



# CHANGING THINKING!

Advisory 24-1 (draft v2)

## Beneficiary Model Criteria & Tools

NOTE: THIS ADVISORY IS FOR INTERNAL USE WITHIN THE CT! PROJECT FOR ORIENTATION AND INFORMATIONAL PURPOSE. THE VERSIONS OF THE CMS CITED INSTRUMENTS REPRODUCED BELOW ARE EXAMPLES OF THE INSTRUMENTS AND ARE SHOWN FOR EDUCATIONAL PURPOSES. IT IS NOT THE INTENT OF THE CT! PROJECT TO USE THE INSTRUMENTS OR PROVIDE THEM TO GUIDE CLIENTS.

This internal advisory encapsulates the determination of eligibility of beneficiaries with dementia for ‘alignment’ with the GUIDE MODEL; these criteria would also apply to adults with intellectual disability (including Down syndrome). The Beneficiary Model Criteria forms the basis for payment under the Participants Monthly Dementia Care Management Payment (DCMP). The payment schedule considers severity of dementia and ancillary issues, as well as caregiver ‘burden.’

CMS notes that ‘Beneficiary Model Tier’ is determined via assessment and is a combination of beneficiary disease stage, presence of a caregiver, and if applicable, their caregiver's needs.

|  | Tier  | Criteria   | Corresponding Assessment Tool Scores |
|--|---|--|--------------------------------------|
| <b>Beneficiaries with a caregiver</b>                | Low complexity dyad tier                    | Mild dementia  | CDR= 1, FAST= 4                      |
|  | Moderate complexity dyad tier               | Moderate or severe dementia AND Low to moderate caregiver strain | CDR= 2-3, FAST= 5-7 AND ZBI= 0-60    |
|  | High complexity dyad tier                   | Moderate or severe dementia AND High caregiver strain            | CDR= 2-3, FAST= 5-7 AND ZBI= 61-88   |
| <b>Beneficiaries without a caregiver<sup>1</sup></b> | Low complexity individual tier              | Mild dementia  | CDR= 1, FAST= 4                      |
|  | Moderate to high complexity individual tier | Moderate or severe dementia                                      | CDR= 2-3, FAST= 5-7                  |

The approved screening tools include two tools to report dementia stage – the **Clinical Dementia Rating (CDR)** or the **Functional Assessment Screening Tool (FAST)** – *and* one tool to report caregiver strain, the **Zarit Burden Interview (ZBI)**.<sup>2</sup> CMS may add screening tools throughout the course of the model (GUIDE Participants can seek CMS’ approval to use an alternative screening tool by submitting the proposed tool, along with published evidence that it is valid and reliable and a crosswalk for how it

<sup>1</sup> Note: Beneficiaries may live independently in their own home or in a community setting such as an assisted living facility or group home. Their caregiver does not have to live with the beneficiary to qualify for participation in the model. In some cases, the caregiver may live in a different home, or in a different state; but they must be actively participating in the beneficiary’s care.

<sup>2</sup> Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. Gerontologist. 1980;20(6):649-55

corresponds to the model's tiering thresholds). Participants are told to report the aggregate scores for each of the instruments used. Instruments included:

### The Clinical Dementia Rating (CDR)

The Clinical Dementia Rating (CDR) scale is a structured, clinician-rated interview designed to evaluate the severity of dementia. It gathers information on cognitive capacity from both the patient and a collateral source. While initially developed to assess dementia severity, it can also be applied to other conditions, such as Parkinson's disease.

The CDR assesses six domains: memory, orientation, judgment, and problem solving, community affairs, home and hobbies, and personal care. Impairment is defined only when it results from cognitive loss rather than physical disability or other non-cognitive factors. Each domain is rated on a 5-point scale (except for personal care), and these ratings are synthesized to assign a Global CDR score. Table 6 from Morris (1993)<sup>3</sup> provides more detail on the criteria.

The Global CDR scores range from 0 to 3:

- 0: No dementia
- 0.5: Questionable dementia
- 1: Mild cognitive impairment (MCI)
- 2: Moderate cognitive impairment
- 3: Severe cognitive impairment

The assessment includes two sets of questions: one for the informant and another for the patient. The informant's questions focus on the patient's memory, judgment and problem-solving ability, community affairs, home life and hobbies, and personal care. The patient's questions address memory, orientation, judgment, and problem-solving ability. See <https://knightadrc.wustl.edu/wp-content/uploads/2021/10/English-New-Zealand.pdf> for a worksheet that produces CDR scores)

**Table 6.2. The Clinical Dementia Rating Scale**

|                                     | <b>NONE 0</b>   | <b>QUESTIONABLE 0.5</b>   | <b>MILD 1</b>  | <b>MODERATE 2</b>   | <b>SEVERE</b>  |
|-------------------------------------|---|---|--|---|--|
| <b>MEMORY</b>                       | No memory loss or slight; inconsistent forgetfulness  | Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness | Moderate memory loss: more marked for recent events; defect interferes with everyday activity                                | Severe memory loss, only highly learned material retained: new material rapidly lost                    | Severe memory loss, only fragments remain                        |
| <b>ORIENTATION</b>                  | Fully oriented  | Fully oriented but with slight difficulty with time relationships                       | Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere | Severe difficulty with time relationships; usually disoriented to time, often to place                  | Oriented to person only  |
| <b>JUDGMENT AND PROBLEM SOLVING</b> | Solves everyday problems and manages business and financial affairs well; judgment good in relation to past performance | Slight impairment in solving problems, similarities, and differences                    | Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained                  | Severely impaired in handling problems, similarities, and differences; social judgment usually impaired | Unable to make judgments or solve problems                       |
| <b>COMMUNITY AFFAIRS</b>            | Independent function as usual in job, shopping, volunteer, and social groups  | Slight impairment in these activities   | Unable to function independently at these activities though may still be engaged in  | No pretense of independent function outside the home; appears well enough to be taken to                | Appears too ill to be taken to functions outside the family home |

<sup>3</sup> Morris, J.C. (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412–2414.

|                         |  |   |   |  |  |
|-------------------------|--|---|---|--|--|
|                         |  |   | some; appears normal to casual inspection   | functions outside the family home  |  |
| <b>HOME AND HOBBIES</b> | Life at home, hobbies and intellectual interests well maintained | Life at home, hobbies, and intellectual interests slightly impaired | Mild but definite impairment of functions at home; more difficult chores, and complicated hobbies and interests abandoned | Only simple chores preserved; very restricted interests, poorly maintained | No significant function in the home                          |
| <b>PERSONAL CARE</b>    | Fully capable of self-care                                       |   | Needs prompting   | Requires assistance in dressing, hygiene and keeping of personal effects   | Requires much help with personal care; frequent incontinence |

**A note of application of the CDR to adults with intellectual disability.** Some work has been done with applying the CDR to adults with Down syndrome<sup>4</sup> with the intent to see if it would discern dementia from inherent cognitive impairment. The CT! Project would benefit from an interpretative advisory on scoring the CDR with adults with pre-existing intellectual disability that would be useful for Participants.

**ALIGNMENT OF BENEFICIARIES WITH GUIDE**

CMS notes that adults with Medicare must have dementia (of any type) to be eligible for voluntary alignment to a GUIDE Participant and may be at any stage of dementia—mild, moderate, or severe.

When an adult with Medicare is first assessed for the GUIDE Model, “CMS will rely on clinician attestation rather than the presence of ICD-10 dementia diagnosis codes on prior Medicare claims.” A clinician, who must be on the **GUIDE Participant’s Practitioner Roster** must attest that based on his or her comprehensive assessment, beneficiaries meet the (1) *National Institute on Aging-Alzheimer’s Association Diagnostic Guidelines for Dementia*<sup>5</sup> and/or the (2) *DSM-5 diagnostic guidelines for major neurocognitive disorder*.

Alternatively, they are permitted to attest that they have received a written report of a documented dementia diagnosis from another Medicare-enrolled practitioner.

