Protocol for Increasing Community Participation for Individuals Aging with a Long-Term Physical Disability

Principal Investigator
Susan Stark, PhD*
Washington University in St. Louis, Program in Occupational Therapy

Co-investigators
Kerri Morgan, PhD
Washington University in St. Louis, Program in Occupational Therapy

Michelle Putnam, PhD
Simmons College, School of Social Work

Aimee Wehmeier, MBA
Paraquad, Inc

*To whom correspondence should be addressed

Washington University School of Medicine
5232 Oakland Ave,
St. Louis, MO 63110

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Clinical Trial #

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Date	Version	Modifications
5/23/18	v2.1	Modifications were made to update the protocol with new measures for the cohort study, change in age inclusion criteria from 50 to 45, and change of the paper version to a phone version (based on feedback from the community organizations).
1/31/19	V2.2	Modifications were made to project 3, adding a key informant interview option for the qualitative research to expand potential recruitment.
11/13/19	V2.3	Peer support was removed from Projects 3 and 4 based on program adaptation study results. Updated outcome measures for Project 4 based on updated cohort study measures (including HRS supplemental questions and fall outcomes).
07/21/2020	V2.4	Updated consent process for Project 4 to include e-consent protocol. Updated outcomes for Project 4 to include the Falls prevention strategy survey and Participation frequency and importance self-efficacy scale based on the adaptation process. Added $5 compensation for reporting falls in Project 4. Updated research description of Project 4 based on adaptation results (inclusion of the Home Hazard Removal Program). Added supplemental COVID-19 survey measures. Updated recruitment status for Projects 2-4. Updated actual date of first enrollment from projected dated. Copy-edited for clarity.
12/15/2020	V2.5	Updated questions included in Project 2, Year 3 to include COVID-19 history.
2/1/2021	V2.6	Updated to add paper consent option for Project 4 due to REDCap IT issues with consent signature uploads.
8/18/2021	V2.7	Updated to add analysis of recordings of the quarterly CBRN meetings and focus groups with CBRN members for Project 1. Updated statistical analysis plan for Project 2 based on revised outcome measures. Updated Project 3 as closed to recruitment.
1/24/22	V2.8	Added member check with waitlist control group. Added questions about participants' COVID vaccination status.
8/18/23	V2.9	Added personnel and project 5 HARP CBRN

Co-Authors:

Susan Stark, PhD, OTR/L
Program in Occupational Therapy
Washington University School of Medicine

Kerri Morgan, PhD
Program in Occupational Therapy
Washington University School of Medicine

Marian Keglovits, OTD, MSCI, OTR/L
Program in Occupational Therapy
Washington University School of Medicine

Emily Somerville, MSOT, OTR/L
Program in Occupational Therapy
Washington University School of Medicine

Jessica Dashner, OTD, OTR/L
Program in Occupational Therapy
Washington University School of Medicine

Michelle Putnam, PhD
Simmons College, School of Social Work

Aimee Wehmeier, MBA
Paraquad, Inc

Yan Yan, MD, PhD
Division of Biostatistics
Washington University School of Medicine

Rebecca Bollinger, OTD, OTR/L
Program in Occupational Therapy
Washington University School of Medicine

Brianna Holden, MSOT, OTR/L
Program in Occupational Therapy
Washington University School of Medicine

WORLD HEALTH ORGANIZATION DATA SET

Primary Registry and Trial Identifying Number	ClinicalTrials.gov:
Date of Registration	
Secondary Identifying Numbers	IRB ID#: 201710186
Source(s) of Monetary Support	National Institute on Disability, Independent Living, and Rehabilitation Research
Primary Sponsor	Program in Occupational Therapy - Washington University School of Medicine in St. Louis, MO
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Contact for Public Queries	Susan Stark, PhD, OTR/L sstark@wustl.edu 314-273-4114 Department of Occupational Therapy Washington University School of Medicine 5232 Oakland Ave St. Louis, MO 63110 United States
Contact for Scientific Queries	Susan Stark, PhD, OTR/L sstark@wustl.edu 314-273-4114 Department of Occupational Therapy Washington University School of Medicine 5232 Oakland Ave St. Louis, MO 63110 United States
Public Title	Increasing Community Participation for Individuals Aging with a Long-Term Physical Disability
Scientific Title	NA
Countries of Recruitment	United States
Health Condition(s) or Problem(s) Studied	PAwLTPD acquired prior to age 18 (e.g. Cerebral Palsy, Muscular Dystrophy) and those who acquire disability in adulthood (e.g. stroke, limb loss).

Intervention(s)	Home Modifications
Key Inclusion and Exclusion Criteria	PAwLTPD acquired prior to age 18 (e.g. Cerebral Palsy, Muscular Dystrophy) and those who acquire disability in adulthood (e.g. stroke, limb loss)
Study Type	Project 4 Testing preliminary efficacy of a program to reduce barriers to community participation. Translational Trial Phase I Allocation: Randomized Intervention model: Parallel Assignment Primary purpose: Community reintegration
Date of First Enrollment	November 3, 2020
Target Sample Size	50
Recruitment Status	Project 4, closed to recruitment
Primary Outcome(s)	**Project 4 Testing Preliminary Efficacy of a Program to Reduce Barriers to Community Participation:** We will test the working hypothesis that an adapted program, focused on resolving environmental barriers and building self-management skills in the home and community, will be feasible and superior to usual care for daily activity performance and participation outcomes. The hypothesis is based on our previous work,[2,3] the work of others,[4-6] and our unpublished preliminary data. **Aim 1.** Determine the acceptability and feasibility of the adapted program. We will conduct a process evaluation[7] of this intervention to evaluate the acceptability and feasibility and to aid in the interpretability of the trial. We will test the **hypothesis** that the adapted program will have high acceptability (80% retention), high fidelity by therapists (95% of elements and 90% of dose delivered), low safety risk (no increased rate of falls or health care use compared with control group), and high adherence (80% of modifications in use) at 6 months. **Aim 2.** Estimate the magnitude of efficacy of the adapted program on the primary outcome of community participation (RNL) and on exploratory outcomes of daily activity performance and self-efficacy (I-HOPE) to select optimal end points for a large pragmatic trial. We will test the **hypotheses** that the adapted program is superior to usual care at 6 months on the primary and secondary end points. **Time Points of Interest:** Baseline, 1 month

ORGANIZATIONAL STRUCTURE AND RESPONSIBILITIES

Principal Investigator:
Susan Stark, PhD, OTR/L

Responsibilities include: Managing the operations of the study, ensuring tasks are completed, ensuring compliance with quality-assurance requirements (e.g., human participant protection), preparing interim reports, and publication of study reports.

