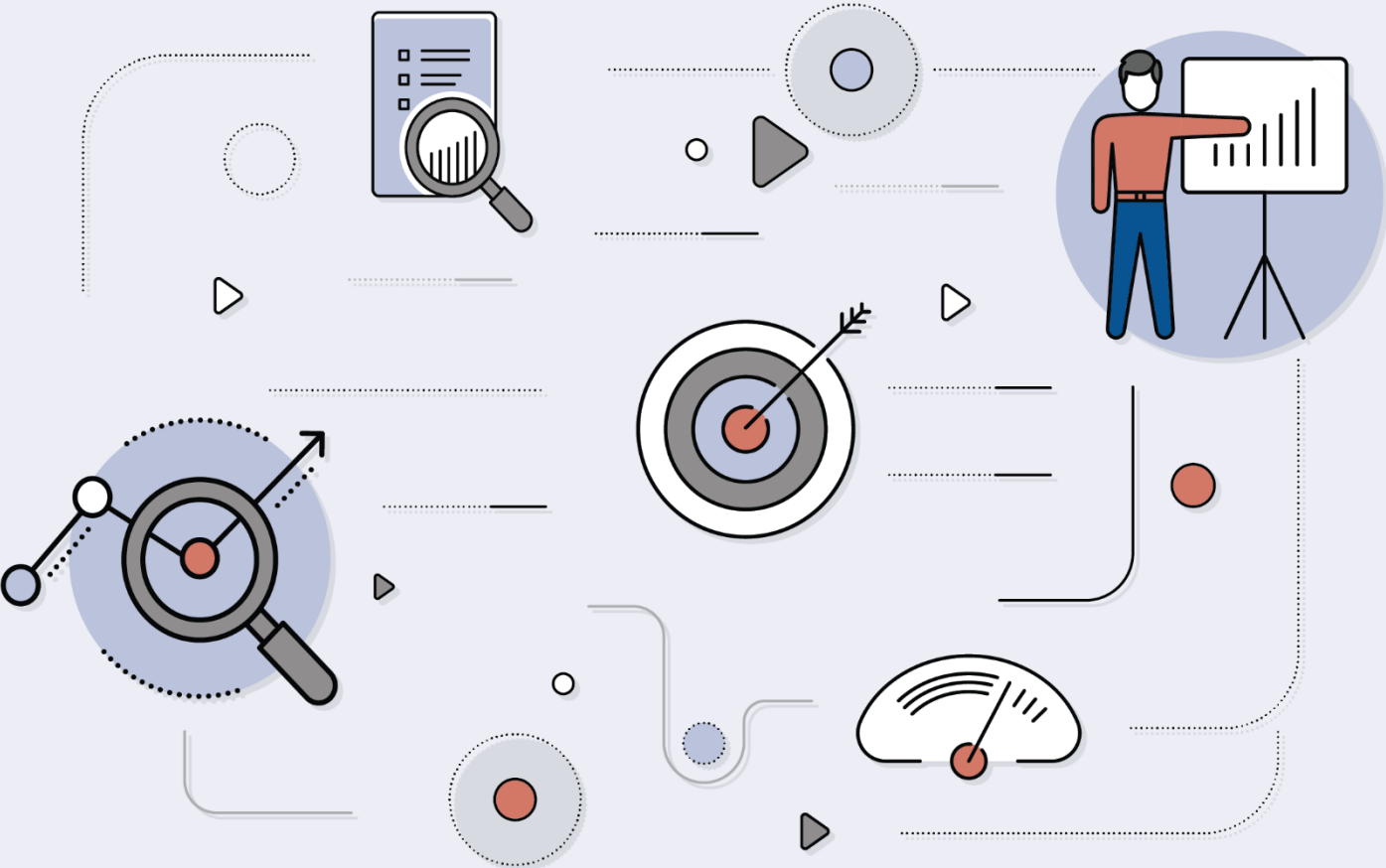


Evaluating Dementia Services and Supports: Instrument Resource List



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Introduction

Robust evaluation plans are key to determining the value and impact of community interventions for people with dementia and their caregivers. Service providers, those who pay for services, and those who fund improvements in service systems all need to describe the characteristics of the people receiving their services and evaluate the extent to which targeted outcomes are achieved.

Dementia services and supports programs, such as the Administration for Community Living (ACL)-funded grants, can save time and enhance the quality of their evaluations by using already validated instruments. This resource list was created to streamline the process of identifying and locating validated instruments for community-based dementia programs.

The list includes well-researched instruments that measure relevant participant characteristics and outcomes. It is not intended as a comprehensive list or as an endorsement of a particular instrument. The resource list was originally released in 2016 and included 31 instruments. The updated 2018 list has more than doubled to include 77 instruments, covering domains such as caregiver burden, depression, social support, dementia knowledge, self-efficacy, health status, cognitive function, and risk/safety.

Development of the Resource List

Instruments on this resource list were identified through several sources, including current and past ACL grant project plans and reports; Alzheimer's, aging, health care, and research websites; and a research literature review.

The following criteria were used in selecting instruments to include:

- **Appropriate to community services**
Only instruments relevant to the community setting were included. Most instruments on the list are brief and do not require extensive staff training or clinical expertise to use.
- **Available**
One of the key goals in developing this resource list is to make it easier for dementia service providers to identify and obtain instruments. Therefore, only instruments readily available at nominal or no cost are included. Often, instruments require permission for their use; in cases where we could not obtain information on permission requirements, the instrument was excluded.

- Valid
Almost all instruments provided within this list have been validated through research; citations are provided in the References section. We included a few instruments that have not been validated because they were developed by experts in the field, including some ACL grantees, and have been used extensively in practice.

How to Use This Document

The table of instruments is organized alphabetically by domain beginning on page [8](#). Within each domain, instruments are listed alphabetically by name.

Where appropriate, instruments are listed within more than one domain. For example, the Caregiver Reaction Scale contains items related to both burden and positive aspects of caregiving.

- **Domains** are listed alphabetically on page [Error! Bookmark not defined.](#) Click on the domain name to go to the section of the table listing instruments for that domain.
- **Instruments** are listed alphabetically beginning on page [4](#). Click on the instrument link to go directly to detailed information on that instrument.

Obtaining Permission to Use Instruments

In some cases, permission is required to use an instrument, or the researcher must be notified. Please follow the guidance provided in the “Permissions” column of the instruments table.

Some instruments indicate “No special permissions required.” These instruments are in the public domain and may be used freely. If the permissions information indicates that “Permission has been obtained for ADSSP, ADI-SSS and ADPI grantees,” active grantees may use the instrument freely. Instructions for other users are provided.

All instruments can be accessed online (the name of the instrument is linked to the online source) or by contacting the researcher (an email address is provided).

Legend

Domain

Indicates the topic that the instrument is intended to measure. Some instruments are listed under more than one domain.

Instrument

Includes the name of the instrument and the name of the researcher(s) who developed or validated the instrument. Instruments available online are hyperlinked.

Citation

The name of the researcher(s) is hyperlinked to the complete research citation in the References section at the end of this document. Proper citation is required to use some instruments.

