



Aging in Central Texas

End of Life Planning Findings
from Focus Groups with Older Adults

Prepared for
St. David's Foundation by
SUMA Social Marketing
March 2020



The important thing to me would be to go over that with my granddaughter and explain to her what I want. **She doesn't have to wonder, and the decision isn't on her back.** Actually talk about it instead of having it in a file. Hanging it in the house was interesting. I think that's very important.

Bastrop Resident

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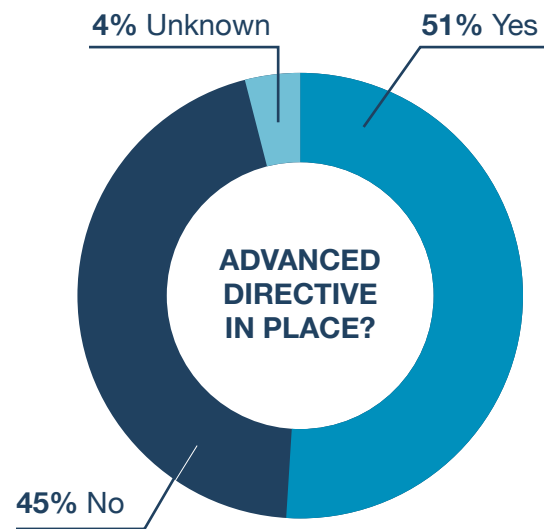
Introduction

In February 2020, SUMA Social Marketing, Inc. (SUMA) conducted research for St. David's Foundation to gather qualitative data with Travis County and Bastrop County low to middle-income older adults to contextualize the findings from a recent quantitative phone and online survey, the Aging Services Council of Central Texas' (ASC), *Older Adults and Their Caregivers Needs Assessment and Gap Analysis*.

The focus group findings will be used to inform a strategic communications tool to increase awareness of issues faced by Central Texas seniors, demonstrate an understanding of their specific experiences, and create a call to action around opportunities to improve the quality of life for this population.

The research explored key areas of interest, including:

- Loneliness
- The extent to which seniors are caregivers for other family members or friends
- Knowledge, challenges, and enablers to establishing an advance directive
- Current sources of information for services
- End of life planning



This report focuses on focus group findings related to end of life planning and expands on the quantitative finding that almost half of older adults report not having an advanced directive in place.

Summary of Findings on End of Life

Many participants have had conversations with loved ones about their end-of-life plans. Those difficult discussions were prompted by getting older and wanting to make things easier on their family, or by seeing someone in their life die without end-of-life plans in place and the resulting stresses on their loved ones.

Some said their children are the biggest barrier to the completion of their end of life plans; adult children often say they do not want to discuss it since they consider the topic morbid or premature.



End of life planning **often involves difficult discussions** and may be prompted by getting older or seeing others die without end-of-life plans in place

Several participants have already set up an advance directive. They consider it important because it will make things easier on their loved ones. They do not want to burden their loved ones with legal problems and do not want there to be arguing or discord among family.

The challenges participants reported with setting up advance directives included cost, choosing who to put in control as a will executor or power of attorney, the complexity of legal documents, and adult children who will not engage on the topic.

[Your Conversation Starter Kit Booklet](#)

Participants reviewed the 12 page toolkit developed by The Conversation Project to support people preparing for the end of life. Overall reactions to the booklet were positive – many participants said it contains useful information that could help people with end-of-life planning. They especially appreciated that the booklet models conversations and provides talking points, since these can be emotional discussions.

[The GIFT Project One-Pager on Advance Directives:](#)

Participants reviewed a one page handout on advanced directives developed by The GIFT (Giving Instructions for Tomorrow) Project by [Hospice Austin](#). Participants praised the one-pager for being concise and easy to understand. Many learned something new from the one-pager, such as that a physician has to sign a DNR (do not resuscitate) order for it to be honored.

EXECUTIVE SUMMARY

When asked what the term “caregiver” means to them, most participants defined a caregiver as anyone who provides some form of support for a person who cannot care for themselves.

Many participants said they had acted as a caregiver for a loved one during recent years, and described it as a complicated, difficult, but also rewarding task. When asked what kinds of support would be helpful for caregivers, suggestions included affordable in-home nursing, affordable handyman/maid services, being aware of available services, having access to an ombudsman who can help them navigate Medicare and other systems, and a website that explains complex systems and processes in simple terms.