Once a beneficiary is voluntarily aligned to a GUIDE Participant, the GUIDE Participant must attach an eligible ICD-10 dementia diagnosis code to each Dementia Care Management Payment (DCMP) monthly claim for it to be paid by CMS.

Internal notes:

- (1) It is unclear from CMS statements whether the National Institute on Aging-Alzheimer’s Association Diagnostic Guidelines for Dementia – which came out in 2011 – will be overwritten by the Alzheimer’s Association’s “Revised Criteria for Diagnosis and Staging of Alzheimer’s Disease: Alzheimer’s Association Workgroup” (Jacks et al., 2024) which were recently issued. These new criteria are more aligned to biomarkers and associated clinical staging for defining the presence of Alzheimer’s disease. Both guidelines were developed for diagnosing Alzheimer’s disease, however, it is assumed that CMS intends that they apply to the diagnosing other forms of dementia.
- (2) We are not yet informed whether the CMS GUIDE will accept the NTG-EDSD when adults with intellectual disability are examined and diagnosed. This is something we will investigate as we move forward.

<sup>4</sup> Lessov-Schlaggar, C.N., del Rosario, O.L., Morris, J.C. et al. Adaptation of the Clinical Dementia Rating Scale for adults with Down syndrome. *J Neurodevelop Disord* 11, 39 (2019). <https://doi.org/10.1186/s11689-019-9300-2>

<sup>5</sup> <https://www.nia.nih.gov/news/alzheimers-diagnostic-guidelines-updated-first-time-decades>

# Functional Assessment Screening Tool (FAST)

## Functional Analysis Screening Tool

Client: \_\_\_\_\_ Date: \_\_\_\_\_

Informant: \_\_\_\_\_ Interviewer: \_\_\_\_\_

**To the Interviewer:** The FAST identifies environmental and physical factors that may influence problem behaviors. It should be used only for screening purposes as part of a comprehensive functional analysis of the behavior. Administer the FAST to several individuals who interact with the client frequently. Then use the results as a guide for conducting a series of direct observations in different situations to verify behavioral functions and to identify other factors that may influence the problem behavior.

**To the Informant:** Complete the sections below. Then read each question carefully and answer it by circling "Yes" or "No". If you are uncertain about an answer, circle "N/A".

**Informant-Client Relationship**

1. Indicate your relationship to the client:  Parent  Instructor  Therapist  Parapro  Residential Staff  Other
2. How long have you known the client? \_\_\_\_\_ years \_\_\_\_\_ months
3. Do you interact with client daily?  Yes  No
4. In what situations do you usually interact with the client?  
 Meals  Academic training  Leisure activities  
 Work or vocational training  Self care  
 Other \_\_\_\_\_

**Problem Behavior Information**

1. Problem behavior (check and describe):  
 Aggression: \_\_\_\_\_  
 Self-injury: \_\_\_\_\_  
 Stereotypy: \_\_\_\_\_  
 Property destruction: \_\_\_\_\_  
 Disruptive behavior: \_\_\_\_\_

2.

|                                 |                                |                                 |                               |
|---------------------------------|--------------------------------|---------------------------------|-------------------------------|
| Frequency:                      |                                |                                 |                               |
| <input type="checkbox"/> Hourly | <input type="checkbox"/> Daily | <input type="checkbox"/> Weekly | <input type="checkbox"/> Less |
3.

|           |  |
|-----------|--|
| Severity: |  |
| mild:     | disruptive but little risk to property or health |
| moderate: | property damage or minor injury                  |
| severe:   | significant threat to health or safety           |

4. Situations in which the problem behavior is most likely:  
Days/Times: \_\_\_\_\_  
Settings/Activities: \_\_\_\_\_  
Persons present: \_\_\_\_\_
5. Situations in which the problem behavior is least likely:  
Days/Times: \_\_\_\_\_  
Settings/Activities: \_\_\_\_\_  
Persons present: \_\_\_\_\_
6. What is usually happening to the client right before the problem behavior occurs?  
\_\_\_\_\_
7. What usually happens to the client right after the problem behavior occurs?  
\_\_\_\_\_
8. How do you handle the behavior when it occurs?  
\_\_\_\_\_
9. Comments:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

|   |  |  |                              |                             |                              |
|---|--|--|------------------------------|-----------------------------|------------------------------|
| 1. Does the client usually engage in the problem behavior when he/she is being ignored or when caregivers are paying attention to someone else?                 |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 2. Does the client usually engage in the problem behavior when requests for preferred activities (games, snacks) are denied or when these items are taken away? |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 3. When the problem behavior occurs, do you or other caregivers usually try to calm the client down or try to engage the client in preferred activities?        |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 4. Is the client usually well behaved when he/she is getting lots of attention or when preferred items or activities are freely available?                      |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 5. Is the client resistant when asked to perform a task or to participate in group activities?  |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 6. Does the client usually engage in the problem behavior when asked to perform a task or to participate in group activities?                                   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 7. When the problem behavior occurs, is the client usually given a break from tasks?  |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 8. Is the client usually well behaved when he/she is not required to do anything?   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 9. Does the problem behavior seem to be a "ritual" or habit, repeatedly occurring the same way?   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 10. Does the client usually engage in the problem behavior even when no one is around or watching?  |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 11. Does the client prefer engaging in the problem behavior over other types of leisure activities?   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 12. Does the problem behavior appear to provide some sort of sensory stimulation?   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 13. Does the client usually engage in the problem behavior more often when he/she is ill?   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 14. Is the problem behavior cyclical, occurring at high rates for several days and then stopping?   |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 15. Does the client have recurrent painful conditions such as ear infections or allergies? If so, please list: _____  |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |
| 16. If the client is experiencing physical problems, and these are treated, does the problem behavior usually go away?  |  |  | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> N/A |

**Scoring Summary - Circle the number from above of each question answered "Yes".**

| Items circled "Yes" |    |    |    | Total | Potential Source of Reinforcement  |
|---------------------|----|----|----|-------|------------------------------------|
| 1                   | 2  | 3  | 4  |       | Attention/Preferred Items [Social] |
| 5                   | 6  | 7  | 8  |       | Escape [Social]                    |
| 9                   | 10 | 11 | 12 |       | Sensory Stimulation [Automatic]    |
| 13                  | 14 | 15 | 16 |       | Pain Attenuation [Automatic]       |

5<sup>th</sup> edition, © 2002, The Florida Center on Self-Injury

Sourced: <https://researchautism.org/wp-content/uploads/2019/08/A1-FAST-2002.pdf>

**FUNCTIONAL ASSESSMENT SCREENING TOOL (FAST)**

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date: \_\_\_\_\_

Behavior Problem: \_\_\_\_\_

Informant: \_\_\_\_\_ Interviewer: \_\_\_\_\_

**To the interviewer:** The Functional Analysis Screening Tool (FAST) is designed to identify a number of factors that may influence the occurrence of problem behaviors. It should be used only as an initial screening tool and as part of a comprehensive functional assessment or analysis of problem behavior. The FAST should be administered to several individuals who interact with the person frequently. Results should then be used as the basis for conducting direct observations in several different contexts to verify likely behavioral functions, clarify ambiguous functions, and identify other relevant factors that may not have been included in this instrument.

**To the Informant:** After completing the section on "Informant-Person Relationship," read each of the numbered items carefully. If a statement accurately describes the person's behavior problem, circle "Yes." If not, circle "No." If the behavior problem consists of either self-injurious behavior or "repetitive stereotyped behaviors," begin with Part I. However, if the problem consists of aggression or some other form of socially disruptive behavior, such as property destruction or tantrums, complete only Part II.

