

University of Washington

Caregiver Benefit Scale (UW-CBS) ©

Users Guide

Version 2.0 – English

Updated: May 29, 2020

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Please cite this UW-Caregiver Benefit Scale user guide and short forms as follows:

University of Washington Caregiver Benefit Scale (UW-CBS) Version 2 Users Guide. 2020.

<https://uwcorr.washington.edu/measures/uw-cbs-userguide.pdf>. Accessed on [date].

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Questions about the UW-CBS Instruments

If you have questions about the UW-CBS instruments or their use in clinical care or research, please contact the University of Washington Center on Outcomes Research in Rehabilitation (UWCORR).

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Overview of the UW-CBS

The University of Washington Caregiver Benefit Scale (UW-CBS) is an Item Response Theory (IRT) based instrument intended for measuring benefits of caregiving in adults. The UW-CBS is a publicly available, psychometrically sound item bank for measuring benefits of caregiving.

Construct

The UW-CBS is intended to measure the benefits of caregiving experienced by caregivers. Through a series of meetings with patients, researchers and clinicians with expertise in pediatric neurology, three definitions pertaining to caregiver benefit were generated.

A **caregiver** is defined as:

A person (most often a family member or legal guardian) who coordinates and provides most of the unpaid day-to-day care for, and is responsible for the raising, the health, and the well-being of a child or recipient of care. In order to be valid, a measure of caregiving impact need not assess the impact of caregiving on the lives of professional caregivers (e.g., nurses or nurse assistants), even if they are providing more hours.

A **care recipient** is defined as:

The person who is receiving care. The care recipient might be a child or an individual of any age who lives with some form of chronic condition that causes difficulties in completing the tasks of daily living.

Caregiver Benefit is defined as:

The caregiver's perception of the beneficial psychological and social impact of caregiving on the caregiver's life.

These definitions guided the development of items across five subdomains of caregiver benefit including: (1) emotional health, (2) sense of confidence in/self-efficacy for caregiving, (3) relationship with spouse/significant other, (4) relationship(s) with other children, (5) relationship(s) with friends.

Additional information about the UW-CBS development can be found in these publication:

1) Jensen MP, Liljenquist KS, Bocell F, Gammaitoni AR, Aron CR, Galer BS, Amtmann D. Life impact of caregiving for severe childhood epilepsy: Results of expert panels and caregiver focus groups. *Epilepsy Behav.* 2017 Sep;74:135-143. doi: 10.1016/j.yebeh.2017.06.012.

2) Amtmann D, Liljenquist KS, Bamer A, Gammaitoni AR, Aron CR, Galer BS, Jensen MP. Development and validation of the University of Washington caregiver stress and benefit scales for caregivers of children with or without serious health conditions. *Qual Life Res.* 2020 [Epub ahead of print]

Calibration Population and Intended Application:

The UW-CBS was developed in a sample of adults (18 years or older) living in the United States who were caring for a child under 18 years of age with either epileptic encephalopathies, Down syndrome, muscular dystrophy or no specific health care needs. The UW-CBS was developed in English and has now been translated (January 2020) into other languages including Italian, German, French and Spanish. Translated versions will be made available on the website sometime in 2020. It was developed to be applicable to primary caregivers of children either with or without specific healthcare needs.

Just over half of the calibration sample (400 out of 722 total) included primary caregivers of children with either epileptic encephalopathies, Down syndrome, or muscular dystrophy. However, scores were centered in a community based sample of caregivers (n=241) of children (i.e., the community based sample was chosen to be typical of caregivers in the community, without any consideration for the health of the children they were caring for).

As a result, **UW-CBS score of 50 with a standard deviation of 10 represents the mean in a community based sample** with the following characteristics:

- Half the sample had income below and half above the median US income from 2014.
- Approximately one-third (35%) of the sample had non-white race, matching the US Census of adults from 2015.
- At least 36% had less than or equal to a high school education, which matches the Child Trends analysis of the Current Population Survey.
- One third of the children of the caregivers were in each of the three age groups (0-5 years, 6-11 years, 12-17 years), matching the distribution of estimated children from the US Census from 2010-2014.
- The number of male caregivers was 25% of the sample.

		Characteristics of Caregiver Sample Used for Centering CSS Scores (N=241)
Caregiver Stress Scale Score		50.0 (SD: 10)
Average Number of Children		1.9
Child Age Group		
	0-5 years	33%
	6-11 years	33%
	12-17 years	33%
Caregiver Gender		
	Male	25%
	Female	75%
Median Household Income		\$53,657
Non-White Race		35%
High School Education or Less		36%
Child Health Condition		
	None listed	60%
	1 Health Condition	18%
	2 Health Conditions	11%
	3+ Health Conditions	11%
Most Commonly Listed Health Conditions		
	ADD/Hyperactivity/Behavioral	16%
	Allergies/Sinus Trouble	14%
	Asthma	14%
	Speech Problems	8%

Focus groups and cognitive interviews were conducted in the process of developing the item bank to ensure that the instrument is both person-centered and clinically meaningful. The item bank was calibrated using IRT, and item parameters for all items are available upon request.

Version 1 and 2 Differences

This user guide contains the Version 2 Short Forms and the full item bank. When translated into German, Italian, Spanish, and French several items did not work as intended and had to be deleted or modified. Version 2 reflects these changes. . In order to provide more flexibility and additional options for administration, we have now included a 3-item short form in this v.2.0 user guide as well. The items in the new short forms function similarly across the 5 languages and worked well when tested in cognitive interviews. Scores based on version 2 short forms are directly comparable to version 1 scores as well as scores generated by computer adaptive testing. The item bank itself did not change between version 1 and 2.

Instructions for Using the UW Caregiver Benefit Scale

Choosing a UW-CBS instrument

Below you will find the full 13 item bank along with a 6-item and 3-item short form. For lowest respondent burden and most reliable score, choose computerized adaptive testing (CAT). If CAT is not available choose the 6-item short form. If the 6-item short form is too long, use the 3-item short form, but understand the limitations of the score based on the 3-item short form (e.g., lower score reliability).

A participant or patient version of the short forms are available on the website as standalone PDFs (<https://uwcorr.washington.edu/measures/uw-cbs/>). Investigator versions with individual item scoring indicated are available below. It is best practice **not to administer the version that shows scoring to the participants**. The full bank, that is all 13 items, is not intended to be administered for any purposes. The full item bank is intended for CAT which uses an algorithm to select items based on responses to previous items. A CAT version is available at <https://uwcorr.washington.edu/measures/uw-cbs/>. If interested in administering the full bank a scoring table is provided below. Please note however that one item (#13) in the item bank is not applicable to people who do not have a spouse/partner. Therefore, this item cannot be scored for some people and IRT scoring is best if this item is to be used.

The 6-item and 3-item short forms can be administered electronically (by computer or tablet) or on paper. The short forms require less than two minutes to administer and are recommended for use in situations where administration of CAT is not possible. The correlation between scores on the 6-item short form and on the full bank is > 0.95.

Scoring

The UW-CBS short forms are scored by summing responses to all 6 or 3 individual items and transforming the summary score to an IRT-based T-score using the conversion tables provided. **The summary score should not be used for any purposes.** All reliability and validation information relates to the IRT based T-scores. Raw scores/codes for each item range from 1 to 5 as indicated in the investigator/clinician versions below. Only complete responses with no missing data can be scored using the provided conversion scoring table. However, information on scoring with missing data on the 6-item short form is also provided under “Scoring with Missing Data” below. Detailed instructions for scoring the short forms are outlined here:

6-Item Short Form: These instructions are only valid if there are complete responses with no missing data on all 6 items. Step 1: The 6 items on the short form are summed using the values provided for each response available in the clinician/researcher version of the form. This will give a summary score that ranges from 6 to 30. This is **not** a score that can be used for clinical or analytical purposes. Step 2: Using the correct “Summary Score to T-score Conversion Table”, use the summary score to look up the IRT-based T-score in the column labeled “T-score” in the conversion table (page 8 below). For example, a person with a summary score of 20 would have a T-score of 40.2. This T-score is your final score you will use for all analyses.