Number of items

Indicates the number of questions or statements on the instrument as a measure of the instrument's length. Please note that in some cases, a question may have more than one part.

Sample items

These are examples of actual questions or statements, intended to give a sense of the tone and focus of each instrument.

Instructions, scoring

Indicates where to find instructions, if available, on administering the instrument and scoring and interpreting the results.

Permissions

Indicates what permission is required to use the instrument, and if applicable, who to contact for permission.

Instrument Domains

[Activities of Daily Living/Instrumental Activities of Daily Living](#)

[Anxiety](#)

[Attitude](#)

[Behavioral symptoms \(including caregiver reaction\)](#)

[Burden](#)

[Cognitive functioning](#)

[Cognitive functioning for persons with intellectual and developmental disability \(IDD\)](#)

[Coping](#)

[Depression](#)

[Exemplary caregiving](#)

[Formal supports](#)

[Health](#)

[Intent to place in nursing home](#)

[Knowledge](#)

[Pain](#)

[Positive aspects of caregiving](#)

[Quality of life](#)

[Risk assessment/safety](#)

[Self-efficacy](#)

[Social functioning](#)

[Social support](#)

[Stigma](#)

[Stress](#)

[Traumatic experiences](#)

[Unmet needs](#)

Instruments, Alphabetically

[Affiliate Stigma Scale](#)

[Alzheimer's Disease-Related Quality of Life \(ADRQL\)](#)

[Alzheimer's Disease Knowledge Scale \(ADKS\)](#)

[Ascertain Dementia \(AD-8\)](#)

[Brief COPE](#)

[Bristol Activities of Daily Living Scale](#)

[Burden Scale for Family Caregivers \(BSFC-s\)](#)

[Care Needs Assessment Tool](#)

[Caregiver Burden Inventory](#)

[Caregiver Burden Scale](#)

[Caregiver Quality of Life \(CG-QOL\)](#)

[Caregiver Reaction Scale](#)

[Caregiver Risk Appraisal Questionnaire \(REACH II\)](#)

[Caregiver Self-Assessment Questionnaire](#)

[Caregiver Strain Instrument](#)

[Caregiver Vigilance Scale](#)

[Caregiver Well-Being Scale](#)

[Center for Epidemiologic Studies Depression Scale - Revised \(CESD-R\)](#)

[Dementia Attitudes Scale \(DAS\)](#)

[Dementia Crisis to Thriving Scale](#)

[Dementia Knowledge Assessment Tool V2 \(DKAT v2\)](#)

[Dementia Quality of Life \(DEMQOL\)](#)

[Dementia Screening Indicator](#)

[Dementia Screening Questionnaire for Individuals with Intellectual Disabilities \(DSQIID\)](#)

[Desire to Institutionalize Scale \(DIS\)](#)

[Duke Health Profile \(DUKE-8\)](#)

[Exemplary Caregiving \(REACH II\)](#)

[Formal Care and Services Use \(REACH II\)](#)

[Fortinsky Caregiver Self-Efficacy](#)

[Frailty Index for Elders \(FIFE\)](#)

[Frustrations of Caregiving \(REACH II\)](#)

[Functional Activities Questionnaire \(FAQ\)](#)

[General Practitioner Assessment of Cognition \(GPCOG\)](#)
[Geriatric Depression Scale](#)
[Global Deterioration Scale](#)
[Healthy Days Core Module](#)
[IDD and Dementia Knowledge Scale](#)
[Instrumental Activities of Daily Living Scale](#)
[Life Events Checklist \(LEC-5\)](#)
[Live Alone Assessment](#)
[Living Environment - Positive Aspects and Hazards \(REACH II\)](#)
[Lubben Social Network Scale](#)
[Making & Executing Decisions for Safe and Independent Living \(MED-SAIL\)](#)
[Measures of Stigma and the Social Impact of Disease](#)
[Memory Impairment Screen \(MIS\)](#)
[Mini-Cog](#)
[Montreal Cognitive Assessment \(MoCA\)](#)
[Multidimensional Scale of Perceived Social Support](#)
[National Task Group on Intellectual Disabilities and Dementia - Early Detection Screen for Dementia \(NTG-EDSD\)](#)
[Neuropsychiatric Inventory \(NPI\)](#)
[Pain Assessment Checklist for Seniors with Limited Ability to Communicate \(PACSLAC\)](#)
[Pain Assessment in Advanced Dementia Scale \(PAINAD\)](#)
[Patient Health Questionnaire \(PHQ-9\)](#)
[Patient Health Questionnaire-4 \(PHQ-4\)](#)
[Patient Reported Outcome Measurement Information System \(PROMIS\)](#)
[Perceived Change Index](#)
[Perceived Stress Scale](#)
[Perceived Support Scale](#)
[Positive Aspects of Caregiving](#)
[Primary Care PTSD Screen \(PC-PTSD-5\)](#)
[PTSD Checklist for DSM-5 \(PCL-5\)](#)
[Quality of Life in Alzheimer's Disease \(QoL - AD\)](#)
[Quality of Life in Late-Stage Dementia Scale \(QUALID\)](#)
[Revised Memory and Behavior Problems Checklist \(RMBPC\)](#)
[Revised Scale for Caregiving Self-Efficacy](#)

[Sense of Competence in Dementia Care Staff Scale \(SCIDS\)](#)

[Short Information Questionnaire on Cognitive Decline in the Elderly \(Short IQCODE\)](#)

[Social Functioning in Dementia Scale \(SF-DEM\)](#)

[St. Louis University Mental Status Exam \(SLUMS\)](#)

[Test for Severe Impairment \(TSI\)](#)

[Unmet Needs](#)

[Zarit Burden Interview](#)

[Zarit Burden - short](#)

Evaluation Instrument Details

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
ADL/ IADL	Bristol Activities of Daily Living Scale (Bucks et al.)	20	Preparing food: <ul style="list-style-type: none"> ▪ Selects and prepares food as required ▪ Able to prepare food if ingredients set out ▪ Can prepare food if prompted step by step ▪ Unable to prepare food even with prompting and supervision ▪ Not applicable 	Administration and scoring instructions are included on the instrument.	Credit the developers by using the complete citation . No other permissions are required.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
ADL/ IADL	Care Needs Assessment Tool (Alzheimer's Greater Los Angeles)	23	<ul style="list-style-type: none"> ▪ Sleep disturbances (waking you or other family members up at night) ▪ Resists bathing or showering ▪ Insists on driving 	Administration and scoring instructions are included on the instrument.	Use this citation. ¹ No other permissions required.
ADL/ IADL	Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody)	8	<p>Shopping:</p> <ul style="list-style-type: none"> ▪ Takes care of all shopping needs independently ▪ Shops independently for small purchases ▪ Needs to be accompanied on any shopping trip ▪ Completely unable to shop 	In each category, score according to the highest level of functioning. Summary scores range from 0 to 8.	Permission is granted to use or reproduce this scale provided that proper attribution is given using the citation on the instrument.
Anxiety	Neuropsychiatric Inventory (NPI) (Cummings)	12	<p>[In relation to each behavioral symptom, is the symptom present? If yes: frequency, severity, and how much distress it causes.] Example: Agitation/aggression</p> <ul style="list-style-type: none"> ▪ Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? ▪ Is he/she hard to handle? Does the patient shout or curse angrily? ▪ Does the patient slam doors, kick furniture, throw things? 	Administration and scoring instructions	Permissions information

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Attitudes	Dementia Attitudes Scale (DAS) (O'Connor & McFadden)	20	<ul style="list-style-type: none"> I feel uncomfortable being around people with ADRD. People with ADRD can feel when others are kind to them. Every person with ADRD has different needs. 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions are required. If research using the DAS is published, please notify Dr. Susan McFadden .
Behavioral symptoms	Revised Memory and Behavior Problems Checklist (RMBPC) (Teri et al.)	24	<p>Caregivers indicate whether each behavioral symptom has occurred in the past week, and if yes, how much it bothered them:</p> <ul style="list-style-type: none"> Asking the same question over and over Trouble remembering significant past events Forgetting what day it is 	Scoring instructions are included on the instrument.	Contact Dr. Linda Teri for permission.
Behavioral symptoms	Care Needs Assessment Tool (Alzheimer's Greater Los Angeles)	23	<ul style="list-style-type: none"> Sleep disturbances (waking you or other family members up at night). Resists bathing or showering. Insists on driving. 	Administration and scoring instructions are included on the instrument.	Use this citation. ¹ No other permissions required.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Behavioral symptoms	Neuropsychiatric Inventory (NPI) (Cummings)	12	<p>[In relation to each behavioral symptom, is the symptom present? If yes: frequency, severity, and how much distress it causes.]</p> <p>Example: Agitation/aggression</p> <ul style="list-style-type: none"> Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle? Does the patient shout or curse angrily? Does the patient slam doors, kick furniture, throw things? 	Administration and scoring instructions	Permissions information
Burden	Burden Scale for Family Caregivers (BSFC-s) (Graessel et al.)	10	<ul style="list-style-type: none"> I often feel physically exhausted. My health is affected by the care situation. I feel torn between the demands of my environment (such as family) and the demands of the care. 	Point values for each item are included on the scale. Scores of 0-4 = low burden; 5-14 = moderate burden; 15-30 = high burden.	The BSFC-s is free of charge for non-commercial usage.
Burden	Caregiver Burden Inventory (Novak & Guest)	24	<ul style="list-style-type: none"> I have to watch him/her constantly. My social life has suffered. I feel ashamed over his/her behavior. 	Scoring instructions are included on the instrument.	Contact Dr. Mark Novak for permission.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Burden	Caregiver Burden Scale (Macera et al.)	15	<p>For each activity, caregiver indicates whether patient needed assistance during the past month, if they provided assistance, if doing so added to their stress level, and why.</p> <p>Examples of activities include: transportation, bathing, and financial record keeping.</p>	Administration and scoring instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Burden	Caregiver Reaction Scale (O'Malley & Qualls)	54	<ul style="list-style-type: none"> To what extent have you lost a chance to do some of the things you planned? How much do you feel that, all in all, you're a good caregiver? How much disagreement have you had with anyone in your family about the need to watch out for your relative's safety? 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions required.
Burden	Caregiver Strain Instrument (Bass, Noelker & Rechlin)	19	<p>During the past four weeks, because of helping the patient:</p> <ul style="list-style-type: none"> I was unsure whether he or she was getting proper care. I felt that I should be doing more for him/her. I felt my physical health was worse than before. 	Scoring and interpretation instructions are included on the instrument.	Contact Dr. David Bass for permission.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Burden	Caregiver Vigilance Scale (Mahoney et al.)	4	<ul style="list-style-type: none"> In the case of a family emergency, are you able to leave (name person) home alone, that is, with no one else there? If yes: How long can you leave (name person) alone? 	Scoring instructions available from the Resource Center.	Contact Dr. Diane Mahoney for a copy of the scale and permission.
Burden	Frustrations of Caregiving (REACH II) p. 65-66 (Wisniewski et al.)	8	<p>How often in the past six months, have you:</p> <ul style="list-style-type: none"> Blamed (care recipient) for having created difficulties? Used a harsh tone of voice with (care recipient)? 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Burden	Zarit Burden - short Zarit Burden - long (Bédard et al.)	4 and 12-item versions	<ul style="list-style-type: none"> Do you feel that because of your relative that you don't have enough time for yourself? Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)? 	Instructional webinar	Noncommercial users may download the instrument . Permissions information
Cognitive functioning	Ascertain Dementia (AD-8) (Galvin et al.)	8	<p>Changes in the last several years:</p> <ul style="list-style-type: none"> Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking). Less interest in hobbies/activities. 	Click the Administration and Scoring bookmark within the AD-8 .	Within the AD-8 , select the Copyright & Permission bookmark.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Cognitive functioning	Dementia Screening Indicator (Barnes et al.)	9	<ul style="list-style-type: none"> How old is your patient? Has your patient ever had a stroke? 	Administration and scoring instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Cognitive functioning	Functional Activities Questionnaire (FAQ) (Pfeffer et al.)	10	Rate the patient's ability: <ul style="list-style-type: none"> Writing checks, paying bills, balancing checkbook Preparing a balanced meal 	Administration and scoring instructions are included on the instrument	Contact Dr. Robert Pfeffer for permission. A nominal fee may be involved.
Cognitive functioning	General Practitioner Assessment of Cognition (GPCOG) (Brodaty et al.)	12	<ul style="list-style-type: none"> Time Orientation: "What is the date?" Information: "Can you tell me something that happened in the news recently?" Does the patient have more trouble remembering things that have happened recently than s/he used to? 	Administration and scoring instructions are included on the instrument. More instructions available.	No special permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Cognitive functioning	Global Deterioration Scale (GDS) (Reisberg et al.)	7	<p>Caregiver observes the individual’s behavioral characteristics and compares them to the GDS levels.</p> <p>Example: Level 2, Very mild cognitive decline - Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.</p>	Administration instructions are included on the instrument.	<p>Permission has been obtained for ADSSP, ADI-SSS and ADPI grantees. Users must provide the citation, the copyright information “Copyright © 1983 Barry Reisberg, M.D.” and indicate “Reproduced with permission.”</p> <p>Other users contact Dr. Barry Reisberg at NYU Langone, (212) 263-8550</p> <p>(continued)</p>

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Cognitive functioning	Making & Executing Decisions for Safe and Independent Living (MED-SAIL) (Mills et al.)	12-18 (6 per scenario)	<p>Interviewer selects 2-3 appropriate scenarios out of 7 possibilities</p> <p>Example: The door to your home is locked and you do not have a key</p> <ul style="list-style-type: none"> What would you do if the door to your home was locked and you didn't have a key? What would you do if [this response] didn't work? What could you do to prevent yourself from getting locked out of your home? 	Administration and scoring instructions are included on the instrument.	No special permissions required.
Cognitive functioning	Memory Impairment Screen (MIS) (Buschke et al.)	4	Patient is given 4 words and asked which category each belongs to. This is followed by free and cued recall activity with same words.	Administration and scoring instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Cognitive functioning	Mini-Cog (Borson et al.)	2	<ul style="list-style-type: none"> 3-word recall Clock drawing 	Administration instructions Scoring instructions	<p>No special permission is required for clinical or educational use by universities, foundations, health professionals, hospitals, clinics, and public health institutes.</p> <p>More information on permissions</p>
Cognitive functioning	Montreal Cognitive Assessment (MoCA) (requires registration) (Nasreddine et al.)	24	<ul style="list-style-type: none"> 5-word recall Read list of digits and have the subject repeat them in forward and backward order. Name as many words as possible in one minute that start with the letter F. 	Basic administration and interpretation instructions Detailed instructions (Select the desired version from the Paper Tests menu.)	<p>Permissions information</p>
Cognitive functioning	Short Information Questionnaire on Cognitive Decline in the Elderly (Short IQCODE) (Iorm)	16	<p>Compared with 10 years ago, how is this person at:</p> <ul style="list-style-type: none"> Remembering things about family and friends e.g. occupations, birthdays, addresses? Recalling conversations a few days later Remembering where things are usually kept 	<p>Administration instructions are included on the instrument.</p>	<p>Notify Dr. Anthony Iorm of use. No other permissions required.</p>

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Cognitive functioning	St. Louis University Mental Status Exam (SLUMS) (Tariq et al.)	11	<ul style="list-style-type: none"> What day of the week is it? Please name as many animals as you can in one minute You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20. How much did you spend? How much do you have left? 	Administration instructions Scoring instructions are included on the instrument.	According to Dementia Friendly America, this tool is in the public domain.
Cognitive functioning-IDD	Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb et al.)	56	Is the symptom there, has it always been there, is it new, has it gotten worse: <ul style="list-style-type: none"> Cannot wash and/or bathe without help. Withdraws from social activities. Needs help eating. 	No instructions provided. Consult with an evaluator for appropriate use.	Contact Dr. Shoumitro Deb for permission.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Cognitive functioning - IDD	Early Detection Screen for Dementia (NTG-EDSD) (National Task Group on Intellectual Disabilities and Dementia)	32	<ul style="list-style-type: none"> Needs help with dressing. Does not follow simple instructions. Check all significant life events in the past year from a list. 	Administration and interpretation instructions	No special permissions are required.
Cognitive functioning - IDD	Test for Severe Impairment (TSI) (Albert & Cohen)	24	<ul style="list-style-type: none"> Motor Performance: "Show me how you would use this comb." Language-Comprehension: "Point to your ear." "Close your eyes." Conceptualization: "Which of these is different?" [of two paper clips and one pen] 	Administration and scoring instructions are included on the instrument.	No special permissions required.
Coping	Brief COPE (Carver)	28	<ul style="list-style-type: none"> I've been turning to work or other activities to take my mind off things. I've been concentrating my efforts on doing something about the situation I'm in. I've been using alcohol or other drugs to make myself feel better. 	Administration and interpretation instructions	No special permissions are required.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Depression	Center for Epidemio-logic Studies Depression Scale - Revised (CESD-R) (Eaton et al.)	20	In the past week or so: <ul style="list-style-type: none"> My appetite was poor. I could not shake off the blues. I had trouble keeping my mind on what I was doing. 	Scoring instructions	No special permissions required.
Depression	Geriatric Depression Scale (Yesavage et al.)	15 and 30-item versions	<ul style="list-style-type: none"> Have you dropped many of your activities and interests? Are you in good spirits most of the time? Do you think that most people are better off than you are? 	Short-form scoring instructions Long-form scoring instructions Information on handling missing responses	No special permissions required.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Depression	Patient Health Questionnaire-4 (PHQ-4) (Kroenke et al.) Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer & Williams)	4 or 9-item versions	<p>Over the last 2 weeks, how often have you been bothered by any of the following problems?</p> <ul style="list-style-type: none"> Feeling nervous, anxious, or on edge. Not being able to stop or control worrying. 	Scoring instructions	No special permissions required.
Exemplary Caregiving	Exemplary Caregiving (REACH II) p. 66-67 (Wisniewski et al.)	18	<ul style="list-style-type: none"> I show special amounts of physical affection to (care recipient). I actively avoid treating (care recipient) like a child. I make sure that where (care recipient) lives is bright and cheery. 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Formal supports	Formal Care and Services Use (REACH II) p. 43-48 (Wisniewski et al.)	22	In the past month, did you or (care recipient): <ul style="list-style-type: none"> ▪ Have a homemaker who helped with shopping, cleaning, laundry, preparing meals, etc.? ▪ Go to a center for low cost meals or have cooked meals delivered to you at home? ▪ Attend a senior day care or senior day health program? 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Health	Caregiver Self-Assessment Questionnaire (Epstein-Lubow et al.)	18	<ul style="list-style-type: none"> ▪ During the past week or so, I have been edgy or irritable. ▪ During the past week or so, I have felt lonely. ▪ Please rate your current health compared to what it was this time last year. 	Scoring and interpretation instructions are included on the instrument.	Contact Health in Aging for permission.
Health	Duke Health Profile (DUKE-8) (Parkerson, Broadhead & Tse)	8	<ul style="list-style-type: none"> ▪ During the past week, how much trouble have you had with feeling depressed or sad? ▪ During the past week, how often did you socialize with other people? 	Administration and scoring instructions are included on the instrument.	Contact Dr. George Parkerson for permission.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Health	Frailty Index for Elders (FIFE) (Tocchi et al.)	10	<ul style="list-style-type: none"> Do you need help getting out of bed? Without wanting to, have you lost or gained 10 pounds in the last 6 months? 	Scoring instructions are included on the instrument.	If research using the FIFE is published, please notify Dr. Christine Tocchi .
Health	Healthy Days Core Module (Moriarty, Zack & Kobau)	4	<ul style="list-style-type: none"> Now thinking about your physical health, which includes physical illness and injury, for how many days in the past 30 days was your physical health not good? Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? 	Administration instructions	No special permissions required.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Health	Patient Reported Outcome Measurement System (PROMIS) (Hays et al.)	10	<ul style="list-style-type: none"> In general, would you say your health is: In general, would you say your quality of life is: [Excellent, Very good, Good, Fair, Poor] 	Administration instructions are included on the instrument.	No permissions required for use in individual research, clinical practice, educational assessment, or other application. Commercial users must seek permission to use, reproduce, or distribute measures. Integration into proprietary technology also requires written permission. Additional permissions information
Intent to place in nursing home	Desire to Institutionalize Scale (DIS) (REACH II) p. 45 (Morycz)	6	<ul style="list-style-type: none"> Have you ever considered or thought about a nursing home for your family member now or for the future? Have you ever felt that someday they might be better off in a nursing home? 	Total score is calculated by summing responses across questions, unweighted. Scores range from 0-6 with higher scores indicating greater desire to institutionalize.	Credit the developers by using the complete citation. No other permissions are required.

(continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Knowledge	Alzheimer's Disease Knowledge Scale (ADKS) (Carpenter et al.)	30	<ul style="list-style-type: none"> People with Alzheimer's disease are particularly prone to depression. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away. 	An answer key is included on the instrument.	<p>Permission has been obtained for ADSSP, ADI-SSS and ADPI grantees.</p> <p>Other users contact Dr. Brian Carpenter for permission.</p>
Knowledge	Dementia Knowledge Assessment Tool V2 (DKAT v2) (Toye et al.)	21	<ul style="list-style-type: none"> Dementia occurs because of changes in the brain. Brain changes causing dementia are often progressive. It is impossible to tell if a person who is in the later stages of dementia is in pain. 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Knowledge	IDD and Dementia Knowledge Scale (McCallion & Janicki)	20	<ul style="list-style-type: none"> Aging affects older persons with intellectual disabilities harder than it does other people. Aging in place means growing older where you are. As people age, some changes in physical and mental abilities are expected. 	An answer key is included on the instrument.	No special permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Pain	Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) (Fuchs-Lacelle & Hadjistavropoulos)	60	<p>An observer indicates which symptoms of pain are present</p> <p>Examples:</p> <ul style="list-style-type: none"> ▪ Grimacing ▪ Verbal Aggression ▪ Pale Face 	Administration and scoring instructions are included on the instrument.	Contact Dr. Thomas Hadjistavropoulos for permission.
Pain	Pain Assessment in Advanced Dementia Scale (PAINAD) (Warden, Hurley & Volicer)	5	<p>Health care provider observes for 5 minutes and rates behaviors such as breathing, facial expression, and consolability based on observation.</p> <p>Example: Breathing</p> <ul style="list-style-type: none"> ▪ 0 = normal ▪ 1 = Occasional labored breathing; short period of hyperventilation ▪ 2 = Noisy labored breathing; long period of hyperventilation; Cheyne-Stokes respirations 	Administration and scoring instructions are included on the instrument. Instructions include definitions for the terms included in the ratings.	No special permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Positives of caregiving	Caregiver Reaction Scale (O'Malley & Qualls)	54	<ul style="list-style-type: none"> To what extent have you lost a chance to do some of the things you planned? How much do you feel that, all in all, you're a good caregiver? How much disagreement have you had with anyone in your family about the need to watch out for your relative's safety? 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions required.
Positives of caregiving	Positive Aspects of Caregiving (REACH II) p. 49 (Tarlow et al.)	11	Providing help to (care recipient) has: <ul style="list-style-type: none"> Made me feel more useful. Made me feel needed. Enabled me to learn new skills. 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Quality of life	Alzheimer's Disease-Related Quality of Life (ADRQL) (Kasper et al.)	40	<ul style="list-style-type: none"> He/she smiles or laughs when around other people. He/she reacts with pleasure to pets or small children. He/she shows interest in events, places or habits from his/her past such as old friends, former residences, church or prayer. 	Administration instructions are included on the instrument.	Permissions information Nonfunded academic users and individual medical practices may obtain the instrument at no cost.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Quality of life	Caregiver Quality of Life (CG-QOL) (Vickrey et al.)	80	<ul style="list-style-type: none"> For each activity, please indicate how much you assisted that person during the last 4 weeks. During the last 4 weeks, did you have any of the following problems with your work or other regular daily activities as a result of being a caregiver? 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions required.
Quality of life	Dementia Quality of Life (DEMQOL) (Smith et al.)	28	<p>In the last week:</p> <ul style="list-style-type: none"> Have you felt cheerful? How worried have you been about forgetting who people are? How worried have you been about your health overall? 	Administration instructions are included on the instrument. Interviewer manual	Credit the developers by using the complete citation. No other permissions are required.
Quality of life	Perceived Change Index (Gitlin et al.)	13	<p>Caregiver indicates whether each item has become worse, stayed the same, or improved in the past month:</p> <ul style="list-style-type: none"> Feeling rested Ability to have time for yourself Feelings of being upset 	Scoring instructions available from the Resource Center.	Notify Dr. Laura Gitlin of use. No other permissions are required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Quality of life	Quality of Life in Alzheimer's Disease (QoL - AD) (Logsdon et al.)	13	Caregivers or PWD rates items such as physical health, mood, and ability to do things for fun.	Administration and scoring instructions are included on the instrument.	Permissions information Not funded academic users and individual medical practice may obtain the instrument at no cost.
Quality of life	Quality of Life in Late-Stage Dementia Scale (QUALID) (Weiner et al.)	11	Informant selects the best descriptor in several areas. Example: Enjoys eating <ul style="list-style-type: none"> ▪ At most meals and snacks ▪ Twice a day ▪ At least once a day ▪ Less than once a day ▪ Rarely or never 	Administration and scoring instructions are included on the instrument.	Contact Dr. Myron Weiner for permission.
Risk assessment/ Safety	Care Needs Assessment Tool (Alzheimer's Greater Los Angeles)	23	<ul style="list-style-type: none"> ▪ Sleep disturbances (waking you or other family members up at night). ▪ Resists bathing or showering. ▪ Insists on driving. 	Administration and scoring instructions are included on the instrument.	Use this citation. ¹ No other permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Risk assessment/ Safety	Caregiver Risk Appraisal Questionnaire (REACH II) p. 68-73 (Wisniewski et al.)	53	<ul style="list-style-type: none"> ▪ Do you or a family member have durable power of attorney or guardianship for [care recipient]? ▪ Do you ever leave [care recipient] alone or unsupervised in the home? ▪ Does [care recipient] drive? 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Risk assessment/ Safety	Dementia Crisis to Thriving Scale (Weaver & Samia)	13	Respondent rates the person’s level of risk on several domains such as food security, in-home care, and falls risk. Example: Falls Risk <ul style="list-style-type: none"> ▪ Falls 2 or more times in past month, with injury, home is unsafe. ▪ Home unsafe. Fall without injury, or no fall in past 3 months. ▪ Home is safe. Fall within three to five months, no injury. Fall risk factors exist. ▪ No falls in past 6 months, home is safe, no fall risk factors. ▪ No falls in past 12 months, gait stable, active, safe home. 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Risk assessment/ Safety	Frustrations of Caregiving (REACH II) p. 65-66 (Wisniewski et al.)	8	How often in the past six months, have you: <ul style="list-style-type: none"> Blamed (care recipient) for having created difficulties? Used a harsh tone of voice with (care recipient)? 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.
Risk assessment/ Safety	Live Alone Assessment (Hall, Bossen & Specht)	29	Observed or reported conditions during a home visit: <ul style="list-style-type: none"> Wandering outside the home. Inability to take medications correctly. Dirty/infested household. 	Scoring instructions are included on the instrument.	Permission has been obtained for ADSSP, ADI-SSS and ADPI grantees. Other users contact the National Alzheimer's and Dementia Resource Center .
Risk assessment/ Safety	Living Environment - Positive Aspects and Hazards (REACH II) p. 64-65 (Wisniewski et al.)	14	<ul style="list-style-type: none"> Do you keep materials present to occupy CR or that provide comfort or meaning (e.g. games, sorting tasks, magazines, photos, stuffed animals)? Observe: Objects on floor or pathways in main areas used by (care recipient) Do you have a grab bar in the bathroom primarily used by (care recipient)? 	Administration instructions are included on the instrument.	Credit the developers by using the complete citation. No other permissions are required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Risk assessment/ Safety	Making & Executing Decisions for Safe and Independent Living (MED-SAIL) (Mills et al.)	12-18 (6 per scenario)	<p>Interviewer selects 2-3 appropriate scenarios out of 7 possibilities</p> <p>Example: The door to your home is locked and you do not have a key</p> <ul style="list-style-type: none"> What would you do if the door to your home was locked and you didn't have a key? What would you do if [this response] didn't work? What could you do to prevent yourself from getting locked out of your home? 	Administration and scoring instructions are included on the instrument.	No special permissions required.
Self-efficacy	Fortinsky Caregiver Self-Efficacy (Fortinsky, Kercher & Burant)	10	<p>How certain are you right now that you can:</p> <ul style="list-style-type: none"> Handle any problems your relative has, like memory loss, wandering, or behavior problems? Do something to keep your relative as independent as possible? 	No instructions provided. Consult with an evaluator for appropriate use.	<p>Instrument questions are in the cited research article (available for a nominal fee). Notify Dr. Richard Fortinsky of use. No other permissions are required.</p> <p>(continued)</p>