**Informant-Person Relationship**

Indicate your relationship to the person: \_\_\_\_\_ Parent \_\_\_\_\_ Teacher/Instructor \_\_\_\_\_ Residential Staff \_\_\_\_\_ Other

How long have you known the person? \_\_\_\_\_ Years \_\_\_\_\_ Months

Do you interact with the person on a daily basis? \_\_\_\_\_ Yes \_\_\_\_\_ No

If "Yes," how many hours per day? \_\_\_\_\_ If "No," how many hours per week? \_\_\_\_\_

In what situations do you typically observe the person? (Mark all that apply)

\_\_\_\_\_ Self-care routines \_\_\_\_\_ Academic skills training \_\_\_\_\_ Meals \_\_\_\_\_ When (s)he has nothing to do

\_\_\_\_\_ Leisure activities \_\_\_\_\_ Work/vocational training \_\_\_\_\_ Evenings \_\_\_\_\_ Other: \_\_\_\_\_

**Part I. Social Influences on Behavior**

|    |   |     |    |
|----|---|-----|----|
| 1. | The behavior usually occurs in your presence or in the presence of others   | Yes | No |
| 2. | The behavior usually occurs soon after you or others interact with him/her in some way, such as delivering an instruction or reprimand, walking away from (ignoring) the him/her, taking away a "preferred" item, requiring him/her to change activities, talking to someone else in his/her presence, etc. | Yes | No |
| 3. | The behavior often is accompanied by other "emotional" responses, such as yelling or crying   | Yes | No |

*Complete Part II if you answered "Yes" to item 1, 2, or 3. Skip Part II if you answered "No" to all three items in Part I.*

**Part II. Social Reinforcement**

|     |   |     |    |
|-----|---|-----|----|
| 4.  | The behavior often occurs when he/she has not received much attention   | Yes | No |
| 5.  | When the behavior occurs, you or others usually respond by interacting with the him/her in some way (e.g., comforting statements, verbal correction or reprimand, response blocking, redirection)     | Yes | No |
| 6.  | (S)he often engages in other annoying behaviors that produce attention  | Yes | No |
| 7.  | (S)he frequently approaches you or others and/or initiates social interaction   | Yes | No |
| 8.  | The behavior rarely occurs when you give him/her lots of attention  | Yes | No |
| 9.  | The behavior often occurs when you take a particular item away from him/her or when you terminate a preferred leisure activity (If "Yes," identify: _____)  | Yes | No |
| 10. | The behavior often occurs when you inform the person that (s)he cannot have a certain item or cannot engage in a particular activity. (If "Yes," identify: _____)                                     | Yes | No |
| 11. | When the behavior occurs, you often respond by giving him/her a specific item, such as a favorite toy, food, or some other item. (If "Yes," identify: _____)  | Yes | No |
| 12. | (S)he often engages in other annoying behaviors that produce access to preferred items or activities.   | Yes | No |
| 13. | The behavior rarely occurs during training activities or when you place other types of demands on him/her. (If "Yes," identify the activities: _____ self-care _____ academic _____ work _____ other) | Yes | No |

Adapted from the Florida Center on Self-Injury

- |   |     |    |
|---|-----|----|
| 14. The behavior often occurs during training activities or when asked to complete tasks.             | Yes | No |
| 15. (S)he often is noncompliant during training activities or when asked to complete tasks.           | Yes | No |
| 16. The behavior often occurs when the immediate environment is very noisy or crowded.                | Yes | No |
| 17. When the behavior occurs, you often respond by giving him/her brief "break from an ongoing task.  | Yes | No |
| 18. The behavior rarely occurs when you place few demands on him/her or when you leave him/her alone. | Yes | No |