While the research was conducted prior to the COVID-19 pandemic reaching Texas, this report was written after Texans had been told to self-quarantine.

As this age group is at higher risk for serious consequences from COVID-19, the research and findings take on a new importance and the recommendations include references to the pandemic.





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to address these issues.

It will be easier for the family.

My mother had 12 children,
and there were things they
never discussed, like wills
and medical directives.

Austin Resident

Methodology

SUMA conducted four focus groups with a total of 24 older adults from 65-82 years old. These participants were of various races, ethnicities, and genders. The groups were held in Austin and Bastrop.

The research team screened all participants prior to participation in the focus groups to ensure that they were residents of either Travis or Bastrop County and had a household income of less than \$60,000 per year.

SUMA used the following strategies to recruit participants:

- Contracted with professional recruiters at ThinkGroup who made calls to people in their 50,000+ person recruiting database, posted information about the focus groups on relevant closed Facebook groups, and developed a flyer.
- Met with community partners identified by the St. David's Foundation (Bastrop County Cares, Bastrop Food Pantry, Texas A&M Agricultural Extension Service), provided them with ThinkGroup's flyers, and requested their assistance with outreach.
- Provided flyers to additional community partners: Bastrop Senior Center, Bastrop Library, and a community leader in Smithville.

- Conducted in-person recruitment at two events: Bastrop Senior Center luncheon, and food distribution day at Bastrop Food Pantry.



Focus group respondents were **65-82 year old residents of Travis or Bastrop County** with a household income of less than \$60,000/year

Qualitative research is defined as studies that focus on why and how things happen and that do not use numerical data as their primary facts.

The focus group findings are qualitative in nature, meaning that they seek to answer questions of “why,” “how,” “when,” and “what,” but not about “how many.”

Consequently, they should be considered directional rather than definitive.

Detailed Findings

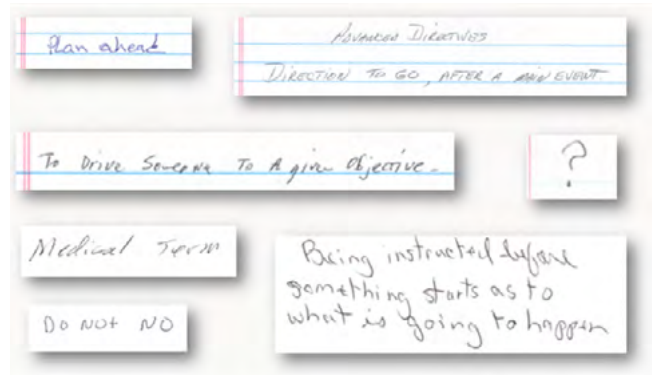
End-of-Life Conversations and Advance Directives

Before asking questions about death and end of life, the moderator instructed participants to write down what they believe “advance directives” are in order to gauge their level of knowledge on the topic at the outset. The moderator then collected the responses and moved on to discuss end-of life conversations.

In post-group analysis of what participants wrote down, about half of participants in each location did not know what advance directives were.

They wrote vague answers having to do with some form of future planning not related to aging or end-of-life, or simply that they did not know:

- Letting you know ahead of time where you are headed
- Do not know
- Plan ahead
- Direction to go, after a main event
- To drive somewhere to a given objective
- Being instructed before something starts as to what is going to happen



The other half of participants did appear to understand advance directives based on their responses.

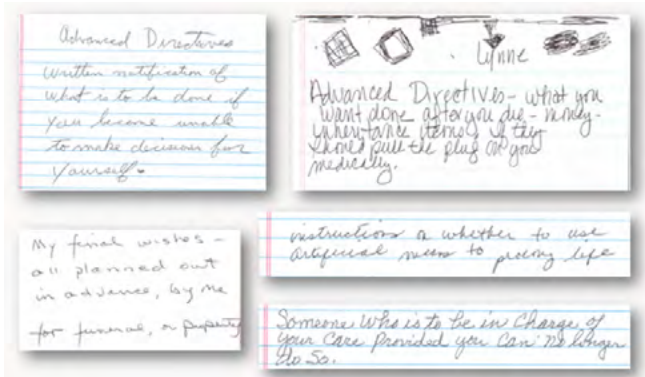
They wrote about particular documents (living wills, DNRs) and that advance directives are about making wishes known in case, in the future, one is not able to communicate.

Several of these responses referenced decisions about life support, with a couple describing it as “pulling the plug:”

- Written notification of what is to be done if you become unable to make decisions for yourself
- Instructions on whether to use artificial means to prolong life
- What you want done after you die – money – inheritance items. If they should pull the plug on you medically.
- My final wishes all planned out in advance, by me, for funeral or property

DETAILED FINDINGS

- Something like a living will (?) Directive for end of life/senior needs



When asked if they had had any conversations with family or loved ones about their end-of-life plans, most participants said they had. Some participants said they had that hard conversation because they were getting older and wanted to make things easier on their family members down the road.

Some participants shared that seeing someone in their life die without end-of-life plans in place, and the resulting stresses on that person's family, prompted them to want to have these conversations with their loved ones proactively.

"For me, it was advanced age. You never really know when you're feeling well. Death is all around us. I talked to my family about what they need to do."

Bastrop Resident

"The need that you have to address these issues. It will be easier for the family. My mother had 12 children and there were things they never discussed, like wills and medical directives."

Austin Resident

"I worked for nursing services and I was a notary. I would do notaries for them. People are lying there in the bed and can't talk or more. Families are trying to get papers signed to have lawyers do what they need to do. They're beyond help. They want me to say I can notarize, but I can't do that. They're not capable of making those rational decisions. They get upset. It made me realize you need to set this up way ahead of time. Everyone should have a directive."

Bastrop Resident

"My sister died in 2015 and we could not find her will. We had to get a lawyer to be declared heirs. It was a huge expense. You want to know the people that you care about are taken care of. My sister left someone 41,000 dollars."

Austin Resident

Some participants explained that they have not yet had an end-of-life conversation because, when they have tried to broach the topic, their children or grandchildren do not want to hear about it. These family members seemed to consider the conversation morbid or premature, participants said.

A few participants said they have not discussed end-of-life plans with loved ones yet because they are healthy and not close to dying.

“I think at one point I had it and it burned in the fire and I haven’t gone back. No wills, no power of attorney, nothing. In having the conversation with my 40-year-old daughter, she says “you’re young” but I’m not that young. So, that’s why. Her not wanting to talk about them, we didn’t. And then I had the papers and don’t anymore.”

Bastrop Resident

“We had someone speak to us at the Optimist Club. I sent paperwork to my brothers, but I haven’t done anything because I feel healthy. I don’t want to jinx it. I’m feeling pretty good. It sounds funny but that’s why I don’t have a will. I feel pretty good.”

Austin Resident

Without prompting from the moderator, some participants shared stories of friends and family that had upsetting disagreements in the aftermath of a loved one’s death.

Several of these stories demonstrated how not having end-of-life plans discussed or legally settled can result in bickering and hurt feelings.

“When my father passed away, my four brothers and I sat down and made a list of everything we agreed on. We agreed that three out of four had to agree before we did anything. Filled out all the information that we agreed on, then when it came to my parents passing away, this all went to hell in a handbasket. We even wrote out that we will never let money come between us. I would never let land come between us. We swore to God about all that stuff. I thought we would honor each other 100 percent.”

Austin Resident

“Brother lived in Chicago. I moved from Houston and South America to take care of my mom. She made changes to her will after my brother and wife did whatever. She made me single executor instead of co-executors, and that made my brother mad. He said early on it’s her money, her stuff, she can do whatever she wants to. Time came around, she did what she wanted to, and I haven’t talked to him since she died. That’s more than 10 years ago.”

Austin Resident

Advance Directives

In the ASC quantitative survey results, respondents were closely split with 51% reporting they do have advanced directives in place, and 45% reporting they do not have advanced directives in place.

Focus group findings were very similar.

The moderator shared a definition of an “advanced directive” with the groups: a written statement of a person’s wishes regarding medical treatment made to ensure those wishes are carried out should the person be unable to communicate them to a doctor.

Examples include a “Living Will,” a “Durable Power of Attorney for Health Care,” and a do-not-resuscitate (DNR) order.

In each group, some participants confirmed they had completed their advanced directives while others had not. Those who had completed them said they consider them important to make it easier on their loved ones after they die. They did not want to burden their loved ones with legal problems and did not want there to be arguing or discord among family.



Examples of advanced directives include a Living Will, a Durable Power of Attorney for Health Care, and a do-not-resuscitate (DNR) order

According to participants, challenges with setting up advance directives include cost, choosing who to put in control as a will executor or power of attorney, and the complexity of legal documents.

“There are so many times in families where there’s a big battle among the siblings. That’s what prompted me to take care of everything myself.”

Bastrop Resident

“You want to make sure the person you leave in charge will do what you want. I talked to my oldest daughter and she didn’t think she could do it.”

Austin Resident

“You do the will, but things get complicated as time goes by. In 30 years, you develop wealth, you develop all this other stuff. What I did was Will Maker. Covers everything you have here. That kind of directive is important. Some of my clients have to go to probate. More importantly, if you can just put it together, then find a place to get buried. Pay for your plots. That came to me last week standing in front of my father-in-law’s gravesite. There were two lots next to him. I’m going to buy them and I’m going to have them make my tombstone.”

Austin Resident

Several participants said that lawyers and doctors have previously spoken to them about advance directives. Some said that a Durable Power of Attorney for Health Care or a DNR order came along with the paperwork for their will, so they filled them out at the same time.

Others said they had not received those additional documents when they met with their lawyer. Similarly, some participants – but not all – said that when they went to their primary care doctor or were admitted to the hospital, a member of the medical staff had asked about their advance directives.

“I think anybody that gets to our age knows they need a will. Then when you go to get a will, this stuff comes with it. They just automatically make it. Most people take it because it’s one piece of paper. When you really think about it, do you want to be hooked up to machines and all that?”

Bastrop Resident

“We’ve probably all been in a hospital. When I was there, the doctor that came in said do you have these papers? They have a checkoff on their list. If you say no, they’ll come say do you want to get one? They will assist you in getting this stuff because you’re in their hospital.”

Bastrop Resident

Several participants said they would like to hear from a lawyer or advocate with a legal background in either a group or individual setting about how to best set up advance directives.

Some participants said they would like to have more guidance and information about getting their affairs in order, as well as direction to help the family member(s) they leave behind manage their plans.

“My mom and I got together a year or two before she actually died, and she said OK, you’re going to sit down and I’m going to show you what I do to pay my bills. She showed me her list of bills. What they don’t tell you is the executor to your will, which is probably one of your children, they should tell you when you die, if your parent is getting social security, you have to make sure they stop getting that check. They made money, they died in last quarter of year, somebody has to pay their income tax.”

Austin Resident

End-of-Life Planning Support Tools: Testing of Creative Materials and Resources

Focus group moderators then showed participants various print pieces, gave them time to review each one, and asked participants for their thoughts on each piece, one by one.

Your Conversation Starter Kit Booklet

After reading through the booklet, several participants commented that they would like to have a copy of it for themselves or loved ones.



Overall reactions to the booklet were positive – many participants said it contains useful information that could help people have these difficult conversations. Participants said the booklet was attractive and easy to read.

DETAILED FINDINGS

“My niece. She lost her husband. No children and her mom has Alzheimer’s. This stuff will help her understand. I have a friend in Los Angeles who has been asking me questions.”

Austin Resident

“It’s important to do something like this. I have five sons. They have different views. When the time comes, I don’t want them to bicker. Want them to know exactly what [I want.]”

Bastrop Resident

Some participants said they like that the booklet models conversations and provides talking points, since these can be emotional discussions. Some participants explained that, even though they had already taken care of some of these advance directives, the booklet is a great resource for seniors more generally.

“The suggestions or questions. What you need to think about or do before you feel ready to have the conversation. Makes you think.”

Bastrop Resident

“It stimulated thoughts of easy ways to start this conversation. My family is 10. Five brothers have had heart attacks. One sister has lung cancer. None have wills.”

Austin Resident

“It’s comprehensive. It’s a good path to follow when having that talk. We might leave something out that important.”

Bastrop Resident

“I think it was great. A lot of people this just comes naturally because when you get the will you get the other things with it. If they don’t think about it, it’s wonderful.”

Austin Resident

Some participants pointed out that, while they think this booklet is helpful for seniors, they also believe that younger people like their children need to prepare advance directives and have living wills for themselves. They would give their children this booklet as a guide.

“You just don’t know. It’s sad when some things happen to prolong life when you may not have wanted that. This should happen at the beginning of your life. It’s not just for old folks.”

Bastrop Resident

DETAILED FINDINGS

"I thought it was good information to review. My children and grandchildren do not have wills in place."

Austin Resident

Participants said they would expect to find this booklet at:

- Doctor's offices
- YMCAs/gyms
- Senior centers
- Community centers
- Insurance offices
- Funeral homes
- Nursing homes
- Libraries

[The GIFT Project One-Pager on Advance Directives](#)



"After reading the one-pager, participants' top-of-mind responses were that this is important information. Participants praised the one-pager for being concise and easy to understand. This makes sense. A lot of sense. Quick, fast, simple. It will sell."

Austin Resident

"It covers issues you're concerned with. People don't think of directives as much as wills. Those come into play when you're alive." (Participant 1)

"It comes into play when you cannot make your own decisions." (Participant 2)

"It causes lawsuits today. They sustain people when there is nothing in place." (Participant 3)

Austin Residents

Several participants remarked that they read something on the one-pager that they did not know before. A few participants in Austin and Bastrop said it was new information to them that a physician has to sign a DNR in order for it to be honored.

For some, they had heard of one or two, but not all three advance directives explained on the one-pager.

Some participants said they had not understood the advance directives to be separate pieces, but perhaps components of a will since they filled them out at the same time.

“I need to check because it says the EMS can’t honor the order unless it’s signed by both me and my physician, and I just don’t remember if I actually had that done.”

Austin Resident

“Didn’t know you can change your directives at any time for any reason.”

Bastrop Resident

“The living will and the medical power of attorney, isn’t that the same? The living will you have to designate somebody to decide when to unplug you.”

Austin Resident

“Is this new? Isn’t this three directives? That’s what it’s saying on here. We wouldn’t have three different directives. We just have one when you go for a will. You have one. They ask me a lot of times when I go to the doctor. I would have just given them the one advanced directive. This breaks it down, which I never heard of. Three different documents.”

Austin Resident

Reading the one-pager generated conversation about where to keep advance directive documents and how to ensure they are found in case of emergency.

Participants had questions about how their primary care doctor, hospitals, EMS workers, and attorneys factor in when it comes to communicating DNR orders or a Medical Power of Attorney.

“I’ve been through all this. My wife has an envelope for medical issues. If you go to a hospital and if it’s late at night, if you have a DNR, they’re in the files and the ER does not have access to it. My wife is medical power of attorney for her mother, so she has the documents. The ER does not have access to that file.”

Austin Resident

“I never thought about having one posted in my home.” (Participant 1)

“No one’s calling the courthouse to find what you have on file.” (Participant 2)

Bastrop Residents

Participants said this one-pager was created for anyone of any age who is looking to plan ahead.

They said they would expect to find this item in:

- Doctor's offices
- Hospitals
- Will Maker software
- Urgent care centers

Closing Thoughts

At the end of the focus groups, participants were asked what the most important thing was they heard about during the session. For many, the information about advance directives stood out as being important, and was often coupled with a new sense of urgency around getting those affairs in order.

"Get organized. I don't have DNR, so I'm going to get that. Make sure I have everything in order."

Bastrop Resident

"My state of mind was that we came to help y'all. I found out y'all helped me just as much as or more with this and I love that."