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Self-efficacy	Revised Scale for Caregiving Self-Efficacy (Steffen et al.)	19	<ul style="list-style-type: none"> How confident are you that you can ask a friend/family member to stay with (person's name) for a day when you have errands to be done? How confident are you that you can control thinking about what you are missing or giving up because of (person's name)? When (person's name) interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice? 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions required.
Self-efficacy	Sense of Competence in Dementia Care Staff Scale (SCIDS) (Schepers et al.)	17	<p>How well do you feel you can:</p> <ul style="list-style-type: none"> Engage a person with dementia in a conversation Change your work to match the changing needs of a person with dementia Keep up a positive attitude towards the people you care for? 	Scoring instructions are included on the instrument.	No special permissions required.
Self-efficacy	Perceived Change Index (Gitlin et al.)	13	<p>Caregiver indicates whether each item has become worse, stayed the same, or improved in the past month:</p> <ul style="list-style-type: none"> Feeling rested Ability to have time for yourself Feelings of being upset 	Scoring instructions available from the Resource Center.	Notify Dr. Laura Gitlin of use. No other permissions are required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Social functioning	Social Functioning in Dementia Scale (SF-DEM) (Sommerlad et al.)	20	Thinking about the past month, how often have you: <ul style="list-style-type: none"> ▪ Seen friends or family in your own home ▪ Had an argument or shouted at other people ▪ Contacted friends or family by phone or computer 	Administration instructions	SF-DEM is freely available for use by other researchers under a Creative Commons Attribution-Noncommercial 4.0 International License.
Social support	Multidimensional Scale of Perceived Social Support (Zimet et al.)	12	<ul style="list-style-type: none"> ▪ There is a special person who is around when I am in need. ▪ There is a special person with whom I can share joys and sorrows. ▪ My family really tries to help me. 	Scoring instructions are included on the instrument. More information on scoring	Credit the developers by using the complete citation. No other permissions are required.
Social support	Lubben Social Network Scale (Lubben)	6 or 12-item versions	<ul style="list-style-type: none"> ▪ How many relatives do you feel close to such that you could call on them for help? ▪ How many of your friends do you see or hear from at least once a month? 	Scoring instructions are included on the instrument. More information on interpretation	Complete the permission form .

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Social support	Perceived Support Scale p. 57-59 (Krause & Markides)	16	<ul style="list-style-type: none"> Overall, how satisfied have you been in the past month with the help you have received from family members, friends, or neighbors? How many relatives, friends, neighbors, other than (care recipient) do you see or hear from at least once a month? How many relatives, friends, neighbors, other than (care recipient) do you feel you can call on for help with chores, transportation, etc.? 	No instructions provided. Consult with an evaluator for appropriate use.	No special permissions required.
Stigma	Affiliate Stigma Scale (Chang, Su & Lin)	22	<ul style="list-style-type: none"> Others will discriminate against me if I am with my family member with dementia. The behavior of my family member with dementia embarrasses me. I have cut down on going out with my family member with dementia. 	Scoring instructions are included on the instrument.	Credit the developers by using the complete citation. Contact Dr. Winnie Mak for a copy of the instrument and for permission. (continued)

Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Stigma	Measures of Stigma and the Social Impact of Disease (Fife & Wright)	24	<ul style="list-style-type: none"> ▪ I feel others avoid me because of my illness. ▪ Some family members have rejected me because of my illness. ▪ I encounter embarrassing situations as a result of my illness. 	No instructions provided. Consult with an evaluator for appropriate use.	<p>Individuals may use this information for research or educational purposes only and may not use this information for commercial purposes. Users must credit the developers; complete citation information is in the References section.</p> <p>When presenting results using any survey information you obtained from the SABI, please acknowledge the University of North Carolina at Chapel Hill Center for AIDS Research (CFAR), an NIH funded program P30 AI50410.</p>

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Stress	Perceived Stress Scale* (Cohen, Kamarck & Mermelstein) *Copy and paste URL	4 or 10-item versions	In the last month, how often have you: <ul style="list-style-type: none"> ▪ Been upset because of something that happened unexpectedly? ▪ Felt that you were unable to control the important things in your life? 	Scoring instructions	This scale may be used for nonprofit academic research or nonprofit educational purposes. For other uses, please contact Dr. Sheldon Cohen .
Traumatic experience	Life Events Checklist (LEC-5) (Gray et al.)	17 or 29-item versions	For events experienced over entire lifetime, indicate: Happened to me; Witnessed it; Learned about it; Part of my job; Not sure; Doesn't apply <ul style="list-style-type: none"> ▪ Natural disaster (for example, flood, hurricane, tornado, earthquake) ▪ Physical assault (for example, being attacked, hit, slapped, kicked, beaten up) ▪ Life-threatening illness or injury 	Administration and scoring instructions	No special permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Traumatic experience	Primary Care PTSD Screen (PC-PTSD-5) (Prins et al.)	5	<p>Respondents are given several examples of possible traumatic events and asked if they have experienced this kind of event.</p> <p>If yes, in the past month, have you:</p> <ul style="list-style-type: none"> Had nightmares about the event(s) or thought about the event(s) when you did not want to? Been constantly on guard, watchful, or easily startled? 	Scoring and interpretation instructions	No special permissions required.
Traumatic experience	PTSD Checklist for DSM-5 (PCL-5) (Blevins et al.)	20	<p>In the past month, how much were you bothered by:</p> <ul style="list-style-type: none"> Repeated, disturbing, and unwanted memories of the stressful experience? Repeated, disturbing dreams of the stressful experience? Avoiding memories, thoughts, or feelings related to the stressful experience? 	Administration, scoring and interpretation instructions	No special permissions required.