Study Coordinators:
Brianna Holden, MSOT, OTR/L and Rebecca Bollinger, OTD, OTR/L

Responsibilities include: Developing all study materials including the Manual of Procedures and study forms, verifying informed consent from each participant, reporting Adverse Events (AEs) and Serious Adverse Events (SAEs), recruiting, screening, and enrolling of participants, randomizing participants; following and scheduling participants through study completion, protecting participants' rights, submitting documents to regulatory bodies, developing and implementing quality control procedures, liaison with community partners.

Data Management Committee:
Susan Stark, PhD, OTR/L
Yan Yan, MD

Responsibilities include: Statistical design of study, data verification, developing and implementing data management procedures including the data flow and procedures for data entry, error identification and correction, preparing quarterly reports-enrollment, participant status (e.g., withdrawals), adverse events independent safety monitoring body reports.

Abstract

Background. People with long-term physical disabilities are living longer and experiencing the challenges of aging, including the onset of secondary and age-related chronic health conditions. This group is at a high risk of diminished functional abilities and compromised participation. The aging of a population of people with disability poses new challenges for Long Term Supportive Service (LTSS) providers that have traditionally addressed either aging or disability service needs, but not both. People aging with long-term physical disability (PAwLTPD) are facing serious gaps in service delivery to support aging-in-place and community living in later life. The nexus of aging and disability and associated risk of dependence will continue to grow as the older population and number of people with long-term disabilities surviving to midlife and beyond increases.

Purpose. We propose a Disability and Rehabilitation Research Program (DRRP) devoted to identifying and addressing barriers to successful community participation for people aging with long- term physical disabilities.

Target populations. PAwLTPD acquired prior to age 18 (e.g. Cerebral Palsy, Muscular Dystrophy) and those who acquire disability in adulthood (e.g. stroke, limb loss).

Goals. The purpose of the proposed DRRP is to conduct a pilot randomized controlled trial to evaluate the feasibility, fidelity and preliminary efficacy of an adapted intervention to address function and community participation for the new target population using the RE-AIM framework as the first program for dissemination and use within our previously developed Community Based Research Network (CBRN). The CBRN is a regional collaborative of centers for independent living (CILs), area agencies on aging (AAAs), and academic researchers.

Proposed Methodological Approach. We will examine the feasibility of implementing the adapted EB program in the CBRN established under a previous project.

Outcomes. This DRRP will expand the portfolio of EB programs that are effective in moderating the negative consequences of aging with disability on participation, and community living.

Background

The United States is facing an unprecedented demographic shift. Older people are living longer and will constitute one-fifth of the population by 2040.[8] People with long-term physical disabilities are also living longer and experiencing the challenges of aging.[9,10] Chief among these challenges is the onset of secondary and age-related chronic health conditions[9] that can further undermine functional abilities and compromise participation, placing them at risk of "premature aging." [11,12] The aging of a population of people with disability poses new challenges for service networks that have traditionally addressed either aging or disability service needs but not both.[13-16] People aging with long-term physical disability (PAwLTPD) who need a holistic service approach are placing new demands on long-term supportive services (LTSS) providers[17] and spotlighting serious gaps in service delivery to support aging in place and community living in later life for PAwLTPD. This growing segment of our population has the potential to fall through service gaps at alarming rates.[14] If this group is able to access services, they are less likely to receive *evidence-based* (EB) interventions, as few have been evaluated for effectiveness for this emerging population. The PAwLTPD population is significantly understudied, as is the issue of participation in later life.[18] We propose to address this critical gap in knowledge between the traditionally distinct bodies of aging and disability research and services to improve the lives of people aging with long-term disability (PAwLTPD) and to support their ability to participate in the community in later life.

We have designed an innovative program of research and knowledge translation that bridges the fields of aging and disability to establish an integrative and collaborative network of researchers and practitioners aimed at improving community participation for people aging with physical disability.[19] Central to our program is the application of effective translational research methods designed to increase the availability of EB practices for PAwLTPD combined with the creation of a self-sustaining community-based research network (CBRN) that includes both aging and disability partners (modeled after successful practice-based research networks [PBRNs]). The network will serve as both a test bed for identifying issues and determining the efficacy and effectiveness of new programs and a platform for disseminating and implementing new EB programs. Translational research methods will be used to guide the adaptation of existing highly effective EB programs developed for older adult populations experiencing disability and to test their efficacy for PAwLTPD in community settings. This transformational community-engaged research agenda will link bodies of research, service providers, and key stakeholders to tackle a looming crisis in the availability of effective community-based services for PAwLTPD.

Target Population and Statement of the Problem:
Aging with long-term disability.

Over the next 3 decades, the United States will experience considerable growth of its older population. By 2050, the population aged ≥65 years is projected to double as surviving baby boomers reach age 85.[20] Advances in medicine and public health are associated with the demographic shift to an aging society. Improvements in health have translated into increased longevity. People with disabilities (now nearly 13% of our population[21]) have also benefitted from these medical advances and are living longer.[22] *Aging with a disability* refers to the subset of people with lifelong and early onset disabilities such as cerebral palsy, post-polio syndrome, spinal cord injury (SCI), and muscular dystrophy, to name just a few, who are surviving into mid- and later life.[13,23] The phrase *aging with disability* can also be applied to people who acquire disabilities in midlife due to limb loss and stroke or disabling conditions such as diabetes and multiple sclerosis and who are also increasingly surviving into later life.[24]

Although differences are associated with the severity of an injury or health condition, people with physical disabilities now have nearly normal life spans.[25-30] While estimates vary with different definitions of disability, the best available estimates suggest about 12 million people older than 65 years are aging with early onset disabilities.[13,31,32] What is clear is that, with increasing age (beginning at 45 years), people with disabilities report greater difficulty with independent living.[22] People aging with early and midlife onset of physical disability are at risk for all common age-related impairments and chronic conditions that threaten the health and independence of the general middle-aged and older population. These include hypertension, heart disease,

diabetes, arthritis and other musculoskeletal disorders, falls or other injuries, obesity, depression, and cognitive decline.[33,34] People with long-term physical disabilities experience these conditions earlier than their nondisabled counterparts, and that may have a greater impact on functional abilities.[35] PAwLTPD simultaneously may confront "secondary conditions" associated with their primary disabling condition. Depending on the type of disabling condition, secondary conditions can include accelerated aging of organ systems,[36,37] pain,[38-40] fatigue,[41,42] weakness,[42] pressure ulcers,[30,43] urinary tract infections,[30,43] and bladder or bowel dysfunction.[42,44] We have discovered aging-related changes in ability, and secondary health conditions can be more disabling and affect independence and community participation more than the primary disability itself among people with early and midlife-onset disability.[45]

