TechSAge Tool: Conducting Research with Adults Aging with Sensory and Mobility Disabilities

Technologies to Support Aging-in-Place for People with Long-Term Disabilities
Rehabilitation Engineering Research Center (TechSAge RERC)
www.TechSAgeRERC.org

Megan A. Bayles (mbayles2@illinois.edu)
Tracy L. Mitzner (tracy@gatech.edu)
Wendy A. Rogers (wendyr@illinois.edu)

Suggested Citation
Bayles, M. A., Mitzner, T. L. & Rogers, W. A. (2021). *TechSAge Tool: Conducting Research with Older Adults Aging with Sensory and Mobility Disabilities.* Rehabilitation Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities.

Acknowledgments
The contents of this tool were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90REGE0006-01-00) under the auspices of the Rehabilitation and Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities (TechSAge; www.rerctechsage.org). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this tool do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

TechSAge Tools Overview

TechSAge has designed this tool series to provide its readers with guides on how to conduct various aspects of human factors research. The tools have a focus on including the target population of older adults with disabilities. TechSAge Tools are designed to:

1) Introduce a variety of research methods, procedures, and protocols

2) Provide guides and the “how to” on implementation

3) Discuss considerations specific to working with adults aging with disabilities

4) If applicable, recommend appropriate wording to describe the method in publications

5) Point to reliable resources for more in-depth information about the method, procedure, or protocol presented in the tool

Table of Contents

Conducting Research with Adults Aging with Sensory and Mobility Disabilities

This TechSAge tool is designed to give an overview of how to incorporate persons who are aging with disabilities into research studies. The four goals of this tool include 1) Discuss the importance and need for including persons with disabilities in research; 2) Offer recommendations for accommodating persons with disabilities throughout the different stages of a research study (i.e., materials design, recruitment, screening, testing); 3) Highlight examples of research studies that include persons aging with disabilities from TechSAge; and 4) Point to useful resources to learn more about working with individuals who are aging with disabilities into research projects.

INTRODUCTION

The focus of this tool is to provide suggestions and considerations for conducting research with participants who are aging with disabilities. Specifically, we focus on how to facilitate research participation for people aging with mobility and sensory (vision and hearing) disabilities. Lack of participation of people with disabilities in research can be the result of many issues including rigid inclusion criteria (Rios et al., 2016), transportation barriers (Farage et al., 2012), and inaccessible research facilities and materials (Moore & Miller, 2001). However, excluding these populations from larger research studies may bring the external validity of those studies into question (Rios et al., 2016), especially given the growing prevalence of the number of persons aging with disabilities in the population.

Prevalence of Older Adults with Sensory and Mobility Disabilities

The number of Americans living with a disability is estimated to be 54 to 60 million people, making them the largest minority group in the United States (Brucker & Houtenville, 2015). As depicted in Table 1, disability prevalence increases with age: 1 in 2 older adults (65+ years of age) report having one or more disabilities. The most prevalent disability is mobility (i.e., serious difficulty walking or climbing stairs), which is reported by 1 in 7 older adults (Okoro et al., 2016). The prevalence rate for vision disability is 6.6% and for hearing it is 14.9% (Okoro et al., 2016). Given these rates, persons with disabilities must be included in research participant populations to produce findings that are generalizable to all older adults.

TABLE 1. Age Ranges and Percentage of Reported Disability (Census Bureau, 2012)

Age Range	Percentage
< 3	2.3%
School Aged	12.2%
15 +	21%
65+	50%

Understanding the Intersection of Aging, Disability, and Impairment

When working with older adults with disabilities, it is important to note that many are aging *with* a pre-existing disability, rather than aging *into* a disability caused by aging. For these individuals, their disability may be compounded by common age-related declines. Some common age-related conditions that can affect an older adult's vision, hearing, or mobility are presented in Table 2. These conditions can lead to additional impairments that then become co-morbidities of the pre-existing disability.

Table 2. Common Conditions That Can Affect Vision, Hearing, and Mobility Abilities of Older Adults

Abilities	Age-Related Conditions
Vision	Presbyopia
	Glaucoma
	Dry Eyes
	Age-Related Macular Degeneration
	Cataracts
	Temporal Arteritis
Hearing	Presbycusis
	Otosclerosis
	Exposure to Loud Noises
	Acoustic Neuroma
	Tumors
	Ménière's Disease
Mobility	Osteoarthritis
	Multiple Sclerosis
	Neuropathy
	Neuromuscular Disorders
	Falls and Injuries
	Arthritis
	Parkinson's Disease

When recruiting people who are aging with a disability it is important to understand the difference between the terms 'impairment' and 'disability'. Impairment refers to an abnormality or a loss of physical, psychological, structure, and function (Carter, 2018). For example, vision loss from glaucoma, memory loss caused by Alzheimer's, or mobility loss due to Multiple Sclerosis are all considered to be impairments. Alternatively, disability is the inability to act or perform a specific way due to an impairment. For example, an individual can have a mobility impairment, but the lack of physical accommodation to access buildings creates a disability. Hence, if an individual has sufficient support, their impairment will not lead to disability (Mitzner et al., 2018).

Culturally and policy-wise, the term 'disability' is currently preferred over the term 'impairment.' Keep in mind, there may be instances where use of the term 'impairment' is more appropriate but also that some populations may not consider their disability to be an impairment, such as those from the Deaf community. In the planning phase of research, it can be useful to interview people who have knowledge of the disability population (e.g., care partners, experts, those with the disability) to ensure the

appropriate language is being used in the research materials (e.g., recruitment scripts). This suggestion, and many others, is included in the section “How Tos for Including Adults Aging with Disabilities in Research.”