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Unmet Needs	Care Needs Assessment Tool (Alzheimer's Greater Los Angeles)	23	<ul style="list-style-type: none"> ▪ Sleep disturbances (waking you or other family members up at night). ▪ Resists bathing or showering. ▪ Insists on driving. 	Administration and scoring instructions are included on the instrument.	Use this citation. ¹ No other permissions required.
Unmet Needs	Caregiver Well-Being Scale - short Caregiver Well-Being Scale - long (Tebb, Berg-Weger & Rubio)	14 45	<p>To what extent has each activity been taken care of in a timely way:</p> <ul style="list-style-type: none"> ▪ Taking care of personal daily activities (meals, hygiene, laundry) ▪ Attending to medical needs ▪ Taking time to have fun with friends and/or family 	No instructions provided. Consult with an evaluator for appropriate use.	Notify Dr. Susan Tebb of use, including the version of the scale.
Unmet Needs	Live Alone Assessment (Hall, Bossen & Specht)	29	<p>Observed or reported conditions during a home visit:</p> <ul style="list-style-type: none"> ▪ Wandering outside the home ▪ Inability to take medications correctly ▪ Dirty/infested household. 	Scoring instructions are included on the instrument.	<p>Permission has been obtained for ADSSP, ADI-SSS and ADPI grantees.</p> <p>Other users contact the National Alzheimer's and Dementia Resource Center.</p>

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Evaluation Instrument Details (continued)

Domain	Instrument and citation links	How many items	Sample item(s)	Instructions, scoring	Permissions
Unmet needs	Unmet Needs (Bass et al.)	49	<p>Do you need more information about or help with this?</p> <ul style="list-style-type: none"> ▪ Planning who would help your (RELATIONSHIP) if you were no longer able to help? ▪ Getting information about your (RELATIONSHIP)'s memory problems? ▪ Ways to make the place where your (RELATIONSHIP) lives safe? 	No instructions provided. Consult with an evaluator for appropriate use.	Contact Dr. David Bass for a copy of the instrument and permission.

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References

- Albert, M., & Cohen, C. (1992). The Test for Severe Impairment: An instrument for the assessment of patients with severe cognitive dysfunction. *Journal of the American Geriatric Society, 40*(5), 449-453.
- Alzheimer's Greater Los Angeles. (2016). *Care Needs Assessment Tool*. Available at <https://www.alzcla.org/wp-content/uploads/2017/01/Care-Needs-Assessment-Tool.pdf>.
- Barnes, D., Beiser, A., Lee, A., Langa, K., Koyama, A., Preis, S., Neuhaus, J., McCammon, R., Yaffe, K., Seshadri, S., Haan, M., & Weir, D. (2014). Development and validation of a brief dementia screening indicator for primary care. *Alzheimer's & Dementia, 10*(6), 656-665.
- Bass, D., Judge, K., Snow, A., Wilson, N., Looman, W., McCarthy, C., Morgan, R., Ablorh-Odjidja, C., & Kunik, M. (2012). Negative caregiving effects among caregivers of veterans with dementia. *The American Journal of Geriatric Psychiatry, 20*(3), 239-247.
- Bass, D., Noelker, L. & Rechlin, L. (1996). The moderating influence of service use on negative caregiving consequences. *Journals of Gerontology, 51*(3), S121-31.
- Bédard, M., Molloy, D., Squire, L., Dubois, S., Lever, J. & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist, 41*(5), 652-657.
- Blevins, C. A., Weathers, F. W., Davis, M. T., Witte, T. K., & Domino, J. L. (2015). The Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5): Development and initial psychometric evaluation. *Journal of Traumatic Stress, 28*(6), 489-498. doi: 10.1002/jts.22059
- Borson, S., Scanlan, J., Brush, M., Vitaliano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive "vital signs" measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry, 15*(11), 1021-1027.
- Brodady, H., Pond, D., Kemp, N., Luscombe, G., Harding, L., Berman, K., & Huppert, F. (2002). The GPCOG: A new screening test for dementia designed for general practice. *Journal of the American Geriatrics Society, 50*(3), 530-534.
- Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Ageing, 25*(2), 113-120.
- Buschke, H., Kuslansky, G., Katz, M., Stewart, W., Sliwisnski, M., Eckholdt, H., & Lipton, R. (1999). Screening for dementia with the memory impairment screen. *Neurology, 52*(2), 231-238.
- Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The Alzheimer's Disease Knowledge Scale: Development and psychometric properties. *The Gerontologist, 49*(2), 236-247. doi: 10.1093/geront/gnp023.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*, 92-100.
- Chang, C., Su, J., & Lin, C. (2016). Using the Affiliate Stigma Scale with caregivers of people with dementia: Psychometric evaluation. *Alzheimer's Research and Therapy, 45*(8).

- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*(4), 385-396.
- Cummings, J. (1997). The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology, 48*(Suppl 6), S10-S16.
- Deb, S., Hare, M., Prior, L., & Bhaumik, S. (2007). Dementia screening questionnaire for individuals with intellectual disabilities (DSQIID). *British Journal of Psychiatry, 190*, 440-444.
- Derived from the DSQIID (Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb et al., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.
- Eaton, W. W., Smith, C., Ybarra, M., Muntaner, C., & Tien, A. (2004). Center for Epidemiologic Studies Depression Scale: Review and revision (CESD and CESD-R). In M. E. Maruish (Ed.). *The use of psychological testing for treatment planning and outcomes assessment* (3rd ed.), Volume 3: Instruments for Adults, pp. 363-377. Mahwah, NJ: Lawrence Erlbaum.
- Epstein-Lubow, G., Gaudiano, B. A., Hinckley, M., Salloway, S., & Miller, I. W. (2010). Evidence for the validity of the American Medical Association's caregiver self-assessment questionnaire as a screening measure for depression. *Journal of the American Geriatrics Society, 58*(2), 387-388. doi: 10.1111/j.1532-5415.2009.02701.x
- Fife, B., & Wright, E. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior, 41*(1), 50-67.
- Fortinsky, R. H., Kercher, K., & Burant, C. J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging and Mental Health, 6*(2), 153-160.
- Fuchs-Lacelle, S. & Hadjistavropoulos, T. (2004). Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Management Nursing, 5*(1), 37-49.
- Galvin, J., Roe, C., Powlishta, K., Coats, M., Muich, S., Grant, E., Miller, J., Storandt, M. & Morris, J. (2005). The AD8, a brief informant interview to detect dementia. *Neurology, 65*(4), 559-564.
- Gitlin, L., Winter, L., Dennis, M., & Hauck, W. (2006). Assessing perceived change in the well-being of family caregivers: Psychometric properties of the Perceived Change Index and response patterns. *American Journal of Alzheimer's Disease & Other Dementias, 21*(5), 304-311.
- Graessel, E., Berth, H., Lichte, T., & Grau, H. (2014). Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics, 14*(23). <http://www.biomedcentral.com/1471-2318/14/23>
- Gray, M., Litz, B., Hsu, J., & Lombardo, T. (2004). Psychometric properties of the Life Events Checklist. *Assessment, 11*(4), 330-341. doi: 10.1177/1073191104269954
- Hall, G., Bossen, A., & Specht, J. (2004). *Live Alone Assessment*. Iowa City, Iowa: The University of Iowa College of Nursing.