As personal abilities change with the aging process, PAwLTPD face increasing barriers to independence and community participation, yet there is a paucity of evidence on aging successfully with a disability.[46] In a secondary analysis[47] of a cohort study conducted by Gray et al[45,48] of 604 people with long-term mobility impairments, we discovered PAwLTPD aged 50-65 years had significantly lower participation rates than those aged 18-49 years, as measured by the Facilitators and Barriers Survey of environmental influences on community participation. Strikingly, participants in the 50-65 age cohort had participation patterns similar to adults aged ≥65 for all destinations (eg, dining out, visiting friends, volunteering or working, shopping) except going to church or the pharmacy. It appears that community participation degradation patterns are similar to other trajectories of functional decline[12] for people aging with disability. It is unknown if intervening to remediate environmental barriers to community participation for people early in the aging process is an effective mechanism to reverse the negative participation trajectory for this population.

A fragmented LTSS delivery system has resulted in a gap in community-based services for PAwLTPD who wish to age in place. More adults with significant disabilities are living in the community as states comply with the Supreme Court decision *Olmstead v. L.C.*, 527 U.S. 581,[49] requiring community options to be available to those who need LTSS. LTSS includes a broad range of paid and unpaid medical and personal care assistance that people may need when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability.[50] Two nationwide community-based service networks offer LTSS: Centers for Independent Living (CILs) and Area Agencies on Aging (AAAs). LTSS offered by CILs generally targets people with disabilities but are not typically focused on issues of aging. LTSS offered by AAAs tends to focus on issues of aging and disability but do not have an independent living lens or emphasis on participation. PAwLTPD are a "crossover" population that potentially qualifies for both aging- and disability-related assistance and supports but often does not fit neatly into either service network's model of LTSS. Although both agencies serve PAwLTPD, they may not have programs or services that can accommodate this population's unique issues. It is unclear how well either type of organization is prepared to provide services to this growing population. Pending changes in the Affordable Care Act[51] and Medicaid funding[52] suggest that cross-network collaborations between CILs and AAAs may be more urgently needed to support people with disabilities to live in the community at all ages.

The nexus of aging and disability and associated risk of dependence will continue to grow as the older population and the number of PAwLTPD surviving to midlife and beyond increase.[23,53] Because the PAwLTPD population is relatively new to both disability and aging service providers, no formal definition of this population exists. For the purposes of this study, we will focus on PAwLTPD[12,13] at greatest risk for losing their independence in the community. We will target PAwLTPD aged 50-65 years who are at high risk of reduced community participation.

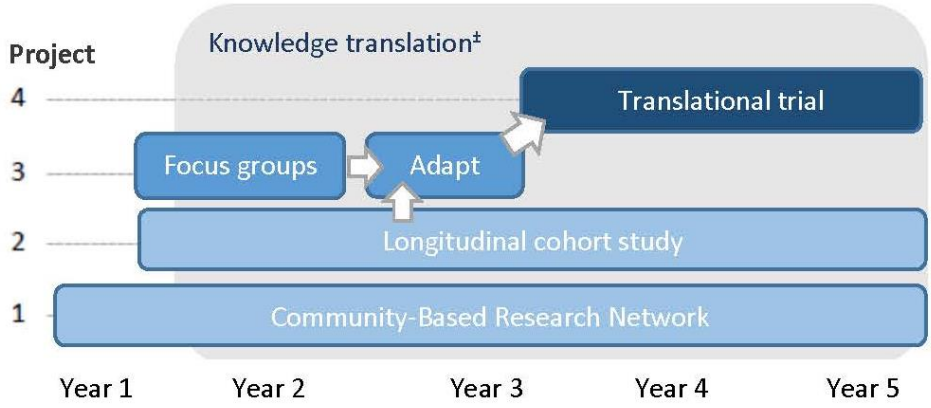
There is a paucity of EB LTSS programs demonstrating effectiveness in facilitating independence and community participation for PAwLTPD. Emerging evidence points to the importance of community participation for successful aging with a disability.[46] Yet, no EB programs that address participation and aging in place have been demonstrated to be effective for PAwLTPD. Although promising programs exists for improving health outcomes of PAwLTPD (see "Living Well with a Disability"[54,55]), LTSS providers have an urgent need for rigorously tested programs for PAwLTPD. The Administration on Community Living places a strong emphasis on developing and funding EB practices among AAAs and has published rigorous standards for defining what is an EB practice; however, to date, few meet these criteria.[56] For LTSS providers to effectively meet the needs

of PAwLTPD, EB programs must be developed and deployed to community agencies such as CILs and AAAs.

PAwLTPD have distinctive characteristics that vary by the nature of diagnosis, impairment, and disability.[57,58] The development of appropriate fall prevention programs, for example, may be needed for persons with MS, who have a higher likelihood of falling than do persons aging without disability.[59] People with physical disabilities, however, are generally excluded from efficacy studies. There is a lack of translation of evidence from either disability or gerontology and rehabilitation to the unique needs of PAwLTPD.[53] We intend to help address this problem.

Research Activities Overview

We will examine the feasibility of implementing an adapted EB program targeting function and community participation in the CBRN established under a previous project. Our prior projects and their relationship to the current study is presented in Figure 1. In brief, our previous work established a regional CBRN consisting of a mix of CILs and AAAs that represent urban and rural communities and serve a diverse population. Members of this CBRN participated in a series of focus groups and key informant interviews with key stakeholders (PAwLTPD and service providers) to identify elements to be adapted from EB interventions targeting function and community participation. This adaptation forms the basis of this study which aims to test the feasibility of this adapted program with PAwLTPD.



Note. ‡Knowledge translation incudes dissemination, technical assistance, and training

Figure 1. Study Overview

Methods

All methods will be implemented according to the proposed study timeline, with revisions as necessary.

