

# Federal Lifespan Respite Program: Data Elements – Definitions and Instructions

version August 19, 2022

**Note on time periods:** Most reported data elements should cover the course of the project period; this is defined as the first day of your current Federal Lifespan Respite Program grant through the last day of the reporting period.

## Section A: Federal Lifespan Respite Program Care Services Delivered

### Item 1 – Federal Lifespan Respite Care delivered

For this item, report only on the respite care services, voucher funds, and other funds administered through your Federal Lifespan Respite grant for the purposes of providing respite.

- Respite care—Planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult. Respite care may be provided directly or through vouchers. In cases where traditional respite care is not available or desirable, respite may be provided through supplies or materials that help caregivers lessen the time or intensity of care.
- Hours of respite care delivered to date—The number of hours of respite care received by caregivers to date through the Federal Lifespan Respite program, reported in increments of 0.25 hours (i.e., 15 minutes). “Received” means that caregivers have utilized the respite. Overnight respite stays should also be counted by the number of hours.
- Expenditures on respite care to date—Federal Lifespan Respite Program Funds spent on respite care delivered to or redeemed by respite care vouchers.

### Item 2 – Federal Lifespan Respite Care delivered via voucher

For grants that provide respite care ONLY through vouchers, numbers in Item 2 will match those in Item 1.

- Respite Voucher—Funds provided to caregivers by the Lifespan Respite program for the purpose of obtaining respite services.
- Units of respite care delivered to date via redeemed vouchers—The number of hours of respite care services caregivers have used through redeemed Federal Lifespan Respite Program vouchers. Redeemed means that the caregiver has not only received the voucher but has also used it. Caregivers may have received more than one voucher. Partial hours of respite care may be combined to arrive at the total. Overnight respite stays paid for with Lifespan Respite Program vouchers should also be counted by the number of hours/units. One hour of respite care = one respite care unit.

- Expenditures to date on respite care via redeemed vouchers—Federal Lifespan Respite Program Funds spent on respite care vouchers that have been redeemed by caregivers.

**Item 3 – Sources of match for the Lifespan Respite Care Program**

- State government funds—Funds received from a state government agency.
- Local/community government funds—Funds received from a county, city, or other local community government agency.
- Foundation funds—Funds received from a private or nonprofit foundation.
- In-kind sources—Nonmonetary sources of match, such as volunteer time, materials, or space.
- Other funding source(s)—All other sources of funds for respite services.

**Item 4 – Location of Federal Lifespan Respite Care**

Individual caregivers may be counted only once per category. Caregivers who receive respite care in more than one location should be counted once for each applicable category.

- In-home respite (day)—Planned services that are provided during the day and originate in the home of the care recipient, the caregiver, or another private home in which the care recipient is temporarily residing.
- In-home respite (overnight)—Planned services that are provided overnight and originate in the home of the care recipient, the caregiver, or another private home in which the care recipient is temporarily residing.
- Out-of-Home respite (day)—Planned services that are provided during the day and originate outside of the location where the care recipient resides.
- Out-of-Home respite (overnight)—Planned services that are provided overnight and originate at a location outside of the place where the care recipient resides.
- Emergency respite—Unplanned respite care provided either in-home or out-of-home, during the day or overnight.
- Respite care location missing—Includes missing data and respite care location not specified by participant.

**Item 5 – Total people served by the Federal Lifespan Respite Program Funds**

Please report the number of unique (i.e., unduplicated) individuals served in each category over the course of the project period.

- Total caregivers served through the Federal Lifespan Respite Program Services—The number of unique (i.e., unduplicated) caregivers who have received respite care services or training. Caregivers who received more than one type of service should be counted only once in this line.

- Caregivers who received respite care—The number of unique (i.e., unduplicated) caregivers who have received respite care services or respite vouchers through the Federal Lifespan Respite Program.
- Caregivers who received training—The number of unique (i.e., unduplicated) caregivers who have fully completed training on the purposes and benefits of respite, how to obtain and manage respite care, how to plan for and use respite care, how to provide care to the care recipient, or how to care for oneself as a caregiver through the Federal Lifespan Respite Program.
- Care recipients—The number of unique (i.e., unduplicated) children and adults for whom Federal Lifespan Respite Program caregivers (i.e., the total caregivers reported in the first line of this item) provided care.

## **Section B: Federal Lifespan Respite Program – Caregiver Demographics**

Please report the cumulative number of unduplicated persons served over the course of the project period. Totals for each item should add up to the same number of caregivers reported in Section A, Item 5, line 1 – *Total caregivers served through Federal Lifespan Respite Program Services*.

### **Item 1 – Caregiver Age**

- 18-24
- 25-39 years
- 40-64 years
- 65 years and over
- Age missing—Includes missing data and age not specified or left blank by participant.

### **Item 2 – Caregiver Gender Identity**

Caregivers (or caregiver proxy) should be given the opportunity for self-identification.

- Woman—A person who identifies as a woman, regardless of the sex assigned at birth.
- Man—A person who identifies as a man, regardless of the sex assigned at birth.
- Nonbinary/nonconforming—A person who does not identify solely as “woman” or “man.”
- Other gender identity—A person who indicates a gender identity different than the options listed.
- Gender missing—Includes missing data, gender not specified, left blank by participant, or not collected by grantee.

### **Item 3 – Caregiver Transgender**

- Transgender—A person whose current gender identity is different from the sex they were assigned at birth.
- Not transgender—A person whose current gender identity is the same as the sex they were assigned at birth
- Transgender missing—Includes missing data, transgender not specified, left blank by participant, or not collected by grantee

### **Item 4 – Caregiver Sexual Orientation**

Caregivers (or caregiver proxy) should be given the opportunity for self-identification.

- Lesbian or gay—A person who identifies as homosexual and is sexually oriented toward people of the same, usually binary, gender.
- Straight, that is, not gay or lesbian—A person who identifies as heterosexual and is sexually oriented toward people of a different, usually binary, gender.
- Bisexual—A person who identifies as sexually oriented toward both men and women.
- Other sexual orientation—A person indicates a sexual orientation different than the options listed.
- Sexual orientation not known by participant—A person indicates not knowing their/proxy’s sexual orientation (i.e., a response of “don’t know” when asked about one’s sexual orientation).
- Sexual orientation missing—Includes missing data, sexual orientation not specified, left blank by participant, or not collected by grantee.

### **Item 5 – Caregiver Geographic Location**

The geographic description of the area where the caregiver lives. Possible ways to collect this include: self (or proxy) report, or by collection of zip code and grantee using Rural-Urban Commuting Area (RUCA) codes<sup>1</sup> to determine the appropriate category.

- Urban—Central places and adjacent densely settled territories with a combined minimum population of 50,000.
- Suburban—A location with a population between 10,000 and 49,999.
- Rural—Open country and settlements with population between 2,500 and 9,999.
- Frontier—Sparsely populated areas that are geographically isolated from population centers and services, with population less than 2,500.
- Geographic location missing—Includes missing data and location not specified by participant.

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<sup>1</sup> <https://oaaps.acl.gov/Resources/rucaRes>

### **Item 6 – Caregiver Ethnicity**

- Hispanic or Latino—A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term “Spanish origin” can be used in addition to “Hispanic or Latino.”
- Not Hispanic or Latino.
- Ethnicity Missing—Includes missing data and ethnicity not specified by participant.

### **Item 7 – Caregiver Race**

Respondents should be given the opportunity for self-identification and must be allowed to designate all categories that apply to them. Therefore, the total here may be greater than the total in Section A, Item 5, line 1.

- American Indian or Alaska Native—A person having origins in any of the original peoples of North America (including Central America) and who maintains tribal affiliation or community attachment.
- Asian or Asian American—A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- Black or African American—A person having origins in any of the black racial groups of Africa.
- Native Hawaiian or Other Pacific Islander—A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- White—A person having origins in any of the peoples of Europe, the Middle East, or North Africa.
- Race Missing—Includes missing data and race not specified by participant.

### **Item 8 – Caregiver Relationship to Care Recipient**

Respondent should be allowed to self-identify the category that applies to their relationship. Caregiver indicates their role by selecting the term that applies to them.

- Adult child—Provides care to a parent.
- Parent – Provides care to a minor or adult child.
- Spouse or partner—Provides care to a spouse or partner.
- Grandparent – Provides care to a grandchild.
- Other kin caregiver—Provides care to a family member or relative not described in the categories above (e.g., aunt, uncle, cousin, sibling, daughter-in-law).
- Other relationship—Provides care to a friend, neighbor, or another person who is not a relative.

- Relationship missing—Includes missing data and relationship not specified by participant.

## **Section C: Federal Lifespan Respite Program - Care Recipient Demographics**

Please report the cumulative number of unduplicated persons served over the course of the project period. Totals for each item should add up to the same number of caregivers reported in Section A, Item 5, line 5.

### **Item 1 – Care Recipient Age**

- Under 18
- 18-24 years
- 25-39 years
- 40-64 years
- 65 years and over
- Age missing—Includes missing data and age not specified or left blank by participant.

### **Item 2 – Care Recipient Gender Identity**

Care recipient (or proxy) should be given the opportunity for self-identification.

- Woman/girl—A person who identifies as a woman or girl, regardless of the sex assigned at birth.
- Man/boy—A person who identifies as a man or boy, regardless of the sex assigned at birth.
- Nonbinary/nonconforming—A person who does not identify solely as “woman/girl” or “man/boy.”
- Other gender identity—A person who indicates a gender identity different than the options listed.
- Gender missing—Includes missing data, gender not specified, left blank by participant, or not collected by the grantee.

### **Item 3 – Care Recipient Transgender for Care Recipients age 18 and older**

- Transgender—A person whose current gender identity is different from the sex they were assigned at birth.
- Not transgender—A person whose current gender identity matches the sex they were assigned at birth.
- Transgender missing—Includes missing data, transgender not specified, left blank by participant, or not collected by the grantee.

#### **Item 4 – Care Recipient Sexual Orientation for Care Recipients age 18 and older**

Care recipient (or care recipient proxy) should be given the opportunity for self-identification.

- Lesbian or gay—A person who identifies as homosexual and is sexually oriented toward people of the same, usually binary, gender.
- Straight, that is, not gay or lesbian—A person who identifies as heterosexual and is sexually oriented toward people of a different, usually binary, gender.
- Bisexual—A person who identifies as sexually oriented toward both men and women.
- Other sexual orientation—A person who indicates a sexual orientation different than the options listed.
- Sexual orientation not known by participant—A person who indicates not knowing their/proxy’s sexual orientation (i.e., a response of “don’t know” when asked about one’s sexual orientation).
- Sexual orientation missing—Includes missing data, sexual orientation not specified by participant, left blank by participant, or not collected by the grantee.

#### **Item 5 – Care Recipient Geographic Location**

The geographic description of the area where the care recipient lives. Possible ways to collect this include self- or proxy report, or by collection of zip code and grantee using RUCA codes<sup>2</sup> to determine the appropriate category.

- Urban—Central places and adjacent densely settled territories with a combined minimum population of 50,000.
- Suburban—A location with a population between 10,000 and 49,999.
- Rural—Open country and settlements with population between 2,500 and 9,999.
- Frontier—Isolated, small rural areas with population less than 2,500.
- Geographic location missing—Includes missing data and location not specified by participant.

#### **Item 6 – Care Recipient Ethnicity**

- Hispanic or Latino—A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term “Spanish origin” can be used in addition to “Hispanic or Latino.”
- Not Hispanic or Latino.
- Ethnicity Missing—Includes missing data and ethnicity not specified by participant.

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<sup>2</sup> <https://oaaps.acl.gov/Resources/rucaRes>

## **Item 7 – Care Recipient Race**

Respondents should be given the opportunity for self-identification and must be allowed to designate all categories that apply to them. Therefore, the total may be greater than the total in line 5, Section A, Item 5.

- American Indian or Alaska Native—A person having origins in any of the original peoples of North America (including Central America) and who maintains tribal affiliation or community attachment.
- Asian or Asian American—A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- Black or African American—A person having origins in any of the black racial groups of Africa.
- Native Hawaiian or Other Pacific Islander—A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- White—A person having origins in any of the peoples of Europe, the Middle East, or North Africa.
- Race Missing—Includes missing data and race not specified by participant.

## **Section D: Federal Lifespan Respite Program - Respite Training**

### **Item 1 – Hours of Respite Training Provided through the Federal Lifespan Respite Program grant**

Indicate the cumulative number of hours of training over the course of the project period. Enter “0” for none.

- Hours of respite training provided through the Lifespan Respite grant to paid and volunteer respite providers, whether in person or online—The hours spent training each person count separately. The number of hours of training through the Federal Lifespan Respite program, reported in increments of 0.25 hours (i.e., 15 minutes). For example, a 2-hour training for 5 participants counts as 10 hours of respite training. Trainer time (including trainer preparation time) is not counted. Count training hours only for attendees who *fully* complete a training.
- Hours of respite training provided through the Lifespan Respite grant to caregivers—The hours spent training each caregiver count separately. The number of hours of training through the Federal Lifespan Respite program, reported in increments of 0.25 hours (i.e., 15 minutes). Training may cover the purposes and benefits of respite, how to obtain and manage respite care, how to plan for and use respite care, how to provide care to the care recipient, or how to care for oneself as a caregiver. Trainer time (including trainer preparation time) is not counted. Count training hours only for attendees who *fully* complete a training.



## **Section E: Awareness**

### **Item 1 – Respite Program Website and Registry for your State**

- Respite program website or webpage—A webpage, website, or other online presence dedicated to providing information on respite services and resources.
- Registry of respite providers—A comprehensive list of active respite care providers, including individuals and organizations, across the state.

### **Item 2 – Access to/Awareness of Respite Program Website and Registry for Your State**

Indicate the cumulative number of unique visitors over the course of the project period. Enter “0” for none or “n/a” if your state does not have a website or registry available to caregivers.

- Total respite program website visitors—The number of visits to the respite website or main webpage; this number may include more than one visit by the same person.
- Total respite registry webpage visitors—The number of visits to the main registry webpage; this number may include more than one visit by the same person. Please count only the primary page that includes registry listings; do not include all affiliated pages.

### **Item 3 – Outreach Activities to Build Respite Program Awareness Across the Lifespan**

Indicate which outreach activities your Lifespan Respite program has engaged in over the course of the project period.

- Hosted respite conference(s)—Conferences focused on respite and hosted by the state Lifespan Respite program or jointly sponsored and organized by the state Lifespan Respite program. A conference commonly involves multiple presentations available to attendees.
- Community presentations—Presentations focused on respite hosted by the state Lifespan Respite program or jointly by the state Lifespan Respite Program and another partner. A community presentation is typically 30 to 120 minutes in length.
- Social media posts—Social media posts created and posted that are dedicated to promoting the Lifespan Respite program or services.
- Radio advertisements—Radio advertisements created and aired that are dedicated to promoting the Lifespan Respite program or services.
- TV advertisements—TV advertisements created and aired that are dedicated to promoting the Lifespan Respite program or services.
- Newspaper advertisements—Newspaper advertisements created and published that are dedicated to promoting the Lifespan Respite program or services.
- PSAs—Public service announcements created and aired that are dedicated to promoting the Lifespan Respite program or services.

- e-Newsletters—A newsletter distributed electronically that includes information on the Lifespan Respite program or services.

#### **Item 4 – Number of e-newsletter subscribers**

- Subscribers—Individuals who regularly receive an e-newsletter that includes information on the Lifespan Respite program or services.

### **Section F: Lifespan Respite Program System and Providers**

#### **Item 1 – Lifespan Respite Program Coalition Meetings**

Indicate the cumulative number of meetings over the course of the project period. Enter “0” for none.

- Lifespan Respite Coalition or organization—A group of individuals and organizations/organizational representatives that convenes regularly, whether in-person or through telecommunications, to discuss, promote, and advance Lifespan Respite services, training, and system enhancement.
- Lifespan Respite coalition or organization meetings—Convening of coalition meetings in-person, via web or telecommunications. Meetings may include discussion of outreach, service provision, sustainability, funding, and enhanced coordination and partnership amongst community organizations and providers. Count only those meetings to which all coalition members are invited; subgroup or workgroup meetings are not included.

#### **Item 2 – Lifespan Respite Coalition Members**

Indicate the current number as of the final date of the reporting period. Enter “0” for none.

- Individual Lifespan Respite coalition members—Individuals who are included in coalition communications and meetings and who participate in a regular or meaningful way. Do not count people who are representing an organization or agency. This may include respite consumers, subject matter experts, or others.
- Organizational Lifespan Respite coalition members—Organizations with one or more representatives who are included in coalition communications and meetings and who participate in a regular or meaningful way.

#### **Item 3 – Lifespan Respite Providers**

Indicate the current number of respite providers as of the final date of the reporting period. Enter “0” for none.

- Number of organizations providing respite in the state—Number of organizations actively providing respite services to the community. Organizations should be counted once. Include all organizational providers of respite services in the state, whether funded by Lifespan Respite or other sources. Providers may be public, nonprofit, or for profit.