Form Approved
OMB No.: XXXX-XXXX
Expiration Date: XX/XX/2017

SECTION 1. BACKGROUND

This section asks about your background, and the person you provide care for.

1. Have you received any caregiver support services within the last 12 months from [*INSERT NAME OF PROGRAM*]? For example, these may include [*INSERT SHORT LIST OF THE TYPES OF SERVICES OFFERED*].

1 ☐ Yes → **PLEASE CONTINUE**

2 ☐ No →**Thank you for your time, but the focus of this survey is on people who have received caregiver support services within the last 12 months.**

2. How long have you been receiving caregiver support services?

1 ☐ Less than 6 months
2 ☐ Between 6 months and 1 year
3 ☐ More than 1 year

3. In your role as a caregiver, how many people do you care for?

1 ☐ 1
2 ☐ 2
3 ☐ 3
4 ☐ 4 or more

3a. If you care for a child/children under 18, how many children do you care for?

1 ☐ 1
2 ☐ 2
3 ☐ 3
4 ☐ 4 or more

For the following questions, think about the person with whom you spend the most time as a caregiver.

4. What is your relationship to the person you care for?

The person I care for is my:

1 ☐ Spouse or partner
2 ☐ Parent

3 ☐ Grandparent
4 ☐ Brother or sister
5 ☐ Aunt or uncle
6 ☐ Adult son or daughter/Son-in-law or daughter-in-law
7 ☐ Child under 18 years old such as a grandchild, great niece or great nephew
9 ☐ Other relative not mentioned above (please describe): _____
10 ☐ Someone else not mentioned above (please describe): _____

5. How old is the person you care for? _____

6. Where does the person you care for live?

1 ☐ Lives alone
2 ☐ Lives with a spouse or partner who is not me
3 ☐ Lives with me
4 ☐ Lives with a family member other than me
5 ☐ Other (please describe): _____

7. Please take a moment to think about all of the care that the person you care for needs. Are you the sole provider of care for that person?

1 ☐ Yes, I am the sole caregiver
2 ☐ No, other people help provide care

7a. If you checked "No", how many other people help provide care to that person?

1 ☐ One other person helps provide care
2 ☐ Two other people help provide care
3 ☐ Three or more people help provide care

8. How many hours in an average <u>week</u> do you spend providing care for this person?

Hours: _____

9. Do you currently have a job for which you receive pay?

1 ☐ Yes, I work full time for wages
2 ☐ Yes, I work part time for wages
3 ☐ No, I am retired
4 ☐ No, I do not currently work a job for wages

SECTION 2. CAREGIVER SUPPORT SERVICES

The questions in this section ask about the caregiver support you may have received in the last 12 months from *[INSERT PROGRAM NAME*].

10. In the last 12 months, has someone from the program given you <u>information to connect you to any services and/or resources,</u> including services or supports for the person you care for?

1☐ Yes
2☐ No

10a. If YES, how easy to understand was the information?

1☐ Very easy to understand
2☐ Somewhat easy to understand
3☐ Not very easy to understand
4☐ Not at all easy to understand

11. As a result of getting this information were you able to connect to the services or resources you needed?

1☐ Yes, I got all of the services and/or resources I needed
2☐ Yes, I got some of the services/resources I needed
3☐ No, I did not get any of the services and/or resources I needed

12. In the last 12 months, have you received a break while someone takes your place as the caregiver? This service is sometimes called "<u>respite care</u>."

1☐ Yes
2☐ No

12a. If YES, which type(s) of <u>respite care</u> do you usually receive in a given <u>month</u>? (CHECK ALL THAT APPLY)

1☐ In-home respite, where someone comes to the home to take care of the person you care for
2☐ Daytime care for an adult or a grandchild, where the person you care for goes to a program during the day
3☐ Overnight respite care in a facility outside the home (e.g., nursing home, childcare facility, etc.)
4☐ Overnight respite care in the home
5☐ Other (please describe): _____

13. How many hours of <u>respite care</u> do you usually receive in a <u>month</u>?

Hours:_____ 1☐ I do not receive this service

14. Overall, how would you rate the respite care you received in the last 12 months?

1☐ Very Good
3☐ Good
4☐ Poor
5☐ Very Poor
6☐ I did not receive this service in the last 12 months

15. Is the number of hours of respite care you receive each month enough?

1☐ Yes, it is enough but more would be better
2☐ Yes, it is enough
3☐ No, it is not enough
4☐ I do not receive this service

16. How many hours of respite care would you like to have in a month?

Hours: _____

17. In the last 12 months, have you received any caregiver training or education, including counseling or support groups, to help you make decisions or solve problems in your role as caregiver?

