

Appendix A: Full Questionnaire

SAMPLE:

- 1= Research Now, consumer ailments panel
- 2= Mental Health America
- 3= National Alliance for Mental Illness

SCREENER

1. How old are you? **[ALLOW 10 TO 110, TERMINATE IF LESS THAN 18]**

- 1a. **[ONLY ASK OF SAMPLE 2 & 3]** Do you live in the United States?
Yes 1
No 2 **TERMINATE**

2. At any time in the last 12 months, have you provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?

This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

Yes 1
No..... 2 **TERMINATE**

3. Did any of those adults you cared for have an emotional or mental health problem?

Yes 1
No..... 2 **TERMINATE**
Not Sure 3 **TERMINATE**

4. Were you caring for five or more adults at the same time, all who had an emotional or mental health problem?

Yes 1
No..... 2 **[SKIP TO Q6]**

5. **[IF YES (Q4=1), ASK]:** Are all of those adults living together in some sort of institutional setting, like a nursing home, school, or group home where you work or volunteer?

Yes..... 1 **TERMINATE**
No 2

6. Please think about the adult you cared for in the past year, who had the most serious emotional or mental health issues. If you've only cared for one adult with a mental health problem, think about that person.

How would you describe that adult's emotional or mental health problem?

- Serious 1
Moderate 2
Mild 3 **TERMINATE**

This is an important study, sponsored by the National Alliance for Caregiving [IF MHA (SAMPLE=2): , in cooperation with Mental Health America/IF NAMI (SAMPLE=3): , in cooperation with NAMI].

For the rest of the questions, please think about that adult you care (or cared) for in the past year who had or has the most serious emotional or mental health issue.

7. Are you currently providing care to this person, or was this something you did in the past 12 months and are no longer doing?

- Currently 1
Past 12 months but not currently 2

8. {Do/Did} you help that adult with any of these things:

Arranging or providing transportation, shopping, housework, preparing meals, managing finances, giving medicines or injections, or arranging services?

- Yes 1
No 2

9. And {do/did} you help them with any of these things:

Bathing or showering, getting to and from the toilet, helping them get out of beds or chairs, dressing, dealing with incontinence or diapers, or feeding them?

- Yes 1
No 2

TERMINATE IF Q8 = 2 AND Q9 = 2 (NOT A CAREGIVER, NO ADL OR IADL).

10. And {is/was} the person you {care/cared} for...

- Male 1
Female 2

11. {Are/Were} you related to the person you {care/cared} for?

- Yes 1
No 2

12. Who {are you caring/did you care} for?

IF FEMALE RELATIVE (Q10=2 and Q11=1), SHOW THESE RESPONSES:

Aunt	1
Cousin	5
Daughter.....	6
Grandmother/Grandmother-in-Law.....	10
Granddaughter	11
Mother	13
Mother-in-Law.....	14
Niece	16
Sister	17
Sister-in-Law.....	18
Spouse	20
Partner/Companion	4
Other relative [Specify: _____]	30
Decline to respond.....	99

IF MALE RELATIVE (Q10=1 and Q11=1), SHOW THESE RESPONSES:

Brother.....	2
Brother-in-Law	3
Cousin	5
Father	7
Father-in-Law	8
Grandfather/Grandfather-in-Law.....	9
Grandson.....	12
Nephew	15
Son	19
Spouse	20
Partner/Companion	4
Uncle	21
Other relative [Specify: _____]	30
Decline to respond.....	99

IF NOT RELATIVE (Q11=2), SHOW THESE RESPONSES:

Friend	41
Neighbor	42
Other [Specify: _____]	43
Decline to respond.....	99

13. [IF CURRENT (Q7=1)]: How old is your [RELATION]? Your best estimate is fine.

[IF PAST (Q7=2)]: How old was your [RELATION], at the time you last provided care?
Your best estimate is fine.

___ ___ ___ [ALLOW 0-130. IF LESS THAN 18, TERMINATE]

Decline to respond..... 999

- 13B. **[IF DECLINE (Q13=999)]:** {Is/Was} your **[RELATION]** age...?
- Under 18 1 **[TERMINATE]**
 - 18 to 34..... 2
 - 35 to 49..... 3
 - 50 to 64..... 4
 - 65 or older..... 5

14. How long {have you been providing/did you provide} care to your **[RELATION]**?
Your best estimate of years of care is fine.

___ ___ years **[ALLOW 1 - 93]**

- Less than six months 96
- Six months to one year 95
- Not sure..... 98

15. About how many hours {do/did} you spend in an average week, helping your **[RELATION]**?

Your best estimate of hours per week is fine.

___ ___ ___ hours **[ALLOW 1-168]**

- Less than 1 hour per week 900
- Constant care (24 hours a day, 7 days a week) 901
- Not sure..... 998

- 15B. **[IF NOT SURE (Q15=998)]:** On average, {do/did} you provide care for...?

- 0 to 8 hours a week 1
- 9 to 20 hours a week..... 2
- 21 to 39 hours a week..... 3
- 40 or more hours a week 4

16. {Has/Was} your **[RELATION]** {ever been/ever} homeless for a period of a month or longer?

- Yes 1
- No..... 2
- Not sure..... 3

17. How far away {does/did} your [RELATION] live {currently/at the time you last provided care}?

If your loved one {is/was} homeless, please indicate the distance {{he/she}} usually {stays/stayed}.

- In your household 1
- Within twenty minutes of your home 2
- Between twenty minutes and an hour from your home..... 3
- One to two hours from your home, or 4
- More than two hours away 5

IF IN HOUSEHOLD (Q17=1), SKIP TO Q19.

18. [IF CR NOT IN CG HH (Q17>1), ASK]: {Does/Did} your [RELATION] live alone [IF PAST (Q7=2): at the time you provided care]?

- Yes 1
- No 2
- {{He/She}} {is/was} homeless 3

DIAGNOSIS AND MISDIAGNOSIS

19. What {is/was} the main emotional or mental health issue your [RELATION] {has/had}, for which {{he/she}} {requires/required} care?

{{He/She}} may {have/have had} multiple conditions, but please mark the main emotional or mental health problem.

[ONLY SHOW CODES IN BLACK FONT ON SCREEN, MAINTAIN ORDER.]

- Anxiety.....2
- Bipolar disorder4
- Depression9
- Paranoia or Paranoid personality disorder22
- Posttraumatic stress disorder (PTSD)26
- Schizophrenia.....29
- Social anxiety disorder31
- Something else [SPECIFY REQUIRED: _____]34
- Not sure35

Additional codes used for coding "other":

- | | |
|---|--|
| <i>Anorexia nervosa 1</i> | <i>Binge eating disorder 3</i> |
| <i>Borderline personality disorder..... 5</i> | <i>Bulimia 6</i> |
| <i>Cyclothymic disorder 7</i> | <i>Delusional disorder 8</i> |
| <i>Dissociative disorder 10</i> | <i>Dyslexia 11</i> |
| <i>Generalized anxiety disorder..... 13</i> | <i>Hoarding 14</i> |
| <i>Hypomania 15</i> | <i>Insomnia 16</i> |
| <i>Kleptomania 17</i> | <i>Mania 18</i> |
| <i>Multiple personality disorder..... 19</i> | <i>Obsessive compulsive disorder..... 20</i> |
| <i>Panic disorder 21</i> | <i>Paraphrenia 23</i> |
| <i>Personality disorder..... 24</i> | <i>Phobia 25</i> |

<i>Pyromania</i>	27	<i>Schizoaffective disorder</i>	28
<i>Schizophreniform disorder</i>	30	<i>Somatic symptom disorder</i>	32
<i>Tourette’s syndrome</i>	33	<i>Eating disorder not specified</i>	40

20. {Does/did} your **[RELATION]** have an alcohol or substance abuse issue?
 Yes 1
 No..... 2
 Not sure 3
21. {Do/Did} you feel your **[RELATION]**’s mental health issues {have been/were} accurately diagnosed?
 Yes 1
 No..... 2
 Not sure 3
22. **[IF PROPERLY DIAGNOSED (Q21=1), SHOW]:** How many years did your **[RELATION]** display symptoms of an emotional or mental health issue before you felt {{he/she}} was accurately diagnosed?
[IF NOT PROPERLY DIAGNOSED (Q21>1), ASK]: How many years {has/did} your **[RELATION]** {been trying/try} to get an accurate diagnosis for {his/her} emotional or mental health issues?
Your best estimate of years is fine.
 ___ ___ years **[ALLOW 1 - 93]**
 Less than six months 96
 Six months to one year 95
 Not sure 98