IRB Revisions and Compliance: Updates to the IRB will be submitted during the planning process for each new component of the research project. Necessary IRB updates (i.e. uploading new or revised study collection instruments, study flyers) will be reviewed by the PI and research coordinator during weekly study team meetings. The research coordinator will be responsible for updates to the protocol and modifications to the IRB throughout the study as individual projects begin. All necessary study team members will be informed of proposed and accepted revisions. Human research approval will be obtained from Washington University prior to enrollment of any research participants for each study project.

Research Design Overview

Adapt an Evidence-Based Intervention for Delivery:

Adaptation: We will conduct a series of focus groups and key informant interviews and use the findings in combination with findings from our prior cohort study to iteratively adapt COMPASS. We will use community-engaged research approaches,[62,63] involving key stakeholders as part of the research team, and an adaptation framework[64] to adapt the program for delivery in the Independent Living and Aging Services Network.[65]

Next, we will adapt the program pragmatically and culturally for delivery within existing CILs and AAAs. To accomplish this aim, we will use the Cultural Adaptation Process (CAP) [66] model and community-engaged research techniques to adapt the program while maintaining the essential elements of the intervention. CAP incorporates the voices of the community, providers, and treatment developer in all stages of adaptation.[64 64] The RE-AIM framework[67] is designed to expand the assessment programs[68] to translation and public health impact. Although *this is not a dissemination study*, we will use RE-AIM to ensure that the final intervention has the greatest potential for future implementation and dissemination (Figure 2). We will use the framework to guide adaptation of the intervention.[68] We will use the ecological validity model[69] to document the changes.

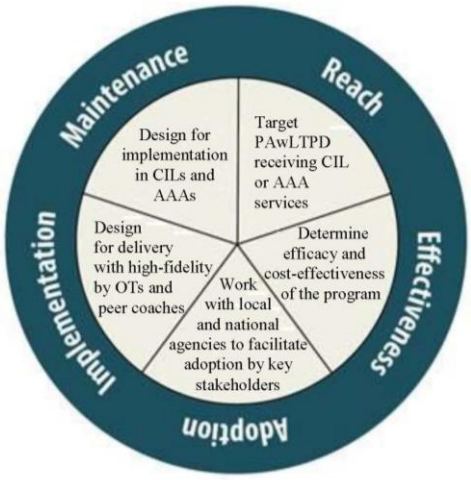


Figure 2. RE-AIM framework used to adapt the program

Testing Preliminary Efficacy of a Program to Reduce Barriers to Community Participation:
We will conduct a trial to reduce the "science to service" gap using the CBRN.[70,71] Hybrid designs examine efficacy while conducting a process evaluation of an intervention.[72] We anticipate that a hybrid approach will lead to more rapid translational gains in intervention uptake, more effective implementation strategies, and more useful information for decision makers. We will facilitate translation by "designing for implementation and dissemination"[73] to ensure that findings are useful, relevant, and ready for widespread dissemination.[74] We will use the RE-AIM framework[67] (Figure 2) to adapt the intervention, to design the trial, and to plan for potential future dissemination through the CBRN.[75] Cost is an important factor that influences decisions and uptake of interventions.[76] To evaluate potential for implementation, we will examine costs to deliver the intervention, with engagement of CBRN members. This approach will provide CBOs with a better understanding of the impact of an intervention and incorporate RE-AIM metrics to aid in understanding the translation and sustainability of the program.

Study Participants

Recruitment
The eligibility criteria include (1) age 45-65 years; (2) self-report of difficulty with ≥2 daily activities using the OARS ADL scale81; and (3) onset of a physical disability 5 years prior to participation (eg, SCI, cerebral palsy, post-polio syndrome, stroke, amputation). We will exclude those currently institutionalized.

To ensure that the sample represents people that this program will target in the future (reach),[82] we will select a sample of 50 adults aging with a long-term disability from the St. Louis members of the CBRN or who have participated in our previous cohort study of PAwLTPD. The CBRN offers access to PAwLTPD who are hard to reach in the traditional health care system and who could benefit from the intervention. In the current cohort of SLAAA participants, 2526 are aged 45-65 years (people with disabilities). Paraquad serves 420 people with physical disabilities aged 45-65 years who meet the eligibility criteria. We will invite eligible participants to participate by telephone. All recruitment and study materials will be IRB approved.

Randomization and Blinding
Participants will be allocated using a 1:1 ratio by block randomization sequences generated a priori using a computerized probability model. The allocation ratio will be maintained at periodic intervals. Groups will be balanced for race and sex. Randomization sequence concealment will be achieved by research electronic data capture (REDCap)[83] after baseline assessment.

Consent

All potential participants will be screened by trained staff using a script. Screening will take place in person or over the phone. Potential participants will be given a copy of the large print informed consent document and a study review sheet written at an appropriate reading level. During screening**,** all participants will: (1) have a detailed explanation of the study and what is expected of them; (2) discuss potential problems that could interfere with participation; (3) have their questions answered; and (4) receive a large print summary of the study and contact information for the PI and study coordinator. **Consent** will occur before the baseline visit. A study team member will call all potential participants and will screen for inclusion criteria and invite them to participate in the study. The informed consent form will be explained over the phone to all potential participants interested in participating in the study. For potential participants who have computer access and capability, the formal study consent process will be conducted using a REDCap-based electronic consent form. The consent form has been developed in REDCap, a secure, web-based HIPAA-compliant, data collection platform with a user management system allowing the PI to grant and control varying levels of access to study staff. Potential participants would receive an email with a unique link to review the informed consent form online. After the research team explains the study and answers any question, the potential participants can electronically fill in an "Agree" button, followed by their electronic signature. Upon completion of the consent, participants are presented with the option to download a copy of the executed form. The research team will provide a copy of the executed form to the participant at the baseline visit if requested. E-consent versioning will be managed using the e-consent Framework in REDCap. Within the e-consent survey options, we have designated the e-consent version number in this application as e-consent version 1. The PDF's of completed responses will have the timestamp, participant name, and e-consent version number inserted in the footer. Future versions of the e-consent will be created by making a copy of the REDCap form and revising it. The old version would be de-activated upon receiving IRB approval for the new version.

If a participant does not have access to a computer or smart device at the time of consent potential participants will be provided with a copy of the informed consent in person or via US mail. Once the potential participant has had time to look over the consent form, a study team member will talk with the participant by phone to review the study information and answer any questions. If they decide to participate, they will be asked to sign the electronic version of the consent using a study provided iPad at the baseline visit. If e-consent is unavailable, paper versions of the consent form will be used and signed either via US mail or in person at the baseline visit. We will email a copy of the consent form if the participant has a valid email address, otherwise we will download a copy and provide it to the participant. Participants will be advised in the consent form that there is a possibility that their medical research record, including identifying information, may be inspected and photocopied by officials of federal or state government agencies and the Washington University Human Research Protection Office (HRPO).

Research Project Descriptions

We propose adapting an effective program designed to remove barriers in the home and community. COMPASS is a complex intervention that combines 2 EB treatment strategies. The program will be adapted culturally and pragmatically. Based on preliminary data, we anticipate that changes to the program will include delivery of self-management training for community participation and process modifications to fit the existing AAA[90] and CIL[91,92] program structure. The essential elements will be maintained.

Based on the results of previous focus groups, we have added additional elements to the proposed intervention to address fall prevention for PAwLTPD. An evidence-based fall prevention program, Home Hazard Removal Program (HARP) was identified and integrated into the new program, Removing Environmental Barriers to Independent Living (REBIL). HARP is based on the Westmead approach[93] and has been shown to be effective in reducing falls in the home for older adults living in the US.

Defining the treatment (Table 1). The treatment theory guiding the intervention is a competence-press model that posits that removing environmental barriers and hazards and adding supports (eg, grab bars near the toilet, using accessible transportation) matched with the PAwLTPD's unique abilities and limitations will improve the outcome of daily activity performance, safety, and participation.[94] The 2 essential components[95] of REBIL are (1) removing environmental barriers and home hazards and (2) strategy training. Both address barriers in the participant's own home and community environment.[96] Independence at home is addressed first. To remove barriers in the home, a tailored home modification intervention is provided.[97-99] Tailoring is necessary, given the heterogeneity of participants and environments.[100] Strategy training will facilitate long-term effects of the intervention by providing PAwLTPD self-efficacy to problem-solve emerging barriers to participation.

Table 1. Program elements

Dosage and timing	One assessment session; four 75-minute visits in the home with OT (over 8 weeks)
Model/Theory	ICF model; Competence-Press theory
Two Components (evidence-based strategies)	**Home modifications and hazard removal** (OT)
	• Assessment • Participants ID problems in the home • Tailored home modifications and hazard removal; shared decision making to select solutions • Active Practice in context
	Strategy training (OT)
	• Participant identifies barriers and resources • Encourages self-efficacy
Approach	• Dose of home modification and hazard removal begins high and tapers; dose of strategy training begins low and increases • Clinician as partners; caregivers included
Standardized elements of tailored approach	• ID up to 10 in-home problematic activities • ID home hazards • ID 3 solutions (for each in-home problem) • Implement selected solutions in-home • In-context training, active practice • ID 2 problematic community activities • Self-management to resolve community barriers

ICF=International Classification of Functioning, Disability, and Health; ID=identify; OT=occupational therapist.

The conceptual model of the intervention (Figure 3). The ICF describes the mechanism of the adapted program. PAwLTPD have a health condition that affects their body structure and function. The home and community environments of PAwLTPD pose barriers that prevent successful and safe performance of daily activities and participation. Intervening to remove barriers and enable PAwLTPD to use problem-solving strategies to overcome barriers will improve daily activity performance and participation outcomes. This conceptual model is empirically supported by our recent work exploring the role of environmental barriers in function.[101]

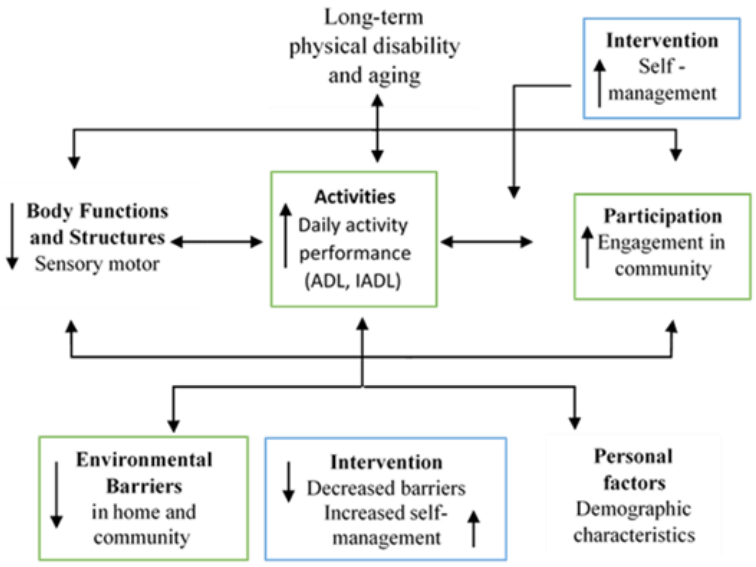


Figure 3. Adapted program conceptual model adapted from the ICF. Blue boxes represent intervention. Blue lines and green boxes represent the hypothesized mechanism of action. By reducing environmental barriers, activity and participation outcomes will improve.

Baseline Home Visit (T1) for all Participants

Outcomes (primary endpoints described in Table 2) will be assessed by blinded evaluators at baseline and 6 months. Additional exploratory outcome measures are listed under the assessments section.

Baseline and 6-month follow-up assessments will be conducted in the home by a trained and certified rater blinded to group allocation. Follow-up assessments will be completed by a blinded rater who did not conduct the T1 evaluation, as new home modifications could reveal group assignment.

Intervention

The occupational therapists will deliver the final adapted program in each participant's home and community. The essential elements include resolving barriers in the home and community and self-management skills to identify and resolve barriers. The intervention will target barriers in the home initially. Participants will identify target activities they want to address. Although problem areas addressed are participant-specific (tailored), the process to identify and address the problems is systematic and reproducible. All participants will receive identical intervention components (see Table 1).

Table 2. Measures: Primary End Points and Rationale for Inclusion

Reintegration to Normal Living Index (RNLI)[48,102-105]	The RNLI measures the extent to which a person is able to complete normal life activities. The 11-item measure quantifies participation. The administration of the RNLI is quick and simple. Individual item scores are converted to 100. The RNLI can be administered in person or by mail.
In-Home Occupational Performance Evaluation (I-HOPE) [106]	The I-HOPE is a performance-based assessment that can measure the performance of the environmental barriers that influence 42 activities performed in the home (person-environment fit).The tool also has a self-efficacy subscale that measures confidence performing activities. The instrument yields 4 subscales with high internal reliability (α = 0.77–0.78) and interrater reliability (0.94 to 1.0).[106] The I-HOPE will yield home assessment information and outcome activity performance assessment

Waitlist Attentional Control Treatment. The waitlist control group will receive the adapted program after the 6-month follow-up is completed. Participants in the waitlist control group will receive interview visits (equivalent in time by an occupational therapy graduate assistant). After the six-month follow-up has been completed, participants in this group will be contacted and asked to participate in a validity check. They will then be offered treatment at the end of the follow-up period.