**Part III. Nonsocial (Automatic) Reinforcement**

- |  |     |    |
|--|-----|----|
| 19. The behavior occurs frequently when (s)he is alone or unoccupied   | Yes | No |
| 20. The behavior occurs at relatively high rates regardless of what is going on in his/her immediate surrounding environment   | Yes | No |
| 21. (S)he seems to have few known reinforcers or rarely engages in appropriate object manipulation or "play" behavior.   | Yes | No |
| 22. (S)he is generally unresponsive to social stimulation.   | Yes | No |
| 23. (S)he often engages in repetitive, stereotyped behaviors such as body rocking, hand or finger waving, object twirling, mouthing, etc.  | Yes | No |
| 24. When (s)he engages in the behavior, you and others usually respond by doing nothing (i.e., you never or rarely attend to the behavior.)  | Yes | No |
| 25. The behavior seems to occur in cycles. During a "high" cycle, the behavior occurs frequently and is extremely difficult to interrupt. During a "low" cycle the behavior rarely occurs. | Yes | No |
| 26. The behavior seems to occur more often when the person is ill.   | Yes | No |
| 27. (S)he has a history of recurrent illness (e.g., ear or sinus infections, allergies, dermatitis).   | Yes | No |

**Scoring Summary**

Circle the items answered "Yes." If you completed only Part II, also circle items 1, 2, and 3

|    |    |    |    |    |    |    |    | <u>Likely Maintaining Variable</u>                         |
|----|----|----|----|----|----|----|----|--|
| 1  | 2  | 3  | 4  | 5  | 6  | 7  | 8  | Social Reinforcement (attention)                           |
| 1  | 2  | 3  | 9  | 10 | 11 | 12 | 13 | Social Reinforcement (access to specific activities/items) |
| 1  | 2  | 3  | 14 | 15 | 16 | 17 | 18 | Social Reinforcement (escape)                              |
| 19 | 20 | 21 | 22 | 23 | 24 |    |    | Automatic Reinforcement (sensory stimulation)              |
| 19 | 20 | 24 | 25 | 26 | 27 |    |    | Automatic Reinforcement (pain attenuation)                 |

Comments/Notes: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Zarit Burden Interview

The Zarit Burden Interview is a caregiver self-report measure originated as a 29-item questionnaire. Each instrument item is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). The instrument is used to assess the level of subjective feelings of burden experienced by caregivers of older persons with dementia and other types of disability. *The current version uses 22 items (ZBI-22).* Below is a shorter, 12 item, version.

### ZARIT BURDEN INTERVIEW

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

|  | Never | Rarely | Sometimes | Quite Frequently | Nearly Always |
|--|-------|--------|-----------|------------------|---------------|
| 1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?     | 0     | 1      | 2         | 3                | 4             |
| 2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?      | 0     | 1      | 2         | 3                | 4             |
| 3) Do you feel angry when you are around the relative?   | 0     | 1      | 2         | 3                | 4             |
| 4) Do you feel that your relative currently affects your relationship with family member or friends in a negative way? | 0     | 1      | 2         | 3                | 4             |
| 5) Do you feel strained when you are around your relative?   | 0     | 1      | 2         | 3                | 4             |
| 6) Do you feel that your health has suffered because of your involvement with your relative?                           | 0     | 1      | 2         | 3                | 4             |
| 7) Do you feel that you don't have as much privacy as you would like because of your relative?                         | 0     | 1      | 2         | 3                | 4             |
| 8) Do you feel that your social life has suffered because you are caring for your relative?                            | 0     | 1      | 2         | 3                | 4             |
| 9) Do you feel that you have lost control of your life since your relative's illness?                                  | 0     | 1      | 2         | 3                | 4             |
| 10) Do you feel uncertain about what to do about your relative?  | 0     | 1      | 2         | 3                | 4             |
| 11) Do you feel you should be doing more for your relative?  | 0     | 1      | 2         | 3                | 4             |
| 12) Do you feel you could do a better job in caring for your relative?   | 0     | 1      | 2         | 3                | 4             |

Total for each column \_\_\_\_\_

Total Score \_\_\_\_\_

To use the longer version ZBI-22, permission must be obtained from: <https://eprovide.mapi-trust.org/instruments/zarit-burden-interview>.

v.8/19/24

This product was supported in part by the Special Olympics Systems Change for Inclusive Health Subgrant, funded by the Centers for Disease Control and Prevention. The contents of this project are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the US Department of Health and Human Services.

FOR CT! PROJECT DISCUSSIONS ONLY