MEDICATION MANAGEMENT

23. {Is/Was} your **[RELATION]** taking any prescription medication(s) to help manage {{his/her}} mental or emotional illness?
 Yes 1
 No 2 **[SKIP TO Q26]**
 Not sure 3 **[SKIP TO Q26]**

24a. **[IF RELATION IS ON MEDICATION (Q23=1), ASK]:** How difficult {is/was} it to find a specific drug and dosage that you {feel works/felt worked} for your [RELATION]'s mental health issue(s)? **[ROTATE HALF 1-5/5-1, ALWAYS SHOW NOT SURE AT BOTTOM.]**

- 1 - Not at all difficult 1
- 2 2
- 3 3
- 4 4
- 5 – Very difficult 5
- Not sure 9

24b. **[IF RELATION IS ON MEDICATION (Q23=1), ASK]:** And how difficult {is/was} it to get your [RELATION] to take {{his/her}} medication as prescribed (the right amount at the right time)? **[ROTATE HALF 1-5/5-1, SAME ORDER AS Q24A.]**

- 1 - Not at all difficult 1
- 2 2
- 3 3
- 4 4
- 5 – Very difficult 5
- Not sure/Not applicable 9

25. **[IF RELATION IS ON MEDICATION (Q23=1), ASK]:** And how well {do/did} you feel your [RELATION]'s condition {is/was} managed with {{his/her}} medication? **[ROTATE HALF 1-5/5-1, SAME ORDER AS Q24A.]**

- 1 – Not managed well at all 1
- 2 2
- 3 3
- 4 4
- 5 – Managed very well 5
- Not sure/Not applicable 9

OTHER SUPPORT

26. {Has/Had} anyone else provided unpaid help to your [RELATION] during the last 12 months **[IF PAST (Q7=2): that you provided care]**?

- Yes 1
- No 2

29. How much do you agree or disagree with each statement below? [RESPONSE SCALE – ROTATE HALF 1-5/5-1]

		Strongly disagree	Disagree	Neither	Agree	Strongly agree
a.	I {am/was} able to leave my [RELATION] alone	1	2	3	4	5
b.	My [RELATION] {can/could} rely on other friends or family to help {{him/her}}	1	2	3	4	5
c.	It {is/was} difficult to speak with others about my [RELATION]'s mental or emotional health issues	1	2	3	4	5

INVOLVEMENT IN CARE PROCESS

30. Where {do/did} you go for help or information about caring for your [RELATION]'s emotional or mental health condition? *Check all that apply* [ALLOW MULTIPUNCH ON 1-7; RANDOMIZE 1 – 7]

- Disease-specific websites 1
- Doctor or health care professional..... 2
- General Internet searches 3
- In-person support groups 4
- Mental health organizations (Mental Health America, NAMI, VA).. 5
- Online support groups 6
- Other [SPECIFY: _____] 7
- Never got help/information 8

31. Have you ever had any kind of education or training to help you care for someone with a mental or emotional illness?

- Yes 1
- No 2

32. {Have/Did} you ever {had/have} a provider or care professional tell you they were not allowed to speak with you about your [RELATION]'s care or condition?

- Yes 1
- No..... 2
- Not sure 3

33. To what extent {do/did} you feel care providers {have/had} included you in conversations about your [RELATION]’s care? [ROTATE 1-5/5-1]

- Not included at all, but you did not need to be..... 1
- Not included at all when you should have been..... 2
- Included by some, but not all..... 3
- Included when needed 4
- Included more than you should have been..... 5

SERVICE ACCESS

34. Select any care or support services you feel your [RELATION] {needs/needed}, even if you {have been/were} unable to locate or find this kind of help. [ALLOW MULTIPUNCH ON RESPONSES 1-8. RANDOMIZE RESPONSES 1-8, KEEP RESPONSE 9 & 10 AT BOTTOM.]

