

# ADRC Participant Access Request

## Access Request Goal

Goal - Formal request for ADRC data

## Principal Investigator

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Name Carolyn Baylor

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Title Associate Professor, Co-Director of the Rehabilitation Science PhD Program

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Institution University of Washington

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Email [speaclab@uw.edu](mailto:speaclab@uw.edu) (<mailto:speaclab@uw.edu>)

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Phone (206) 221-3563

No Co-PI listed in survey

# Study and Theme Details

## Hypothesis

This project builds on biopsychosocial models of health, specifically on the role of the environment in shaping outcomes and daily life experiences for adults with communication disorders, specifically adults with communication impairments related to early stage dementia. This project proposes a new construct related to social support / stigma specifically as it pertains to communication disorders, and the facilitators / barriers that communication partners pose for participation in daily activities for adults with communication disorders. This project also explores the reciprocal impact of communication disorders in terms of understanding third party disability - or the impact of the communication disorders on family members and others in their social environments

## Specific Aims

Specific Aim 1: To demonstrate that 'perceived social support for communication' is a unique construct, separate from social support as it is generally defined in healthcare, contributing to communicative participation outcomes for adults with communication disorders (in this study specifically people with mild cognitive impairment / early dementia).

Specific Aim 2: To measure third-party disability in family members of adults with communication disorders related to mild cognitive impairment / early dementia and its contribution to perceived social support for communication and communicative participation outcomes for both the person with the communication disorder and the communication partner.

Specific Aim 3: To compare the experiences of communicative participation, social support for communication, and third-party disability across communication disorder diagnoses including data from this study and data from a closely related study with other communication disorder populations (UW IRB STUDY00012675).

**This study is not related to Deep South disparities**

# Funding and IRB Details

Funding source - Already funded

Entity - NIH funded grant/application

Details - National Institute on Deafness and Other Communication Disorders (NIDCD), Grant Office ID: A171647, Funding Source ID: 3R01DC019352-02S1

IRB Contact - Yes, we have IRB approval

IRB Protocol # - UW IRB STUDY00015857

# Subject Sample Size and Profile

## Sample size by cognitive ability

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MCI 100

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Mild Dementia 100

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**Total N 200**

## Additional inclusion/exclusion details

Has noticed changes in thinking and memory, and is diagnosed with or concerned about dementia or Mild Cognitive Impairment

Lives in the US

Able to complete questionnaires about their experiences communicating with other people with the help of a research assistant standing by on phone or zoom video call

Able to complete questionnaires in English

Has at least 1 family member or friend who agrees to also participate in the study to complete their own questionnaires

Lives in the community (not a nursing home)

Age 18 years or older

## Racial minorities and other stratification

This study does NOT test hypothesis on racial disparities

# Requested Resources

## Human subject involvement

### Study procedures

Participants are asked to answer a series of questionnaires related to their communication, social participation, and health. Participants may choose to complete the surveys online via REDCap, or paper surveys mailed to them. PwAD/D will be instructed that if they do not feel comfortable completing the questionnaires independently, a research assistant can meet with them via phone or video call. The research assistant can provide whatever assistance is needed such as walking them through accessing the survey website, guiding them through the questionnaires, or even administering the questionnaires to them verbally. Answering all questions takes participants ~1 hour, and can be completed over multiple sessions if preferred by the participant.

As part of the study requirements, each participant with dementia will be asked to include at least one (or up to two) family members or close friends who are in frequent contact with them and could report on how their own interactions with the person are impacted by the dementia. These family / friends are expected to be spouses / partners or other immediate family members with whom the person with dementia lives or has close, frequent contact. The targeted enrollment is 200 people with dementia with at least one family member per person with dementia.

### Study duration

6

### Compensation

\$25

### Statistical support

Statistician has already been consulted - Alyssa Bamer