Criticality of Involving Disability Populations in Research

Researchers should include persons with disabilities to increase generalizability of their findings, as well as to better serve and support diverse populations. If researchers come to conclusions about a disability population based on research that did not include representatives of that population, those conclusions are likely to be inaccurate. For example, Jeamwatthanachai, Walk, & Willis (2019) conducted a study with people who had a vision disability and those who were sighted. Each group was asked how helpful each type of assistance would be for someone with a visual disability. They found that the sighted participants thought the most helpful assistance for someone who had a vision disability would be a cane. However, those with the vision disabilities elected a sighted guide to be the most useful form of assistance for their population.

Table 3. Assistance Rankings from Persons with Vision Disability and Sighted Participants

Type of assistance	Visually impaired people		Sighted people	
	BSR	Ranking	BSR	Ranking
Sighted guide	109	1	49	2
White cane	76	2	63	1
Tactile map	9	3	13	3
Guide dog	6	4	13	3

Note: The Board Scoring Rule (BSR) value equals the number of votes given for each type of assistance when participants were asked which assistance option provided the most helpful assistance.

The data in Table 3 demonstrate the erroneous assumptions that can be made when people without disabilities determine what supports and interventions are best for people with disabilities. A better strategy is to involve those with disabilities in research studies to gather scientific data about their needs. Although it is important to include those with disabilities in research, it can be challenging because they are a diverse and complex user group. The following section provides ‘How Tos’ for overcoming many challenges associated with including adults who are aging with disabilities in research.

HOW TOS FOR INCLUDING ADULTS AGING WITH DISABILITIES IN RESEARCH

The following section provides specific recommendations about how to include older adults with disabilities in your research. Much of the discussion is relevant to older adults, in general, regarding how to overcome barriers to including them in a research context. However, we provide elaborations on how sensory or mobility disabilities may compound these barriers. Barriers can stem from (1) older adults' limitations, or (2) limitations the researcher is unintentionally imposing by lacking accommodations. The strategies for overcoming these barriers are presented in the context of the different stages of a research study: study materials design, recruitment, screening, and testing.

Study Materials Design

Additional time and effort may be needed to make study materials accessible. However, the benefit of designing accessible materials is that the materials will be more usable for all people. Table 4 has some recommendations to keep in mind when designing materials for adults aging with disabilities. These considerations are relevant to materials used in all the study processes (e.g., recruitment, screening, testing).

Having accessible materials from the start of the research process could potentially increase the amount of interest in your study, simply by having recruitment documents that are accessible by all audiences. Further, by reducing participants' efforts to access study materials, you will likely increase their enjoyment during the study and their ability to focus on the part that really matters—completing the study activities.

Table 4. Study Material Recommendations for Older Adults with Disabilities

Participant Population	Study Material Recommendations
All Older Adult Participants	Use size 14 pt. font, high contrast, minimize background noise, provide adequate lighting
	Set line spacing to 1.5 to improve readability
	Limit the number of fonts
	Face towards the participant, make eye contact, talk clearly
	Incorporate visual feedback when appropriate
	Allow participants to choose seating to orient themselves for best view
	Use lay language, avoid technical jargon
Hearing Disability	Keep in mind that English may not be primary language
	Offer American Sign Language interpretation (e.g., pre-recorded video)
	Ensure, if they have a device, it is utilized
	Provide assistive technology (e.g., captioning, screen reader)
	Confirm participant can understand clearly at the beginning, check often
Vision Disability	Use large-print font for all printed documents (e.g., flyers, questionnaires)
	Provide Braille versions of documents, if possible
	Include visual media (e.g., alt text, audio description)
	Provide alternative consent form options (e.g., waiver of written consent or audio recording of verbal consent, witness signatures)
	Ensure compatibility of online text with screen readers
	Offer oral administration or computerized text-to-speech
	Verbally identify interviewer at the beginning of the interview
	Limit use of capital letters and italicization
Mobility Disability	Offer ergonomic technology when available (e.g., ergonomic keyboard)
	Converse at eye-level (rather than looking down at participant using a wheeled device)
	Ask if assistance is needed/desired, before providing it
	Make sure materials can be reached comfortably

Recruitment Strategies

Additional steps may be needed to make sure adults aging with disability are receptive when recruiting for a research study. This section discusses methods to increase the likelihood that your study is perceived as credible, as well as accessible.

Recruitment barriers can relate to trust, transportation, accessibility, time constraints, financial constraints, medical concerns, and sensory and mobility limitations. Below, we provide tips on addressing each of these barriers to improve recruitment for adults aging with disabilities. We also provide suggestions about recruitment avenues for reaching adults aging with disabilities

Trust Barriers

Lack of trust or mistrust can be a barrier that prevents individuals from enrolling in research studies. To reduce this barrier, it is important to establish the legitimacy of the study and research team. The following can provide legitimacy and facilitate trust:

- Provide Institutional Review Board or approval information
- Avoid lengthy text and jargon in consent forms
- Confirm the research team credentials; use name tags or business cards
- Include known companies/university information on the recruitment materials (e.g., forms, flyers, emails)
- Provide a significant contact (e.g., the Principal Invesitgator) for confirmation and questions

Transportation Barriers

Transportation barriers inhibit the participant's ability to get to a laboratory setting. These barriers can stem from a range of reasons including having no car, no care partner, limited money for gas, public transportation schedule limitations, no accommodations for disability, and being intimidated by unfamiliar places. The following strategies can be used to address transportation issues:

- Assist in arranging transportation
- Compensate for participation
- Waive or pay for fees associated with coming to the testing center (e.g., parking meters, ride share)
- Suggest meeting at participant's home or a location they are comfortable with (e.g., coffee shop, library, senior center)
- If possible, collect data via telephone or videoconference