1	Day programs or day treatment
2	Pharmacy that {has/had} needed medications
3	Mental health professional, like a psychiatrist, therapist, or counselor
4	Case manager
5	Treatment program or facility for substance abuse or alcohol issues (rehab)
6	Peer support, like peer coaches, counselors, or support groups
7	In-patient mental health facility or hospital
8	Medical provider (doctor or nurse practitioner) who {understands/understood} {{his/her}} mental health issues
9	None needed
10	Not sure

IF NONE OR NOT SURE (Q34=9 or 10), SKIP TO Q36A-B.

35. Of the care or support services you {feel/felt} your [RELATION] {needs/needed}, which {have been/were} difficult to find in {{his/her}} area or community?

[MULTIPUNCH ALLOWED; SHOW ONLY THOSE SELECTED IN Q34, MAINTAIN ORDER AND FORMATTING OF Q34. ALWAYS SHOW RESPONSES 9-10 AT BOTTOM.]

1	Day programs or day treatment
2	Pharmacy that {has/had} needed medications
3	Mental health professional, like a psychiatrist, therapist, or counselor
4	Case manager
5	Treatment program or facility for substance abuse or alcohol issues (rehab)
6	Peer support, like peer coaches, counselors, or support groups
7	In-patient mental health facility or hospital
8	Medical provider (doctor or nurse practitioner) who {understands/understood} {{his/her}} mental health issues
9	None were difficult to find
10	Not sure

How satisfied {are/were} you with:

36a. Amount of community services for people with mental health issues in your [RELATION]'s area? [ROTATE HALF 1-5/5-1, ALWAYS SHOW NOT SURE AT BOTTOM. MAINTAIN SAME ROTATION FOR ALL Q36 SERIES]

- 1 - Not at all satisfied 1
- 2 2
- 3 3
- 4 4
- 5 – Very satisfied 5
- Not sure 9

36b. Quality of community services for people with mental health issues in your [RELATION]'s area? [SHOW SCALE IN SAME ORDER AS Q36A]

- 1 - Not at all satisfied 1
- 2 2
- 3 3
- 4 4
- 5 – Very satisfied 5
- Not sure 9

INPATIENT SERVICE

37. In the time you have {been providing/provided} care to your [RELATION], {has/did} {{he/she}} ever {gone/go} to an emergency room, hospital, or other facility due to an urgent or crisis situation for {{his/her}} mental health issues?

- Yes 1
- No 2 [SKIP TO Q40]
- Not sure 3 [SKIP TO Q40]

38. Of all the times your [RELATION] went to an emergency room, hospital, or other facility due to an urgent mental health issue, do you feel {{he/she}} was ever sent home too early or too quickly?

- Yes 1
- No 2
- Not sure 3

FINANCES, LEGAL

40. {Do/Did} you help manage your [RELATION]'s care paperwork or finances, including forms, bills, payments, or health insurance?
Yes 1
No..... 2 [SKIP TO Q43]
41. **[IF HELPS MANAGE CARE PAPERWORK (Q40=1), ASK]:** How time consuming {is/was} it for you to help your [RELATION] with {{his/her}} care paperwork or finances? **[ROTATE 1-5/5-1]**
1 - Not at all time consuming 1
2 2
3 3
4 4
5 – Very time consuming 5
Not sure 9
43. How financially dependent {is/was} your [RELATION] on {{his/her}} family or friends? **[RANDOMIZE HALF 1-5/5-1, SAME ORDER AS Q41]**
1 - Not at all dependent 1
2 2
3 3
4 4
5 - Completely dependent 5
Not sure 9
44. {Do/Did} you have any legal responsibility for your [RELATION], such as guardianship, power of attorney, or medical power of attorney?
Yes 1
No..... 2
45. {Has/Was} your [RELATION] ever {been arrested/arrested}?
Yes 1
No..... 2
Not sure 3
46. {Do/When you were last providing care, did} you want more information or help dealing with legal issues related to your [RELATION]?
Yes 1
No..... 2

STRESS OF CAREGIVING

47. How emotionally stressful would you say that caring for your [RELATION] {is/was} for you? [ROTATE 1-5/5-1]

- 1 – Not at all stressful 1
- 2 2
- 3 3
- 4 4
- 5 – Very stressful..... 5

48. {Do/Did} you or your [RELATION] have plans in place for who {will take/would have taken} care of {{him/her}} if you {are/had been} unable to?

