

NPRC Outcomes Evaluation QoL Grantee End-User Survey¹

Section 1. Introduction

The Administration for Community Living (ACL) is conducting an evaluation of the **National Paralysis Resource Center (NPRC)**, which is implemented by the Reeve Foundation. The purpose of this evaluation is to learn more about the Reeve Foundation's programs and what lessons can be learned to inform other ACL programs.

As part of this evaluation, ACL needs your help. You have been specially selected because you or someone you care for participated in a program run by a local organization that received a grant from the Reeve Foundation. Your participation in this survey will ensure that the evaluation captures the full range of participants' experiences with the Reeve Foundation programs and services.

If you are receiving this survey because you are the contact person for someone who participated in a local organization's program, please ask the participant to complete the survey.

[ORGANIZATION NAME TO BE PROVIDED PRIOR TO SURVEY LAUNCH.
PROGRAMMER: CREATE A SPECIFIC LINK FOR EACH ORGANIZATION.]

Section 2. Program experience

(Required) Q1. In the past 12 months, have you had contact with the following organization: [FILL-IN ORGANIZATION NAME]?

- a. Yes
- b. No [GO TO END1]

Q2. How long have you been in contact with this organization?

- a. Less than 1 month
- b. 1-6 months
- c. 7-12 months
- d. More than 1 year

(Required) Q3. Which of the following choices best described you when you participated in this local organization's program(s) or service(s)?

- a. Someone living with paralysis
- b. Caregiver to someone living with paralysis

Section 3. Quality of Life grantee outcomes

Q4. When you first contacted this organization, what did you hope to gain? Choose up to three of the following answers.

[PROGRAMMER: USE HIDE OPTION LOGIC FOR FILL INS. UPON SELECTION, SHOW FILL INS FOR Q4 TO Q6.2]

- a. Better physical health [FILL IN TEXT: your physical health]
- b. Better mental health [FILL IN TEXT: your mental health]
- c. Improvement in abilities, skills, or knowledge about living with paralysis [FILL IN TEXT: your abilities, skills, or knowledge about living with paralysis]
- d. Learn about services for those living with paralysis [FILL IN TEXT: your knowledge about services for those living with paralysis]
- e. Access services that could be helpful to me [FILL IN TEXT: your access to services that would be helpful for you]
- f. Increase sense of control over decisions (empowerment) [FILL IN TEXT: your sense of control]
- g. Feel more confident to take action to achieve life goals [FILL IN TEXT: your sense of confidence]
- h. Greater independence [FILL IN TEXT: your independence]

¹ Unless flagged, questions are not required and will only get a soft prompt encouraging them to answer to the best of their ability.

- i. Strengthen my support network [FILL IN TEXT: your support network]
- j. Participate more in community life [FILL IN TEXT: your ability to participate in community life]
- k. Other (Specify) [FILL IN TEXT: write in reason]

The following questions will ask about the types of things you hoped to achieve from this organization’s program(s). We will also ask how you felt about these aspects of your life before and after participating in this organization’s program(s) or service(s).

Q5. [IF Q3=a, then FILL2=“your paralysis”; ELSE IF Q3=b, then FILL2=“paralysis in someone you care for”]
Thinking about your situation **before** contacting this organization, to what extent did [FILL2] affect [PROGRAMMER: INSERT WITH FILL IN OF FIRST ORDERED SELECTION IN Q4]

1	2	3	4	5	6	7
Not at all			Somewhat			To a great extent

Q6. On a scale from 1 to 7, how was [PROGRAMMER: INSERT FILL IN TEXT OF FIRST ORDERED SELECTION IN Q4] **just before** participating in this organization’s program(s) or service(s)?

1	2	3	4	5	6	7
Poor			Neutral			Excellent

Q7. On a scale from 1 to 7, how is [PROGRAMMER: INSERT FILL IN TEXT OF FIRST ORDERED SELECTION IN Q4] **after** participating in this organization’s program(s) or service(s)?

1	2	3	4	5	6	7
Poor			Neutral			Excellent

Q5.1 [IF Q3=a, then FILL2=“your paralysis”; ELSE IF Q3=b, then FILL2=“paralysis in someone you care for”]
Thinking about your situation **before** contacting this organization, to what extent did [FILL2] affect [PROGRAMMER: INSERT WITH FILL IN OF SECOND ORDERED SELECTION IN Q4]

1	2	3	4	5	6	7
Not at all			Somewhat			To a great extent

Q6.1 On a scale from 1 to 7, how was [PROGRAMMER: INSERT FILL IN TEXT OF SECOND ORDERED SELECTION IN Q4] **just before** participating in this organization’s program(s) or service(s)?

1	2	3	4	5	6	7
Poor			Neutral			Excellent

Q7.1 On a scale from 1 to 7, how is [PROGRAMMER: INSERT FILL IN TEXT OF SECOND ORDERED SELECTION IN Q4] **after** participating in this organization’s program(s) or service(s)?

1	2	3	4	5	6	7
Poor			Neutral			Excellent

Q5.2 [IF Q3=a, then FILL2=“your paralysis”; ELSE IF Q3=b, then FILL2=“paralysis in someone you care for”]
Thinking about your situation **before** contacting this organization, to what extent did [FILL2] affect [PROGRAMMER: INSERT WITH FILL IN OF THIRD ORDERED SELECTION IN Q4]

1	2	3	4	5	6	7
Not at all			Somewhat			To a great extent

Q6.2 On a scale from 1 to 7, how was [PROGRAMMER: INSERT FILL IN TEXT OF THIRD ORDERED SELECTION IN Q4] **just before** participating in this organization’s program(s) or service(s)?

1	2	3	4	5	6	7
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Poor			Neutral			Excellent
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Q7.2 On a scale from 1 to 7, how is [PROGRAMMER: INSERT FILL IN TEXT OF THIRD ORDERED SELECTION IN Q4] after participating in this organization's program(s) or service(s)?

1 Poor	2	3	4 Neutral	5	6	7 Excellent
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Section 4. Background information

Q8. How old are you?

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 or over

Q9. Which of the following describes you? Select all that apply.

- American Indian/Alaska Native
 - Black/African American
 - Native Hawaiian/Pacific Islander
 - Asian
 - White/Caucasian
 - Some other race
99. Prefer not to answer

Q10. Are you of Hispanic, Latino, or Spanish origin or descent?

- Yes
 - No
98. Don't know
99. Prefer not to answer

Q11. What is the highest level of school you have completed?

- Less than high school
- High school or equivalent
- Some college/university, no degree
- College or university degree
- Postgraduate degree

Q12. What sex were you assigned at birth, on your original birth certificate?

- Female
 - Male
98. Don't know
99. Prefer not to answer

Q13. What is your current gender?

- Female
 - Male
 - Transgender
 - [If Q9=a] Two-Spirit
 - I use a different term. (OPEN ENDED)
98. Don't know
99. Prefer not to answer

Q14. Which of the following best represents how you think of yourself?

- a. Lesbian or gay
- b. Straight, that is, not gay or lesbian
- c. Bisexual
- d. [If Q9=a] Two-Spirit
- e. I use a different term (Specify)
- 98. Don't know
- 99. Prefer not to answer

Q15. [IF Q3=a, then question="Please provide the approximate date of the onset of paralysis.";

ELSE IF Q3=b, then question="Please provide the approximate date of your caregiving role."]

[PROGRAMMER: CALENDAR QUESTION FORMAT MONTH/YEAR]

- 98. Don't know

Q16. [If Q3=a, then question="What caused your paralysis? Select all that apply."

Else if Q3=b, then question="What caused the paralysis of the person you are providing care for? Select all that apply.]

- a. Spinal cord injury
- b. Brain injury
- c. Disease or syndrome
- d. Result of surgical or medical procedure
- e. Stroke
- f. Other (Specify)
- 98. Don't know

Q17. [If Q3=a, then question="What type of paralysis do you have? Choose one of the following answers."

Else if Q3=b, then question="What type of paralysis do you provide care for? Choose one of the following answers.]

- a. Paraplegia (T1 and below)
- b. Hemiplegia
- c. Quadriplegia (C8 and above)
- d. Other (Specify)
- 98. Don't know

[GO TO END2]

Section 5. End

END1. Thank you for your willingness to participate; however, you are ineligible at this time.

END2. We thank you for your time and cooperation in this study. Your anonymous responses are very important and will help the Administration for Community Living improve its support to resource centers nationwide.

Public Burden Statement:

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