 to 33/hour for medical support. Most agencies have a minimum of 2 to 3 hours.

Task Force Members Questions/Comments

- Are we assuming that all solo seniors are isolated? As a state we push living at home. As solos age, is living at home the right model or does it encourage isolation?
- I wonder if we should be talking "aging in community"?
- "People need to be repotted." Trend is mega centers that are removed from community. Move but not away from your community.
- People don't want older adult living facilities in neighborhoods. They resist, get push back from neighbors. Even residential care centers (small 6 to 8 people) are not welcomed.
- Smaller living situations work well for people living in them.

- NORCs (Naturally Occurring Retirement Communities) – help people band together to pay for shared services.
- The Beacon Hill model (Mill City Commons) is a community model that provides support.
- We are not talking about housing here. We are focused on healthcare decision-making.
- What do you mean by healthcare decision-making? 80 percent of health is based on social determinants. Are we only talking about what happens in the medical, clinical care?
- Central to our inquiry is the “who”. Who will make decisions if I can’t?
- The person named in a healthcare directive might also have the power to decide where you live. Many of us think about it as the end-of-life decisions but it also so much more. Might not be as easy as someone has a heart attack and do I keep him on life support. Might also be a stroke and might include a lot more complicated decisions.
- What does the infrastructure needed to support healthcare decisions for solos look like?
- How to plan for incremental changes in health needs?
- “When I had cataracts surgery, I ended up having to lie to the anesthesiologist, telling him that I would have someone with me for 24 hours. I live in a community where I have plenty of support but he would not accept that as sufficient.” This wasn’t about the advance directive. That didn’t even come into play.
- Many people don’t have an advance directive but may have a healthcare directive. **[Not sure I got this right]**
- Do solos who live in contiguous communities have good access to support in healthcare decisions? It is harder for those who live alone to get support?
- Churches have traditionally provide this kind of support. Do they have a role? Online churches are the fastest growing communities of faith and they won’t be much help for these situations.
- Solos need relationships to help navigate these issues. Everything is connected to everything. It does matter where you live; can’t ignore housing. “Going back to my mother-in-law. In the past 6 months she lost 20 lbs. Since she came to live with us she has gained back 3 of those pounds. The only difference is that she is now living in community.”

- If someone lives alone, research shows that they eat less.
- Do we need a master aging plan?
- What's in scope and out of scope?
- What percent of people will need decision making support? Not everyone who is a solo will need someone to step in to make decisions for them. What is the scope of the problem?
- Just about everyone needs it at some point. Unless you have a sudden death.
- What is our purpose in the task force? Just medical? Also addressing social determinants?
- It is person-centered?
- Are there gaps in what we are considering? What happens when I can no longer live independently?
- I just finished my health care directive. There is nothing in it about housing, just about medical. There are gaps in our planning documents.
- Who makes the decisions about housing if a person can't?
- The population of solos is fluid. There is no one place to go to learn about solos. We need better data.
- It isn't as simple as just putting a name on a healthcare directive. What are the barriers that stop people from naming a health care agent, doing advance care directives? Personality, life experiences, what's available in the community.
- Another barrier is that people are reluctant to talk about end-of-life issues.

Linda drew attention to a list of possible questions to explore in the three-ring binder under the Project Info tab.

How the Task Force will Move Forward

Julie brought attention to information in the Project Info tab.

Project materials will be on the Citizens League website at <http://citizensleague.org/solos>. You can reach the project team at solos@citizensleague.org.

On page 16 there is a beginning flow for task force process. At the October 10 meeting we will look at current laws and existing supports for healthcare decision making with Marit Peterson, Minnesota Elder Justice Center. The document lists other potential sources of information. What do you need to know? Who do you want to hear from?

How do you want to do that? We have some tools: bringing people into speak to us, have experts join us by webinar. We also have the ability to do focus groups, interviews, surveys, etc. We will talk more at our next meeting about what we need to learn and how we want to do that. Be thinking about it between now and then.

Member: Surprised about the lack of diversity in the task force.

Julie described the work we have done to recruit people of color to the task force. A lot of names were floated to us and we invited several. As mentioned earlier, Pahoua is working to assemble an advisory group to bring those voices in. If you have suggestions on people to include, let us know at solos@citizensleague.org and we will reach out to them.

Member: Can we also take some of our meetings to their locations?

Member: Linda wrote a compelling white paper about this topic and I recommend you read it. (It will be on the website page: citizensleague.org/solos).

Evaluation

Sean described the process Citizens League uses to evaluate task force meetings. We always start with revisiting the objectives of the meeting, both the project objectives and the particular meeting objectives. Ask everyone to rate the meeting from 1 to 5 and tell why they rate it that way. 5 is we hit the objectives of the meeting. 1 is you will never get the hours back and you are mad about it. Staff will use what you say to make adjustments to future meetings.

Members rated the meeting: 4, 4, 5, 5, 5, 5, 5, 5, 5, 5

- Don't feel I have enough knowledge about solos and infrastructure.
- I think very productive discussions towards clarifying goals, great cross-section of perspectives.
- Everyone spoke up. Symbol of a good meeting.
- Good that we don't exactly know our goal. Will take time to gather info and marinate.
- Feel we are on the right track. My head is buzzing
- Moving in a nice direction. Feel a little unsatisfied but that's okay.
- A lot of information I need to learn. Wonderful rich group of folks, perspectives.
- I have worked on projects like this where there is a desired outcome and people are invited to guess that outcome. This doesn't feel like that.

- Want an opportunity to learn more about the infrastructure and framework that's out there.

Co-chair Mark: I learned some things today about my own family. If we can help that happen we will do well. We are not yet where we need to be but we will continue to refine. Next meeting is Oct 10 at Wilder Center on Lexington Parkway. A meeting notice will be sent out. Thank you all.