- Yes 1
- No..... 2

49. As a caregiver, how much do you agree or disagree with each statement? [ROTATE 1-5/5-1]

		Strongly disagree	Disagree	Neither	Agree	Strongly agree
a.	I {have/had} less time for myself than I {like/liked}	1	2	3	4	5
b.	My [RELATION] {shows/showed} real appreciation for what I {do/did} for {{him/her}}	1	2	3	4	5
c.	Helping my [RELATION] {helps/helped} me feel close to {{him/her}}	1	2	3	4	5
d.	I {find/found} it difficult to take care of my own health	1	2	3	4	5
e.	I {feel/felt} alone	1	2	3	4	5

50. {How would you describe your health?/When you were last caregiving, was your health...}? [ROTATE 1-5/5-1]

- Excellent 5
- Very good 4
- Good 3
- Fair 2
- Poor..... 1

51. How would you say taking care of your [RELATION] [IF PAST (Q7=2): has] affected your health? [ROTATE 1-3/3-1]
- Made it better 1
 - Not affected it 2
 - Made it worse 3

CAREGIVER SUPPORT & INFORMATION

52. Which of the following policies or programs would {be/have been} most helpful to you as a caregiver? [RANDOMIZE 1-4, KEEP NONE AT BOTTOM]
- Training for law enforcement and first responders about mental or emotional health issues 1
 - Requiring health insurance plans to cover mental or emotional health care at similar levels as they cover medical care 2
 - Education for you about caring for someone with a mental or emotional health issue 3
 - Care navigator to help you or your [RELATION] figure out mental health care system and service providers 4
 - None of the above 9

HARMING

53. Have you ever been concerned that your [RELATION] would do any of the following? *Please select all that apply.* [SHOW RESPONSES IN ORDER, MULTIPUNCH 1-5]
- Be hurt by someone 1
 - Destroy property 2
 - Hurt themselves..... 3
 - Hurt you or someone else 4
 - Other [SPECIFY REQUIRED:_____] 5
 - None of the above 6
54. {Have/Were} you {ever been/ever} concerned that your [RELATION] would die by suicide?
- Yes 1
 - No 2
55. What is the one thing that would {help/have helped} you most as a caregiver of someone with mental illness? [OPEN-ENDED]
-

DEMOGRAPHICS

Finally, we just have a few basic questions for classification purposes only.

56. Did your **[RELATION]** serve in the US armed forces?
- Yes 1
No..... 2
Not sure..... 3
57. {Does/Did} your **[RELATION]** live in a rural area **[IF PREVIOUS CAREGIVER: at the time you provided care]**?
- Yes 1
No..... 2
58. Are you...
- Male..... 1
Female 2
59. What is the last grade of school you completed?
- Less than high school 1
High school grad/GED..... 2
Some college..... 3
Technical school or associate's degree..... 4
College graduate with bachelor's degree 5
Graduate school/ Grad work or professional degree 6
60. {Are/When you were last caregiving, were} there any children or grandchildren living in your household under 18 years of age?
- Yes 1
No..... 2
Decline to respond..... 3
61. Are you Hispanic or Latino?
- Yes 1
No..... 2
Decline to respond..... 3

62. Are you...

Please select all that apply. [ALLOW MULTIPUNCH 1-5]

- White 1
- African-American/Black 2
- Asian/Pacific Islander 3
- Native American/Alaskan Native 4
- Other [SPECIFY _____] 5
- Decline to respond..... 6

63. {What is/At the time of caregiving, what was} your annual household income?

- Under \$15,000 1
- \$15,000 to \$29,999..... 2
- \$30,000 to \$49,999..... 3
- \$50,000 to \$74,999..... 4
- \$75,000 to \$99,999..... 5
- \$100,000 or more 6
- Decline to respond..... 7

64. Do you have any final comments, either about your experiences as a caregiver or about this survey?

No comment 99

CLOSE: Thank you for participating in this important research project. You can see results of this study on www.caregiving.org in late 2015/early 2016.