3-Item Short Form: These instructions are only valid if there are complete responses with no missing data on all 3 items. Step 1: The 3 items on the short form are summed using the values provided for each response available in the clinician/researcher version of the form. This will give a summary score that ranges from 3 to 15. This is **not** a score that can be used for clinical or analytical purposes. Step 2: Using the correct Summary Score to T-score Conversion Table, use the summary score to look up the IRT-based T-score in the column labeled “T-score” in the conversion table (page 9 below). For example, a person with a summary score of 10 would have a T-score of 40.0. This T-score is your final score you will use for all analyses.

Scoring with Missing Data: For missing data on either of the short forms IRT scoring should be used if possible. To do so item parameters can be requested by emailing uwcorr@uw.edu. If IRT software is not available, the short form score for the 6-item form can be approximated if a person skips up to two questions. If more than 2 of the items are missing, a score cannot be generated without IRT software (note: the three item short form cannot be scored with missing data without IRT software). Step 1: For respondents with missing data on the 6-item form, first check how many items were answered and confirm that at least 4 items of the 6 items were answered before proceeding. Step 2: Next, sum the response scores from the items that were answered. Multiply this sum by 6 (i.e. the number of items used in scoring the short form). Step 3: Next divide by the number of items that were answered (this will be either 4 or 5). If the result is a fraction, round up to the nearest whole number. This will give a pro-rated summary score that ranges from 6 to 30. This is **not** a score that can be used for clinical or analytical purposes. Step 4: Finally, using the 6-item Summary Score to T-score Conversion Table (page 8), translate the pro-rated summary score into a T-score for the respondent just as you would for any person who did not have missing responses.

Again, the formula is:

$$\frac{\text{(Raw sum x 6)}}{\text{(Number of items actually answered)}} = \text{Pro-rated summary score (round up to nearest whole number)}$$

For example, if a respondent answered 4 of 6 questions and answered all items with the second lowest response option (2), you would sum all responses (8), multiply by the number of items in the short form (6) and divide by the number of items that were answered (4). Here: $(8 \times 6) / 4 = 12$. If the result is a fraction, round up to the nearest whole number; the pro-rated summary score of 12 is translated to a T-score of 28.8. This T-score is your final score you will use for all analyses.

Interpreting UW-CBS Scores

The UW-CBS T-score is a standardized score with a mean of 50 and a standard deviation (SD) of 10. A higher T-score represents a higher level of perceived benefits of caregiving. T-scores are comparable across all UW-CBS instruments. This means that a score obtained by a respondent using the 6-item short form may be compared directly to a score obtained by a respondent using the 8-item v.1.0 short form, full bank or a CAT administration of the scale with the understanding that the score based on CAT is more reliable (i.e., accurate) than the score based on the short form. T-scores of 50 represent the mean score of the community based sample described on page 4 above. Based on a normal distribution of UW-CBS T-scores, 50% of caregivers in the community have a T-score of 50 or higher (see Figure 1 below). A respondent that receives a T-score of 60 has reported a level of benefits of caregiving approximately 1 standard deviation above the mean of other caregivers and their perceived benefits of caregiving level is higher than 84% of individuals in the community based centering sample.

