

**Supporting Statement for Paperwork Reduction Act Submissions
Evaluation of the Supportive Services Demonstration
(OMB# xxxx-xxxx)**

**Appendix J: Moderator Guide for Focus Groups with Caregivers of
IWISH Participants**

J.1. Written Consent Form for Caregivers

Privacy and Consent Terms Integrated Wellness in Supportive Housing (IWISH) Caregiver Focus Group

The United States Department of Housing and Urban Development (HUD) funded the Integrated Wellness in Supportive Housing (IWISH) program to help older adults in HUD-assisted housing stay healthy and life safely in their homes. The Resident Wellness Director [INSERT NAME(S)] and Wellness Nurse [INSERT NAME(S)] at [PROPERTY NAME] are part of IWISH.

HUD is sponsoring an evaluation study to understand residents' experiences in properties that have an IWISH program. HUD has hired an independent research firm, Abt Associates Inc., to conduct the study. **You are invited to take part in this important study.** As a caregiver of a resident participating in IWISH, your participation will help us learn what HUD can do to help residents of HUD-assisted housing improve their health and stay in their homes as they age.

The questions in this focus group have been reviewed by the Office of Management and Budget (OMB) under the Paperwork Reduction Act of 1995. Public reporting burden for this collection of information is estimated at up to 105 minutes per response, including up to 90 minutes of discussion and an additional 15 minutes to complete the consent process. HUD may not conduct or sponsor, and a person is not required to respond to, a collection information unless that collection displays a valid OMB control number XXXX-XXXX, expiring XX-XX-XXXX.

What does it mean to be part of the study?

- Taking part in this study is completely voluntary.
- Taking part in the study means participating in a focus group with other residents of [INSERT PROPERTY NAME].
- The focus group will last between 60 and 90 minutes.
- You can choose not to answer any question.
- You can leave the focus group at any time. All you have to do is get up and walk out.
- You will receive a \$40 Visa gift card to thank you participating in the focus group.

What type of information will the study collect?

- The researcher will ask you questions about your experiences as a caregiver of someone enrolled in IWISH, including your interactions with the Resident Wellness Director and Wellness Nurse.
- You may consider some of these questions personal and sensitive. The study team has taken many steps to protect your privacy.

Why do we need to audio-record the focus group?

- We are audio-recording the focus group.
- Audio-recording means the facilitator can focus on listening to you and asking questions.
- Audio-recording the focus group means we have an accurate record of what you say.

What are the risks and benefits of participating in this study?

- The research team has taken careful steps to reduce the risks to you associated with participating in this study. Even so, you may still face some risks.
- These risks may include giving information that you consider to be personal and sensitive.
- We will ask all focus group participants to not share information they hear in the focus group. However we cannot guarantee that someone else in the focus group will not share things you said.
- Although you may not benefit directly from this study, your input will help us understand the issues faced by people like you. This allows the government to improve programs for older adults in HUD-assisted housing.
- Any services you or your family may receive **will NOT be affected** in any way by taking part or choosing not to take part in this study.

Will my information be kept private?

The research team is committed to keeping your personal information private to the extent allowed by law. However, there is a small risk of a loss of privacy. We will take strong precautions to make sure this does not happen.

- Any piece of paper that includes your name or other identifying information will be kept in a locked storage area and destroyed after the study ends.
- Any computer files with your name or other identifying information will be protected by a password and stored on a secure network.
- HUD will receive notes and summary reports from the focus groups, but neither the notes nor the reports will include your name, the name of this property, or the location of this property.
- If during the course of the focus group you report that you or someone else is at risk of harm, we may need to tell someone.
- Our reports will combine your responses with responses from others and will not use your name. People who read the reports will not be able to identify responses you give.

For questions or concerns about the research, call Abt Associates toll-free at [insert number]. For questions or concerns about your rights as a research participant, call the Abt Associates Institutional Review Board toll-free at 877-520-6835. If you have questions, you may contact the study director, Jennifer Turnham, at Jennifer_Turnham@abtassoc.com or (301)-347-5289.

Consent to Participate in this Study

I have read the information in this consent form. I have discussed my questions with a member of the research staff. I voluntarily agree to participate in this interview. I have received a copy of this signed and dated consent form.

I give my permission to be audio-recorded for this focus group.

Participant Name (please print): _____

Participant Signature: _____

Date: _____

Name of Researcher obtaining this Authorization: _____

Documentation of Receipt of Visa gift card

I have participated in the focus group and received a gift card in the amount of _____

Gift Card number _____

Participant Study ID _____

Participant Signature: _____

Date _____

Signature of Abt Staff: _____

J.2. Moderator Guide:

Introduction

Thank you all for participating in the focus group today. We really appreciate this opportunity to hear about your experiences with the IWISH program. My name is [INSERT NAME] and I'll be leading our discussion today.

The first thing I'll do is obtain your formal consent to take part in the discussion today. Everyone has in front of them a document that explains the purpose of the focus groups and your rights as a participant. We'd like you to read the document, ask questions, and if you feel comfortable, sign the document.