1☐ Yes
2☐ No

17a. If YES, which type(s) of service did you receive? (CHECK ALL THAT APPLY)

1☐ Caregiver education or training, such as classroom or Internet courses
2☐ Individual counseling to assist with your specific caregiver situation
3☐ Caregiver support groups
4☐ Other (please describe): _____

17b. If YES, did any of the training, education, counseling or support group services talk about dementia or Alzheimer's?

1☐ Yes
2☐ No

18. Overall, how would you rate the caregiver training, education, counseling, or support group services you received in the last 12 months?

1☐ Very Good
2☐ Good

3 ☐ Poor
4 ☐ Very Poor
5 ☐ I did not receive this service in the last 12 months

The next questions ask about <u>other</u> services —these do <u>not</u> include help connecting to services/resources, or respite care, or education/training, or counseling/support groups— that you as the caregiver, or the person you care for, have received in the last 12 months.

19. In the last 12 months, has the program provided you with any <u>supplemental services</u> to help you provide care? Supplemental services may include transportation; nutritional supplements, such as Boost or Ensure; devices, such as potty seats, canes or walkers; a personal emergency response system; stipends; etc.?

1 ☐ Yes
2 ☐ No

19a. If YES, which <u>supplemental services</u> did you receive? (CHECK ALL THAT APPLY)

1 ☐ Devices (e.g., canes, walkers, potty seats)
2 ☐ Case management (i.e., coordination and care management)
3 ☐ Congregate meals (e.g., meals at a center)
4 ☐ Home-delivered meals
5 ☐ Home health aide (not respite)
5 ☐ Chore assistance (e.g., light housekeeping, laundry, chopping wood)
6 ☐ Home modification or adaptive equipment (e.g., grab bars, ramps, bath chair)
7 ☐ Incontinence supplies (e.g., Depends, Poise)
8 ☐ Legal assistance
9 ☐ Medical devices (e.g., nebulizer, hospital bed, wheelchair)
10 ☐ Nutritional supplements (e.g., Ensure, Boost)
11 ☐ Personal emergency response system
12 ☐ Emotional or mental health services for the person you care for
13 ☐ Transportation
14 ☐ Emergency supplies for children
15 ☐ Stipends
16 ☐ Other (please describe): _____

19b. If YOU DID NOT receive any supplemental services in the last 12 months, which supplemental services do you think would be helpful to receive?

(CHECK ALL THAT APPLY)

1. ☐ Devices (e.g., canes, walkers, potty seats)
2. ☐ Case management (i.e., coordination and care management)
3. ☐ Congregate meals (e.g., meals at a center)
4. ☐ Home-delivered meals
5. ☐ Home health aide (not respite)
5. ☐ Chore assistance (e.g., light housekeeping, laundry, chopping wood)
6. ☐ Home modification or adaptive equipment (e.g., grab bars, ramps, bath chair)
7. ☐ Incontinence supplies (e.g., Depends, Poise)
8. ☐ Legal assistance
9. ☐ Medical devices (e.g., nebulizer, hospital bed, wheelchair)
10. ☐ Nutritional supplements (e.g., Ensure, Boost)
11. ☐ Personal emergency response system
12. ☐ Emotional or mental health services for the person you care for
13. ☐ Transportation
14. ☐ Emergency supplies for children
15. ☐ Stipends
16. ☐ Other (please describe): _____

20. Overall, how would you rate the supplemental services you received in the last 12 months?

1. ☐ Very Good
2. ☐ Good
3. ☐ Poor
4. ☐ Very Poor
5. ☐ I did not receive this service in the last 12 months

21. In the last 12 months, have you received a voucher, cash, or individual budget from the program that allows you to purchase goods or services for the person(s) you care for? By "voucher or budget payment," we mean that you were given an allowance where you can decide by yourself what to buy or whom to hire.

1. ☐ Yes
2. ☐ No

21a. If YES, how did you use the voucher, cash, or individual budget?

(CHECK ALL THAT APPLY)

1. ☐ Purchase supplies
2. ☐ Pay for a service (e.g., transportation, meals)
3. ☐ Hire a person to assist with caregiving activities or tasks
4. ☐ Pay for Respite Services
5. ☐ Other (please describe): _____

6☐ Don't know

Now, the next questions ask you to think back to <u>all</u> of the caregiver support services you have received (e.g., help connecting to services/resources, respite care, education/training, counseling/support groups, and supplemental service such as transportation, nutritional supplements, assistive devices, such as canes or walkers, stipends) —that you as the caregiver, or the person you care for, have received in the last 12 months.

22. In the last 12 months, was there a time when you could not receive the services you needed?

1☐ Yes
2☐ No

22a. If YES, which services were you unable to receive? (CHECK ALL THAT APPLY)

1☐ Help connecting to services and resources for the adult care for
2☐ Help connecting to services and resources for children I care for
3☐ Respite care
4☐ Caregiver training, education, counseling, or support groups
5☐ Supplemental services

22b. If YES, what were the reason(s) you were not able to receive the service(s)? (CHECK ALL THAT APPLY).

