

Study Information for Participants

Title of Study: *Caregiver Burden, Social Support, and Quality of Life among Caregivers of Individuals with Intellectual Disability and Dementia*

Principal Investigator (PI): Christina Marsack-Topolewski, School of Social Work, Eastern Michigan University, Ypsilanti, Michigan (+1 248-961-0704)

Purpose: You are being asked to participate in a research study that seeks to examine caregiver burden, social support, and quality of life among caregivers of individuals diagnosed with both intellectual disability (ID) and dementia.

Study Procedures: To be eligible to participate in this study, you must be at least 18 years of age and the primary caregiver of an individual with ID and a co-morbid diagnosis of dementia. If you take part in the study, you will be asked to complete a web-based survey, including a demographic portion. Questions seek to gain information related to demographics, such as, age, gender/sex, ethnicity, marital status, level of education, and employment status. You will be asked about your social support, health, finances, and feelings of burden. The survey and demographic questionnaire will take approximately 20 minutes to complete. At the end of the survey, you will be asked if you would like to participate in a one-on-one interview to answer more questions regarding your experiences of caring for an individual with ID and a diagnosis of dementia.

Benefits: As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks: You may experience some emotional discomfort while completing items on the survey. Emotional discomfort may include negative feelings such as sadness, anger, or anxiety.

Costs: There will be no costs to you for participation in this research study.

Compensation: You will not be paid for taking part in this study. Participants who would like to be included in the drawing will be randomly selected to receive one of three \$20 gift cards.

Confidentiality: All information collected about you and your loved one with ID and dementia during this study will be kept without any identifiers. It is intended that the results of this study will be published. No information that can identify you will be published. Your information you provide will be kept confidential and secure. The data will be stored on a password protected USB drive that will be stored in a locked file cabinet when not in use for analysis. All data will be de-identified. Data will be stored indefinitely. Data may be used for future research projects. These future research projects may be related or unrelated to the purpose of the current study.

Voluntary Participation/Withdrawal: Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with Eastern Michigan University or its affiliates.

Questions: If you have any questions about this study now or in the future, you may contact Christina Marsack-Topolewski at the following phone number: **+1 248-961-0704** or by email at ctopole1@emich.edu.

If you have questions or concerns about your rights as a research participant, please contact Eastern Michigan University's Office of Research Development at orda_dept@emich.edu.