- Hays, R. D., Bjorner, J. B., Revicki, D. A., Spritzer, K. L., & Cella, D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research, 18*(7), 873-880.
- Jorm, A. F. (1994). A short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): Development and cross validation. *Psychological Medicine, 24*(1), 145-153.
- Kasper, J., Black, B., Shore, A., & Rabins, P. (2009). Evaluation of the validity and reliability of the Alzheimer's Disease-Related Quality of Life (ADRQL) assessment instrument. *Alzheimer's Disease and Associated Disorders, 23*(3), 275-284. doi: 10.1097/WAD.0b013e31819b02bc
- Krause, N., & Markides, K. S. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development, 30*(1), 37-53.
- Kroenke, K., Spitzer, R., & Williams, J. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*(9), 606-613.
- Kroenke, K., Spitzer, R., Williams, J., & Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: THE PHQ-4. *Psychosomatics, 50*(6), 613-621. doi: 10.1176/appi.psy.50.6.613.
- Lawton, P. (1971). The functional assessment of elderly people. *Journal of the American Geriatric Society, 19*(6), 465-481.
- Logsdon, R., Gibbons, L., McCurry, S., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64*(3), 510-519.
- Lubben, J. (1988). Assessing social networks among elderly populations. *Family & Community Health: The Journal of Health Promotion & Maintenance, 11*(1), 42-52.
- Macera, C. A., Eaker, E. D., Jannarone, R. J., Davis, D. R., & Stoskopf, C. H. (1993). A measure of perceived burden among caregivers. *Evaluation & the Health Professions, 16*(2), 204-211.
- Mahoney, D., Jones, R., Coon, D., Mendelsohn, A., Gitlin, L., & Ory, M. (2003). The Caregiver Vigilance Scale: Application and validation in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. *American Journal of Alzheimer's Disease and Other Dementias, 18*(1), 39-48.
- McCallion, P., & Janicki, M. (2000). *IDD and Dementia Knowledge Scale*. Center on Intellectual Disabilities, University at Albany.
- Mills, W., Regev, T., Kunik, M., Wilson, N., Moye, J., McCullough, L., & Naik, A. (2014). Making and Executing Decisions for Safe and Independent Living (MED-SAIL): Development and validation of a brief screening tool. *American Journal of Geriatric Psychiatry, 22*(3), 285-293.
- Moriarty, D. G., Zack, M. M., & Kobau, R. (2003). The Centers for Disease Control and Prevention's Healthy Days Measures – Population tracking of perceived physical and mental health over time. *Health and Quality of Life Outcomes, 1*, 37.
- Morycz, R. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*(3), 329-361.
- Nasreddine, Z., Phillips, N., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatric Society, 53*(4), 695-699.

- Novak, M., & Guest, C. I. (1989). Application of a multidimensional Care-giver Burden Inventory. *Gerontologist, 29*, 798-803.
- O'Connor, M., & McFadden, S. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*. doi:10.4061/2010/454218
- O'Malley, K., & Qualls, S. H. (2017). Preliminary evidence for the validity and reliability of the Caregiver Reaction Scale. *Clinical Gerontologist, 40*, 281-294. doi: 10.1080/07317115.2016.1198858
- Parkerson, G., Broadhead, W., & Tse, C. (1990). The Duke Health Profile. A 17-item measure of health and dysfunction. *Medical Care, 28*(11), 1056-1072.
- Pfeffer, R., Kurosaki, T., Harrah, C., Chance, J., & Filos, S. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology, 37*(3), 323-329. doi: 10.1093/geronj/37.3.323
- Prins, A., Bovin, M. J., Smolenski, D. J., Mark, B. P., Kimerling, R., Jenkins-Guarnieri, M. A., Kaloupek, D. G., Schnurr, P. P., Pless Kaiser, A., Leyva, Y. E., & Tiet, Q. Q. (2016). The Primary Care PTSD Screen for DSM-5 (PC-PTSD-5): Development and evaluation within a veteran primary care sample. *Journal of General Internal Medicine, 31*, 1206-1211. doi:10.1007/s11606-016-3703-5
- Reisberg, B., Ferris, S. H., de Leon, M.J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139*(9), 1136-1139.
- Schepers, A., Orrell, M., Shanahan, N., & Spector, A. (2012). Sense of Competence in Dementia Care Staff (SCIDS) scale: Development, reliability, and validity. *International Psychogeriatrics, 24*(7), 1153-1162. doi:10.1017/S104161021100247X
- Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R. H., Foley, B., Smith, P., Cook, J. C., Murray, J., Prince, M., Levin, E., Mann, A., & Knapp, M. (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychological Medicine, 37*(5), 737-746.
- Sommerlad, A., Singleton, D., Jones, R., Banerjee, S., & Livingston, G. (2017). Development of an instrument to assess social functioning in dementia: The Social Functioning in Dementia scale (SF-DEM). *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. doi: 10.1016/j.dadm.2017.02.001
- Steffen, A., McKibbin, C., Zeiss, A., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: reliability and validity studies. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 57*(1), 74-86.
- Tariq, S., Tumosa, N., Chibnall, J., Perry III, H., & Morley, J. (2006). Comparison of the Saint Louis University mental status examination and the mini-mental state examination for detecting dementia and mild neurocognitive disorder—a pilot study. *American Journal of Geriatric Psychiatry, 14*(11), 900-910.
- Tarlow, B., Wisniewski, S., Belle, S., Rubert, M., Ory, M., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging, 26*(4), 429-453.

- Tebb, S. S., Berg-Weger, M., & Rubio, D. M. (2013). The Caregiver Well-Being Scale: Developing a short-form rapid assessment instrument. *Health & Social Work, 38*(4), 222-230.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging, 7*(4), 622-631.
- Tocchi, C., Dixon, J., Naylor, M., Sangchoon, J., & McCorkle, R. (2014). Development of a frailty index measure for older adults: The Frailty Index for Elders. *Journal of Nursing Measurement, 22*(2), 223-240.
- Toye, C., Lester, L., Popescu, A., McInerney, F., Andrews, S., & Robinson, A. (2014). Dementia Knowledge Assessment Tool Version Two: Development of a tool to inform preparation for care planning and delivery in families and care staff. *Dementia (London, England), 13*(2), 248-56.
- Vickrey, B., Hays, R., Maines, M., Vassar, S., Fitten, J., & Strickland, T. (2009). Development and preliminary evaluation of a quality of life measure targeted at dementia caregivers. *Health and Quality of Life Outcomes, 56*(7).
- Warden, V., Hurley, A., & Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association, 4*(1), 9-15.
- Weaver, E. & Samia, L. (2016). Dementia Crisis to Thriving Scale. Southern Maine Agency on Aging.
- Weiner, M., Martin-Cook, K., Svetlik, D., Saine, K., Foster, B., & Fontaine, C. (2000). The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association, 1*(3), 114-116.
- Wisniewski, S., Belle, S. H., Coon, D., Marcus, S., Ory, M., Burgio, L., Burns, R., & Schulz, R. (2003). The Resources for Enhancing Alzheimer's Caregiver Health (REACH) project design and baseline characteristics. *Psychology and Aging, 18*(3), 375-384.
- Yesavage, J., Brink, T., Rose, T., Lum, O., Huang, V., Adey, M., & Leirer, V. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research, 17*(1), 37-49.
- Zimet, G. D., Dahlem, N. W., Zimet, S. G. & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment, 52*, 30-41.