Meeting Minutes
A Backup Plan for Solos Task Force
Tuesday, December 12, 2017 – 7:30 to 9:30 AM
Wilder Center, St Paul, MN

Task Force Members Present: Joyce Edwards, Genevieve Gaboriault, Ellie Hands (co-chair), Susan Henry, Greg Owen, Karen Peterson, Mark Peterson, Peter Rothe, Sabina Sten, Patty Thorsen, Martin Wera

Members Not Present: Kathleen Dempsey, James Falvey, Darla Kashian,

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

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:
Learn about medical decision-making and patients' rights from Thaddeus Pope, Mitchell-Hamline. Discuss pathway for next steps: What else do we need to know and how we go about getting what we need?

Welcome/Negotiate Agenda
Co-chair, Ellie Hands, called the meeting to order at 7:30 AM. Asked for additions, deletions, changes to the minutes of the 11/21/17 meeting. Date of meeting in the notes is incorrect and should be changed to 11/21/17. Minutes were approved with change.

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

Updates and Check-ins
- A member suggested doing an interview with Krista Boston, Director of Consumer Assistance Programs, Minnesota Board on Aging.
- The Governor's Elder Abuse Consumer Workgroup is requesting feedback from consumers, providers and other interested people. Written feedback will be accepted until January 10, 2018, via email to aarpmn@aarp.org, Subject: Elder Abuse Workgroup, or by mail to: Ms. Mary Jo George, Associate State Director for Advocacy, AARP Minnesota, 30 E. 7th Street, Suite 1200, St. Paul, MN 55101.
- A member suggested that task force members are careful not to assume someone is a solo. Need to let them define for themselves.
- A member shared that recent conversations at the task force have been challenging for him. His mother took a bad fall and he has had to look into her power of attorney and health care agent. How do we kick in to make decisions for her when she can't? It has been emotionally

challenging to see my mom lose agency. Understand better how it feels to be the person named on the health care directive sheet.

- A member interviewed an African American woman from Louisiana who moved to Minnesota. She recognized a cultural commitment to the family in the African American culture that isn't necessarily as strong in white culture. How do we better understand cultural barriers and differences?
- A member told of taking an individual to the emergency room. Had a presumption that he was not prepared and was surprise to learn that he had done a lot of planning. Had health care power of attorney. Had connections. Had a lifetime of reaching out and asking people to help. You don't come upon help accidentally.

Thaddeus Pope, PhD

Guest presenter. Director, Health Law Institute, Mitchell-Hamline School of Law.

Pope said that most of his work is more narrowly focused on crisis situations. Someone in a hospital or long term care facility, lacks capacity to make a decision and doesn't have anyone else to make the decision. Audience is generally health care professionals. The question is "What should we do." The status quo way of handling it is bad. It results in a lot of under-treatment. Do nothing and wait until the patient deteriorates and the emergency exception kicks in. Then the attending physician can take action without consent. Also, there is a problem of over-treatment. That's more common in long-term care. They will err on side of aggressive treatment. They are worried about being fined. Often either case doesn't match the individual's preferences. When there is no one to authorize treatment, people are stuck. This also means people don't get moved to a different, more appropriate setting. It is risky to be in a hospital when you don't need to be. Exposure to all the risks with none of the benefits.

Individual hospitals have policies and they are all different. Whole systems sometimes have policies. We have drafted a systems-wide policy at Fairview but it is stalled. Social workers are a key element in these systems. In 90 percent of cases, a social worker will find someone. For those for whom they cannot, the institution acts as the surrogate. Usually in the form of a multi-disciplinary committee. Usually with a community member on the committee so it's not all inside the organization.

Two terms are commonly used: unbefriended and unrepresented. Unbefriended is used most often. Many people have a friend or family available but are not authorized to make decisions. They are unrepresented. Minnesota has no default surrogate law. In contrast, North Dakota has a long default surrogate list. In states with default surrogate law, it is less likely that a patient will become unrepresented. Most people haven't completed health care directives and if they have one, it is not available when needed. Procedurally, the attending does what he or she feels should be done. That is efficient but it does not have due process. Never have a second person weighing in, never have to explain the decision to anyone.

