

Focus on Data 2025 Wisconsin Respite Summit

Presented by

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Objectives

- Explore the importance of measurable outcomes in respite care
- Learn best practices for collecting and using data to strengthen programs, demonstrate impact, and secure resources
- Identify respite caregiver outcome measures to collect to show the value of respite in Wisconsin

Fist to Five: *How do you feel about data?*



An Inclusive Definition of Respite*

“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some *measurable improvement* in the well-being of the caregiver, care recipient, and/or family system”

(Kirk & Kagan, 2015)

***Pre-pandemic**



Why Caregiver Outcome Measures Matter

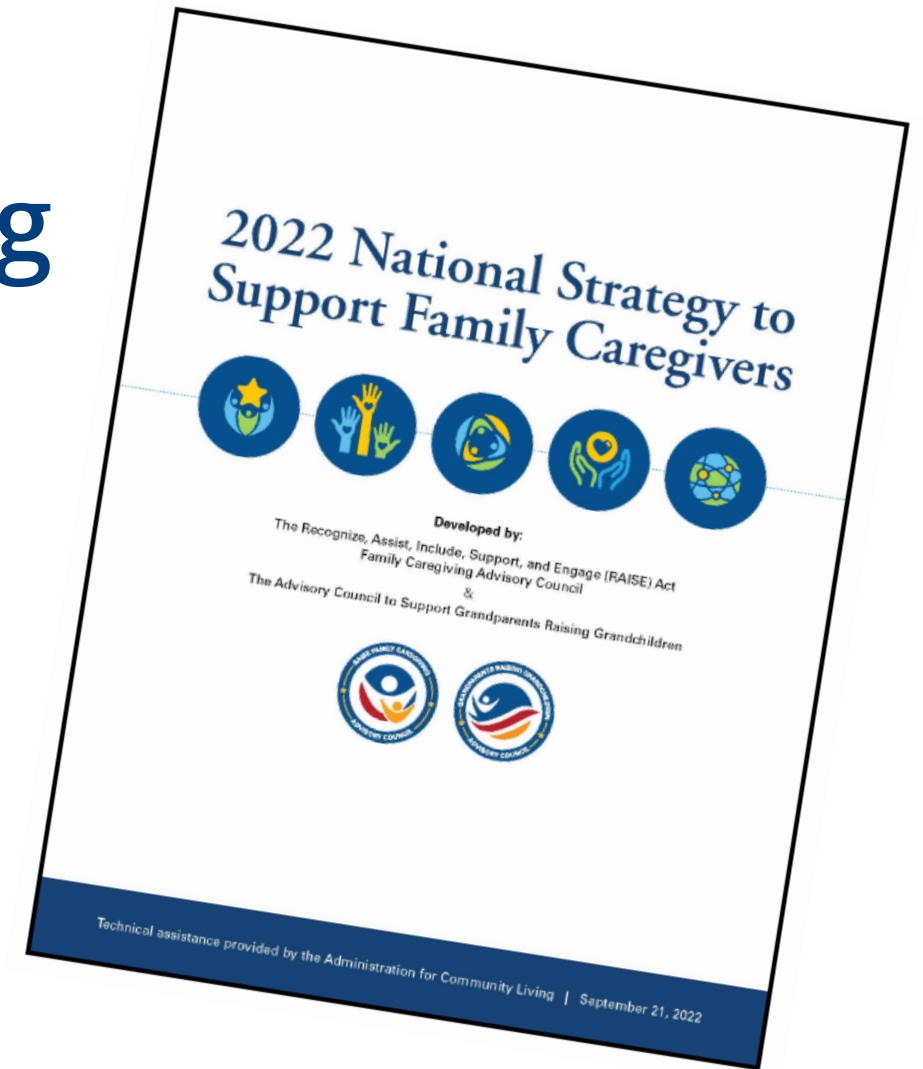


Why Caregiver Outcome Measures Matter

- Understand and demonstrate program impact
- Allows you to benchmark and compare across programs and over time
- Justify funding and support grant submissions
- Continuous quality improvement
- Support advocacy efforts
- Combine numbers + stories = *Data tells. Stories sell.*

2022 National Strategy to Support Family Caregiving

- Goal 5: Expand data, research, and evidence-based practices to support family caregivers



Small Group Discussion

- What respite caregiver outcome data do you *currently* collect?
- What do you *wish* you knew about the impact of respite on caregivers?
- What is the biggest *challenge* to collecting respite caregiver outcome data?

ARCH Committee for Advancement of Respite Research (CARR)



Measuring the Value of Respite

Recommended Common Data Elements
(CDEs) for Respite-related Research

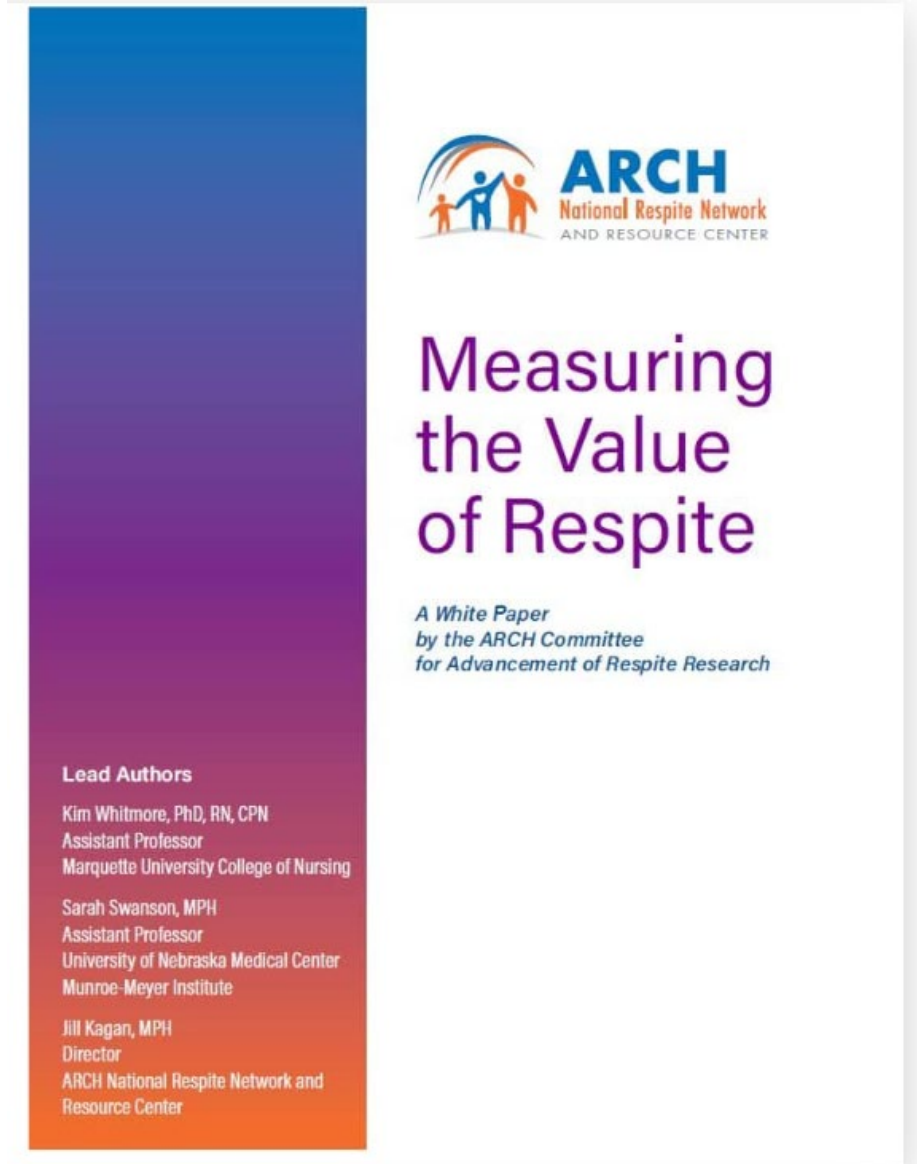
Learn more and download at
archrespite.org/research