Our conversation today will last about an hour and a half. If you wish to leave at any time during the focus group, please feel free to get up and go. With your permission, we will audio record this focus group so that we make sure we capture everything that is said today. We will use what we learn from you and others across the country to prepare several reports for HUD about how residents and their caregivers experience the IWISH program and what improvements could be made.

We will be including quotes from this focus group in our reports, but we will not use your name in our reports. We will not share the audio recording from this session with anyone outside the study team, but at the end of the study we will provide our notes from this group to HUD. The notes will not include anyone's names or the property's names. The audio recordings will be destroyed at the end of the project. We will not share what you say with staff on the property here and we ask that you not repeat what others say outside this room. We want everyone to feel comfortable speaking openly and candidly in today's group.

[Moderator collects a signed informed consent document from each participant.]

I work for an independent research company called Abt Associates. We have been hired by the U.S. Department of Housing and Urban Development (HUD) to evaluate the IWISH program. IWISH is a new program being tested in 40 senior housing properties across the country. IWISH funds a Residential Wellness Director and a Wellness Nurse to work with residents and bring in services and programming to help improve their health and well-being. The overall goal of IWISH is to help residents be able to stay in their homes for as long as they want to. The IWISH program started here at [PROPERTY NAME] in March 2018.

As someone who cares for a person enrolled in the IWISH program, we want to understand your experiences with the program. The information that you provide will help improve programs like IWISH for older adults living in HUD-assisted housing.

We want to keep the discussion informal and relaxed. My role is to raise topics we're interested in hearing about from you, and to keep the conversation flowing. Before we begin, let me go over a couple of ground rules.

- Please feel free to get up and get food or drinks any time you would like and use the restrooms as needed.
- Please also feel free to leave the discussion at any time, for example if you find yourself getting tired.

- During the discussion, please ask questions if something is not clear.
- You do not have to answer any specific questions you do not want to answer.
- There are no right answers or wrong answers. We are interested in everyone's experience, good or bad.
- Please don't share what is said today outside this room.
- Finally, please turn off your cell phones or put them on vibrate. If you need to take a cell phone call, please do so outside of this room.

Before we start, does anyone have any questions?

Participant Introductions

Let's start by getting to know each other a little bit. Let's go around the room, and each of us share your first name, how long you have been caring for someone here at [PROPERTY], and what their relationship is to you.

Housing and Community

We are going to first talk a little about your perceptions of what it's like for the person you care for to live at this property and in this community.

1. From your perspective, what are some of the features of this place that make it easy for the person you care for to live here?
2. From your perspective, what are some the features of this place that make it hard for them to live here?

IWISH Experiences

Now let's talk about your experiences with the IWISH program.

3. How did you first hear about the IWISH program?
4. What did you think the program was going to offer?
 - Did you encourage the person you care for to participate?
5. Have you seen changes in the person you care for since they joined the IWISH program? This could be physical changes, changes in their mental health, changes in their level of happiness, or other types of changes. [*Probe for links to the IWISH program.*]
6. Has your experience as a caregiver changed? If so, how?
 - How has your caregiving role changed since your loved one started participating in IWISH? Has the amount of time and effort associated with providing support changed at all?

We'd like to talk now about your experiences working with the resident wellness director(s) and wellness nurses as you are supporting the person you care for. In this part of the discussion, we want to be careful that you don't share private information about the person you care for or about their

health, since that information should be kept private. So we ask that you focus your answers on what kinds of help the staff provided and not on the condition or problem they helped you address.

7. How many of you have interacted with the resident wellness director(s) [INSERT RWD NAME(s)] related to the person you care for? [SHOW OF HANDS]
 - Tell me about your experiences with him/her/them. [Facilitator should probe for whether their interactions have changed since the start of IWISH.]
8. How many of you have interacted with the wellness nurse(s) [INSERT WN NAME(s)] related to the person you care for? [SHOW OF HANDS]
 - Tell me about your experiences with him/her/them. [Facilitator should probe for whether their interactions have changed since the start of IWISH.]

The person you care for may have gone to the hospital or a nursing home some time since March 2019. If so, I'm interested to hear about your experiences during this time.

9. If you helped the person you care for through a hospital or nursing home stay or admission sometime since March 2019, please tell me about the types of assistance that the wellness nurse or resident wellness director provided at this time.
10. In your opinion, is there more the resident wellness director could be doing to support the person that you care for? To support you? What types of assistance could they be providing?
11. Is there more the wellness nurse could be doing to support the person that you care for? To support you? What types of assistance could they be providing?

Programs and Services

Now I'd like for us to talk a bit about the programs and services that are available here at [PROPERTY NAME] and in the community.

12. What kinds of programs are offered here at [PROPERTY NAME] for residents?
13. What kinds of programs do residents access in the community around here?
14. Have you observed any changes in either the number or the type of services offered, here or in the community, since the IWISH program came along in March 2018?
15. From your perspective, are there enough programs to support the person you care for as they age?
 - If not, what other programs or services would you like to see here on the property?
 - If not, what other programs or services would you like to see here in the community?

Wrap up

Before we end this group, are there any further comments anyone would like to share? Thank you so much for your time.