

OFFICIAL TITLE OF STUDY:

Statewide Implementation of CAPABLE-
Community Aging in Place, Advancing Better
Living for Elders in the Michigan Medicaid
Home and Community Based Waiver Program

NCT NUMBER: NCT03634033

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Research Study

Title: Statewide Implementation of CAPABLE (Community Aging-in-Place, Advancing Better Living for Elders) in the Michigan Medicaid Home and Community Based Waiver Program (NIA1R15AG058193-01A1S1; NCT03634033 Registered August 16, 2018)

Researcher: Sandra L. Spoelstra

As an informal caregiver of a participant in the Michigan Medicaid MI Choice Waiver program, you are being asked to participate in a research study. The box below highlights key information about this study for you to consider when deciding whether or not to participate. Carefully consider the information before you decide whether to participate.

Key Information for You to Consider

Voluntary Consent. You are being asked to volunteer for this research study. It is up to you whether you choose to participate or not. If you choose NOT to participate, do not sign this form.

Purpose. The purpose is to help caregivers provide care to care recipients in phase 3 of the study.

Duration. It is expected that your participation will last 4 months, but could take up to 1 year.

Procedures and Activities. You will complete a survey asking about you and the participant. Then, you will be given a toolkit to use when providing care. You will complete surveys asking your use and satisfaction with the toolkit and the participant's health status.

Risks. It is not expected that you will be placed at any physical, financial, or legal risk or harm as a result of taking part in this study.

Benefits. There are no direct benefits to you, but we believe the knowledge gained from the study will assist you as a caregiver to care for the participant.

Alternatives. Participation is voluntary, if you choose to not participate, participant care will not be affected.

How will this study help me?

Information from this study may help researchers understand how caregivers assist participants.

Who can participate?

We are inviting informal caregivers of a participant with Alzheimer's Disease or dementia in the MI Choice Waiver who did not Opt-out of the Main Trial, as agreement to participate is still valid, are 18 years of age or older, speak and read English, and located in Michigan to participate.

We are also inviting participants enrolled in the waiver who did not Opt-out of the Main Trial, as agreement to participate is still valid, are diagnosed with Alzheimer's Disease or dementia, have a LAR or DPOA that are activated for healthcare decision making, are 18 years of age or older, speak English, and located in Michigan to participate.

What will you receive?

If you agree to take part of the study you will:

- Receive a toolkit to use when providing care to your participant
- Complete phone surveys asking about your characteristics, self-efficacy, and relationship to the

participant (10 minutes); your use of the toolkit (5 minutes) monthly for 3 months; and your self-efficacy, satisfaction with the toolkit, and the participant's health status (15 minutes).

- Upon completion of the study, you will receive up to \$250 to compensate time spent on five surveys, prorated at \$50 for each survey completed.

What information will be used for research?

We will be collecting your data in surveys and notes. This will include information about your characteristics, relationship to the participant, self-efficacy, the participant's health status, use of the toolkit, and satisfaction. We will have your name, phone number, and address but this information is ONLY known by the researcher and will be stored on a secure server. To prevent your identity being connected with your data, we will remove individual identifiers (name and phone) from the data. NO private information will be shared with anyone other than the researcher, and your results will be pooled among the other caregivers.

Are there risks?

It is not expected that you will be placed at any physical, financial, or legal risk as a result of taking part in this study. A Certificate of Confidentiality has been obtained from the Department of Health and Human Services for this study. To help protect your privacy, this certificate prevents researchers from being required (subpoenaed) to disclose identifying sensitive information collected for this study for use in court in most cases.

What if I change my mind during the study?

You are free to change your mind at any time and you may withdraw from the study if you like by calling Sandra Spoelstra at 616-331-5905. We will remove your data from our study.

If you have questions about the research study call:

Sandra Spoelstra, Grand Valley State University, at 616-331-5905

If you have any questions about your rights as a research care recipient:

Contact the Office of Research Compliance & Integrity at Grand Valley State University, 1 Campus Dr., Allendale, MI Phone 616-331-3197. E-mail: rci@gvsu.edu

What do I have to do?

If you are willing to let us use your information to better understand how to use a toolkit for caregivers, please give consent to be included in the study by signing below. If you do not wish to participate, do not sign below.

If you do not wish to participate, do not sign below.

Name of Caregiver (Study Participant): _____ Date: _____

Signature of Caregiver (Study Participant): _____ Date: _____

Witness: _____ Date: _____

This study was approved by the Grand Valley State University Human Research Review Committee (Protocol 20-213-H) on 2/19/2020.