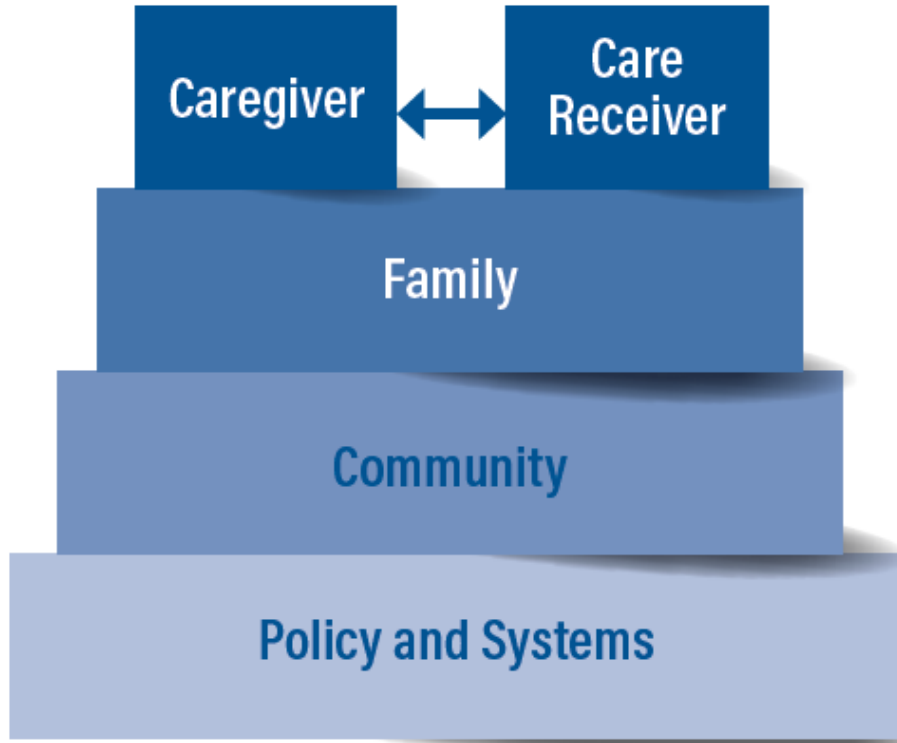
Measuring the Value of Respite White Paper and Framework



Purpose

Provide an in-depth description of the current challenges related to measuring the economic value of respite and to offer a new framework for research and evaluation





- Health and well-being (physical, mental, social, spiritual, and financial)
- Quality of life (individual and family)
- Societal outcomes
- Cost of care (direct and indirect)

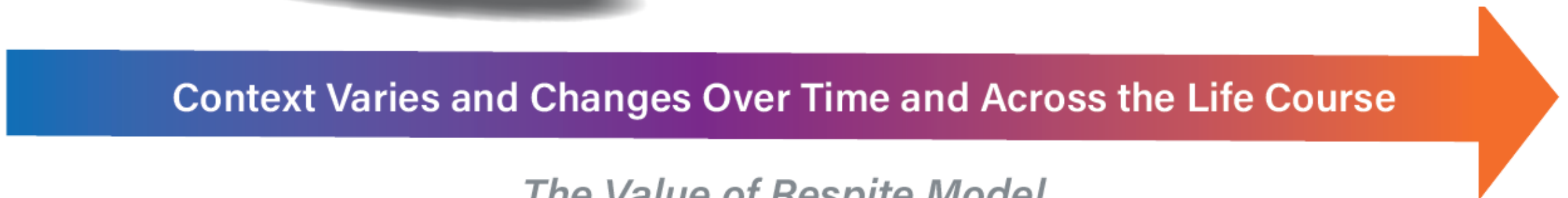
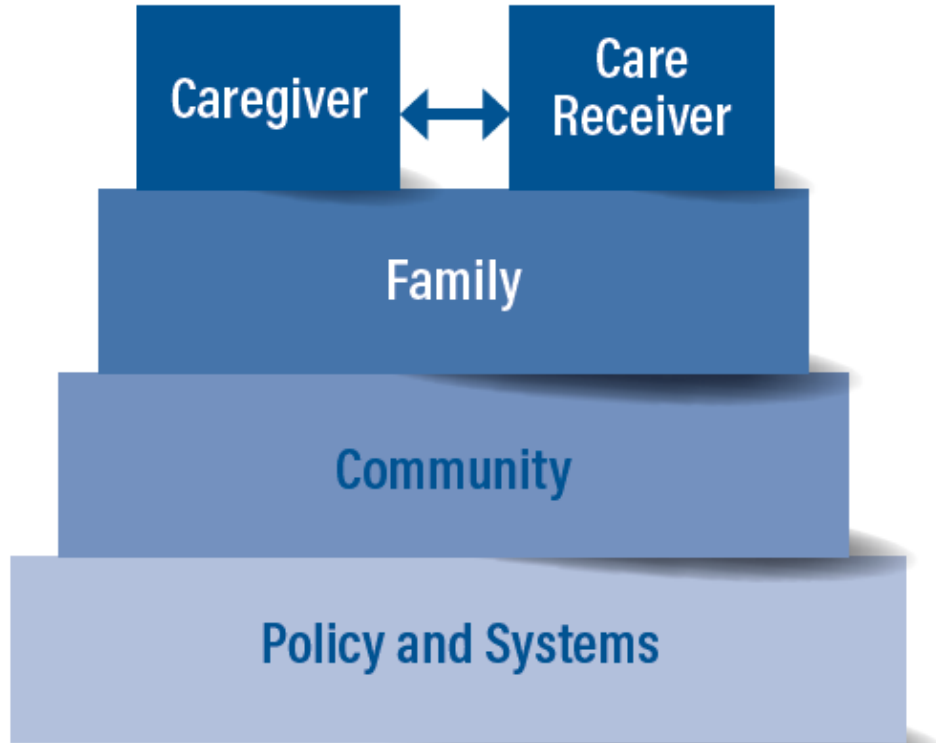
Context Varies and Changes Over Time and Across the Life Course

The Value of Respite Model



In this model...

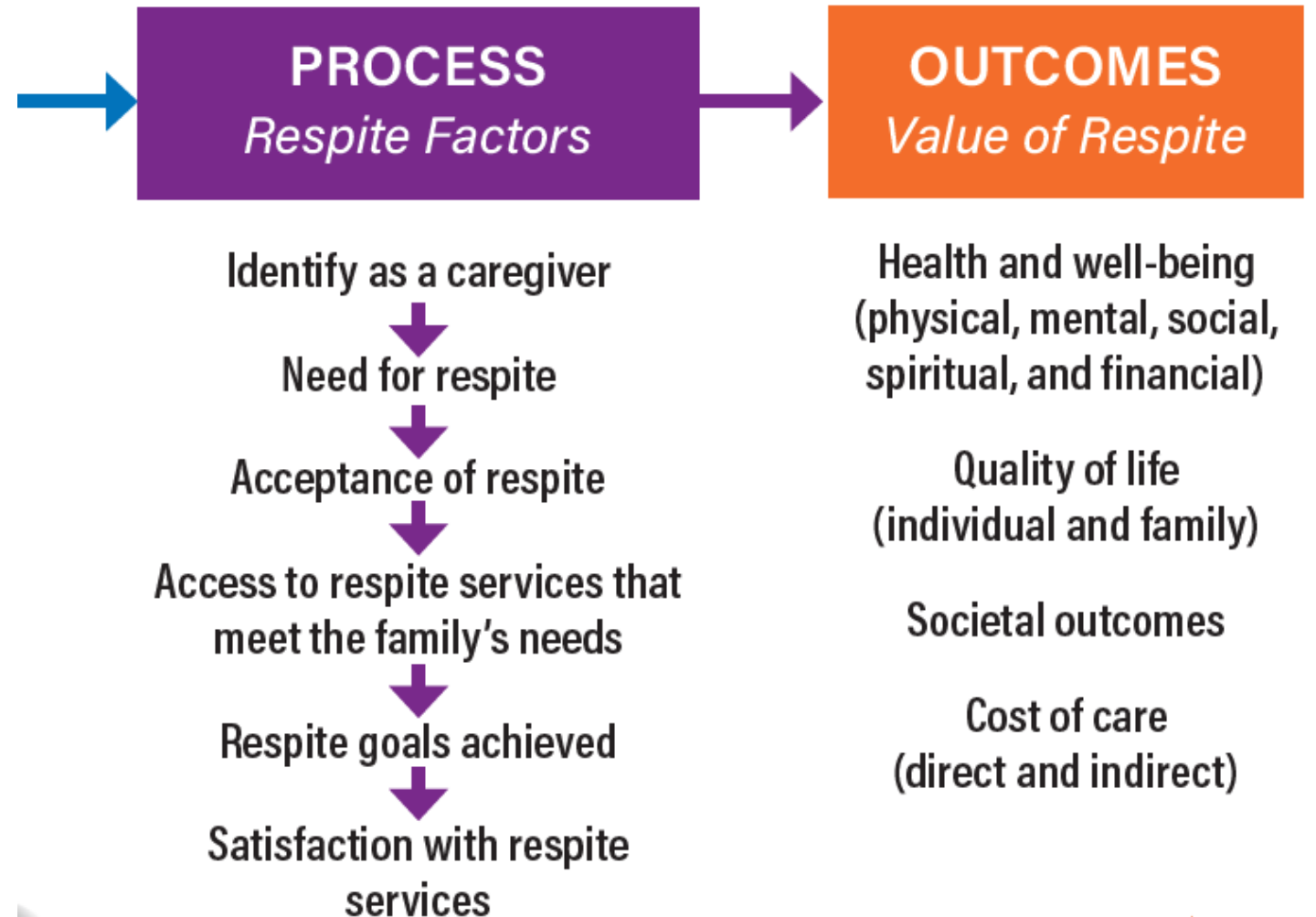
- The caregiver is the main beneficiary of respite.
- However, the caregiver is interconnected with the care receiver.
- Both are situated in the context of their family, community, and policy and systems.
- These contextual factors can help protect the caregiver or put them at risk for negative outcomes.
- The context varies and changes over time and across the life course of both the caregiver and the care receiver.



