

Attachment A

DRAFT FOCUS GROUP DISCUSSION GUIDE

Understanding How Families Access and Use LTC Services

April 2016 DRAFT

SECTION I: SESSION AND PARTICIPANT INTRODUCTIONS (10 minutes)

Introduce Moderator

- Thank you for joining me this evening. I appreciate you giving us your time and thoughts.
- My name is Lee Zacharias; I'm here to facilitate our discussion this evening.
 - I'm an independent professional moderator, not employed by the organizations that are sponsoring this research.
 - I'm not selling anything and have no vested interest in the results of our conversation this evening.
- We're here tonight to find out what Americans experience when they have an older relative who needs long term care. As part of this project, we will be conducting focus groups like this one in other parts of the state over the next few days.

Purpose of Session

- All of you have something in common - when we invited you to participate in tonight's session, you indicated that you have gone through the experience of helping a loved one find the type of care that someone need as they age, become disabled or have a condition such as Alzheimer's disease. This type of care is typically called "long term care"
- This evening we'll be talking about your experiences as you went through that process.
- We hope to learn specifically what helped you be successful in that endeavor as well as hearing about the impediments you encountered.

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- We are very interested in hearing about the unique experience you had and how well it worked or didn't work for you and your family. In addition, we would like for you to think about your whole experience, from beginning to end (or if you're currently going through the process), how it has gone up to the present.
- Ultimately, we hope you can help us identify ways to make the process of finding LTC services better.

We'll get more specific in a minute, but first I'd like to share with you the very easy "ground rules" for our time together and also take a few minutes just to get acquainted.

Disclosure and Ground Rules

- I am interested in all of your ideas, comments and suggestions
 - There are no right or wrong answers to the questions
 - All comments – both positive and negative – are valuable.
 - Differences of opinion are expected and welcomed.
 - The objective is not to build consensus among group members.
- I'd like to hear from everyone.
 - It's important that you all get equal "airtime."
 - No one should monopolize the conversation; no member's opinion is more or less valuable than another's.
 - Respect each other by giving all members an opportunity to give their viewpoint.
- My colleagues have joined me behind the one-way mirror; they are here to listen and learn from you.
- Before coming into the room you signed a release allowing us to audio [and videotape] this discussion.
 - Audio/videotapes allow us to review the session and better understand your feedback.
 - Your comments are confidential and used for research purposes only; I will not use any names in the report I submit to my colleagues
 - We may share these tapes with other colleagues who were not able to join us this evening
- I want our tape to pick up all of your comments
 - Please refrain from having side conversations
 - Please speak up
- Our discussion will last just under two hours and will cover several topics
 - I'd like this to be a group discussion, so you needn't wait for me to call on you.

- Please ask me to clarify any questions you do not understand or terminology that is unfamiliar to you.
- I'll guide you when it may be necessary for us to move quickly in some areas.
- If you need to use the restrooms at any time, please feel free to do so but please try to only leave the room one at a time so we can keep the conversation going.

Introduction of Participants

- I'd like you each to introduce yourself by first name; tell us something about your work and your family. [*add "warm up" exercise here.*]
- I'll start. You already know my name is Lee Zacharias and what I do for work – I talk to people like yourselves so that my clients can learn more about people's preferences on a wide variety of topics. [Additional personal points to set the tone...]

SECTION II: LONG TERM CARE BASICS AND OUR CAREGIVING (20 minutes)

As I said before, one thing you all have in common is that, when we called to ask if you would participate in this session, you all said that you had helped a close friend or family member who needed long term care find the services or facility that could meet their care needs.

I want to start off by introducing this important topic: long-term care. We're going to be talking a lot tonight about that topic and it probably means many different things to all of us. We'll talk a lot more about that, but first, just to make sure we're all on the same page, I'd like us all to read this brief definition of long term care.

WHAT IS LONG TERM CARE?

- Not medical care.
- Care provided in your home, your community or a facility, such as an assisted living facility or nursing home.
- Provided by a nurse, nurse's aide, home health aide, homemaker or family member or friend to people who have chronic illnesses or long-lasting disability
- Provided to people who need help with normal activities of daily living, like eating, bathing, using the toilet or dressing. (Also called Personal Care)
- Long term care also includes support and supervision for people with a cognitive impairment such as Alzheimer's disease.
- Not covered by traditional health insurance, Medicare, Medicare Supplement, or disability insurance. Medicaid only pays for long term care if you are poor or become poor paying for care.

So to make sure we're all on the same page, please look at this definition of long term care. Does anyone have any questions about that definition?

Caregiving Stories

Over the next two hours, we will be talking about the types of care needs you were looking to address, how you started that process, the twists and turns that you probably went through and the feelings that go along with that. We value everything you have been through and want to share, but we also acknowledge that we only have a short amount of time to hear from everyone. I know there can be a lot of comfort in sharing your stories. But I may, at times, have to ask you to give the "Readers' Digest" version just to make sure that we explore all the aspects of these issues and hear from everyone.

When we invited you all to participate tonight, we specifically sought out people with different types of experiences. This handout summarizes that diversity.

HANDOUT – CAREGIVER EXPERIENCE.

[This handout will indicate key variables of the experiences of each participant, but without identifying the participant associated with the experience. For example, it will say "Adult daughter....nursing home placement for dad at age 82....needed due to sudden stroke, etc." Key factors such as the care setting, person needing care, gradual or immediate care need, and other attributes will be displayed.]

Does anyone in the group want to take a minute or two to "tell their story" in just a few words to put a little color around these facts? As an example, can you tell us (1) the person's relationship to you (mother, father, sibling, etc.), (2) age when they started to have some trouble with everyday activities, (3) type of care they needed, and (4) any other relevant information.

[Invite a few diverse examples to "talk through" the chart. No one will be pressured to tell their story, nor will everyone be invited to do so. This is important for time management. Or maybe show of hands for each domain with regard to PERSON, TYPE OF CARE NEED, SETTING, etc.??]

SECTION III – DETAILS OF THE PROCESS

(60 minutes)

Tonight we're going to focus on three parts of the process of getting LTC for a loved one:

1. **DEFINING CARE NEEDS.** First we'll talk about the beginning of the process when you (and others involved) identified the need for care and began to identify the type of care needed.
2. **FINDING PROVIDERS.** Next, we'll talk about how you decided which providers you'd use to deliver those services (or what facility to choose).

3. **CRITICAL THINKING.** Finally, I really want to hear about your thoughts and feelings on the entire process – what makes it difficult, what helps you through it, and what you wish could be different.

Defining Care Needs.

- What event or events triggered the realization that care was needed?
- Who was involved in the process of deciding whether and what type of care was needed?
- Which part was harder – whether or what?
- What were the family dynamics like?
- What personal or family logistics made it easier or harder to get through this process?

Let's talk about the type of help you may have gotten from resources, professionals or advisors outside of the family.

[Have participants select (and specify) which of the following resources were included or consulted in this process. Use this to guide discussion (tally on the board) and ask for descriptions of how each was used, value and concerns, how identified, satisfaction, etc. Perhaps ask the group to “score” each resource based on their experience and interaction. This might be done individually on paper and then ask respondents who selectively reveal their responses and discuss why they gave the score(s) they chose.]

Resource List:

- *Word of mouth, friends, family*
- *Physician*
- *Hospital discharge planner/social worker*
- *Geriatric care manager*
- *Service provider (specify)*
- *Government resource such as AAA/ADRC (specify)*
- *On-line resources (specify)*
- *Other health care provider (specify)*
- *Clergy or religious organization*
- *Employee assistance program or insurance company advisor*
- *Other (specify)*

Finding services/providers

Now let's talk about the steps you went through to find the specific services, facility or providers for your loved one's needs. Did you use any of the following resources?

[Consider repeating the various approaches/exercises outlined above.]

After identifying which if any of these resources were used, talk about the nature of that experience, concerns, adequacy, timeliness and suitability of information obtained, etc.

How relevant, useful and knowledgeable were these resources? What was best about them? What were they lacking? What factors such as money, family dynamics, location, or others facilitated or impeded your ability to access any of these resources?

Resource List:

- Word of mouth, friends, family
- *Physician*
- *Hospital discharge planner/social worker*
- *Geriatric care manager*
- *Service provider (specify)*
- *Government resource such as AAA/ADRC (specify)*
- *On-line resources (specify)*
- *Other health care provider (specify)*
- *Clergy or religious organization*
- *Employee assistance program or insurance company advisor*
- *Other (specify)*

Community-specific resources

Some of you have mentioned specific organizations (entities) by name which are unique to this community. In preparing for tonight's conversation, we've identified some specific resources in the community that are intended to help people with these kinds of decisions. I'd like to name some of these and ask if any are familiar to you? Do they sound like they could have been useful? Did you consider using them or maybe even use them? Any interactions, impressions or experiences specifically with regard to these resources that you'd like to share?

[Insert here the community-specific resources identified]

SECTION IV – HOW WOULD THINGS BE DIFFERENT THE NEXT TIME? (20 Minutes)

We know that "experience is the best teacher...." Even if sometimes it is more painful to learn that way. I'd like you to share your thoughts with us now for what you'd do differently (or the same) next time if you had to do this again? Or what advice would you give to someone else going through this process, based on what you've learned about it yourself?

Overall, thinking about the entire process of defining care needs and finding care, let's discuss:

- *What would you do differently? The same?*
- *What circumstances do you wish were different that might have made the process easier?*
- *Who/what would you expect to be more helpful than it was?*

- *How would you like to see the resources you used improved or changed to be more helpful?*
- *What would have helped most?*
- *What made this process the most difficult?*
- *What made it easier than perhaps you thought it would be?*
- *How would you advise others to start this process to get the best results?*
- *In retrospect, what do you wish you had known when you started looking into care that would have made this process easier?*
- *What information was either not available or not readily accessible to you when you were looking at options for care?*
- *What concerns did you have about the information you had or the resources with whom you consulted?*
- *In what way were outside resources MOST helpful? Least helpful? Give specific examples?*
- *How could the process of looking for this care be improved? What would you tell other families in a similar position to do?*

SECTION V. WRAP UP

(10 minutes)

Do you have closing ideas on how to make it easier to find information on long-term care and to make it understandable?

I'd like to thank you all for your thoughtful insights and opinions and for sharing your stories with us. I really appreciate the time and thoughtfulness you put into your answers.

[Details about parking validation, incentives, and other housekeeping]

Have a great night!

SECTION VIII: Conclusion

(10 minutes)

Ask 'behind the glass' observers for any additional questions, clarifications

- **Close:** Thank all for their contributions.
- Ask permission for "follow-up" contact with client if interested

The discussion will seek to capture the following:

- Where do consumers turn for information and education on how to select and find LTC services?
- How much time and effort went into the process?
- What roles do various members of the family, community and care providers play in the process?
- How satisfied are consumers with the information provided, the resources available to them, in the process of making these connections, and the follow-up if any that was provided to them?
- How do factors such as family dynamics, urgency and nature of the care need, finances and other considerations play in the process of finding options and selecting care?
- What improvements are needed to better support families in defining care needs and finding services to meet those needs?
- For specific resources that were used or considered, how helpful did consumers find these and what concerns with them did they encounter?
- What other known resources or services available in the community were not used or considered? What are the reasons for this?