Follow-Up Periods

6-month follow-up assessments will be conducted in the home by a trained and certified rater blinded to group allocation. Follow-up assessments will be completed by a blinded rater who did not conduct the T1 evaluation, as new home modifications could reveal group assignment.

Program Revisions

Based on data from our prior cohort study and focus groups, we will produce adapted program materials that maintain the "essential ingredients" of the program but are culturally tailored and deployable within the limits of current CILs and the Aging Services Network. We will develop a new set of materials including procedures and an interventionists' manual.

To ensure fidelity to the original program, draft materials will be reviewed by Dr. Stark (developer of the original program) to ensure that the "essential elements" are maintained in the program. We will use the ecological validity and sensitivity framework [69] to document changes.

The new program will be iteratively piloted with 3-6 individuals living with a long-term physical disability. The pilot participants will identify potential problems with acceptability of the program structure or process and information delivered to the participant. The program will be iteratively revised until a final program is sufficiently ready to deploy in a larger sample.

Outcomes will be assessed by blinded evaluators at baseline and 6 months. Our goal is to optimize the design of future trials, so we will examine a series of measures to evaluate their utility in the trial setting. Baseline and 6-month follow-up assessments will be conducted in the home by a trained and certified rater blinded to group allocation. Follow-up assessments will be completed by a blinded rater who did not conduct the T1 evaluation, as new home modifications could reveal group assignment. We will also track falls on a monthly basis.

Assessments

Primary Outcomes

In-Home Occupational Performance Evaluation (I-HOPE): The I-HOPE will be used to measure current activity patterns of participants, identify activities that are difficult but important to them, and identify the environmental barriers that influence those activities (person-environment fit). The I-HOPE is a multi-step assessment that evaluates the performance of people doing 42 activities in the home. Using labeled pictures of each home activity (e.g., washing dishes, getting in and out of bed), participants identify and prioritize preferred activities for intervention and give a subjective performance, satisfaction, and self-efficacy score for each activity. A trained rater (e.g., OT) observes the participant perform the activity and quantifies the person-environment fit (or misfit). The instrument yields five subscales- the activity subscale [α = 0.78 (6 items)]; performance subscale [α = 0.85 (8 items)]; satisfaction subscale [α = 0.77 (8items)]; self-efficacy subscale [α = 0.90 (10 items)]; and the environmental barrier subscale [α = 0.77 (6 items)]. Intraclass correlation coefficients were calculated for the I-HOPE subscales on a sample of 10 participants, and scores ranged from .94 to 1.0 for raters.[141]

Reintegration to Normal Living Index (RNLI): The RNLI is a disability-related quality-of life-instrument that will be used to measure participants' satisfaction with their home and community participation and has been validated on a population of community-dwelling individuals with chronic conditions.[142] Participants will read 11 statements relating to their monthly activity patterns and assign each one a score based on a 10-point ordinal scale with 1 indicating "does not describe my situation at all" and 10 indicating "fully describes my situation." Participants will complete the RNL at home and return it by mail.

Westmead Home Safety Assessment (WeHSA)[93]: The Westmead Home Safety Assessment will be used to identify the number of environmental hazards in all areas of the home (e.g., seating, bedroom, medication management) via 72 standardized categories. Each category is specified with explicit descriptors to qualify a given fall hazard with a score of 0 for absent and 1 for present. Total hazards are summed. A trained rater will complete the assessment at baseline and at the 6-month follow up.

Exploratory Outcomes

Health and Retirement Study[1] (HRS) Activity Supplement 2015: The Health and Retirement Study is a

longitudinal study designed to address important questions on the challenges and opportunities of aging. The activity supplement questionnaire will be used to provide descriptive information on activity participation. Modifications have been made to allow for additional qualitative responses describing barriers and limitations to activities.

Falls prevention strategy survey (FPSS): The FPSS is a self-report instrument addressing protective behaviors related to fall risk among adults.[143] Response options reflect the frequency with which the respondent engages in twelve different fall prevention behaviors behavior (never, sometimes, regularly).

Participation frequency, importance and self-efficacy: The participation frequency, importance and self-efficacy measure address four areas of participation: routines, recreation, responsibilities and relationships.[144] Twenty-five different activities are rated by the participant on a 1-5 Likert-type scale in the areas of frequency, importance, and self-efficacy to complete the activity.

Falls: Calendars reporting falls and health care utilization will be collected monthly via REDCap survey (using an automated system and/or in person).

Covariates

Demographics: Basic demographic information will be collected for all participants. Information collected will include age, race/ethnicity, sex, gender identity, marital status, level of school, primary disability, use of a mobility device, and living arrangement.

Bayliss Comorbid Conditions: The Bayliss is a multimorbidity scale that assesses the impact of different conditions on daily activities as a measure of disease severity, conceptualized as self-reported disease burden. This scale was designed in order to create a subjective measure of comorbidity, to be used especially in studies using QoL outcomes, where the patient's perception plays an important role.[118-120]

Process Evaluation

Reach. Enrollment and retention will be tracked by the research coordinator using REDCap, an online data entry program. Recruitment information for each participant will include the potential participant's initials, gender, birthdate, race, zip code. Reasons for denying participation in the study as well as study attrition will also be tracked via REDCap.

Fidelity. In order to guarantee treatment fidelity, or our ability to provide the same treatment as planned to each participant, we will use a Session by Session checklist following similar methods of Weersing et al.[145] This grid specifically outlines the pre-, during, and post-treatment visit requirements for each treatment session. It is designed to be a checklist in which therapists check off the action once it is completed. During weekly interventionist meetings, the lead therapist will review the treatment grid for each participant to guarantee the necessary components of the intervention are being delivered. A fidelity checklist designed to assess therapist adherence and competence in delivering the treatment intervention will also be used.[146]

Dose. In order to effectively measure the dose of treatment provided for each participant, we will measure both the dose that was delivered to each person (minutes of each treatment session and number of session) as well as the dose received (recommendations implemented/total recommendations). We will use a spreadsheet or Time Log to track minutes spent in each treatment session and another spreadsheet or Prescription Log to track the recommendations made and implemented for each participant.