The Value of Respite Model

In this model...

- The caregiver goes through a process that begins with identifying themselves as a caregiver.
- If all respite factors in this process align positive outcomes can occur and the value of respite can be measured at the individual, family, community, or policy and systems level.



Recommendations

- The value of respite cannot be quantified merely by **financial measures**
- “Value” should be **defined by the caregiver** to ensure we are measuring person-centered outcomes that are culturally and contextually appropriate
- Critical that respite-related research and evaluation include a focus on **caregiver outcomes**
- Important to identify and consistently use **common data elements** that align with the *Value of Respite Model*

Recommended Common Data Elements for Respite Research White Paper



Purpose

Provide recommendations for the use of common data elements for respite research that align with the *Value of Respite Model*, developed by the ARCH Committee for Advancement of Respite Research



Recommended Common Data Elements for Respite Research

A white paper by the ARCH Committee for Advancement of Respite Research

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Common Data Elements (CDEs)

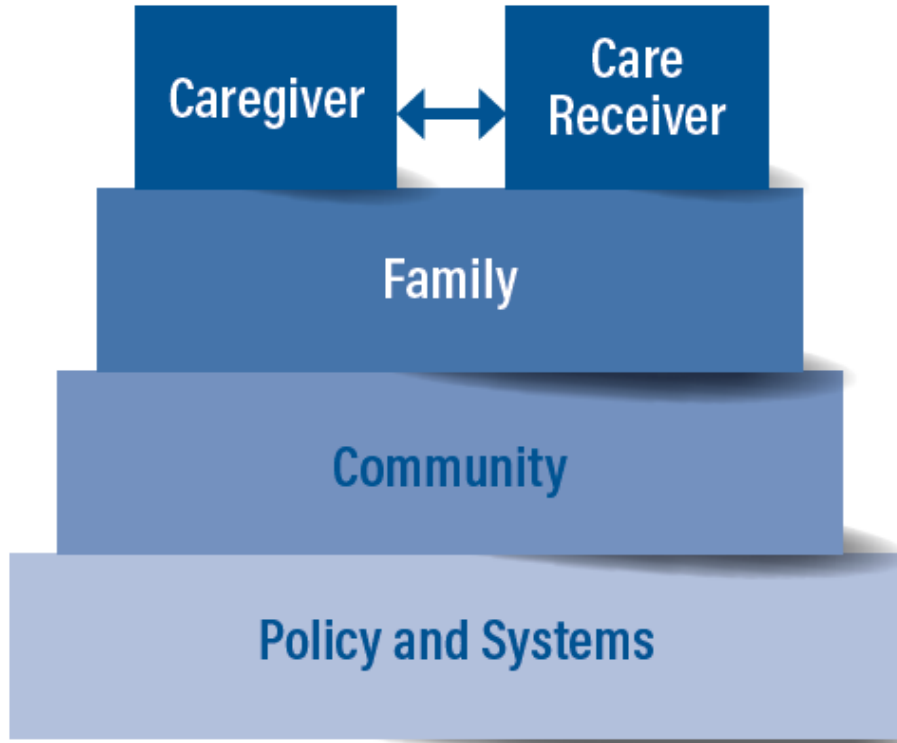
- “A common data element is a standardized, precisely defined question that is paired with a set of specific allowable responses, that is then used systematically across different sites, studies, or clinical trials to ensure consistent data collection.” (National Institutes of Health)
- Developed so that data can be collected in the same way across multiple research studies.