Accessibility Barriers

Physical accessibility may also be of concern for older adults with disabilities. Different limitations and disabilities should be met with specific considerations for that group. It is important to remember that the participants may not disclose a limitation, so researchers should be following the guidelines below as common practice:

- Confirm the testing center is ADA compliant (e.g., wheelchair accessible, sufficient lighting, no trip hazards)
- Ask participants if they need assistance from their vehicle, meet them at entrance to the building, and walk with them to the testing location
- Provide written instructions to get to the building (include instructions for using ramp or elevators, in case of wheelchair use)
- Make sure accessible parking is available, if needed, and include location in the directions, which should be mailed prior to the testing session
- Provide proper signage in the building to direct participants to the testing area (via stairs and ramp or elevator)

Time Constraints

Many older adults keep their days busy; do not assume they have free time at your convenience. Furthermore, some may prefer not to drive during certain times of the day, which can limit their availability. Some of the following tactics can be used to address such time constraints:

- Have a research team with flexible hours (i.e., after 5 PM, weekends)
- Work around participant's schedule
- Communicate that their time is valuable and appreciated
- If the study allows, split the study up into different sessions

Financial Constraints

Many older adults live on a fixed income. These financial constraints can deter them from participating in your study. Costs they may be concerned about include getting to the testing center, parking, accommodations, and the value of their time. The following suggestions can help ease their concerns:

- Communicate what accommodations can be provided
- Pay transportation costs (e.g., bus, taxi, parking)
- Compensate fairly for participation, considering time and effort demands

Medical Concerns

When working with older adults, there may be medical concerns stemming from the study itself. For example, participants may feel that the study may impact their health directly (e.g., receiving a treatment) or that they do not have control of their health (e.g., enrolling in a cognitive training study and getting the control treatment). Some approaches to ease these medical concerns include:

- Communicate the potential risks and the research team's plan to mitigate those risks
- Clearly state if there are not any expected risks upfront
- Let participants have control (and know they have control) where they can (e.g., they can end participation at any point, take breaks)

Sensory and Cognitive Limitations

Lastly, sensory or cognitive limitations can produce barriers to research participation. A sensory or cognitive barrier can arise from having inaccessible recruitment materials. Further, as discussed in the physical access section, potential participants may feel they cannot participate because of their limitations. Some methods for making your study more inclusive include:

- Ensure recruitment materials are written at the 6^{th} to 8^{th} grade level
- Offer accommodations, such as captioning or oral presentation of information, for older adults with disabilities, and note that accommodations are available on recruitment materials

Recruitment Avenues

Knowing the proper locations to recruit participants can be critical to a study's success. It is always important to establish good relations with recruitment locations and to touch base intermittently, as some may have frequent staff turnover. Some potential avenues and locations for recruiting older adults can be found in Table 5. Also, a good practice is to ask current participants where they learned about the study; this will enable you to focus recruiting efforts, in the future, to locations that have proven successful. Also note that we have established the TechSAge Participant Registry.

Table 5. Potential Recruitment Avenues for Older Adults With and Without Disabilities

Type	Recruitment Avenues
Community	Associations and Federations
	Bus Stops
	Churches
	Community Centers
	County Agencies on Aging and Care Coordinators
	Grocery Stores
	Health Fair Programs
	Home Phone
	Libraries
	Local Events
	Meals-On-Wheels Affiliates
	Non-Profit Organizations
	Older Adult Transportation Services (OATS)
	Retirement Facilities
	Senior Centers
	Service Clubs
Businesses	Eye Clinics
	Eye Doctors
	Grocery Stores
	Hearing Aid Providers
	Hearing Clinics
	Hospitals
	Rehabilitation Services
Other	Care Partners
	Mailing to Medicare Beneficiaries
	Social Media
	Support Groups
	University Partners

Screening Strategies

The screening process can be a crucial time to ensure the participants being enrolled in your study fit the goals of the study. Several screening strategies can be used to determine potential participants' disability status and to ensure that research materials and protocols are accessible for all participants regardless of that status. To ensure research materials and protocols are accessible, researchers can ask questions to determine if and, if so, what accommodations are needed (e.g., interpreter, screen reader, audio amplification, mobility supports). Table 6 presents some example questions that can be used during the screening process.

Table 6. Example Screening Questions

Disability Type	Example Questions
Vision	Can you read typical printed material (e.g., newspapers, books, pamphlets) with or without glasses?
Hearing	Do you have any difficulty hearing during typical daily conversation?
Fine Motor	Do you have any difficulty using a touchscreen, such as an iPad or tablet?
Mobility	Do you use any assistive devices to get around, such as a walker, cane, or wheelchair?
Color Discrimination	Have you ever been told you are colorblind?
Speech	Do you have any difficulty speaking so that others can understand you?
Reading	Do you have any difficulties with reading that we should be aware of?

Having the proper screening questions is a good starting place, however, if your potential participant does have a disability, they may need accommodations to engage in the screening process. Table 7 presents some examples of considerations when screening older adults to make the experience inclusive.

In addition, researchers may want to consider collecting supplemental information related to disability and functional ability, in addition to the descriptive information traditionally collected. For example, it may be useful to know the age of onset (of disability), if it is progressive, how the disability was caused (i.e., hearing loss due to trauma versus disease) to describe the population you are studying. Examples of supplemental information surveys from the TechSAge ACCESS study can be found in the Appendices of this tool **(See Appendix A-C)**.

Table 7. Disability-Specific Screening Considerations

Participant Population	Study Materials Considerations
All Older Adults	Make first attempts at screening calls in the mornings
	Reiterate you are from a reliable institution
	Be grateful for their time
	Send reminders for screening appointments
Hearing Disability	Speak loudly and clearly
	Offer to meet on video conference for visual lip reading
	Offer to follow up with email with the screening script
	Offer to meet in person
Vision Disability	Have screen readers available
	Use alternative text for images
	Allow more time for the researcher to read aloud written materials
	Provide oral descriptions of study materials
	Provide hands-on support, if in person (e.g., If there is an image of a cellphone in the instructions or materials, provide a tangible device)
Mobility Disability	Offer participation times later in the day, as they may require more time in the morning
	Make sure an accessible parking space will be available
	Allot more time to test participants, as physically moving and taking breaks may take longer
	Be flexible around their transportation needs (see recruitment barriers; pp. 9-12)

Testing Strategies

In addition to designing research materials to be appropriate and accessible, researchers can make the testing experience and environment more accessible, comfortable, and safe. When working with older adults with disabilities in a research testing session, there are a number of considerations that can be implemented to help them feel at ease and encourage participation. Some of these considerations include accommodating assistance from a spouse, friend, or care partner; having an accessible physical laboratory environment; and keeping the environment comfortable. Lastly, if possible, it may be helpful to conduct the study in the participant's home.

Accommodating Assistance

Accommodating assistance from a spouse, friend, or care partner (or other type of assistance) can alleviate some challenges to gaining research participants. For some studies a care partner, or someone to assist, is needed to accompany the older adult to the testing center, to help sign consent, understand forms, read documents, or interpret.

Testing Environment: Accessibility, Comfort, and Safety

An inaccessible, uncomfortable, or unsafe physical environment in which the study is to take place can produce a barrier for participation. The environment for your study should be safe, and suitable for participants to feel relaxed and comfortable. Lighting is a key component to creating an optimal testing environment. Light can impact an older adults' mood, health, and wellbeing (Technical Consumer Products Inc., 2017). The laboratory or room in which the study is taking place should have adequate, adjustable lighting, with multiple sources of light (e.g., overhead lights, as well as table or floor lamps). Layered lighting can limit glare and shadows, and support visual task performance; it can also reduce the chance for falls. Adequate lighting is needed to effectively use alternative communication modes, as well, such as signing or assistive communication devices (Kroll, 2011).

The temperature of the testing environment can be equally as important to making a participant feel comfortable. During the winter, room temperature should be between 68 and 70 degrees for older adults (NIH, 2020). Thermal comfort requirements are similar for people with and without physical disabilities (Parsons, 2002).

Lastly, the testing room should be arranged to allow space for a participant to navigate using a wheelchair and to provide minimal distractions. Tables should be able to accommodate to the height of the wheelchair (Rios et al., 2016). It can be helpful to provide a variety of seating options for participants, so they can choose something that is most comfortable or change seating during the study. Additional recommendations for the testing environment are in Table 8.

Table 8. Testing Environment Recommendations for Older Adults with Disabilities

Testing Environment Recommendations
Discuss with the participant who and where they will be meeting (offer to meet at specific locations, such as bus stops, placed signs, elevators).
Prior to the testing day, send directions with highlighted maps of parking (including accessible) and testing location, as well as the phone number and name of the researcher, so participants have a way to contact them.
If possible, provide transportation to and from study locations.
To the extent possible, remove physical obstacles and barriers in testing room, including unnecessary tables and chairs, to allow maximum mobility.
Ensure other spaces are accessible, as well (e.g., parking bays, entrance ways, bathrooms).
Offer assistance for navigating around crowded areas.
If possible, reduce or eliminate background noise.
Include breaks and check-in points in protocols.
Remind participants they can stop any time if they need a break or have a question.

Sources: Kidney & Mcdonald, 2014; Kroll, 2011; Pichora-Fuller, 2003; Rios, Magasi, Novak, & Harniss, 2016.

The considerations discussed above will help the participants feel comfortable and optimize their performance. Further, these considerations can also keep participants safe from falls and fatigue.

Home Visits

Depending on the participant's preference or abilities, or on the nature of the research study, it may be optimal to conduct the testing in their home. Being in their own environment can help the participant feel comfortable and may help them relax and engage in the study. Below are some considerations for preparing for the home visit and tips for managing interruptions and safety issues.

Preparing for the Home Visit

Make sure you have the correct telephone and address.

Confirm the appointment date and address prior to the visit.

Provide participant with an overview of the assessment process (e.g., what you will do first, time it will take to complete).

Make sure to give the participant your information in case of any last-minute changes.

Google address (bring a hardcopy of the map).

Plan the trip (the time it will take you, plus 10-15 minutes to account for unforeseen problems).

Make sure to dress professionally.

Take a small bottle of water in case you need to drink water during the interview.

Make sure you have all of the needed materials (e.g., assessment materials, writing utensils, note pad, study flyer.).

Provide supervisor with a schedule of your visits.

Ask participant if they need any accommodations for participating from home.

Managing Interruptions

Table 9 presents some possible interruptions that could occur during the home visit as well as some suggested responses.

Table 9. Example Interruptions and Suggested Responses

Example Interruptions	Suggested Responses
Frequent Interruptions (e.g., phone rings, someone comes in the room, a pet creates a distraction).	We have limited time and I want to be able to accurately capture your responses, so would you be able to unplug/turn off the phone during the study? Or…would we be able to find a more private (or quiet) location?
Participant goes off on a tangent (e.g., begins to tell you a story and gets off track, brings up problems related or unrelated to the interview question).	I would really like to hear that story after we are done if there is time. Right now, I would like to focus on the study tasks so we can be sure to get through everything.
Starts to focus on other things (e.g., watching TV, reading other materials, talks to other people in the home).	We have limited time and I want to make sure to get through everything. Would you please wait to do [activity] until we are done?
Gives conflicting answers (e.g., provides two different answers to similar questions, answers are conflicting).	Point out the discrepancy and ask participant which one they feel is most accurate.
Gets frustrated with the interview process (e.g., feels it's taking too long, the questions sound the same, they are never going to finish).	Ask the participant if they would like a break and provide them with an estimate of the remaining time. Also remind them that they can quit at any time without repercussion.

Gets upset with questions (e.g., feels that they have answered the question, can't come up with one answer).	Tell the participant that some of the questions might be similar and to please just answer the best they can.

Safety Issues

All research staff should be attentive to safety issues associated with being in unfamiliar areas. The following considerations should be observed:

Schedule an appointment during daylight hours.

Prior to making a home visit, confirm the appointment with participant so that he/she is expecting you.

Obtain clear directions regarding how to locate the home.

Prepare and organize home-visit materials in advance so that all aspects of the visit can be implemented efficiently.

Take responsibility for transport vehicle (i.e., car in good repair, gasoline).

Be sure to have a cell phone available during travel and visit.

If uncertain about the safety of making the visit alone, contact the project coordinator, and arrangements will be made for an additional staff member to go.

If any suspicious-looking activity is observed around the home upon arrival, or if anything untoward occurs during the visit itself that arouses concern, terminate the visit with participant and advise that a follow-up call will be made.

Call 911, if necessary, in response to an emergency, and contact the study project coordinator and/or principal investigator immediately.

EXAMPLES OF TECHSAGE RESEARCH STUDIES

Below are two examples of TechSAge research studies that included participants who were aging with disabilities. The associated publications can be a used as guidelines for developing research materials for working with disability populations.

Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS)

This project is an in-depth interview study working with older adults with long-term (at least 10 years) disabilities (hearing, vision, mobility). The interview was used to learn more about their barriers to daily life and, if any, solution strategies to address those barriers.

There were 60 participants interviewed for each disability group (N=180) with an age range of 60-79. For the hearing group, we recruited participants who identified as Deaf and used ASL as their primary form of communication. The vision participants identified as blind or low vision. The participants with mobility disabilities reported using a mobility aid or having serious difficulty walking or climbing stairs. This study has now been extended to new groups to include older adults who are late-deafened, have Glaucoma or Macular Degeneration, or have Multiple Sclerosis. Interviews were updated and edited based on lessons learned from the first deployment of materials for the second study. Examples of the updated supplemental surveys about specific disability groups from the TechSAge ACCESS study can be found in the Appendices of this tool **(See Appendices A-C)**.

Related publications:

Gonzalez, E. T., Mitzner, T. L., Sanford, J. A., & Rogers, W. A. (2016). *TechSAge Minimum Battery: Overview of Measures* (TechSAge-TR-1601). Atlanta, GA: Georgia Institute of Technology, Rehabilitation Engineering Research Center on Technologies to Support Successful Aging with Disability.

Koon, L. M., Remillard, E. T., Mitzner, T. L., & Rogers, W. A. (2020). Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) for adults aging with a long-term mobility disability. *Disability & Health Journal, 13*. *https://doi.org/10.1016/j.dhjo.2020.100936*

Remillard, E. T., Griffiths, P. C., Mitzner, T. L., Sanford, J. A., Jones, B. D., & Rogers, W. A. (2020). The TechSAge Minimum Battery: A multidimensional and holistic assessment of individuals aging with long-term disabilities. *Disability and Health Journal, 13*, 1-9. https://doi.org/10.1016/j.dhjo.2019.100884

Remillard, E. T., Mitzner, T. L., Singleton, J. L., & Rogers, W. A. (2018). *Developing the ACCESS Interview Study* (TechSAge-TR-1801). Atlanta, GA: Georgia Institute of Technology, Rehabilitation Engineering Research Center on Technologies to Support Successful Aging with Disability.

Tele Tai Chi

This project is using video-based conferencing to translate an in-person, evidence-based Tai Chi class to an online, social experience. The Tele Tai Chi intervention study is exploring whether the Tele Tai Chi program can increase social interaction and positive health behaviors (i.e., physical exercise frequency) among older adults with long-term mobility disabilities.

The target population for this study includes those who self-identify as having a long-term mobility disability, defined as use of a mobility aid (i.e., cane, crutches, wheelchair, walker, or scooter) or having serious difficulty walking or climbing stairs, for at least 10 years.

Related publications:

Mitzner, T. L., Remillard, E. T., Cohen, K., & Cochran, L. (2021). *TechSAge Tool: Guidelines for delivering telewellness programs to older adults with disabilities*. Rehabilitation Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities.

Mitzner, T. L., & Remillard, E. T. (2019). How one telewellness project focused on helping older adults with mobility disabilities age in place. *The Journal on Active Aging, 18*(4), 72-77.

Mitzner, T. L., Stuck R., Hartley, J. Q., Beer, J. M., & Rogers, W. A. (2017). Acceptance of televideo technology by adults aging with a mobility impairment for health and wellness interventions. *Journal of Rehabilitation and Assistive Technologies Engineering, 4*, 1-12. doi:10.1177/2055668317692755. PMCID: PMC6453068

Mois,G., Mackin, T., Datta, A., Koon, L., Rogers, W. A., Mitzner, T. L., & Beer, J. M.(2019). Perceptions from people aging with a mobility impairment towards using tele-technology for exercise. *Proceedings from the Human Factors and Ergonomics Society's 2019 Annual Meeting*. Seattle, WA.

RESOURCES AND USEFUL WEBSITES

The following resources provide additional information about working with adults aging with disabilities.

- TechSAge Background Questionnaire and Minimum Battery: Recommended as streamlined questionnaires for gathering key background information about aging with disability
    - Remillard, E. T., Griffiths, P. C., Sanford, J. A., Mitzner, T. L. & Rogers, W. A. (2020). *TechSAge Background Questionnaire: Overview of Measures* (TechSAge-TR-2001). Rehabilitation Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities. https://techsage.gatech.edu/sites/default/files/2021-01/TechSAge-TR-2001-BackgroundQuest.pdf
    - Remillard, E. T., Griffiths, P. C., Sanford, J. A., Mitzner, T. L. & Rogers, W. A. (2021). *TechSAge Minimum Battery 2: Overview of Measures* (TechSAge-TR-2104). Rehabilitation Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities. https://techsage.gatech.edu/sites/default/files/2022-01/TechSAge-TR-2104-MinimumBatteryVersion2_final.pdf
- The DRS' People First 4151
    - https://www.dhs.state.il.us/OneNetLibrary/27897/documents/Brochures/4151.pdf
    - A short guide to interacting with disabilities, preferred language, and etiquette tips.
- Respectability.org
    - https://www.respectability.org/inclusion-toolkits/etiquette-interacting-with-people-with-disabilities/
    - A short video and general rules regarding etiquette on interacting with people with disabilities.
- National League for Nursing

    - http://www.nln.org/docs/default-source/professional-development-programs/ace-series/gettting-started-communication-with-pwd.pdf?sfvrsn=8
    - General rules for communicating with people with disabilities, as well as recommendations for specific groups: mobility limitations, vision loss, hearing loss, speech disabilities, and cognitive disabilities.
- Australian Network on Disability
    - https://www.and.org.au/pages/etiquette.html
    - Basic tips for disability etiquette and a link to an inclusive language factsheet.
- New York State Dep. of Health
    - https://www.health.ny.gov/publications/0951.pdf
    - A guide on how to treat everyone with respect with proper disability etiquette.

CONCLUSION

This TechSAge tool was designed to give an overview of how to incorporate persons aging with disabilities in research. The four goals of this tool were to 1) Discuss the importance and need for including persons with disability in research; 2) Offer recommendations for accommodating persons with disabilities throughout the different stages of a research study (e.g., materials design, recruitment, screening, testing); 3) Highlight examples of research studies that include persons aging with disabilities from TechSAge; and 4) Provide pointers to useful resources to learn more about working with individuals who are aging with disabilities in your research.

By including older adults with and without disabilities in your research, your findings will be more generalizable to a growing portion of the population. The considerations and recommendations offered in this tool will help to ensure participants have a successful and enjoyable research experience.

REFERENCES

Brucker, D. L., & Houtenville, A. J. (2015). People with disabilities in the United States. *Archives of Physical Medicine and Rehabilitation*, *96*(5), 771–774. https://doi.org/10.1016/j.apmr.2015.02.024

Carter, S. L. (2018). *Impairment, Disability and Handicap*. Emory University Shield. Retrieved November, 2, 2021, from https://med.emory.edu/departments/pediatrics/divisions/neonatology/dpc/impairment-mx.html.

Farage, M. A., Miller, K. W., Ajayi, F., & Hutchins, D. (2012). Design principles to accommodate older adults. *Global Journal of Health Science*, *4*(2), 2–25. https://doi.org/10.5539/gjhs.v4n2p2

Jeamwatthanachai, W., Wald, M., & Wills, G. (2019). Indoor navigation by blind people: Behaviors and challenges in unfamiliar spaces and buildings. *British Journal of Visual Impairment, 37*(2), 140-153. doi:10.1177/0264619619833723

Kidney, C. A., & Mcdonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society, 29*(7), 1013-1030. doi:10.1080/09687599.2014.902357

Kroll, T. (2011). Designing mixed methods studies in health-related research with people with disabilities. *International Journal of Multiple Research Approaches*, *5*(1), 64–75. https://doi.org/10.5172/mra.2011.5.1.64

Mitzner, T. L., Sanford, J. A., & Rogers, W. A. (2018). Closing the capacity-ability gap: Using technology to support aging with disability. *Innovation in Aging, 2(1)*, 1–8.

Moore, L. W., & Miller, M. (1999). Initiating research with doubly vulnerable populations. *Journal of Advanced Nursing*, *30*(5), 1034–1040. https://doi.org/10.1046/j.1365-2648.1999.01205.x

National Institutes of Health (NIH). (2020, December 29). Cold Weather Safety for Older Adults. Retrieved from https://www.nia.nih.gov/health/cold-weather-safety-older-adults

Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting accessible research: Including people with disabilities in public health, epidemiological, and outcomes studies. *American Journal of Public Health, 106*(12), 2137-2144. doi:10.2105/ajph.2016.303448

Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2018). Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults - United States, 2016. *MMWR. Morbidity and Mortality Weekly Report*, *67*(32), 882–887. https://doi.org/10.15585/mmwr.mm6732a3

Parsons, K. (2002). The effects of gender, acclimation state, the opportunity to adjust clothing and physical disability on requirements for thermal comfort. *Energy and Buildings, 34*(6), 593-599. doi:10.1016/s0378-7788(02)00009-9

Pichora-Fuller M. K. (2003). Cognitive aging and auditory information processing. *International Journal of Audiology*, *42 Suppl 2*, 2S26–2S32.

Technical Consumer Products Inc (TCPI). (2017, August 01). Understanding the Lighting Needs of the Aging Eye. Retrieved from https://www.tcpi.com/lighting-aging-eye-understanding-lighting-need-growing-population/

APPENDIX

Appendix A: ACCESS 1 Mobility Supplemental Questionnaire

1. What is your date of birth? _ _-_ _-_ _ _ _

2. What was the primary cause of your mobility impairment? Please select one and describe.

☐ Condition or Illness ☐ Accident or Event ☐ Unknown

Please describe:

2a. At what age did your mobility impairment begin?_____

3. Which type(s) of mobility impairment do you have? Select all that apply.

☐ Arm Strength (Upper limbs are not strong enough to use a walker, crutches or a cane)
☐ Balance (Loss of ability to ambulate without feeling as if you are going to fall)
☐ Endurance (Loss of energy to continue on)
☐ Leg Strength (Lower limbs are not strong enough to ambulate)
☐ Motor Control (Difficulty moving limbs in coordination)
☐ Pain (Discomfort limits ability to ambulate)
☐ Range of Motion (Difficulty moving limbs fully)
☐ Sensation (Loss of feeling in a body part)
☐ Other_____

4. What is your degree of mobility loss with walking?

☐	I can walk and run
☐	I can walk but not run
☐	I can walk with cane
☐	I can walk with a walker
☐	I can move using a wheelchair
☐	I can only move if someone else assists with the wheelchair

Appendix B: ACCESS 2 Group Questionnaire: Late-Deafened

The following questions ask about your experience with hearing loss. This survey will take approximately 5-10 minutes. All questions are required, but you can select 'do not wish to answer' or write in "skip".

1. At what age did you first develop your hearing loss? _____

b. Was this before or after you learned to speak? (Choose one).

☐ Before learning to talk
☐ After learning to talk
☐ Do not know
☐ Do not wish to answer

2. What was the primary cause of your deafness or hearing loss? Choose one).
☐ Trauma
☐ Hereditary Disorder (e.g., parents passed on the gene)
☐ Genetic Disorder (e.g. mutated gene)
☐ Noise Exposure
☐ Medications
☐ Disease
☐ Other: _____
☐ Do not know
☐ Do not wish to answer

3. How would you classify your degree of hearing loss without amplification (e.g., hearing aid or cochlear implant)? (Choose the one that best describes you).

☐ MILD: You may hear some speech sounds, but soft sounds are hard to hear.
☐ MODERATE: You may hear almost no speech when another person is talking at a normal level.
☐ SEVERE: You do not hear conversation when a person is talking at a normal level and may only hear shouted speech.
☐ PROFOUND: You do not hear any speech and many only hear very loud sounds.
☐ Do not know
☐ Do not wish to answer

4. Which type of hearing loss do you have? (Choose one).
    a. Bilateral OR Unilateral? (Choose one)
        ☐ Bilateral: hearing loss in both ears
        ☐ Unilateral: hearing loss is normal in one ear but there is hearing loss in the other
        ☐ Do not know
        ☐ Do not wish to answer
    b. Symmetrical OR Asymmetrical?
        ☐ Symmetrical: degree and configuration of hearing loss are the same in each ear
        ☐ Asymmetrical: degree and configuration of hearing loss are different in each ear
        ☐ Do not know
        ☐ Do not wish to answer
    c. Progressive OR Sudden?
        ☐ Progressive: hearing loss that becomes worse over time
        ☐ Sudden: hearing loss that happens quickly; requires immediate medical attention to determine its cause and treatment
        ☐ N/A from birth
        ☐ Do not know

☐ Do not wish to answer

d. Fluctuating OR Stable?

☐ Fluctuating: hearing loss that changes over time—sometimes getting better, sometimes getting worse

☐ Stable: hearing loss does not change over time and remains the same

☐ Do not know

☐ Do not wish to answer

5. Do you know your hearing loss range in decibels? (Choose one for each ear).

	Left Ear		Right Ear
☐	-10 to 15	☐	-10 to 15
☐	16 to 25	☐	16 to 25
☐	26 to 40	☐	26 to 40
☐	41 to 55	☐	41 to 55
☐	56 to 70	☐	56 to 70
☐	71 to 90	☐	71 to 90
☐	91+	☐	91+
☐	Do not know	☐	Do not know
☐	Do not wish to answer	☐	Do not wish to answer

6. How do you <u>primarily</u> communicate with your family? (Choose one).

☐Spoken English

☐Written English

☐ASL

☐Other:_____

☐Do not wish to answer

7. How do you <u>primarily</u> communicate with your friends? (Choose one).

☐Spoken English
☐Written English
☐ASL
☐Other:_____
☐Do not wish to answer

8. How do you primarily communicate with people you don't know well (e.g., store clerks, servers at a restaurant, healthcare professionals) (Choose one).
☐Spoken English
☐Written English
☐ASL
☐Other:_____
☐Do not wish to answer

9. When you were growing up, did your family encourage you to develop your speech and lip-reading skills? (Choose one).
☐Yes
☐No
☐Other:_____
☐Do not know
☐Do not wish to answer

10. Which of the following have you ever received or used? (Check all that apply).
☐Audiologist services for hearing aids (e.g., programming/re-programming of digital hearing aids)
If Yes, within the last year? Yes No Do not know Do not wish to answer
☐Audiologist services for cochlear implants (e.g., mapping of cochlear implants)
If Yes, within the last year? Yes No Do not know Do not wish to answer
☐Auditory training

If Yes, within the last year? Yes No Do not know Do not wish to answer

☐Counseling on use of communication strategies (e.g., avoiding noisy areas)

If Yes, within the last year? Yes No Do not know Do not wish to answer

☐Speech-language therapy

If Yes, within the last year? Yes No Do not know Do not wish to answer

☐Training for you to use and maintain your hearing assistance device

If Yes, within the last year? Yes No Do not know Do not wish to answer

☐Others: _____

☐Do not know

☐Do not wish to answer

11. Do you participate in any of the following? (Check all that apply).

☐Support groups for deaf or hard of hearing people

☐Advocacy groups/organizations for deaf or hard of hearing people

☐Social activities with other deaf or hard of hearing people

☐None of the above

☐Do not wish to answer

Thank you. We look forward to discussing your experience in more detail during the interview.

Appendix C: ACCESS 2 Group Questionnaire: Vision

The following questions ask about your experience with vision loss. This survey will take approximately 5-10 minutes. All questions are required, but you can select 'do not wish to answer' or write in "skip".

1. Approximately what age did you first experience vision loss? _____

2. Which of the following categories best describes your visual loss? (Choose one).
   - ☐**Mild visual loss** (20/40 to 20/60 visual acuity)
   - ☐**Moderate visual impairment** (20/70 to 20/160 visual acuity)
   - ☐**Severe visual impairment** (20/200 to 20/400 visual acuity OR visual field of 20 degrees or less, but more than 10)
   - ☐**Profound visual impairment** (20/500 to 20/1,000 visual acuity OR visual field of 10 or less)
   - ☐**Near total visual impairment** (≤ 20/1,000 visual acuity OR ≤ 5 degrees of visual field)
   - ☐**Total visual impairment** (No light perception)
   - ☐None of these
   - ☐Do not know
   - ☐Do not wish to answer

3. Are you legally blind? (Choose one).
   Legal blindness is defined as a visual acuity of 20/200 or less in the better-seeing eye with best conventional correction (meaning with regular glasses or contact lenses) OR a visual field (the total area an individual can see without moving the eyes from side to side) of 20 degrees or less (also called tunnel vision) in the better-seeing eye.

☐ Yes ☐No ☐Do not know ☐Do not wish to answer

4. Outside of regular reading glasses, do you need any additional magnification to read your mail? (Choose one).

☐Yes ☐No ☐N/A (No visual reading) ☐Do not know ☐Do not wish to answer

Macular Degeneration

5. Have you ever been told by a doctor or other health professional that you have Macular Degeneration? (Choose one). ☐Yes ☐No *(Skip to question #6)* ☐Do not know ☐Do not wish to answer

b. At what age were you diagnosed with Macular Degeneration? _____

c. If Yes, in one or both eyes? (Choose one).

☐One eye ☐Both eyes ☐Do not know ☐Do not wish to answer

d. If Yes, what type? (Choose one).

☐Wet ☐Dry ☐Do not know ☐Do not wish to answer

e. Have you had laser surgery for Macular Degeneration? (Choose one).

☐Yes ☐No ☐Do not know ☐Do not wish to answer

f. What types of Macular Degeneration treatments are you currently using? (Check all that apply).

☐Nutritional supplements (e.g., vitamins, minerals)
☐Eating eye-healthy food (e.g., Dark leafy greens, yellow fruits and vegetables, fish)
☐Other medications
☐Injections (e.g., anti-VEGF)
☐None of the above

☐Other (please specify): _____
☐Do not wish to answer

Glaucoma

6. Have you ever been told by a doctor or other health professional that you have **Glaucoma**?
   ☐Yes ☐No *(Skip to question #7)* ☐Do not know ☐Do not wish to answer

   b. At what age were you diagnosed with Glaucoma? _____

   c. If Yes, in one or both eyes? (Choose one).
      ☐One eye ☐Both eyes ☐Do not know ☐Do not wish to answer

   d. If Yes, what type? (Choose one).
      ☐Primary open angle
      ☐Angle closure
      ☐Other (please specify): _____
      ☐Do not know
      ☐Do not wish to answer

   e. Have you had any of the following surgeries for glaucoma? (Check all that apply).
      ☐Laser surgery (e.g., trabeculoplasty, iridotomy)
      ☐Operating room surgery (e.g., filtering surgery (trabeculectomy), iridectomy, glaucoma drainage devices)
      ☐None of the above
      ☐Do not know
      ☐Do not wish to answer

   f. What types of glaucoma treatments are you currently using? (Check all that apply).
      ☐Eye drop medication
      ☐Oral medications to reduce eye pressure (e.g., Neptazane, Diamox)

☐Nutritional supplements (e.g., vitamins, minerals)
☐None of the above
Other (please specify): _____
☐Do not know
☐Do not wish to answer

7. Which of the following have you ever received or used? (Check all that apply).

☐Low vision/blindness skills training
If Yes, within the last year? ☐Yes ☐No ☐Do not know ☐Do not wish to answer
☐Everyday living skills (personal hygiene, home management)
If Yes, within the last year? ☐Yes ☐No ☐Do not know ☐Do not wish to answer
☐Orientation and mobility training
If Yes, within the last year? ☐Yes ☐No ☐Do not know ☐Do not wish to answer
☐Training to maximize current vision through visual exercises
If Yes, within the last year? ☐Yes ☐No ☐Do not know ☐Do not wish to answer
☐Training in the use of low vision devices
If Yes, within the last year? ☐Yes ☐No ☐Do not know ☐Do not wish to answer
☐Vocational rehabilitation
If Yes, within the last year? ☐Yes ☐No ☐Do not know ☐Do not wish to answer
☐None of the above
☐Other (please specify): _____
☐Do not know
☐Do not wish to answer

8. Do you participate in any of the following? (Check all that apply).

☐Support groups for people with vision loss
☐Advocacy groups for people with vision loss
☐Social activities with other people with vision loss

☐None of the above
☐Do not wish to answer

Thank you. We look forward to discussing your experience in more detail during the interview.