Adherence. Adherence measures the participant's continued use of the implemented modifications. We will use the standardized approach of Cumming et al.[147] to calculate adherence as recommendations used/total recommendations. Interventionists will rate adherence with intervention at the final session by using the Prescription Log to track recommendations made, implemented and reasons that any recommendations were not implemented. Initial adherence will be a proportion of the number of recommendations implemented /recommendations suggested. Finally, we will determine the number of recommendations used/recommendations suggested at 6 months. Reasons for abandoning strategies will be examined using the Adherence Log, in which the participant will report on current level of use for each modification: very useful, somewhat useful, not at all useful, no longer use equipment. Any independence that was regained by improved sensorimotor performance will not count against the adherence rating.

Cost. The cost of the treatment will be measured by tracking cost of modifications and adaptive equipment for each participant. This will be tracked using the Invoice Form which includes both costs from the contractor as well as costs of any equipment ordered from a medical supply company or obtained from a community resource (medical equipment lending program). The total amount of money spent on each person will be tracked on this form.

Safety. To explore the safety of our study, we will measure the number of falls and the circumstances surrounding the falls with a self-report Fall Form used at the 6 month follow up visit. The rate and severity of the falls will be calculated using a standardized algorithm established by Tinetti, et al, 1988.[148] We will also track health care utilization for participants in both groups (# of emergency room and outpatient visits, # of hospitalizations, and number of days in therapy) using the Health Care Utilization Form.

Process Evaluation

The components and data sources of the process evaluation are presented in Table 4. We will conduct a process evaluation to understand the feasibility and to refine the components of the intervention in preparation for a definitive trial.[162] We will monitor recruitment metrics for all eligible participants including demographic characteristics, enrollment status, and reason for decline. We will determine the fidelity of the intervention by determining whether the intervention was delivered as planned and calculating the dose of the intervention received by both groups (number of minutes and number of sessions delivered). Interventionists will rate adherence at last visit as the number of recommendations implemented per recommendations suggested.[163] Long-term adherence will be calculated as the number of recommendations used at 6 months per recommendations suggested. We will examine reasons for abandonment of strategies. Environmental modifications are not provided as part of standard care in the United States; therefore, reliable cost data are not available. We will track the cost of service provision (in the treatment group) to prepare for future cost-effectiveness studies. We will record occupational therapist time to provide services (direct and indirect). The hourly wage of the contractor will be estimated using wage rates for the St. Louis area as reported by the US Bureau of Labor Statistics.[164] All materials costs will be captured from invoices. Costs will be estimated from the payer perspective (eg, Medicare allowable will be used to estimate covered clinical encounters.)[165]

Table 4. Process Evaluation Construct Data: Source and Form

Reach	Enrollment; retention*	Reason eligible not enrolled; recruitment rate; retention rate
Fidelity	Implemented per plan^	Session by session checklist of each component
	Dose delivered^	Minutes of treatment at each session; number of sessions
	Dose received^	Recommendations implemented/total recommendations
Adherence	Adherence to recommendations+	Recommendations used/total recommendations at 6 months; cause of abandonment
Costs	Costs^	Final prescription and invoice (materials); treatment grid (time)

Notes: Data source *Recruitment coordinator; ^Interventionist notes; + 6- and 12-month follow-up assessment.

Statistical Analyses

First, we will examine the distributional characteristics of study variables (outcomes, covariates). Basic descriptive statistics for each measure and the intercorrelations among study variables will provide a simple initial view of the sample characteristics (demographic and health-related variables). Second, we will determine whether participants are representative of the eligible population by comparing baseline sociodemographic characteristics (eg, age, gender, education) of the study population with those eligible to participate in the study but who declined to participate. Continuous variables will be analyzed with the appropriate parametric methods (eg, *t* test) to test for differences between the participants in the study and those who refused. Discrete variables will be analyzed with the appropriate nonparametric test (eg, chi-square test of association) to test for differences between the participants in the study and those who refused.

Next, we will use unpaired *t* tests and chi-square tests to compare baseline characteristics in the 2 groups for descriptive information (except when statistical assumptions are not met, in which case we may use Wilcoxon or Fisher exact tests). We will examine the process data before the efficacy analyses.[170] The goal of Aim 1 is to examine the feasibility of conducting a larger trial by conducting a process evaluation. We will conduct between-group comparisons of process end points collected at 6 months (eg, health care utilization rate, safety, dosage delivered, and adherence rate) using unpaired *t* tests or chi-square tests. We will compare the characteristics of patients that complete the assigned intervention to those who do not for differences in disability severity and comorbidities. Descriptive statistics will be used for costs per participant and adherence.

The goal of Aim 2 is to test the hypothesis that the adapted program will result in greater improvements in participation and daily activity performance than control at 6 months after intervention. Mixed-model repeated-measures analysis of variance will be used for longitudinal analyses of variables measured at >2 time points (ie, Reintegration to Normal Living Index, I-HOPE). The focus of this analysis will be the significance of the interaction between group and time. Hypotheses will test for interactions in terms of the equality of changes over time in the 2 groups. Contrasts will be used in testing the null hypothesis that changes between 2 specific time points in one group are equal to corresponding changes in the group. I-HOPE scores will be analyzed with analysis of covariance with the 6-month value as the dependent variable and the baseline value as the covariate. For all analyses, we will determine whether required distributional and model-specific assumptions are satisfied. To explore the potential trial end points, we will select the best independent indicator of participation and compare the measures for sensitivity and statistical efficiency with data collected at 6 months after intervention.

Sample Size Calculations

Although statistical significance is not the goal of this study, we estimated a sample size using a power analysis for a 2-sided, 2-sample, unequal-variance *t* test using G*Power with a significance level of 5% and power of 80%.[173] The sample size calculation includes a correlation between baseline and follow-up measures and is based on analysis of change scores, which is equivalent in efficiency to the proposed analytic model. Data were used from a pilot study with a total of 113 community-dwelling older adults.[100] We estimated the sample size for the mechanism of action (reducing environmental barriers). Environmental barrier mean changes in intervention and control groups were 26.28 (SD 18.03) and 10.09 (SD 22.27), respectively. A sample size of 50 (25 in each group) is needed to provide 80% power.