Benefits to using CDEs

- Allows for more meaningful comparison of data across and between studies, between study populations across age, disability, and culture, and over time
- Increases statistical power when data are aggregated from multiple sources.

Potential barriers to using CDEs

- Adequate human and technical resources
- Associated costs
- Availability of psychometrically sound measures
- Ease or difficulty administering measures
- Participant burden
- Utility of collecting data to participating programs
- Relevance of data elements to research aims



Context Varies and Changes Over Time and Across the Life Course

The Value of Respite Model

A large orange arrow pointing to the right, containing the text 'Context Varies and Changes Over Time and Across the Life Course'. Below the arrow is the title 'The Value of Respite Model' in italics.

Recommended Common Data Elements for Respite Research

- Recognize that it is not feasible to measure *every* concept in the Value of Respite Model
- Recommended core concepts within *each* of the four domains:
 - Caregiving Factors
 - Care Receiver Factors
 - Respite Factors
 - Outcomes (with a focus on caregiver outcomes)

Recommended Core Concepts Aligned with the Value of Respite Model

CONTEXT <i>Risk and Protective Factors</i> CAREGIVER	CONTEXT <i>Risk and Protective Factors</i> CARE RECEIVER	PROCESS <i>Respite Factors</i>	OUTCOMES <i>Value of Respite</i>
<p><i>Core concepts that help to describe risk and protective factors of the caregiver, include:</i></p> <p>Caregiver Demographics</p> <ul style="list-style-type: none"> - age - race/ethnicity - language <p>Caregiver Wellbeing*</p> <ul style="list-style-type: none"> - physical - mental - social - spiritual - financial - quality of life 	<p><i>Core concepts that help to describe risk and protective factors of the care receiver, include:</i></p> <p>Care Receiver Demographics</p> <ul style="list-style-type: none"> - age - race/ethnicity - language <p>Care Receiver Wellbeing</p> <ul style="list-style-type: none"> - condition(s)/disability(ies) - functional status - condition stability 	<p><i>Core concepts that help to describe respite factors, include:</i></p> <p>Description of Respite Model</p> <ul style="list-style-type: none"> - type of respite - timing of respite - location of respite - dose of respite - cost of respite - respite service model - person- and family-centeredness - respite provider - cultural and linguistic competence <p>Caregiver Experience with Respite</p> <ul style="list-style-type: none"> - identify as a caregiver - need for respite - acceptance of respite - access to respite services that meet the family's needs - respite goals achieved - satisfaction with respite services 	<p><i>Core concepts that help to describe the value of respite, include:</i></p> <p>Caregiver Physical Wellbeing</p> <ul style="list-style-type: none"> - global health - sleep - fatigue <p>Caregiver Mental Wellbeing</p> <ul style="list-style-type: none"> - stress - anxiety - depression - self-efficacy - resilience <p>Caregiver Social Wellbeing</p> <ul style="list-style-type: none"> - loneliness - social engagement <p>Caregiver Spiritual Wellbeing</p> <p>Caregiver Financial Wellbeing</p> <ul style="list-style-type: none"> - financial burden - job loss/reduced hours <p>Quality of Life</p> <ul style="list-style-type: none"> - individual - family
<p>Caregiving Circumstances</p> <ul style="list-style-type: none"> - relationship to care receiver - time as a caregiver - care receiver needs (companion vs skilled) - care complexity of care receiver - living situation - perception of caregiving burden - caregiving intensity 			

* We recommend obtaining baseline measures of caregiver wellbeing that align with outcome measures of interest, when feasible.

Three types of data elements

- Existing multi-item measurement tools
- Single non-proprietary items
- Original items

CONTEXT: CAREGIVER

Core concepts that help to describe risk and protective factors of the caregiver

Core Concept: Caregiver Demographics	Recommended Common Data Elements (Items or Measures)
Age	What is your age in years? (U.S. Census)
Race/ethnicity	What is your race or ethnicity? <i>Please select all that apply.</i> <input type="checkbox"/> White <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Black or African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Middle Eastern or North African <input type="checkbox"/> Native Hawaiian or Pacific Islander (Federal Register, proposed changes to U.S. Census, 2023)

PROCESS: RESPITE FACTORS

Core concepts that help to describe respite factors

Core Concept: Description of Respite Model

Recommended Common Data Elements (Items or Measures)

Type of respite

Timing of respite

Location of respite

Dose of respite

Cost of respite

Respite service model

Person- and family-
centeredness

Respite provider

Cultural and linguistic
competence

Description of Respite Model Tool (See Appendix B, page 26.)