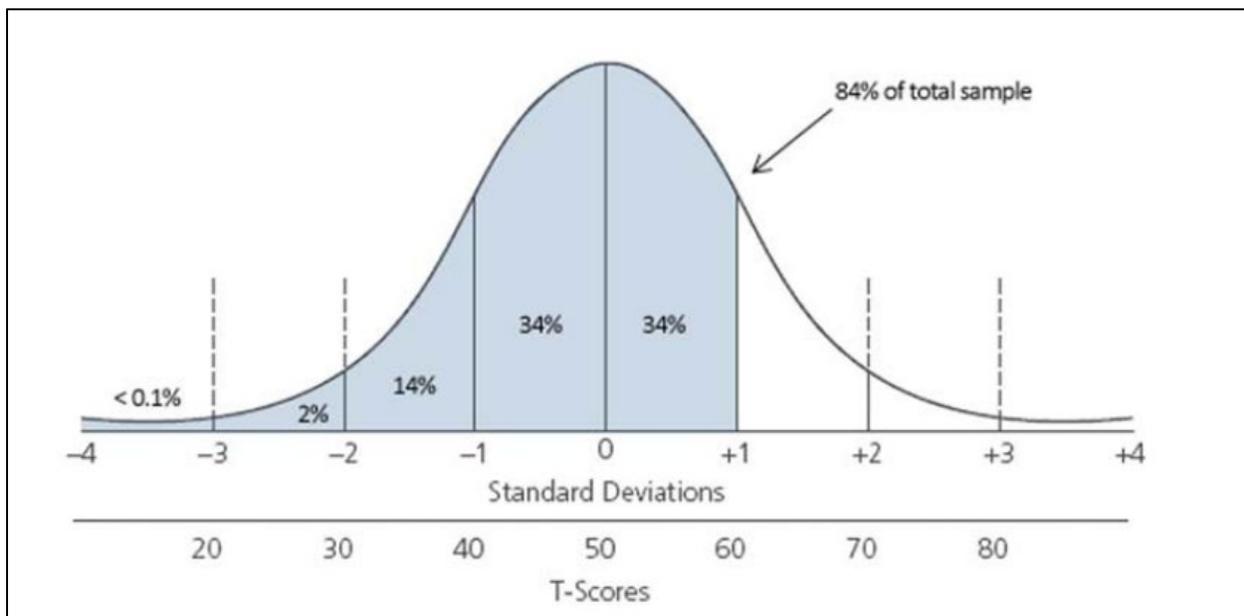


Figure 1 – A UW-CBS T-score of 60 indicates that approximately 84 percent of persons in the community sample reported lower benefits of caregiving, as reflected by the shaded area.

Summary Score to T-score Conversion Tables

6 Item Short Form V.2.0 – UW-CBS Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
6	16.5	4.2
7	19.7	3.6
8	22.0	3.4
9	24.0	3.3
10	25.7	3.2
11	27.3	3.1
12	28.8	3.1
13	30.3	3.1
14	31.7	3.1
15	33.1	3.1
16	34.5	3.1
17	35.9	3.1
18	37.3	3.1
19	38.7	3.1
20	40.2	3.1
21	41.7	3.1
22	43.2	3.1
23	44.8	3.1
24	46.3	3.2
25	48.0	3.2
26	49.9	3.3
27	51.9	3.5
28	54.4	3.8
29	57.4	4.3
30	62.6	5.6

3 Item Short Form V.2.0 – UW-CBS Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
3	19.3	4.6
4	23.7	4.3
5	27.0	4.2
6	29.8	4.1
7	32.4	4.1
8	35.0	4.1
9	37.5	4.1
10	40.0	4
11	42.7	4
12	45.5	4
13	48.6	4.1
14	52.5	4.5
15	59.4	6.1