About 5% of ICU and 4% of nursing home are unrepresented. Approximately 1400 in state of MN. In other states a statute defines documents like the POLST—what it is and what includes. Minnesota doesn't. Minnesota is "law light" in many of the areas we are talking about. Changing best practices might be more achievable than changing legislatiion. Guidance from AMA and other professional organizations could provide best practice. It if was supported by two or three or four organizations it would almost have force of law.

Member asked why is MN an anomaly? Not a population that can speak for self – no literature on the topic. Talked to legislative lobbyist about this. They are afraid that if they ask for change, what will come out will be worst – status quo not that bad.

Member said that her understanding was that It was intentionally left fluid to provide leeway for same sex partners. Barbara Blumer, attorney involved in advance directive stature that was put into place in 1993, told her that.

ND surrogate law is better than most. Comma after each person in list with explanatory comment such as “adult child, who has close relationship with the parent.” If there is a designated health care agent, that person jumps to the top of the list. In Colorado, all potentially authorized surrogates are instructed to get together and figure out who will make the decision. In Tennessee, attending physician picks the person they think is the best surrogate for the person. Provides flexibility to the healthcare provider but the discretion can be abused.

Member: Is the POLST a stand in for the decision maker for an unbefriended? As an attorney, I am wondering if I should recommend to people who have capacity but don’t have someone to put on their health care directive as agent that they complete a POLST.

That’s not good. For people who are expected to die in next year or two, a POLST is good. If you are not terminally ill, it is probably not a good idea to have a POLST. If the POLST says do not resuscitate, EMS won't, even if the circumstances suggest you would want to be. Seems like a bad idea to have a POLST. Whole point of this is that we are trying to preserve peoples’ autonomy. If it was an informed decision it is okay. Maybe for some people it is not fully informed.

Member said that many senior living situations require a POLST even if there is no underlying diagnosis.

That’s not an appropriate use of POLST. MN POLST committee is looking at.

Another risk: health care professionals see a POLST and assume it is DNI even if it is not. Studies show this.

Member asked about guardianship process. If you run out of officially identified options then you should get a guardianship – public guardians – courts across state are uneven on how fast the process works. They are difficult to get. Not cheap, can take 6, 8, 12 weeks and still have to find someone who is willing to be the guardian. Sometimes the public system opts out and say you can take care of it in the hospital. If person is poor, there is no estate and therefore no money to pay for. Then you need a volunteer guardian. Not a lot of people want to do it. In states where special medical guardians are allowed, they still have problems finding people who will do it. In Indianapolis there is a kind of pro bono system. (http://www.eskenazihealth.edu/programs/medical-legal-partnership)

Member said that there is a guardian *ad litem*. (Fact sheet from Mid-Minnesota Legal Aid and Legal Services State Support: https://www.lawhelpmn.org/files/1765CC5E-1EC9-4FC4-65EC-957272D8A04E/attachments/14EABCC6-E7B0-47C0-A83A-6DC53BA0E8CF/f-8-guardians-ad-litem.pdf) Ton of those. My understanding is that a guardian doesn’t has the authority to withhold life support.

Allina asked the Supreme Court about that in a case and the court ruled that guardians have the authority to do so. More often the problem is that a guardian either doesn’t know they have the authority or are not willing to exercise it.

Member: Can a spouse consent to withdrawn of life support in absence of a health care directive?

Happens all the time. No law that says that the spouse can make that decision. Hospital could say no but that is very rare.

Attending physician is the person who determines who has the decision making power. Custom and practice of looking to family members has the force of law. If you have a conflict between two people there is no guidance. Everyone thinks guardianship is the worst possible solution. If at all possible do something other than guardianship. Who is the person that is closest to the person who is likely to make the decision that the person would have wanted?

Member: Research shows that groups are willing to make more risky decisions than individuals. Are you aware of any studies on this?