Core Concept: Caregiver Experience with Respite

Recommended Common Data Elements (Items or Measures)

Identify as a caregiver

Need for respite

Acceptance of respite

Access to respite services
that meet the family's
needs

Respite goals achieved

Satisfaction with respite
Services

Caregiver Experience with Respite Tool (See Appendix C, page 31.)

OUTCOMES: VALUE OF RESPITE

Core concepts that help to describe the value of respite

Core Concept: Caregiver Physical Wellbeing	Recommended Common Data Elements (Items or Measures)
Global health	PROMIS® Scale v1.2 – Global Health-2 (GH2) PROMIS® Scale v1.0 – Global Health Short Form Zarit Burden Interview – (22-, 12-, or 4-item)
Sleep	How often do caregiving responsibilities negatively impact your quality of sleep? <input type="checkbox"/> All the time <input type="checkbox"/> Some of the time <input type="checkbox"/> None of the time How many nights a week on average do you get up during the night to provide care? _____ How many times on average do you get up in a single night to provide care? _____ (Original items)
Fatigue	PROMIS® v1.0 – Fatigue – Short Form A PROMIS® Global Health Short Form v1.0

Helpful Tools

- Respite Model Description Tool
- Caregiver Experience with Respite Tool
- Common Data Elements for Respite Research Worksheet

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.*

—

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

Caregiver Experience with Respite Tool

The purpose of the **Caregiver Experience with Respite Tool** is to help researchers better understand the respite process and caregiver experience with respite using common data elements that align with the *Value of Respite Model*. The following is a comprehensive list of questions that researchers can use to help describe key aspects of the respite process and caregiver experience with respite. While it may not be feasible to assess all aspects, we encourage researchers to include as many questions as possible in order to provide a comprehensive description of the respite process and caregiver experience with respite.

Identify as a Caregiver

A family caregiver is someone who provides care and support to a family member, neighbor, or friend of any age who is ill or has a disability, or is at risk for adverse experiences. A family caregiver is not a paid professional. Care and support can include help with daily activities, managing medications, coordinating

medical appointments, providing transportation, managing finances, running errands and providing emotional support.

Do you **identify** as a family caregiver?

Yes No Unsure

Need for Respite

Respite is commonly referred to as a "break" from the demands of caregiving.

improvement in the wellbeing of the caregiver, care receiver, and/or family system."

The ARCH Expert Panel on Respite Research defined respite as "planned or emergency care that provides a family caregiver some time away from caregiver responsibilities, and results in some measurable

Do you feel you have a **need** for respite?

Yes No Unsure

Overall, are your respite needs being **met**?

Yes No Unsure

Common Data Elements for Respite Research Worksheet

The purpose of the **Common Data Elements for Respite Research Worksheet** is to help researchers identify the most appropriate common data elements for their projects by selecting from the list of recommended core concepts aligned with the *Value of Respite Model*.

Step 1

First, answer the following questions.

1. What **question(s)** do you hope to answer from your research or evaluation?
2. What **caregiver factors** do you need to know about to best understand the question you are trying to answer?
Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.
3. What **care receiver factors** do you need to know about to best understand the question you are trying to answer?
Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.
4. What **caregiver circumstances** do you need to know about to best understand the question you are trying to answer?
Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.

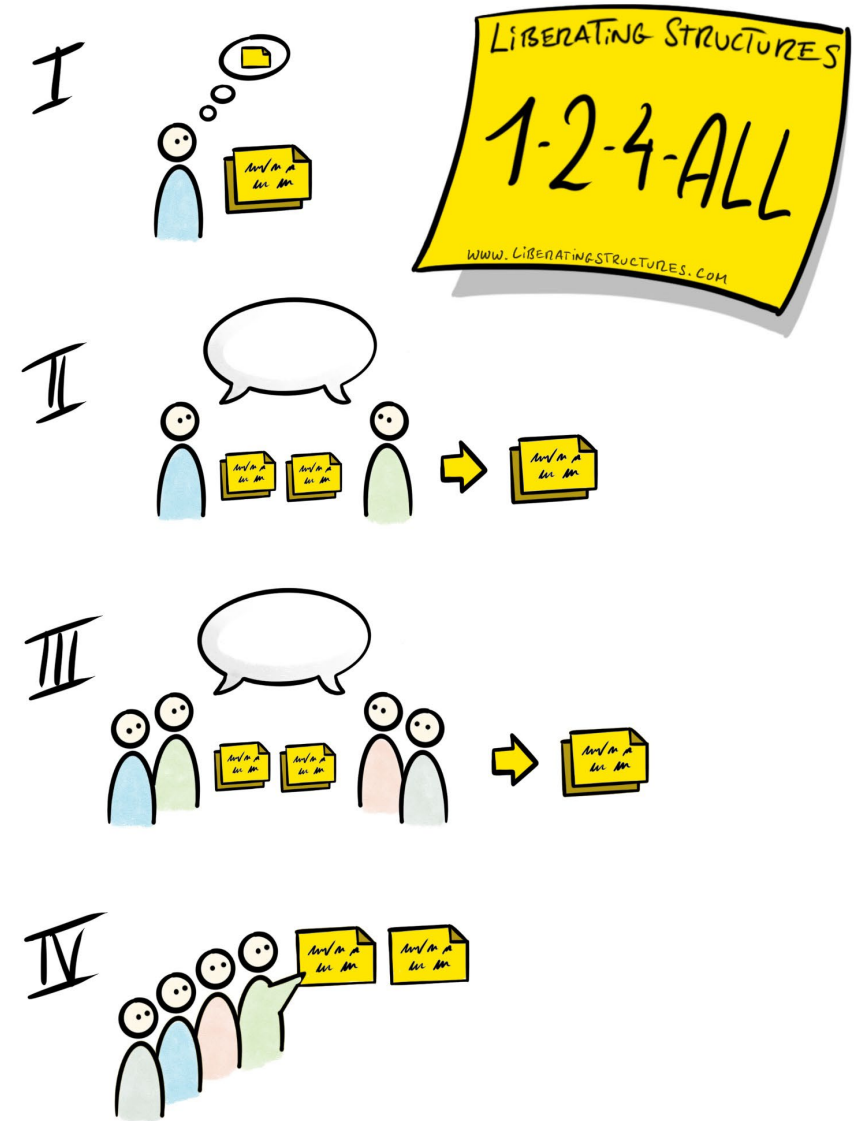
Implications for Research, Evaluation, and Policy

- **Researchers** should utilize the recommended common data elements to enhance the ability to compare outcomes across studies
- Common data elements may also be useful for respite program **evaluation**
- State and federal programs that **fund** respite should consider adopting CDEs.
- **Policies** that incentivize data collection among respite programs should be explored and should include an emphasis on collecting data with historically marginalized populations.
- We encourage **state and national leadership** to adopt these measures in the HCBS Quality Measure Set and other HCBS measures developed by the Centers for Medicare and Medicaid Services (CMS) for evaluation of Medicaid Home and Community Based Services (HCBS).

Small Group Discussion

- What respite caregiver outcome data do you think is *most important* to collect to show the value of respite in Wisconsin?
- What respite caregiver outcome data do you think is *feasible* to collect across programs in Wisconsin?
- What *support and resources* are needed to help support the collection of respite caregiver outcome data?

What is the MOST important respite caregiver outcome measure to collect to show the value of respite in Wisconsin?





CALL TO ACTION

- Choose ONE respite caregiver outcome measure to adopt or improve
- Join the Respite Research Consortium
- Join the BREAK Exchange

Respite Research Consortium

- **CONNECTS** interested researchers and funders to engage in respite research that will strengthen the evidence base for respite services
- Get **UPDATES** on new research studies, current literature reviews, data sources, funding opportunities, upcoming events and new report releases
- **SHARE** information about your respite research study on the ARCH website in order to recruit family caregivers, respite providers or other study participants
- **SUBSCRIBE** at archrespite.org/research/respite-research-consortium/#Subscribe

Join the BREAK Exchange



- International group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care
- Currently, there are more than 292 members from 18 countries in the Exchange!
- Follow the BREAK Exchange on Social Media
- Visit our website, join the email list, and complete your member profile at breakexchange.org
- Email us at info@BREAKexchange.org

Fist to Five: *How do you feel about data?*





CONTACT INFORMATION

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Lifespan Respite Technical Assistance Center

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