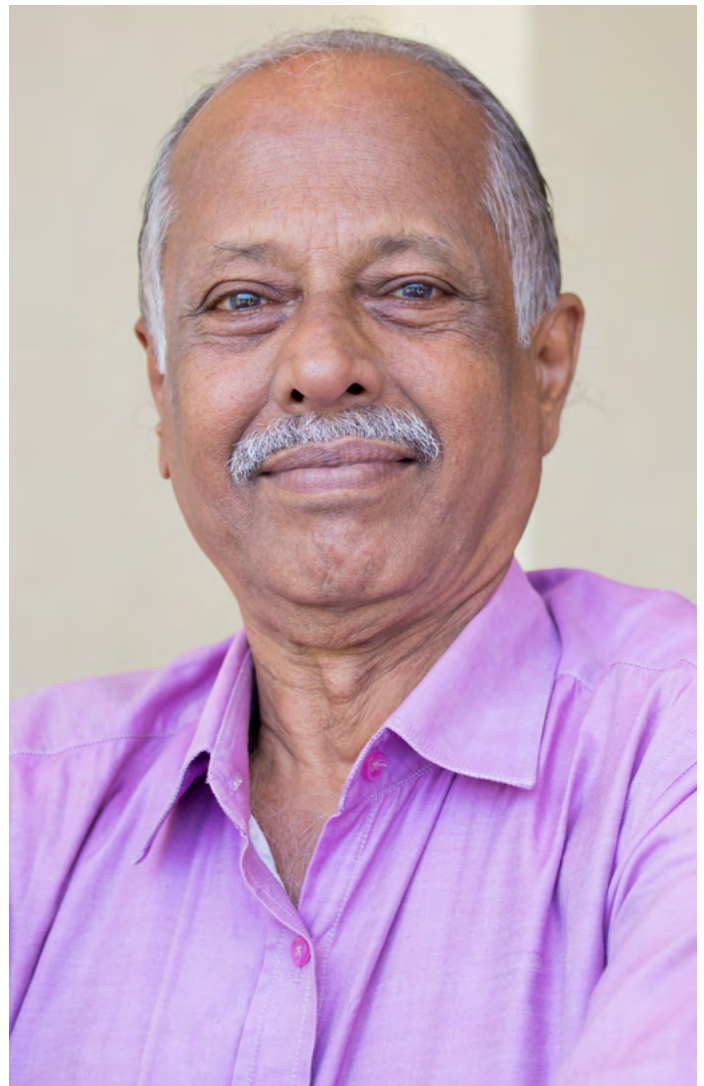
Austin Resident

"Be more detailed in my preparation. My wishes."

Bastrop Resident

"The important thing to me would be to go over that with my granddaughter and explain to her what I want. She doesn't have to wonder, and the decision isn't on her back. Actually talk about it instead of having it in a file. Hanging it in the house was interesting. I think that's very important."

Bastrop Resident



Recommendations

RECOMMENDATION #1

Create a **communications campaign that promotes a broad approach** on how to plan for aging **with a positive emphasis** on starting “the next chapter” or “a new adventure” in their lives.

This can include:

- End-of-life planning and estate planning
- Navigating Medicaid/Medicare
- Modeling having difficult conversations about end-of-life with family members
- Options or alternatives for assisted living

It can also include more upbeat topics, such as:

- Volunteer opportunities
- Fun day trips for seniors and senior discounts
- Meet ups at local events and social clubs
- Activities for grandparents and grandchildren

RECOMMENDATION #2

In Bastrop, create a pilot community campaign to promote the importance of advanced directives.

Hold workgroups to assist older adults with completing their advanced directives. Partner with local churches and community groups as well as social media to promote the effort. Measure the impact using a pre- and post-test research model.

RECOMMENDATION #3

Provide ombudsman or other legal consulting to older adults for end-of-life planning and navigating issues specific to those over 65 years of age as an additional service for participants in the program who want more personalized, in-depth assistance.

RECOMMENDATION #4

Promote the Your Conversation Starter Kit and the GIFT Project One-Pager on Advance Directives. Participants found them informative, well designed, and easy to understand. Several learned new information about advance directives from reading them in the focus groups.



My state of mind was
that we came to help y'all.
**I found out y'all helped me
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with this and I love that.

Austin Resident



Conclusion

While several of the seniors in these groups have already had some hard talks with their families about end-of-life plan, they would like more support and information about navigating the complexities of the healthcare and legal systems to better prepare themselves and their families for what needs to happen to have their wishes honored.

Some participants still feel healthy and so have not yet discussed their death with their family members. Others have family members who do not want to talk about it.

Reliable advisors would help participants feel confident in how they set up their advance directives and manage their affairs in preparation for end of life.

Acknowledgments

Researchers and Authors

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SUMA Social Marketing

prepared this report for St. David's Foundation



St. David's Foundation is committed to strategic grantmaking through its **Older Adults Age in Place portfolio**.

Led by Andrew Levack, MPH, Senior Program Officer, **the Foundation seeks to increase support for older adults to live safely and independently in their own community by:**

- Helping them to remain safe and independent in their homes as they age;
- Having honorable and improved end of life care;
- Helping them to engage and contribute as a vital part of the community;
- Ensure adequate supply of accessible, high quality services.

Note: this report focuses on a portion of the full report findings. To obtain a copy of the full report including additional information on research tools, please contact:

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