Potential Benefits, Risks and Alternatives

Benefits
All participants will receive a baseline assessment provided by a registered and licensed occupational therapist. In addition, all participants will receive the intervention at no cost. Participants will receive $5 for each month that falls are reported (waitlist control will receive the intervention after the 6 month follow-up is completed). Participants that participate in the COVID-19 pandemic survey will be entered to win a $50 gift card for each survey that is completed.

Risks
Potential risks of research participation (physical, psychological, financial and legal risks among others) are considered minimal in all the projects (45 CFR46.404). Minimal risk may be involved as the general data collection procedures involve participant interviews and questionnaires that are time consuming (for participants receiving the intervention, 90 minutes for the initial home assessment with follow-up visits at 6 months) and may result in fatigue or aggravation. In addition, some questions may touch on emotionally sensitive issues that could cause anxiety or other forms of emotional stress. The performance-based testing (I-HOPE) involves observation of everyday activities that may result in fatigue or embarrassment. Participants will be informed that their involvement in this research study is voluntary and that they may choose not to participate or withdraw their consent at any time. Withdrawal from the study will not affect the commitment of the community agency to administer care, and there will be no penalty or loss of benefits to which participants are otherwise entitled. Participants who undergo the study visits will be given the option to reschedule the visit

or take a break at any time during the study if necessary. All research-related information will be kept confidential and accessible only to authorized members of the research team.

Minimization of Risks and Confidentiality
Training and Compliance. All study personnel involved in the conduct of this research will receive the required education on the protection of human research participants prior to the funding of this project in accordance with the NIH policy. We are a HIPAA-covered entity and comply with all HIPAA regulations. To protect against and minimize potential risks, participants will be carefully screened and evaluated.

Safety. To minimize the risk of a fall, participants will wear a gait belt during the in-home evaluation of performance. Participants will be trained in the use of all modifications by a licensed and registered OT. Participants (newly enrolled and those still receiving any in-person study-related visits will be asked their COVID vaccination status.

Minimize discomfort. To avoid or minimize symptoms of fatigue, agitation, or emotional distress due to testing, participants will be instructed to notify the rater or interventionist if they experience any discomfort. They will also be periodically questioned about their tolerance for the tests/intervention. Testing and interviews will be terminated if participants develop fatigue, agitation, or emotional distress.

Protect identifiers. An ID number will be assigned to each participant. All data collected from a participant will be labeled with the ID number. All participant electronic and hard-copy data will be kept under double-lock protection. All hard-copy forms that contain personal identifiers (e.g., name, address, phone numbers) will be stored in a separate locked file drawer under double-lock protection. No publication or presentation of the study data will uniquely identify or provide sufficient information to uniquely identify participants.

To guard against unauthorized data access, all shared-use computer systems at Washington University School of Medicine are protected with passwords, which are changed at four-month intervals. Only individuals with a particular "need to know" status are given access, and system privileges are carefully restricted. All personal computers are located within a secure area, and the system is locked when not in use.

For data entry (in the field or from paper forms), the Washington University Division of Biostatistics Informatics Core will be used as a central location for data processing. Washington University belongs to a consortium of institutional partners that work to maintain a software toolset and workflow methodology for electronic collection and management of research and clinical trial data. REDCap (Research Electronic Data Capture) data collection projects rely on a thorough study-specific data dictionary defined in an iterative self-documenting process by all members of the research team with planning assistance from the Division of Biostatistics Informatics Core. REDCap servers are securely housed in an on-site limited access data center managed by the Division of Biostatistics at Washington University. All web-based information transmission is encrypted. The data is all stored on a private, firewall protected network. All users are given individual user identification and passwords and their access is restricted on a role-specific basis. REDCap was developed specifically around HIPAA-Security guidelines and is implemented and maintained according to Washington University guidelines. All paper forms collected in the field with or without personal identifiers will be transported via locked brief cases.

SAS software package will be used for data analysis. Datasets generated from these programs will be password protected, which will make accessing study data difficult even in the event of unauthorized computer access occurs. Systems connected to the Ethernet are carefully controlled, and all systems without Ethernet access control are insulated from the backbone by bridges or routers. The Ethernet cable itself is routed only through secure passageways.

Adverse Event Reporting and Safety Monitoring
Because risk in the proposed study is considered minimal, the DSMB will meet semi-annually to review overall study progress, safety, and efficacy. However, if more frequent monitoring is required, it will be implemented accordingly. At the meetings, Dr. Stark will review progress of the data collection process, evaluate any unanticipated or anticipated effects of study participation, and monitor the integrity and the accuracy of the data generated from the study. Dr. Stark will present progress in the study and interim analyses at each meeting.

Minutes of each meeting will be reported to the HRPO. Dr. Stark will be responsible for executing recommendations made by the committee.

All serious adverse events will be reported to the HRPO in the following time frames: a) death, immediately; b) life-threatening, within seven calendar days; and c) all other SAEs, within 15 calendar days using the Electronic Serious Adverse Event Reporting System. Should there be a serious adverse event that occurs that increases the risks to the participants, the study will be stopped, an investigation will be conducted, and a findings report will be generated before the study is resumed.

Indemnity
Washington University School of Medicine is responsible for any non-negligent damage incurred as a result of participating in the trial. The indemnity is renewed on an annual basis. Washington University School of Medicine assures that it will continue renewal of the indemnity for the duration of the trial.

Ethics and Dissemination
This protocol and the template informed consent forms will be reviewed and approved by the Washington University institutional review board with respect to scientific content and compliance with applicable research and human subjects regulations. All study personnel involved in the conduct of this research will receive the required education on the protection of human research participant rights. Study projects will not begin until the IRB has reviewed and approved all study materials. The protocol will be updated as needed and submitted to the IRB for review.

On publication of the study results, participants will be invited to attend a community meeting during which the results of the study will be reported. The information will be repeated during three community sessions to be held during daylight hours. Participants will receive a mailing announcing the meetings and summarizing the study findings. The location of the meetings will be in a fully accessible auditorium with accessible parking and access to public transportation. A written report will be distributed, and the results will be presented by the study investigators, followed by a question-and-answer period. Refreshments will be served, and participants and their family members will be thanked for their generous support of the project.

Authorship Eligibility and Contributorship
Authorship for this study will be given to key personnel involved in study design, recruitment, data collection, and data analysis. There are no publication restrictions and no professional writers will be involved in the generation of the manuscript. S. Stark is responsible for conceptualizing study design.

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Competing Interests
None of the authors has conflicts of interest to disclose.

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