

**Kentucky's Department for Aging and Independent Living's
Adaptation of Quality of Life Changes***

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(PDS/FOLLOW UP – Caregiver or Participant)

Rev. 08/2016

Regional ID

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Participant ID

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Interviewer ID

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Date

M	M	D	D	Y	Y

Developed/adapted for Kentucky's Department for Aging and Independent Living

275 East Main Street, 3E-E

Frankfort, Kentucky 40621

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Adaptation of Quality of Life Changes*

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Participant characteristics:

- a. Age _____ Years _____ Months
- b. Sex _____ 0 Male _____ 1 Female

Caregiver characteristics:

- c. Age _____ Years _____ Months
- d. Sex _____ 0 Male _____ 1 Female

Waiver:

- a. ABI-A _____
- b. ABI-LTC _____
- c. HCB _____
- d. SCL _____
- e. MPW _____

If the caregiver plans to answer all the questions on behalf of the participant, please ask all the questions of the caregiver in Section I. **If the participant plans to answer the questions himself/herself, please skip Section I.**

In Section II ask the waiver participant or the caregiver on behalf of the participant to rate the qualities of his/her life at the point of time you are asking the question. For persons participating in the survey, this means trying to remember what life was like in the previous 3 months not just the current day. Specifically, the question should be asked in two consecutive formats. For example, for question #1, "Would you say your health is good or bad?" (In between is implied if the person says "neither" or "OK" or any other similar response; however, answers like that have to be checked by probing with "So, it's in between, not really good or bad?")

Each "good" or "bad" response received in Section I is then further defined with "Either-Or" questions. For example, if the response on the first item is "Good", the "Either-Or" clarification is, "Would you say your health is either "Good" or "Very Good"? (In between is implied, if the person says "Neither" or "OK" or "Neither" or any similar response; however, answers like that have to be checked by probing with "Oh, so it's in between, not really good or bad?")

*Questions 1-7 adapted with permission from Quality of Life Changes
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SCRIPT: There will be multiple response options for the first three questions. After each question, I will summarize all of the possible answers and will ask you to choose only one.

Section I.

1. In your experience as a caregiver, what would you say is the one most positive aspect of caregiving?
[READ LIST. CHECK ONLY ONE.] Would you say that the one most positive aspect is ...

- Helping your care recipient, 1
- Helping your other family members, 2
- Feeling a sense of accomplishment, 3
- Caring for someone who cared for you, 4
- Being appreciated, or 5
- Providing companionship for you?..... 6
- OTHER (SPECIFY: _____)..... 7
- NONE..... 8
- REFUSED..... -7
- DON'T KNOW..... -8

2. Which of these difficulties is the greatest difficulty you have faced in your caregiving?
[READ LIST. CHECK ONLY ONE.] Would you say caregiving's greatest difficulty is that it...

- Creates a financial burden, 1
- Doesn't leave enough time for yourself, 2
- Doesn't leave enough time for your family, 3
- Interferes with your work, 4
- Creates or aggravates health problems, 5
- Affects your family relationships, or..... 6
- Creates stress? 7
- OTHER (SPECIFY: _____)..... 8
- REFUSED..... -7
- DON'T KNOW..... -8

3. What is your relationship to [PARTICIPANT'S NAME]? Are you his or her...

- Husband 1
 Wife 2
 Son 3
 Son-in-Law 4
 Daughter 5
 Daughter-in-Law 6
 Father 7
 Mother 8
 Brother 9
 Sister 10
 Granddaughter 11
 Grandson 12
 Niece 13
 Nephew 14
 Other relative [Not a relative mentioned above]
 (SPECIFY: _____) 15
 Friend or Neighbor or Another Person 16
 REFUSED - 7
 DON'T KNOW - 8

SCRIPT: The next section includes a total of ten (10) questions. Please feel free to ask me to repeat any question or answer category so that the question is fully understood.

Section II.

1. Would you say your health is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

2. Would you say your ability of running your own life and making your own choices is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

3. Would you say your family relationships are good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

4. Would you say your relationships with friends are good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

5. Would you say your ability of getting out and getting around is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

6. Would you say your overall quality of life is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

7. Would you say the quality of the services you receive is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

8. Would you say the respect you receive from employees or service providers is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

9. Do you have any unmet needs you would like to share?

Yes	No	Sometimes	Unsure/No Answer

Detail:

10. Are there any other concerns or experiences you would like to share with us?

Yes	No	Sometimes	Unsure/No Answer

Detail:

SCRIPT: The next and final section includes a total of nine (9) questions specifically related to Participant Directed Services. Please feel free to ask me to repeat any question or answer category so that the question is fully understood.

Section III.

11. Would you say your satisfaction with participant directed services is good or bad?

Very Bad (1)	Bad (2)	OK (3)	Good (4)	Very Good (5)

Detail:

12. Since you have been receiving participant directed services, has your paid caregiver always arrived at your home when he or she was scheduled to arrive?

Yes	No	Sometimes	Unsure/No Answer

Detail:

13. Since you have been receiving participant directed services, has your paid caregiver always completed the tasks that were stated on his or her timesheet?

Yes	No	Sometimes	Unsure/No Answer

Detail:

14. Since you have been receiving participant directed services, have you been satisfied with your paid caregiver's schedule?

Yes	No	Sometimes	Unsure/No Answer

Detail:

15. Have the participant directed services that you are receiving NOW made a positive difference in your life?

Yes	No	Sometimes	Unsure/No Answer

Detail:

16. Are your employees or service providers getting paid on time?

Yes	No	Sometimes	Unsure/No Answer

Detail:

17. Would you recommend this program to a friend?

Yes	No	Sometimes	Unsure/No Answer

Detail:

18. Do you have any unmet needs you would like to share?

Yes	No	Sometimes	Unsure/No Answer

Detail:

19. If you have a question or concern regarding payments to your employee, is the issue handled to your satisfaction?

Yes	No	Sometimes	Unsure/No Answer

Detail:

20. Are there any other concerns or experiences you would like to share with us?

Yes	No	Sometimes	Unsure/No Answer

Detail: