

Respite Model Description Tool

The purpose of the **Respite Model Description Tool** is to help researchers describe key aspects of respite interventions using common data elements that align with the *Value of Respite Model*. The following is a comprehensive list of questions that can be used to help describe key aspects of respite interventions. While it may not be feasible to assess all aspects, researchers are encouraged to include as many questions as possible in order to provide a comprehensive description of the respite intervention.

Population Served

What **age(s)** does the respite model serve? *Select all that apply.*

- Infants (birth to 3 years old)
- Preschool-age children (3-5 years old)
- School-age children (6-12 years old)
- Adolescents (13-17 years old)
- Young adults (18-29 years old)
- Adults (30-64 years old)
- Older adults (65 years and older)
- Other (please describe)

What types of **disabilities** and **conditions** does the respite model serve? *Select all that apply.*

- Physical disabilities (e.g., brain and spinal cord injury, amputations, spina bifida, multiple sclerosis, cerebral palsy, muscular dystrophy, epilepsy, and other neuromuscular disorders)
- Sensory disabilities (e.g., deafness/hard of hearing, visual impairment including blindness, sensory processing disorder)
- Intellectual and developmental disabilities (e.g., Autism/ASD, Down syndrome)
- Behavioral disabilities (e.g., generalized anxiety disorder, obsessive compulsive disorder, PTSD)
- Alzheimer's and Dementia
- Complex medical conditions
- Palliative or hospice care
- Functional limitations
- None
- Other (please describe)

Does the respite model serve any of the following historically **underrepresented populations**? *Select all that apply.*

- Hispanic or Latino
- Black or African Americans
- Asian
- American Indian or Alaska Native
- Middle Eastern or North African
- Native Hawaiian or Pacific Islander
- Immigrants
- Refugees
- LGBTQ+
- Individuals experiencing homelessness
- Children served in crisis nurseries
- Children living in environments that increase the risk of adverse experiences
- Children cared for by grandparents or other relatives
- Veterans or military families
- Other (please describe)

Location of Respite

Where does respite occur? *Select all that apply.*

- | | |
|--|---|
| <input type="checkbox"/> Caregiver's home | <input type="checkbox"/> Skilled nursing facility |
| <input type="checkbox"/> Care receiver's home | <input type="checkbox"/> Assisted living |
| <input type="checkbox"/> Respite provider's home | <input type="checkbox"/> Adult Day Services |
| <input type="checkbox"/> Respite facility | <input type="checkbox"/> Group home |
| <input type="checkbox"/> Community-based | <input type="checkbox"/> Foster home |
| <input type="checkbox"/> Faith-based | <input type="checkbox"/> Virtual (by phone or internet) |
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Other (please describe) |

Type of Respite

Which of the following describes the **type** of respite provided? *Select all that apply.*

- Formal respite program (administered by an organization)
- Informal respite (provided by family and friends)
- Volunteer respite program (provided by volunteers)
- Faith-based respite program (provided by faith-based organization)
- Student respite program (provided by students)
- Shared respite model (caregiver participates with care receiver during respite)

What type of **care** is provided during respite? *Select all that apply.*

- Companion care
- Instrumental care (activities of daily living)
- Administering medication
- Medical (non-nursing) care
- Skilled nursing care
- Therapies (physical, occupational, speech)
- Other (please describe)

What **activities** do respite providers do with the care receiver during respite? *Select all that apply.*

- Rest and relaxation
- Self-care activities (i.e. take a bath, get a massage, enjoy time in nature)
- Housework (i.e. cleaning, doing dishes, doing laundry)
- Watch TV
- Run errands (i.e. get groceries, get gas, go to post office)
- Go shopping
- Help others
- Eat
- Cook
- Exercise
- Read or write
- Time with friends
- Listen to music
- Travel
- Personal or medical care
- Recreation
- Participate in sports
- Play cards or board games
- Arts and crafts
- Watch movies
- Attend concerts
- Attend plays and musicals
- Go out to eat
- Go to the movies
- Attend community events
- Other (please describe)

Timing of Respite

When is respite provided? *Select all that apply.*

- Regular scheduled/preventive
- As needed/on demand
- During transitions
- Crisis/emergency respite
- Other (please describe)

Is there currently a **waitlist** for respite?

- Yes (please describe)
 - How many people are currently on the waitlist?
 - What is the average wait time for services?
- No

Is **free transportation** provided to/from respite?

- Yes
- No
- Not applicable

What type of **community** does the respite model serve? *Select all that apply.*

- Rural (open country and towns or cities with fewer than 2,500 people)
- Small town or city (towns or cities between 2,500 and 49,000 people)
- Medium city (between 50,000 and 99,000 people)
- Medium-large city (between 100,000 and 250,000 people)
- Large city (over 250,000 people)

Dose of Respite

Describe the **dose** of respite. Consider both frequency (how often) and duration (how long) respite occurs.

Examples:

- 2 hours of respite 5 days a week during the school year (9 months/year)
- 8 hours of overnight respite every month
- 3 weekends of respite per year
- 1 week of respite every summer

Cost of Respite

How are respite costs **paid**? *Select all that apply.*

- Caregiver pays out of pocket
- Public insurance (e.g., Medicaid, Medicare, Veterans Affairs)
- Private insurance
- Government funding
- Grant funding
- Charitable organization
- Individual sponsors/donors
- Other (please describe)

What is the out-of-pocket **cost** of respite to caregivers?

- No cost (Free to caregiver)
- Sliding scale based on income (please describe)
- Set amount per unit of respite (please describe)
- Other (please describe)

Respite Service Model

Which of the following best describes the **respite service model**?

- Stand-alone service
- Integrated within another program
- Other (please describe)

How long (in years) has the program provided respite?

_____ years

Person- and Family-Centeredness

Which of the following **core concepts** of Person- and Family-Centered Care* for planning, delivery, and evaluation of respite services are achieved by the respite model? *Select all that apply.*

- Respect and Dignity**
Respite providers listen to and honor the perspectives and choices of family caregivers and care receivers. Caregivers' and care receivers' knowledge, values, beliefs, and cultural backgrounds are integrated into the planning and delivery of respite services to ensure that care respects their unique needs and preferences.
- Information Sharing**
Respite care providers communicate and share complete, unbiased information with family caregivers and care receivers in ways that are clear and supportive. Caregivers receive timely, accurate,

and relevant information to actively participate in the planning and decision-making related to respite.

- Participation**
Family caregivers, and care receivers (if possible), are encouraged and supported to engage in the planning and decision-making of respite at their preferred level. They have the opportunity to be involved in decisions that affect the care of their loved ones, according to their comfort and preference.
- Collaboration**
Family caregivers, care receivers, and respite providers collaborate in developing, implementing, and evaluating respite services. This collaboration ensures that caregiver input and feedback are integral to the delivery and improvement of respite.

* Adapted from the [Institute for Patient- and Family-Centered Care](#) and informed by the [National Center on Advancing Person-centered Practices and Systems \(NCAPPS\)](#)

Respite Provider

Which of the following describes the **respite providers**? *Select all that apply.*

- Respite providers are **trained**
- Respite providers are **experienced**
- Respite providers are **paid**
- Respite providers receive **benefits**
- Respite providers are **volunteers**
- Respite providers receive **volunteer hours**
- Respite providers are **students**
- Respite providers receive **course credit**
- Respite providers understand the **culture** of the caregiver
- Respite providers speak the preferred **language** of the caregiver
- Respite is consistently provided by the **same** provider or group of providers
- Respite is provided by **different** providers as available
- Other (please describe)

Cultural and Linguistic Competence

Which of the following **culturally and linguistically competent services standards*** are achieved by the respite model? *Select all that apply.*

- Provide effective, equitable, understandable, and respectful quality respite services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.
- Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and respite workforce that are responsive to the population in the service area.
- Educate and train governance, leadership, and respite workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.
- Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to respite services.
- Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

** Adapted from the [CLAS Standards](#) and informed by the [ARCH Cultural and Linguistic Competence Assessment for Respite Organizations](#)*

Open Ended

Please provide any **additional information** that helps to describe the respite intervention.

The *Respite Model Description Tool* was developed by Dr. Kim Whitmore in conjunction with the work of the ARCH Committee for Advancement of Respite Research. This tool has not yet undergone formal validation procedures. For more information about the tool, email kimberly.whitmore@marquette.edu.

Suggested Citation: Whitmore, K. (2024). *Respite Model Description Tool*. ARCH National Respite Network and Resource Center. Available online at <https://archrespite.org/library/cde-white-paper/>.

This publication was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