Legally one person is always the decision maker. In practice every hospital talks to everyone involved. They want everyone on board. To make sure that it is the best decisions and has least moral distress.

Montana and Colorado have good systems. First goal is prevention. Can you still ask the patient? Surrogate is another physician and has to be vetted by the ethics committee. There are some questions about using internal ethics committees. People are employees of the hospital and have financial interest in the decision. Cannot name a physician or other employee of hospital as your agent.

Member: Familiar with individuals with disabilities and wonder if professionals dealing with them see them just as their disability. This summer a long-term friend who is legally blind and admitted to the hospital. Sibling was decision maker but hadn’t seen her for 7 years. Doctor asked me what’s normal for her. Doctors presume, simply based on a disability, that people aren’t able to live on their own. Need a broader view of people with disabilities. I was frightened I would be put in a position to make those decisions.

This is why it is hard. Physician making the decision is efficient and works but there is a bias problem. Racial bias and disability bias and other biases.

Maybe a hospital committee should have representative diversity. Yes, but where do we find these people and how do you get them all together in time sensitive situations? Not practical.

Main thing is to help people do advance care planning. We should train people to be health care surrogates. It is a hard job. We need professional surrogates. Training could include warnings about biases, principles, etc. If we could have 50 or 100 of these across Minnesota we would be in better shape. We need an army of surrogate decision makers. It would be a great public service. In an ideal world they would have met person before he or she loses capacity.

Member: Are there any requirements for appointed guardians to spend time with individual?

Normally no. Guardians have to report back to judge. Some guardians tend to overdue it to get reimbursed. Probate judge is keeping eye on in theory but they don't really have the time to do it thoroughly.

What More Do We Need to Learn?

Task force members generated list. What else do we need to know? Who else should we hear from?

- Paid and unpaid health care agents
- *Possible solution item:* Senior LinkAge Line as a resource – could be used to generate awareness

- *Possible solution item:* Training for senior linkage line specialists about solos, surrogacy, etc.
- *Possible solution item:* Training for surrogates (possibly a video similar to what guardians watch) – American Bar Association has some tools (link in guide).
- Diverse voices – Advisory committee, other methods (Pahoua is working on, has asked several people – people are very stretched – continuing to work on) Member suggested we set a date for by when we will do this.
- Perspectives of individuals with disabilities – I could approach advocacy organizations I know about
- *Possible solution item:* public awareness campaign to help motivate individuals
- Knowledge about what works to motivate people to make change (Clearway MN)
- Policymaker – state legislator (Pahoua said she would talk to Karin Housley, chair of the Aging and Long-Term Care Policy Committee, MN Senate)
- About LaCrosse Gunderson system high level of health care directives (https://www.forbes.com/sites/offwhitepapers/2014/09/23/how-to-die-in-america-welcome-to-la-crosse/#3cfab060e8c6)
- Social worker
- Perspective of people of different socio-economic status
- Legal aid
- Tend to think 90% of solution is people motivation to act on creating a health care plan. Is there evidence that public awareness campaigns work? What would work to nudge people towards action? Member mentioned that in Clearway project on smoking, public awareness was the least effective. How do you change social norms? Legislation was most effective. Difference in Clearway is we were trying to stop an action. Here we are trying to motivate people to do something.
- Information about costs.
- Share the VOA report (http://www.mngero.org/downloads/UnbefriendedElders.pdf)

Updates and Check-in

Evaluation

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

- Productive. Met goal.
- Helpful to frame up a lot of issues.
- Answered a lot of questions.
- Head is swimming.
- A lot of focus has been on upstream. We need to focus on downstream
- Thaddeus did great job. Parse questions well.
- Kind of guy we should probably have back.

Next Meeting: Have interviews to solos@citizensleague.org by the 10th of January and bring hard copy to the January meeting. Next meeting is January 16 at Wilder Center, 451 Lexington Pkwy N. St Paul, MN, 7:30 to 9:30 AM. Thank you all.