13 Item Full Bank V.1.0 – UW-CBS Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
13	9.3	4.4
14	11.8	3.9
15	13.6	3.7
16	15.2	3.5
17	16.6	3.3
18	17.9	3.2
19	19.1	3.1
20	20.2	3.0
21	21.2	2.9
22	22.2	2.8
23	23.2	2.8
24	24.1	2.7
25	25.0	2.7
26	25.9	2.7
27	26.8	2.7
28	27.6	2.6
29	28.4	2.6
30	29.2	2.6
31	30.0	2.6
32	30.8	2.6
33	31.6	2.6
34	32.4	2.6
35	33.2	2.6
36	34.0	2.6
37	34.8	2.6
38	35.6	2.6

Summary Score	T-score	SD of T-score
39	36.4	2.6
40	37.2	2.6
41	38.0	2.7
42	38.8	2.7
43	39.6	2.7
44	40.5	2.7
45	41.3	2.7
46	42.1	2.7
47	43.0	2.7
48	43.9	2.7
49	44.7	2.7
50	45.6	2.7
51	46.5	2.8
52	47.5	2.8
53	48.4	2.8
54	49.5	2.9
55	50.5	3.0
56	51.7	3.1
57	52.9	3.2
58	54.2	3.4
59	55.6	3.6
60	57.2	3.8
61	58.9	4.1
62	60.9	4.4
63	63.0	4.8
64	65.5	5.2
65	68.8	5.9

UW Caregiver Benefit Scale[®] Investigator or Clinician Forms

Versions 2.0 – English

UW Caregiver Benefit Scale 6-Item Short Form V.2.0©
(Investigator/Clinician Version)

Instructions: Please choose the response that best describes how you **usually** feel about caregiving. By **caregiving** we mean all aspects of taking care of a child or children under 18 years -- that is providing help and support (typically unpaid and typically by a parent or guardian) for their physical, psychological, or developmental needs. When choosing your answers consider how having a child or children you take care of affects all areas of your life.

	Not at All	A little bit	Some-what	Quite a bit	Very much
1. How much does caregiving help you find new strengths in yourself?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. How much does caregiving add meaning to your life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. How much do you feel caregiving has made you a better person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. How much does caregiving help you be more caring?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. How much does caregiving help you become a more patient person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. How much do you feel that caregiving has made you a stronger person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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UW Caregiver Benefit Scale 3-Item Short Form V.2.0©
(Investigator/Clinician Version)

Instructions: Please choose the response that best describes how you **usually** feel about caregiving. By **caregiving** we mean all aspects of taking care of a child or children under 18 years -- that is providing help and support (typically unpaid and typically by a parent or guardian) for their physical, psychological, or developmental needs. When choosing your answers consider how having a child or children you take care of affects all areas of your life.

	Not at All	A little bit	Some-what	Quite a bit	Very much
1. How much does caregiving add meaning to your life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. How much does caregiving help you be more caring?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. How much do you feel that caregiving has made you a stronger person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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UW Caregiver Benefit Scale Item Bank©
(Investigator/Clinician Version)

Instructions: Please choose the response that best describes how you **usually** feel about caregiving. By **caregiving** we mean all aspects of taking care of a child or children under 18 years -- that is providing help and support (typically unpaid and typically by a parent or guardian) for their physical, psychological, or developmental needs. When choosing your answers consider how having a child or children you take care of affects all areas of your life.

	Not at All	A little bit	Some-what	Quite a bit	Very much
1. How much does caregiving help you appreciate what is important in life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. How much does caregiving help you find new strengths in yourself?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Are you a better advocate for your child/children because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. How much do you feel caregiving has made you a better person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. How much do you feel that caregiving has helped you put life in perspective?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. How much does caregiving help you become a more patient person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. How much do you feel that caregiving has made you a stronger person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Have you gained confidence in yourself because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. How much does caregiving add meaning to your life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. How much does caregiving make you a more accepting person?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. How much does caregiving help you be more caring?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

		Never	Rarely	Some- times	Often	Always
12. How often does caregiving make you feel closer to other adults who are important to you?		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
	N/A (I don't have a partner)	Never	Rarely	Some- times	Often	Always
13. How often do you feel closer to your partner because of caregiving?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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