1☐ Service was not available in my area
2☐ There was a waitlist to receive the service
3☐ Unable to schedule at a convenient time
4☐ Provider cancelled or did not show up
5☐ Lack of transportation to access service
6☐ Other (please describe): _____
7☐ Don't know

SECTION 3. OUTCOMES OF CAREGIVER SUPPORT

The questions in this section ask about how the caregiver support experiences have affected your life.

SERVICES

23. As a result of the caregiver support services do you:

(CHECK ONE BOX ON EACH LINE)	Yes	No	
a. Have more time for personal activities?	1☐	2☐	
b. Feel less physical stress?	1☐	2☐	
c. Feel less emotional stress?	1☐	2☐	
d. Feel less worried about money?	1☐	2☐	
e. Have a better understanding of how to get needed services for the person you care for?	1☐	2☐	
f. Feel more confident in providing care to the person you care for?	1☐	2☐	
			Not Applicable
g. [If caring for an adult] Know more about the condition or illness of the adult person you care for?	1☐	2☐	3☐
h. [If caring for grandchildren] Know more about the needs of the child/children you care for?	1☐	2☐	3☐
i. [If employed] Have fewer conflicts with your job?	1☐	2☐	3☐

24. Have the caregiver support services you've received helped you to provide care for a longer period of time than would have been possible without these services?

1☐ Yes, definitely
2☐ Yes, probably
3☐ No, probably not
4☐ No, definitely not
5☐ Don't know

25. Would the person you care for have been able to continue to live in the community (outside of a nursing home or other care facility) if <u>you had not</u> received caregiver support services?

1☐ Yes, definitely
2☐ Yes, probably
3☐ No, probably not
4☐ No, definitely not
5☐ Don't know
6☐ The person I care for does not live in his/her own home

26. To what extent have the caregiver support services improved your quality of life?

1☐ Very much
2☐ Somewhat
3☐ Very little
4☐ Not at all
5☐ Don't know

SECTION 4. CAREGIVER HEALTH

The questions in this section ask about some potential benefits and challenges you may have when providing care to the person you care for.

27. In your experience as a caregiver, how important is each of the following?

(CHECK ONE BOX ON EACH LINE)	Not at all Important	Not Important	Somewhat Important	Very Important
a. Helping the person I care for live at home	1☐	2☐	3☐	4☐
b. Spending time with someone I care about	1☐	2☐	3☐	4☐
c. Feeling a sense of accomplishment	1☐	2☐	3☐	4☐
d. Satisfaction that my care and attention are received	1☐	2☐	3☐	4☐
e. Being appreciated	1☐	2☐	3☐	4☐
f. Fulfilling a duty	1☐	2☐	3☐	4☐
g. Other, please specify: _____	1☐	2☐	3☐	4☐

28. Do you have any kind of health problem, physical condition, or disability that affects the amount or type of care that you can provide?

1☐ Yes
2☐ No
3☐ Don't know

29. How <u>physically difficult</u> would you say it is for you to provide care to the person you care for?

1☐ Not at all difficult
2☐ A little difficult
3☐ Somewhat difficult
4☐ Very difficult

30. How <u>emotionally difficult</u> would you say it is for you to provide care to the person you care for?

1☐ Not at all difficult
2☐ A little difficult
3☐ Somewhat difficult
4☐ Very difficult

31. How <u>financially difficult</u> would you say it is for you to provide care to the person you care for?

1☐ Not at all difficult
2☐ A little difficult
3☐ Somewhat difficult
4☐ Very difficult

32. Has your caregiving ever interfered with your employment?

1☐ Yes, but I continue to work
2☐ Yes, I took a leave of absence but went back to work
3☐ Yes, I reduced my hours as a result
4☐ Yes, I retired early as a result

5 ☐ Yes, I quit work as a result
6 ☐ Yes, I lost my job as a result
7 ☐ No
8 ☐ I was never employed while providing care

SECTION 5. A LITTLE ABOUT YOU!

33. What is your age? _____

34. What is your sex?

1 ☐ Male
2 ☐ Female
3 ☐ Other

35. What is your race? (CHECK ALL THAT APPLY)

1 ☐ White
2 ☐ American Indian or Alaska Native
3 ☐ Asian
4 ☐ Black or African American
5 ☐ Native Hawaiian or Other Pacific Islander

36. Are you of Hispanic, Latino/a, or of Spanish Origin?

1 ☐ Yes
2 ☐ No

37. What is your marital or relationship status?

1 ☐ Married
2 ☐ Partnered
3 ☐ Widowed
4 ☐ Divorced
5 ☐ Separated
6 ☐ Never married

38. In general, how would you rate your overall health?

1 ☐ Excellent
2 ☐ Very good
3 ☐ Good
4 ☐ Fair
5 ☐ Poor

Thank you very much for completing this survey. Please return it in the envelope provided to: