



ARCH
National Respite Network
AND RESOURCE CENTER

Strengthening the Evidence for Respite

*Findings and Recommendations from the
Respite Research Summit
October 28-30, 2024*



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About ARCH

The mission of the [ARCH National Respite Network and Resource Center](#) is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums. The ARCH National Respite Network includes [the National Respite Locator](#), a service to help caregivers and professionals locate respite services in their community, the [National Respite Coalition](#), a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the [Lifespan Respite Technical Assistance Center](#) which is funded by the [Administration for Community Living](#) in the US Department of Health and Human Services.

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I. Executive Summary




The Respite Research Summit hosted by the ARCH National Respite Network and Resource Center’s Lifespan Respite Technical Assistance Center (TARC) and the [Committee for Advancement of Respite Research \(CARR\)](#), and supported by the Administration for Community Living, was devoted to augmenting the research and evaluation capacity of community-based providers and state- and federal-level organizations with the goal of ensuring that respite care and caregiver¹ services are of high quality, meaningful for family caregivers, replicable, and informed by evidence.

This document provides an overview of the sessions presented during the 3-day Summit with a focus on the application of the [Framework for Measuring the Value of Respite](#) and [Recommended Common Data Elements for Respite Research](#) developed by the CARR. Sessions highlighted cutting-edge national, state and local respite and caregiving research and evaluations that align with and elevate this work including examples of research-ready innovative and exemplary respite services from around the country.

This report summarizes recommendations and key themes from the deliberations of Summit participants. The emergent themes include the importance of:

- **Caregiver-Centered Approaches.** Placing caregivers at the core of respite research and program design should be a basic tenet of respite research.
- **Advancement of Measurement and Evaluation.** A need to improve the ways respite is measured should be a priority.

¹ Throughout this paper, we use the terms “caregiver” and “care receiver”; however, we recognize that some situations may involve multiple caregivers and/or multiple care receivers. The terms “family caregiver” and “caregiver” are used interchangeably; include family, friends, and neighbors; and are meant to be differentiated from professional, paid caregivers. The term “care receiver” and “care recipient” are also used interchangeably and include persons of all ages and conditions who require supportive care.

- 
- **Building Research Capacity in Respite Programs.** Building research-ready respite programs requires practical support in designing and implementing program evaluation plans and in collecting, using, interpreting, and sharing standardized data.
 - **Community and Caregiver Engagement.** Meaningful engagement with family caregivers consistently identified as both vital and under-resourced.
 - **Addressing Systemic and Structural Barriers.** Ongoing administrative barriers, funding limitations, workforce shortages, and institutional challenges hinder respite service delivery and research efforts.

The recommendations made by both researchers, funders, advocates, providers, family caregivers, and other Summit participants will be used to advise ARCH and other interested entities on the next phase of advancing respite research.

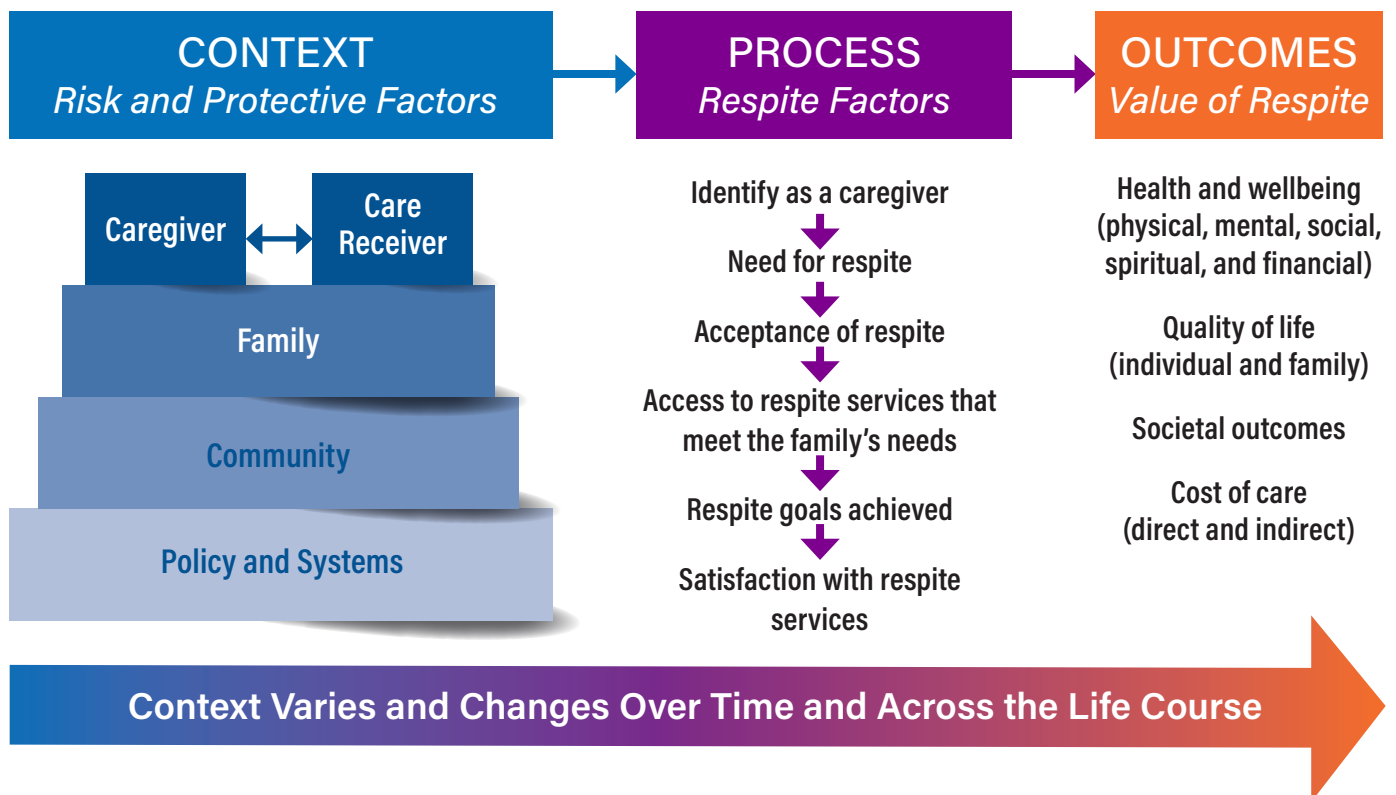
Much of the work of the CARR aligns with the [National Strategy to Support Family Caregivers](#) as illustrated in this [crosswalk document](#). It is the hope of ARCH and the CARR that the Summit's findings and recommendations will also help inform and advance Goal 5 of the National Strategy: Expand data research and evidence-based practices to support family caregivers, as well as Goal 3, Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs.

For more information, please see [Respite Research Summit Proceedings](#), which include the summit agendas, presenter bios, presentation slides and session recordings. For key CARR documents, see [Committee for Advancement of Respite Research Publications](#).

II. Introduction

In October 2024, the Respite Research Summit convened national, state, and local stakeholders to explore research and evaluation of innovative and evidence-based approaches to respite care aligned with the **Value of Respite Model (Figure 1)**. In this model, the caregiver is the main beneficiary of respite. 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 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.

Figure 1. Value of Respite Model



III. Key Themes and Recommendations

Over three days, Summit participants shared emerging research, exemplary programs, and opportunities to elevate respite services through evaluation and collaboration. Several consistent themes emerged, alongside clear recommendations for building a stronger evidence base for respite care.

Key Themes

Caregiver-Centered Approaches

A central theme across the summit was the importance of placing caregivers at the core of respite research and program design. Participants emphasized that what constitutes respite care must be defined by caregivers themselves, reflecting their needs, preferences, capacity, and lived experiences. A person- and family-centered approach is essential to delivering meaningful and effective services. This aligns with the **Value of Respite Model** which recognizes the caregiver is interconnected with the care receiver and both are situated in the context of their family, community, and policy and systems.

Advancement of Measurement and Evaluation

Summit discussions highlighted a need to improve the ways respite is measured. Specifically:

- Determining the minimum effective “dose” of respite beyond simple measures of frequency or consistency.
- Accounting for informal respite that is provided outside of the formal service system, such as respite provided by family and friends, and its impact on caregiver wellbeing.
- Developing new tools and metrics that reflect caregiver-defined outcomes.
- Emphasizing the value of both quantitative and qualitative data.
- Standardizing evaluation through use of common data elements (CDEs) as an essential strategy to align efforts across programs and studies, and allow cross program and service analyses.

This aligns with the [recommendations](#) of the CARR to use common data elements for respite research that align with the **Value of Respite Model** and develop validated respite measurement tools that are informed by and validated with caregivers.

Building Research Capacity in Respite Programs

Many respite providers face barriers to participating in research due to a lack of dedicated resources, program-relevant measurement tools, and training in research and evaluation. Building research-ready programs requires practical support in designing and implementing program evaluation plans based upon evaluation frameworks like the **Value of Respite Model** and in collecting, interpreting, using, and sharing standardized data. Stronger partnerships between programs and researchers can also promote mutual learning and the identification of outcomes relevant to caregivers and respite providers.

The CARR [Recommended Common Data Elements](#) white paper highlights that common data elements can help programs monitor progress toward goals, establish fidelity to the service model, evaluate program effectiveness over time, and allow for comparison to other programs or services. For respite programs to be “research ready,” the CARR recommends the use of common data elements as part of their evaluation plan. However, additional guidelines and resources for using common data elements in respite program evaluation are needed.

Community and Caregiver Engagement

Meaningful engagement with family caregivers consistently was identified as both vital and under-resourced. Key points included:

- Recognizing caregivers as experts and compensating them fairly for their participation in research.
- Prioritizing trust-building and asset-based rather than deficit- or problem-based approaches.
- Acknowledging that basic needs must be met before caregivers can effectively engage in or benefit from respite care. Similar to [Maslov’s hierarchy of needs](#), there may be a caregiving hierarchy of needs. If a caregiver is struggling to afford rent, pay for groceries, or access transportation, respite may not be a priority.
- Accounting for the time, effort, and resources required for genuine community engagement, which are often absent from funding models.

In the **Value of Respite Model** “Process,” caregivers must identify as a caregiver, have a need for respite, be willing to accept respite services, have access to respite services that meet the family’s needs, achieve their respite goals, and be satisfied with respite services in order to maximize the potential benefits of respite. These factors may also correlate with the process of engaging in research. Caregivers will not respond to requests to participate in caregiving research if they do not see themselves as caregivers. Therefore, researchers need to carefully review recruitment materials to ensure they are using language that resonates with their target population. Caregivers must also recognize the importance of engaging in research and be willing to take on the responsibilities that participation entails. The research process must also meet the needs and capabilities of the family, align with their own goals for engagement, and be a satisfactory experience in order for them to have a positive experience.

Addressing Systemic and Structural Barriers

Ongoing funding limitations, workforce shortages, and institutional challenges hinder respite service delivery and research efforts. Administrative barriers (e.g., restrictive participant compensation policies, tenure guidelines that do not account for the unique factors involved in community-engaged research, and limited data-sharing agreements) may also limit academic researchers' ability to engage with communities effectively.

Recommendations

To support the development of a comprehensive, evidence-informed approach to respite care, the following next steps are recommended:

1. Promote Standardized Models and Data Use

Researchers and respite programs should adopt the CARR **Value of Respite Model** and use **Common Data Elements** to guide both evaluation and service delivery, and to allow cross program comparisons and analyses.

2. Develop and Test New Measures

New respite-specific measurement tools need to be developed in collaboration with caregivers to ensure they reflect caregivers' experiences and outcomes, allowing research and evaluation to focus on what truly matters to caregivers and families.

3. Support Program Capacity Building

Develop practical toolkits and resources—such as training, templates, and technical assistance—to help respite programs become research-ready and support performance-based evaluation and ongoing decision-making.

4. Foster Cross-Sector Partnerships

Encourage collaborations among respite programs, researchers, caregivers, and communities to co-design and implement research that is meaningful to multiple audiences and consumers.

5. Center Lived Experience in Research

Ensure family caregivers are included as equal partners in all phases of research, with fair compensation and shared decision-making authority. Some examples include hiring caregivers as part of the research team, creating a caregiver advisory board, and sharing research results with caregivers to help validate findings and co-develop recommendations.

6. Increase Funding and Infrastructure Investment

Advocate for dedicated funding for research and evaluation to:

- Advance respite-specific research.
- Support model respite demonstration projects.
- Support costs associated with developing and sustaining authentic trusting relationships with caregivers and community partners
- Establish a centralized repository or database of common data elements and research findings.

7. Expand Global Learning Opportunities

Leverage international networks like the [BREAK Exchange](#) to share respite research knowledge, innovations, and best practices across borders.

IV. Summaries of Summit Presentations and Discussions

DAY 1: THE VALUE OF RESPITE MODEL AND COMMON DATA ELEMENTS

Presentation of Committee for Advancement of Respite Research (CARR) Work

The aim of this session was to highlight findings from the Measuring the Value of Respite and Recommended Common Data Elements for Respite Research White Papers developed by the **Committee for the Advancement of Respite Research (CARR)**.

- *Kim Whitmore, PhD, RN, Assistant Professor, College of Nursing, Marquette University and ARCH Consultant*
- *Sarah Swanson, MPH, Assistant Professor and Family Support Coordinator, UNMC Munroe-Meyer Institute, University of Nebraska Medical Center, Omaha, NE*

1. Measuring the Value of Respite

The current challenges in measuring the economic value of respite care are significant and multifaceted. Research and evaluation methods often fail to accurately assess the full economic benefits of respite. Key difficulties include:

- 1. Numerous Types of Respite:** Both formal and informal respite care are hard to quantify, as there is no standardized definition or “unit of service” for respite.
- 2. Limited Use and Sample Sizes:** Due to the limited use of respite services, it’s difficult to gather large enough sample sizes for robust studies.
- 3. Caregiver Identification Issues:** Many caregivers do not recognize themselves as such, leading to challenges in recruiting participants.
- 4. Data Collection and Consistency:** Respite programs often lack uniform data collection practices. Additionally, most programs only collect care-recipient data since funding is often tied to the care recipient and not the caregiver.
- 5. Methodological Gaps:** Research methods for evaluating the value of respite care are still underdeveloped, as highlighted in the [Research Agenda for Respite Care](#).

In response to these issues, the **CARR** developed the **Value of Respite Model (Figure 1)**. This model is a conceptual framework that helps researchers and evaluators better measure the value of respite care. Influenced by theories such as the [Individual and Family Self-Management Theory](#), the [Life Course Framework](#), and the [Socioecological Model](#), the model provides a multi-dimensional approach to understanding and evaluating the diverse effects and benefits of respite care. It aims to improve the evidence base for respite interventions and their impact on caregivers.

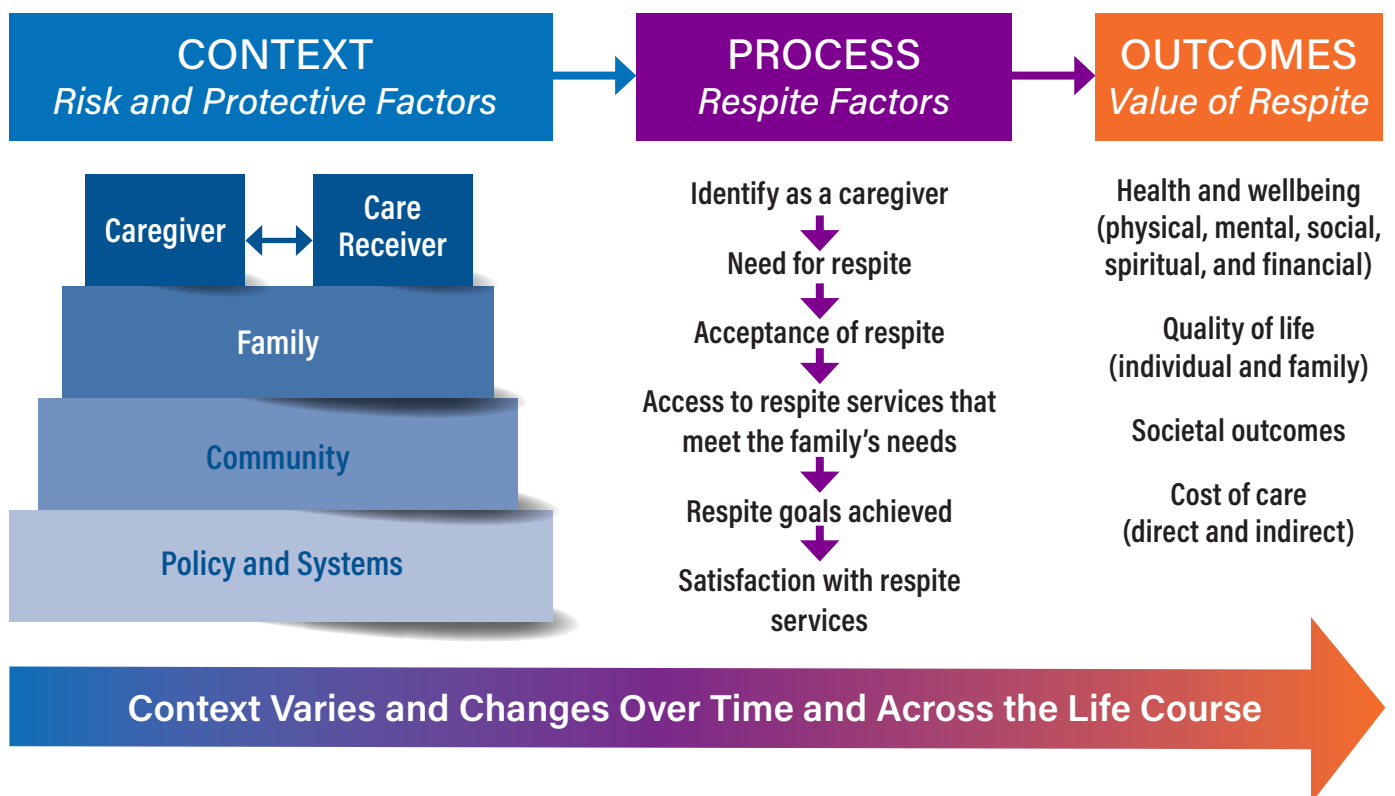
Context: Risk and Protective Factors

Context is crucial in understanding the impact of respite care, as caregivers are the primary beneficiaries, but they are deeply interconnected with the care receiver. Both are influenced by their family, community, and policy environments. The model illustrates this with layered circles, where:

- **Family Level:** Includes individuals defined as family by the caregiver, such as partners, children, siblings, or extended family.
- **Community Level:** Encompasses the caregiver’s neighborhood, schools, employers, community organizations, and faith-based groups.
- **Policy and System Level:** Represents the broader socio-political context shaped by laws, regulations, and funding.

These contextual factors can either support or exacerbate risks for the caregiver’s wellbeing, affecting their outcomes.

Figure 1. Value of Respite Model



Process: Respite Factors

The process of accessing respite care involves several stages for caregivers, beginning with recognizing the need for assistance and the potential benefits of asking for help. However, many caregivers struggle to identify themselves as caregivers, often seeing themselves simply as a parent, spouse, or child. This can prevent them from seeking caregiving support, such as respite.

Once caregivers acknowledge their need for respite, they must overcome barriers like cultural or social stigma that may hinder their willingness to accept services. If they are open to respite, they need access to services that meet their unique family needs. Key considerations include cultural appropriateness, type of respite (e.g., in-home, community-based), provider qualifications, location, timing, duration, frequency, and affordability.

Additionally, caregivers must set and achieve their goals for respite, such as how to use the time away. Satisfaction with the services is crucial for positive outcomes. If any part of the process—such as accessibility or provider quality—fails to align, it could result in negative experiences and a reluctance to use respite in the future. These factors should be seen as moderating variables that influence the overall effectiveness of respite care.

“Over time in our 32 years of practice, we slowly learned that families in our area wanted more than just a few hours a day of respite. Agape Respite Care, then opened up opportunities for evening hours and then grew to an overnight out of home respite care home for over 22 years now. It is so important to evaluate the needs of the persons we are serving and learning to see what we can do to grow in their needs with them.

– Summit Participant

Outcomes: Value of Respite

The value of respite care can be measured through various outcomes at the individual, family, community, or policy level. These outcomes span four main domains:

- 1. Health and Wellbeing:** Includes physical, mental, social, spiritual, and financial health.
- 2. Quality of Life:** Encompasses both individual and family quality of life, as defined by the individuals themselves.
- 3. Societal Outcomes:** Involves relationships, socialization, inclusion, community connectedness, and employment.
- 4. Cost of Care:** Covers direct costs, indirect costs, caregiver time cost equivalent, healthcare utilization, and social services utilization.

The **Life Course Perspective** emphasizes that health outcomes should be understood as part of a broader, multidimensional developmental process. It acknowledges that the context of caregiving evolves over time and varies across the life course of both the caregiver and the care receiver, as represented by the large arrow in the model.

“I'd like to explore the idea of what are the financial benefits on the caregiver side—like lower spending services for them such as emergency room visits from caregiving related injuries or less need for mental health counseling, etc.

– Summit Participant

2. Recommended Common Data Elements for Respite Research

The CARR Common Data Elements Work Group², aimed to identify data elements for use in respite research to enable cross-study comparisons, benchmark progress, and highlight the value of respite.

Their process began with a comprehensive review of measures and constructs in respite and caregiving research. An initial draft of data elements aligned with the **Value of Respite Model** was created and reviewed by CARR members and field experts. The Work Group refined the draft through iterative discussions, ensuring alignment with the model and identifying additional necessary data categories.

Five criteria guided the inclusion of data elements:

1. Alignment with the **Value of Respite Model**, such as tools measuring caregiver burden or stress.
2. Established reliability and validity of measures.
3. Use of widely accepted data elements, like demographic or health condition data.
4. Inclusion of essential but less commonly measured concepts, like caregiver trust.
5. Preference for low-burden measures, such as short-form instruments.

This process resulted in a structured approach to advancing respite research and evaluation.

“I really wanted to hear a common, clear definition of respite that would serve as the basis for the [use of] common data elements and I got that. Clarifying that respite should result in some form of self-care vs so I can go to work was helpful. Whether everyone agrees with that 'definition' is one thing, but as long as we are measuring a 'common definition' of respite, we can better capture data to help affect change and improvements in supporting family caregivers.

– Summit Participant

² CARR Common Data Element Workgroup members included: Thomas V. Caprio, MD, MPH, MS, Professor of Medicine/Geriatrics and Chief Medical Officer, University of Rochester Medical Center; Tamar Heller, PhD, Distinguished Professor, Disability and Human Development Director, Institute on Disability and Human Development, University of Illinois Chicago; Susan Peschin, MHS, President and CEO, Alliance for Aging Research; Cordelia Robinson Rosenberg, PhD, RN, Professor Emerita, University of Colorado School of Medicine; Sarah A. Sobotka, MD, MSCP, Associate Professor of Pediatrics, Department of Pediatrics, Section of Developmental and Behavioral Pediatrics, University of Chicago; Sarah Swanson, MPH, Assistant Professor, Munroe Meyer Institute, University of Nebraska Medical Center; Rebecca L. Utz, PhD, Associate Dean of Research and Graduate Education and Professor, Department of Sociology, College of Social and Behavioral Science, University of Utah; and Kim E. Whitmore, PhD, RN, CPN, Assistant Professor, College of Nursing, Marquette University.



Results

The CARR acknowledges that measuring all concepts within the **Value of Respite Model** in a single study is impractical. However, they recommend that each study measures at least one core concept from each of the model's four domains: **Caregiving Factors, Care Receiver Factors, Respite Factors, and Outcomes** (with an emphasis on caregiver outcomes).

Key Recommendations for CDEs

- Utilize the list of recommended core concepts (**Figure 2**) and tools like the [Respite Model Description Tool](#) and the [Caregiver Experience with Respite Tool](#).

• *Figure 2. 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

Caregiving Circumstances

- 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.

- Validate new items and measures with caregivers and care receivers and develop additional validated measures for all concepts in the model.
- Reference the [Common Data Elements for Respite Research Worksheet](#) to identify appropriate data elements for studies aligned with the model.

CARR encourages researchers, administrators, and evaluators to adopt additional meaningful measures to their specific respite models. Incorporating multiple measures can enhance understanding of relationships among factors and provide a more comprehensive view of the value of respite. While validated measures are preferred, new original items and measures are also proposed due to current limitations.

Discussion Summary

The discussion following the presentations focused on key challenges and opportunities in advancing data collection and research on respite care, with active participation from community providers, researchers, and program leaders.

Key Points

1. Data Sharing and Infrastructure Needs

Participants emphasized the difficulty in collecting and submitting respite data in digestible formats for broader research. There was consensus on the need for a centralized data repository to streamline reporting. While there is enthusiasm for a national respite data base, building such a system requires significant funding, technical infrastructure, and time. In the absence of this infrastructure, one-on-one partnerships and data-sharing agreements with researchers and organizations like ARCH were suggested as interim solutions.

2. Tools and Practical Applications

Conversation among participants raised the need to develop practical tools to help respite programs capture common data elements to help create more research ready programs. There was strong interest in translating research terminology into practical tools for everyday respite care use.

3. Definition and Scope of Respite

Questions arose about aligning the definition of respite with the 2022 National Strategy to Support Family Caregivers that defines respite broadly. Respite should be broadly defined as temporary relief for caregivers, which can take various forms; however, in research and evaluation, when measuring outcomes from respite, the respite model needs to be clearly described in detail in order to be able to attribute the outcomes to the model and to make valid comparisons across respite types.

“One takeaway for me is looking into how our data collection can be revised to be more consistent across funding sources/initiatives.”

– Summit Participant

4. Clarifying Confusion

About Respite vs. Other Services

There is confusion among funders and families about what constitutes respite versus other services like adult day care. The group emphasized distinguishing between respite as a **service** and respite as an **outcome**, noting that a service must result in caregiver relief to truly qualify as respite.

5. Data Collection Practices

Programs that survey caregivers after each event were advised to either collect demographic data annually and use unique identifiers for tracking, or to collect demographics at each event if feasible, as these factors can change over time.

6. Implementation Support

Participants suggested creating a “support group or learning community” to implement common data elements. Dr. Whitmore proposed leveraging the [BREAK Exchange](#), an international academic-practice collaborative, as a platform for ongoing support.

Conclusion

Participants expressed strong support for better tools, infrastructure for data collection, and community to advance respite research. The group underscored the importance of defining and measuring respite effectively, building shared resources, and fostering collaboration across sectors to improve caregiver respite outcomes.

“For families unable/ineligible on the waiting list for waiver services, how do we work with insurance providers and other funders to pay for respite when the focus is on caregiver outcomes?”
– Summit Participant

“I think one way to start is to work with Managed Care Organizations who can offer ‘value-added services.’”
– Sarah Swanson, MPH, University of Nebraska



National Initiatives that Align with the CARR's Value of Respite Framework and Recommendations for Common Data Elements

The aim of this panel presentation was to describe national research, evaluation and data collection initiatives that align with the CARR's Value of Respite Framework and Common Data Elements. Brief summaries of each of the formal presentations are presented in this section.

1. *Guiding an Improved Dementia Experience (GUIDE) Model Evaluation*

- *Lynn Miescier, PhD, MHA, Center for Medicare & Medicaid Innovation, Centers for Medicare & Medicaid Services*

Overview

Dr. Miescier described the purpose of the CMS Innovation Center model evaluations; shared a description of the [Guiding an Improved Dementia Experience \(GUIDE\) Model](#); explained the GUIDE Model evaluation approach to date, with a focus on respite care; and discussed alignments with ARCH's Committee for Advancement of Respite Research framework and common data elements.

The GUIDE Model aims to test whether a comprehensive service package, including respite care, can:

1. Improve the quality of care and life for people living with dementia.
2. Reduce caregiver burden and strain.
3. Delay or reduce long-term nursing home stays, enabling more people to remain at home.

In developing GUIDE, CMS recognized the important role of family and friend caregivers and especially the need for respite care. Dementia care is provided through an interdisciplinary teams and nine services are required, including respite care (**Figure 3**). Caregivers can receive up to \$2,500 per year for respite in the home, adult day center, or a facility.

“...we're focused on common data elements. Those are all quantitative pieces of information, and a lot of times policymakers are motivated by a combination of quantitative and qualitative data that is put together in a way that tells a more compelling narrative....I can show you this data point and this data point. But to partner with advocates and community members to bring in their more qualitative anecdotal information. Put that together. You know I find that that tends to be more powerful....not simply to rely on quantitative data.

- Lindsay DuBois, PhD, MPH,
Human Services Research Institute
(HSRI)

Evaluation Goals

The Model is currently being implemented in close to 400 sites including physician group practices, health systems, hospices, home health agencies and community-based and telehealth agencies, in 46 states. The program is administered through the Center for Medicare and Medicaid Innovation, Centers for Medicare & Medicaid Services, and anticipates serving 200,000 Medicare beneficiaries with dementia and their families over an 8-year test period.

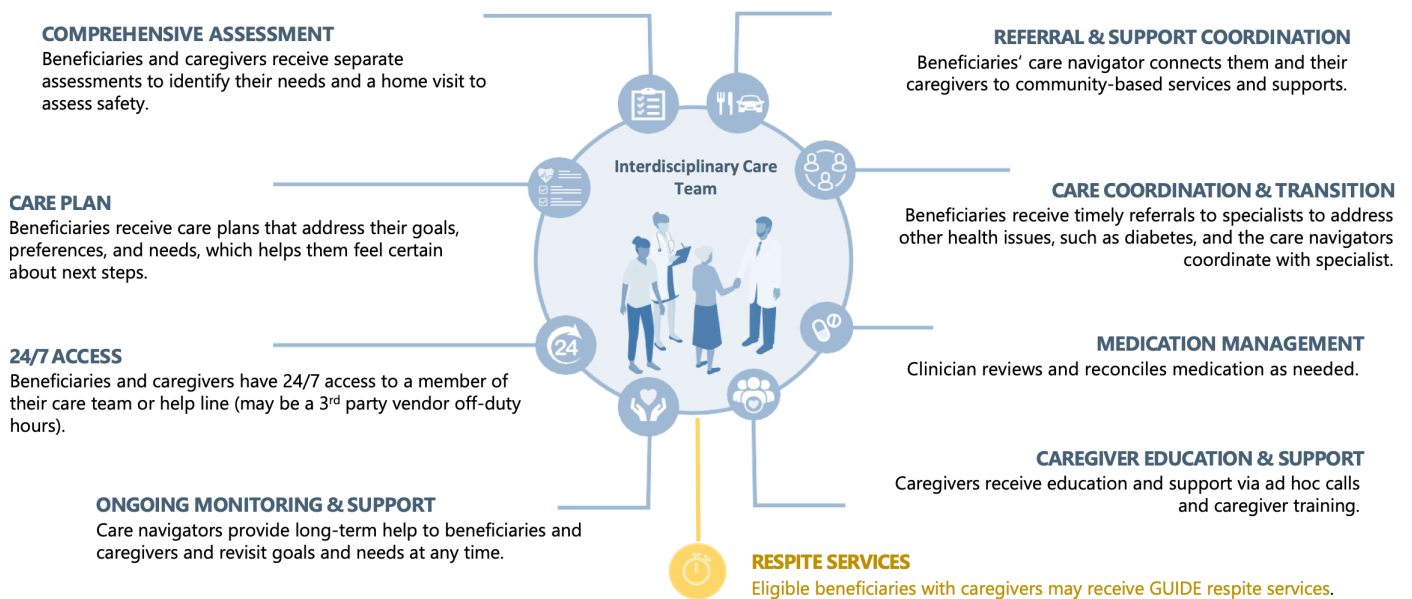
Dr. Miescier noted the importance of the use of consistent and inclusive definitions and terminology related to respite, recognition of the many needs and responsibilities of family caregivers, and the importance of including respite measures in the GUIDE evaluation.

An integrated mixed methods approach is planned to evaluate the model.

1. Assess GUIDE's impact on:
 - Quality of life and care for beneficiaries.
 - Caregiver burden and experiences of care.
 - Medicare expenditures and nursing home stays.
 - Health care service use and disparities in health outcomes.

Figure 3. Required Services Provided by the GUIDE Model

GUIDE Model Care Delivery Requirements





2. Understand factors influencing GUIDE's effects, including components like respite care and differences across participants.
3. Examine care decisions and the implementation of GUIDE.

Data and Outcomes

To estimate impact:

- Surveys of beneficiary-caregiver dyads to measure experiences, quality of life, and caregiver burden.
- Medicare and Medicaid claims data to track service use, expenditures, and care quality.
- Disparities analysis using survey and claims data.

Model implementation and patient experience will also be assessed.

Alignment with Value of Respite Model and CARR Recommended CDEs

The GUIDE model evaluation approach aligns with the ARCH CARR framework and Common Data Elements (CDEs) in the following key ways:

- **Consistent Definitions:** It uses consistent definitions of respite care, such as that from the National Institute on Aging.
- **Clear Communication:** Surveys will include descriptive language to ensure understanding, even for those unfamiliar with the term respite care.
- **Caregiver Sensitivity:** Data collection methods will consider the unique needs of caregivers and minimize burden (offered via web, phone, paper, etc., aiming for surveys under 20 minutes).
- **CDE-Aligned Measures:** Evaluation will use measures consistent with CARR's CDEs and incorporate claims and programmatic data to assess respite service use, assess frequency of respite services, and align with earlier discussed CDEs.
- **Qualitative Insights:** Interviews will explore caregiver identity, reasons for using care, satisfaction, physical/emotional wellbeing, and unmet needs.
- **Outcome Assessment:** The evaluation will analyze the combined impact of GUIDE's services, including respite and caregiver education, on outcomes such as reduced caregiver burden, delayed nursing home or hospice care, and health service use.

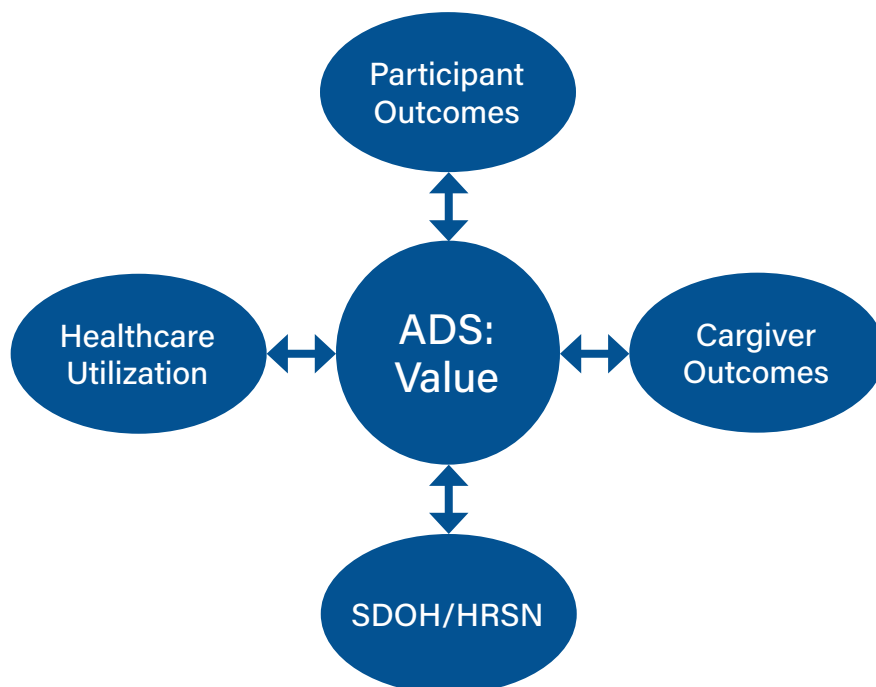
2. Adult Day Services Use of Common Data Elements


- William Zagorski, CEO, American Senior Care Centers, Inc., Chair, Board of Directors, and Chair, Research Committee of the National Adult Day Services Association (NADSA)

This presentation highlighted efforts by the [National Adult Day Services Association \(NADSA\)](#) that align with CARR's recommendations for Common Data Elements to standardize the collection of data within and across Adult Day Services (ADS) sites (**Figure 4**). This initiative was launched in 2023 to further demonstrate the value of ADS. Goals are to quantify the benefits of ADS for participants, caregivers, and the community, as evidenced by positive health outcomes, burden reduction, and cost savings.

The long-term goal of this initiative is to integrate person-centered outcome measures across ADS to ensure that programs nationwide are all delivering person-centered Alzheimer's Disease and Related Dementia (ADRD) care that enhance quality of life for persons living with dementia (PLWD). Use of person-centered quality of life measures for use in Adult Day Services capture the values and preferences of PLWD in these settings.

Figure 4. Alignment of ADS Outcomes with CARR Value of Respite Model and CDEs (Health and Wellbeing, Quality of Life, Societal Outcomes, Cost of Care) for Care Receiver and Caregiver





Strategies include the use of a proprietary cloud-based software (RTZ Systems) specialized in care management to collect:

- Detailed participant demographics and high-cost health care utilization data are collected, including ER visits, hospital admissions, and medication use.
- Participant outcomes are measured using tools like the Katz Index for ADLs, Lawton Scale for iADLs, and GDS-15 for depression.
- Phase 2 (2025) will include caregiver outcomes and social determinants of health (SDOH) data.
- Phase 3 (2026) will focus on person-centered outcomes for individuals with dementia, aiming to enhance their quality of life.

Focus groups with PLWD and caregivers provided qualitative context.

As of September 2024, data collection was active in 47 sites in 17 States. Preliminary data from 2024 shows high acuity and need among ADS participants, with significant percentages requiring assistive devices, showing signs of depression, and having high nutritional risk. While outcome data are not yet statistically significant, reductions in depression and loneliness scores after utilization of adult day services for 6 months have emerged.

Next steps involve the full release of data collection phases, educational webinars, partnerships for data aggregation and analysis, and the development of operational manuals and training videos.

3. Creating and Advancing Caregiving Research and Evidence Network (CARE Network)

- *George Kueppers, PhD, Senior Research Manager, National Alliance for Caregiving*

Dr. Kueppers outlined the goals and objectives of the [Creating and Advancing Caregiving Research and Evidence \(CARE\) Network](#) led by the National Alliance for Caregiving (NAC). The CARE Network is funded by Administration for Community Living (ACL) as part of a multifaceted initiative to increase the recognition, support, and inclusion of family, kin, and tribal caregivers across the country, resulting in measurable improvements in the capacity of the network to assess caregiver needs, provide supportive services, collect data, and—most importantly—support the wellbeing of caregivers and the people receiving care.

“It's really exciting to see how this work is aligning, and I'm excited to continue conversations to show how we can continue to strengthen that alignment across all of these great initiatives, because we know how important it is that we are using the same language, having common definitions, measuring things consistently across these great national initiatives.

- Summit Participant

Under this broader initiative, the CARE Network is charged with addressing specific objectives under Goal 5 of the National Strategy to Support Family Caregivers to expand data research and evidence-based practices to support family caregivers. The CARE Network aims to create unified, adaptable national infrastructure for family caregiver research to support the collection of population-based data, to use consistent language to define caregiving, and support the expansion of research on family caregivers served across the National Family Caregiver Support Program (NFSCP) and the Native American Caregiver Support Program (NASOSP) networks.

Objectives include developing a broad research network of partnerships including research entities, aging services, disability services and family caregiver support providers; creating a shared research agenda; and developing a learning community to increase capacity for caregiving research.

The fourth objective that aligns most closely with the CARR's CDE recommendations is to centralize and promote use of consistent measures on family caregiving among caregiving researchers, aging services, disability services and family caregiver support providers.

Methods employed by the CARE Network to identify common data elements in caregiving research include environmental scans, literature searches, and surveys administered to caregiving researchers and service providers. Results of this work will be published on the ACL [National Caregiver Support Collaborative](#) website and include a matrix of recommended common data elements.

4. National Core Indicators

- *Laura Vegas, Director of Quality Initiatives and Supporting Families, National Association of State Directors of Developmental Disabilities Services (NASDDDS)*
- *Lindsay DuBois, PhD, MPH, Research Associate, Human Services Research Institute (HSRI)*

The [National Core Indicators' \(NCI\)](#) tools collect information on performance and quality of life indicators directly from people who use disability and/or aging services systems, families, and those who deliver services. NCI is national collaborative effort of the [Human Services Research Institute \(HSRI\)](#), [The National Association of State Directors of Developmental Disabilities Services \(NASDDDS\)](#) and [ADvancing States](#). Goals of NCI are to:

- Establish a nationally recognized set of performance and outcome indicators for aging and disability (including intellectual and development disability [IDD]) service systems

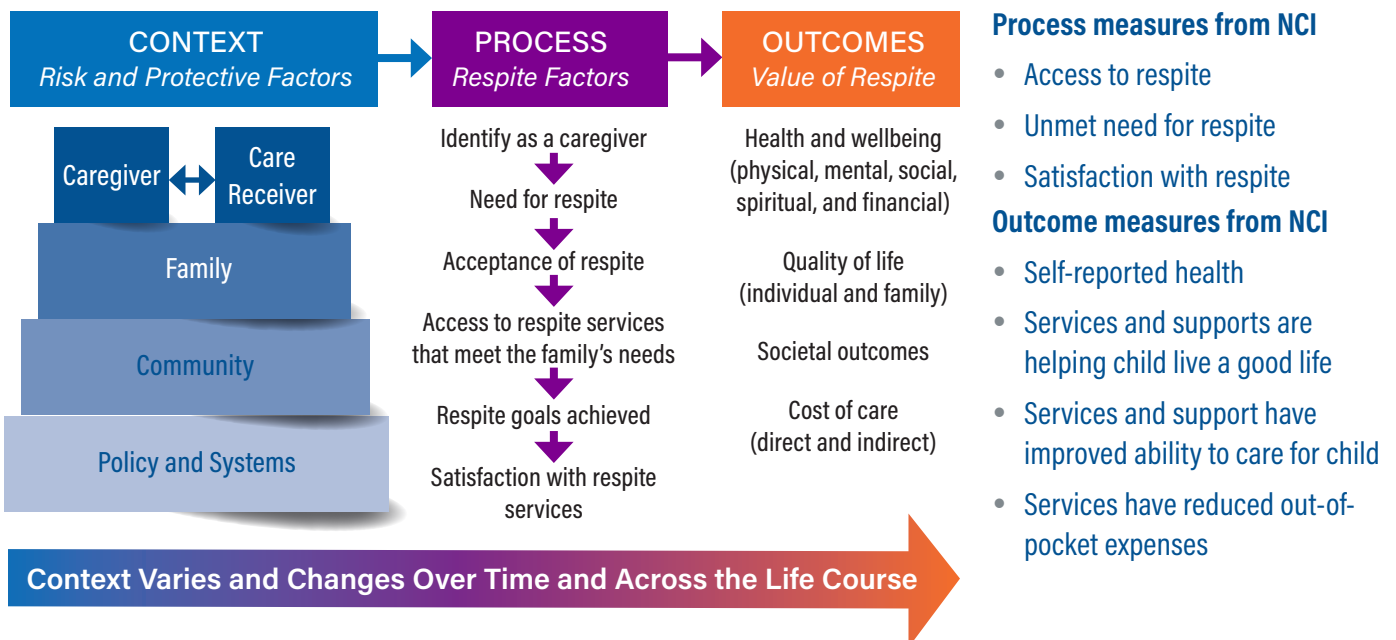
- Use valid and reliable data collection methods and statistical techniques, and
- Report individual state results and national benchmarks of indicators of system-level performance

This information is collected through three national surveys:

- Adult Family Survey (AFS)—sent to families who live with the person with IDD
- Family Guardian Survey (FGS)—sent to families who do not live with the person with IDD
- Child Family Survey (CFS)—sent to families who live with a child with IDD

The NCI goals align with the **Value of Respite Model** and the measurement tools align with the **Common Data Elements** recommended by the CARR (**Figure 5**). The NCI tools collect specific respite related factors including process measures of access, need, and satisfaction with respite, and outcome measures of self-reported caregiver health and ability to provide care, care recipient quality of life, and impact on out-of-pocket expenses. The NCI tools also gather information on the context (risk and protective factors) of the caregiver and care recipient environment.

Figure 5. NCI Process and Outcome Measures for Respite that Align with CARR CDEs and the Value of Respite Model



While there are limitations associated with the NCI data, this resource can be used to examine the impact of the use of respite services, who has access to respite services, the unmet need for respite and associations with demographic characteristics, and caregiver satisfaction with respite quality. Findings validate the importance of respite for families of children with IDD. Family members who access respite have better self-reported health; say the services improved their ability to care for their child; and that services and supports reduced their family out-of-pocket expenses for their child's care. The data also report, however, that access to respite services is an issue for many families.

Future directions include recommended use of NCI data to examine outcomes for families as actions from the National Strategy to Support Family Caregivers are implemented.

Day 1 of the Respite Research Summit concluded with questions and observations provided by conference participants.

Discussion Summary

This in-depth discussion following the presentations focused on critical issues around respite care access, effectiveness, measurement, and funding, with participants sharing research insights, implementation challenges, and family caregiver perspectives.

Key Points

1. Measuring the “Dose” of Respite

The discussion focused on the critical but complex issue of defining, measuring, and meeting an effective “dose” of respite care to support family caregivers—prompting questions around what constitutes a minimal effective dose or a tailored dose for each family caregiver. Some participants emphasized that consistency and reliability in respite—something caregivers can count on—may be more meaningful than a specific quantitative dose.

2. Person-Centered Planning and Tailored Respite

In the IDD space, person-centered planning was highlighted as essential to matching families with the level of respite they truly need. State-imposed limits (e.g., annual respite caps) don't always reflect actual family needs. It was suggested aligning respite dose with tools like the [Supports Intensity Scale](#) to determine appropriate service levels based on support needs.

“One thing that came up a lot to me was this concept of dose of respite... How do we measure that dose? How can we get a better handle on what is a minimal effective dose? Or what's a tailored dose or way to calculate the right dose of respite for the right family...”

- Summit Participant

3. Context Matters

When studying respite outcomes, the caregiver's environment, number of dependents, availability of informal supports, and state policy landscape all influence what respite is needed and what works best. One-size-fits-all approaches fail due to the wide variation in caregiver situations.

4. Need to Include Informal Respite

Many families rely on informal supports (e.g., friends, relatives), which are not well captured in current data systems. There was strong agreement that data collection should include informal respite use and preferences, without diminishing the need for robust formal respite funding.

5. Caregiver vs. Care Receiver Focus

A systemic misalignment exists: although respite primarily benefits the caregiver, most funding and eligibility are tied to the care receiver. This makes it difficult to collect data on caregiver outcomes or demonstrate cost-effectiveness of respite for caregivers. It was suggested programs should consider incentivizing caregiver participation in evaluation to improve data collection on their outcomes.

6. Equity, Access, and Communication

Meeting caregivers where they are—via preferred communication methods; in community rather than in formal service settings; and with appropriate outreach—is essential. Caregivers are often overwhelmed and may not identify as such, limiting their access to help unless proactive outreach occurs.

7. Funding, Policy, and Systems Challenges

Respite eligibility and funding vary widely by state and system (e.g., managed care vs. waiver-based programs). In addition, eligibility for respite is typically tied to the needs of

the care recipient, not the tasks performed by the caregiver. Participants questioned whether it might be possible to reverse this logic and base eligibility on caregiver burden or effort—a significant structural shift. The fragmented and variable nature of service delivery across and within states complicates efforts to standardize definitions and practices.

8. Quantitative and Qualitative Data Needs

Caregiver outcomes (e.g., stress, emotional health, ability to continue providing care) are often measured, but respite-specific data is lacking. Qualitative data (e.g., stories, testimonials) are crucial for policy impact, complementing quantitative metrics like hospitalization rates and program participation. It was suggested that standardized qualitative questions across programs be added to the recommended CDEs to improve advocacy and evaluation. Use a mix of data and compelling caregiver stories to influence policy and funding decisions.

9. Terminology and Common Language

Lack of standard terminology across and within states creates confusion (e.g., same services named differently). Common definitions and language are needed before tasks or outcomes can be consistently tied to funding or policy changes.

Conclusion

The discussion underscored the complex, interconnected nature of respite care systems—from defining and measuring “dose,” to improving access, capturing outcomes, and aligning policies. Participants agreed that caregiver-centered approaches, system-wide coordination, flexible funding, and standardized data collection (both qualitative and quantitative) are all critical to advancing the effectiveness and sustainability of respite care.

DAY 2: ENGAGING RESPITE PROGRAMS IN RESEARCH AND EVALUATION

Developing Research-Ready Respite Services—ARCH Innovative and Exemplary Respite Services Evaluation Grantees

This session highlighted the process for and the value of preparing community-based respite programs to engage in meaningful evaluation. One goal is to assist such programs to be positioned—or research-ready—to engage in more rigorous research and evaluation.

- *Introduction and Panel Moderation by Susan Janko Summers, PhD, ARCH*

The programs showcased participated in the ARCH [Innovative and Exemplary Respite Services Evaluation Project](#) which was informed by the work of the CARR. The programs were selected from the pool of ARCH Innovative and Exemplary Respite Programs and provided with:

- mini-grants and technical assistance designed to enhance knowledge and skills related to process and outcome program evaluation strategies;
- guidance on use of a common framework and common data elements consistent with the CARR recommendations; and
- the opportunity to reflect on evaluation issues and challenges.

The programs were guided through a self-discovery process that included development of a service map, examination of the program's theory of change, identification of context, process (program performance and fidelity), and outcome measures, and exploration of mixed data collection methods and opportunities to triangulate findings from multiple data sources. Each program produced an [Evaluation Data Brief](#) showcasing the results from their evaluation plan developed through the Respite Services Evaluation Project.

The overarching lessons learned through this project, particularly those that relate to the **Value of Respite Model** and the CARR's **Recommended Common Data Elements**, include both individual and organizational level considerations. These include:

- Individual level:
 - Program personnel need to be empowered to speak the language of research and evaluation by providing training and support.

“Not sure exactly how to measure this [person and family-centered services], but I think it has to do with measuring communication, trust, access to support when it is needed, and using process measures (as presenter Laura Vegas suggested yesterday), and mixed methods (as presenter Lindsay Dubois spoke about yesterday).”

- Summit Participant

- An attitude of curiosity should be cultivated to allow staff to speculate about how particular aspects of one's respite service model influences beneficial change for caregivers, care receivers, and families, and be able to identify ways to capture how and whether change occurred.
- Program evaluators should prioritize identifying and then measuring what matters to caregivers.
- Organizational level:
 - Sufficient resources (financial, personnel, and time) must be available to support evaluation or research.
 - Program personnel must be willing to communicate and work collaboratively with colleagues and external partners to design and conduct evaluation that results in increased mutual understanding and improved respite services.

Panel Presentations by Programs Participating in the ARCH Innovative and Exemplary Respite Services Evaluation Project

The following presentations provide a brief description of each of the three programs engaged in the ARCH Innovative and Exemplary Respite Services Evaluation Initiative and the evaluation processes undertaken by each program that align with the **Value of Respite Model**. The [Evaluation Data Brief](#) produced by each program resulted from their 12-month evaluation implemented with technical support from ARCH.

1. Center for Volunteer Caregiving

- *Elaine Whitford, Executive Director, Center for Volunteer Caregiving, Cary, NC*

The [Center for Volunteer Caregiving \(CVC\)](#) Respite Services offer a person-centered approach with a one-on-one volunteer match with family caregivers of older adults. Volunteers typically provide 2-3 hours of respite per week.

Engagement in the ARCH Innovative and Exemplary Respite Services Evaluation Project led to the following changes in CVC evaluation strategies to measure caregiver satisfaction and caregiver burden:

- collection of data at multiple points in the program through use of rolling phone-based assessment at intake and 2-months and 12-months after initiation of services; and
- the addition of the Zarit Scale of Caregiver Burden.

“One informal way we've been able to “measure” how much our programs match with caregiver needs is how quickly our various programs fill up and if they don't fill up, that tells us something as well.

– Summit Participant

These enhancements have increased response rates to the assessments, accuracy of results due to collection of data closer to provision of service, and more touchpoints for communication with caregivers and support staff. Lessons learned include the importance of using data to inform and guide program staff in making changes in programming and processes.

2. Claude Moore Precious Time Pediatric Respite Care Program

- *Hyuntae Kim, MSW, Julianne Secrist, MSN, RN, and Jolynne Bartley, MPA, Claude Moore Precious Time, James Madison University, Harrisonburg, VA*

The [Claude More Precious Time](#) pediatric respite care program creates mutually beneficial relationships to support families of children with special health care needs (CSHCN) with respite and to educate nursing and health and human service students at James Madison University. The program is funded by the Claude Moore Charitable Foundation and delivered through the Institute for Innovation in Health and Human Services at James Mason University (JMU). JMU nursing students are matched with a family who has a child or children with special health care needs and provide 7-16 hours of respite care per semester.

Program outcomes include monitoring the impact the program has on caregiver wellness and self-efficacy and change in student confidence and knowledge of CSHCN and their families. While the evaluation activities are new, launched in Fall 2024, lessons learned through participation in the ARCH Innovative and Exemplary Respite Services Evaluation Project included:

- Insights about self-efficacy and caregiver empowerment and the measurement of these factors.
- Challenges associated with establishing evaluation protocols for two unique groups (families and students).
- Importance of recognizing the capacity of a small staff to conduct program evaluation and the impact of changes in personnel on evaluation continuity.

3. Vanessa Behan

- Amy Knapton Vega, MSW, Executive Director, Vanessa Behan, Spokane, WA

[Vanessa Behan](#), established in 1987, provides 24/7/365 emergency respite childcare, parent education and support programs, a diaper bank and courthouse childcare. The mission of the Center is to keep children safe, build strong families, and create a healthier community in an environment of authenticity and adaptability.

Participation in the ARCH Innovative and Exemplary Respite Services Evaluation Project led to refinement of evaluation protocols to include standardized demographic questions across programs, an increased focus on caregiver wellness, as defined by the caregiver, stress, mental and social health, and support systems. Lessons learned included:

- the complexity of assessing caregiver wellness, especially within an emergency respite model and with caregivers experiencing immediate difficult life circumstances;
- logistical considerations of evaluation activities, such as, allowing time for review by an Institutional Review Board when using a university as an outside evaluator, or tailoring surveys for limited English language speakers; and
- challenges of adding surveys to the discharge process that led to investments of additional time by caregivers and staff during this transitional phase of service.

Discussion Summary

During the discussion which followed the presentations, presenters reflected on personal and organizational challenges they encountered in conducting evaluation, particularly in the context of program implementation and regulatory changes. The value of capturing qualitative process changes in program evaluation, not just quantitative outcomes, was emphasized.

In closing, panelists offered advice to other programs looking to improve evaluation. One presenter simply encouraged: “Just do it.” Another elaborated, reassuring others that programs often already have the necessary

data and processes—they just need to reframe their perspective and align it with evaluation goals.

Conclusion

This exchange underscored the importance of adaptability, reframing challenges as opportunities for improvement, and recognizing the often-overlooked value of process-oriented outcomes. It also emphasized the supportive infrastructure available to programs aiming to strengthen their evaluation efforts.

Emerging National, State, and Local Respite Services Evaluations

The aim of this session was to showcase program evaluations at the national, state and local programmatic levels that reflect the application of the concepts of Context, Process, and Outcomes identified in the **Value of Respite Model**.

1. Center for Dementia Respite Innovation Overview and Evaluation

- *Rebecca Utz, PhD, Associate Dean of Research and Graduate Education and Professor, Department of Sociology, College of Social and Behavioral Science, University of Utah*
- *Joseph Gaugler, PhD, Distinguished McKnight University Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging; Director, Center for Healthy Aging & Innovation, School of Public Health, University of Minnesota*

“Where this overall research on respite has been challenging is in finding effect [because] many of the outcome measures we use aren’t individualized at all....They tend to be standardized measures often developed in other contexts for other health care services that don’t match what respite is designed to do and provide. To show effect of these programs, our outcomes have to be personalized, and that’s easier said than done. Many funders aren’t necessarily comfortable with those types of measures, at least at this point, although many more are getting to that point.

– Joe Gaugler, PhD, University of Minnesota

The presentation by Drs. Utz and Gaugler provided an introduction to the [Center for Dementia Respite Innovation \(CDRI\)](#) funded by the Administration for Community Living, and a description of how the proposed evaluation plan for the work conducted through the Center aligns with the **Value of Respite Model** and the CARR’s **Recommended Common Data Elements**.

The purpose of the CDRI is to increase the availability and improve the delivery of person-centered respite care for people with dementia and their family caregivers. The first round of funding awards was released in July 2024. Aims include development and pilot testing of cost-efficient, effective, strengths-based, person-centered, innovative models of dementia-specific respite care that will reach underserved populations. To ensure successful implementation and sustainability, grantee services are provided comprehensive and robust support including community listening sessions, educational resources, marketing and outreach, and ongoing comprehensive technical assistance.

The CDRI will conduct an independent evaluation of the project including the impact of dementia-specific respite services on the quality of life of service participants and caregivers, and the overall success of the Center’s activities.

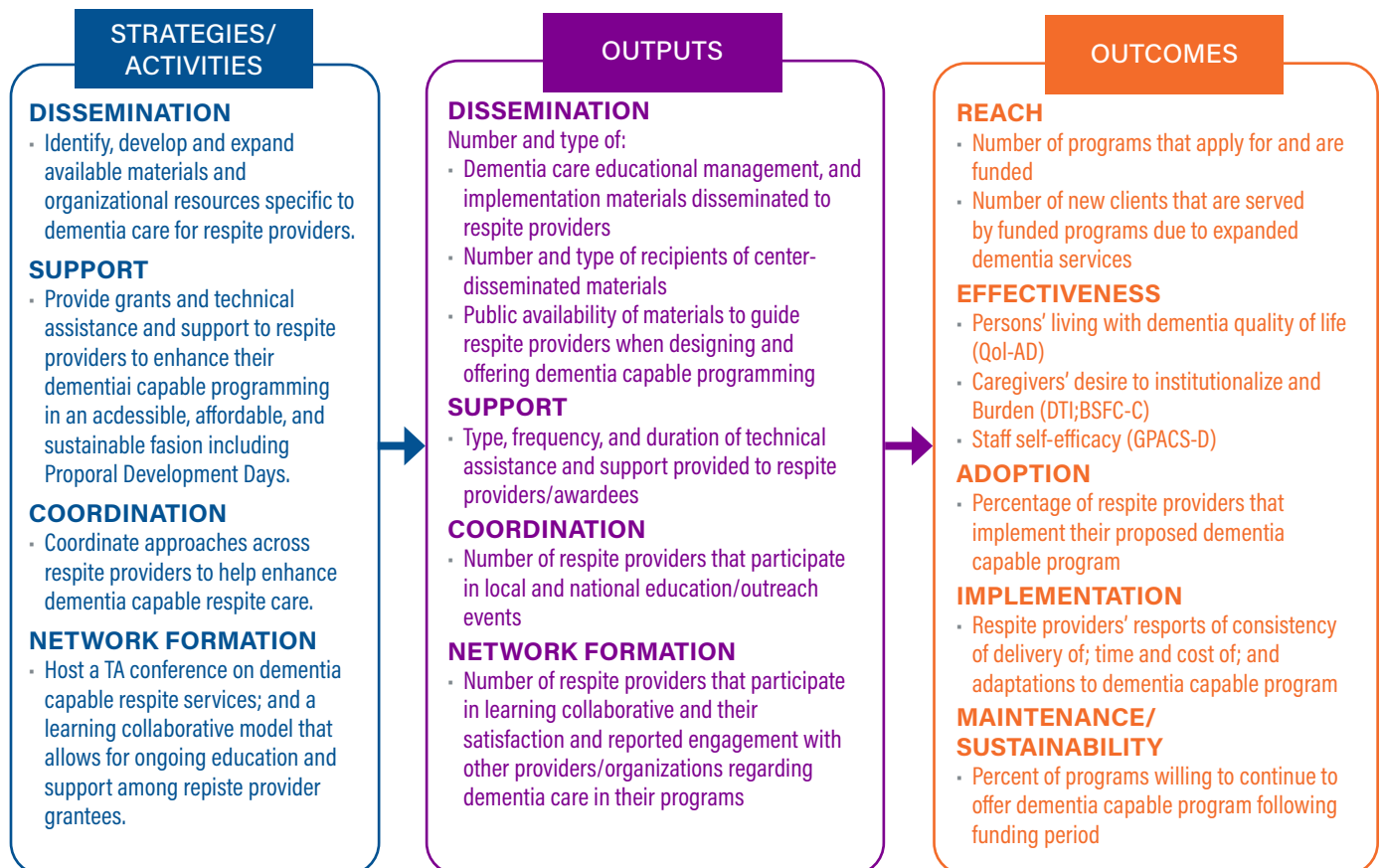
“Our work shows that caregivers benefit from whatever kind of activity they choose or want to do—i.e., recreational or self-care activities are not necessarily more beneficial ways to spend respite than running errands. Napping and cleaning a closet can be very beneficial if it is what they “want” to do!

– Rebecca Utz, PhD, University of Utah

The graphic in **Figure 6** details the logic model developed to guide the CDRI program evaluation on the impact of Center’s activities to support the respite grantees. The outcomes included in **Figure 6** are driving the **RE-AIM** evaluation of the impact of the CDRI initiative, and include the reach of the program; the program’s effectiveness—especially on family caregivers’ quality of life (caregiver burden and positive aspects of caregiving, caregiver wellbeing, social engagement), and the caregivers’ desire to institutionalize the person with dementia (PWD); and also, on staff self-efficacy. The evaluation will also measure the percentage of respite providers who implement their proposed program, and how they implemented and sustained services.

Full standardized tools were not always used—selected items from validated measures were employed to reduce the burden of those being surveyed. Evaluators developed in-take forms to help programs collect comprehensive demographic information, and are also making measurement tools available in multiple languages. Caregiver outcome data will be collected with utmost care in protecting confidentiality.

Figure 6. Logic Model for CDRI Evaluation



The technical assistance and evaluation efforts employed by CDRI align with all components of the **Value of Respite Model** and the CARR's **Recommended Common Data Elements (CDEs)** as represented by the following graphic in **Figure 7**. The check-marks (✓) identify the data elements that will be collected and used to inform the work of the CDRI.

Figure 7. CDRI Outcome Measures that Align the CARR's Recommended CDEs and 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 <div style="background-color: #0070C0; color: white; padding: 10px; margin-top: 10px;"> <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 </div>	<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

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

“Goal Attainment Scaling could be powerful in measuring fit to family needs.”
 – Susan Janko Summers, PhD, ARCH Consultant and Summit Presenter

2. Massachusetts Respite Innovation Grants Evaluation

- Sarah Harrigan, MPA, PMP, Senior Consultant, Aging and Disability Services, Public Consulting Group
- Amy Nazaire, MA, Regional Self Direction Manager, Massachusetts Department of Developmental Services

The [Massachusetts Respite Innovation Grants](#) initiative leveraged one-time American Rescue Act (ARPA) funds. More than \$18 million was awarded by the State to 40 community-based organizations across the state. The goals of the initiative were to enhance, improve, expand and/or reorganize the way that respite is currently provided in the state; identify promising practices to relieve caregivers; close service gaps; provide person-centered respite; and recruit and retain respite workers. Another priority was to implement programs proposing creative or experimental ways to address unmet respite needs that also had strong evaluation components to determine efficiency and efficacy.

The evaluation conducted through this initiative applied the CARR **Value of Respite Model** and **Common Data Set** using mixed methods, including periodic performance reports from programs that captured quantitative as well as qualitative information, learning communities, focus groups, and caregiver surveys, and the collection of data about the context of the caregiver and care recipient, the respite process, and outcomes. Individual grantees identified custom metrics for their programs using both process and outcome measures that align with the **Value of Respite Model (Figure 8)**.

Figure 8. Massachusetts Respite Innovation Grants Evaluation Outcomes that Align with CARR Recommended Core Concepts

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>Core concepts that help to describe risk and protective factors of the caregiver, include:</p> <ul style="list-style-type: none"> ▪ Caregiver Demographics ▪ Caregiver Wellbeing 	<p>Core concepts that help to describe risk and protective factors of the care receiver, include:</p> <ul style="list-style-type: none"> ▪ Care Receiver Demographics ▪ Care Receiver Wellbeing 	<p>Core concepts that help to describe respite factors, include:</p> <ul style="list-style-type: none"> ▪ Description of Respite Model ▪ Caregiver Experience with Respite 	<p>Core concepts that help to describe the value of respite, include:</p> <ul style="list-style-type: none"> ▪ Caregiver Wellbeing <ul style="list-style-type: none"> ▪ Physical ▪ Mental ▪ Social ▪ Spiritual ▪ Financial ▪ Quality of Life

The presenters provided examples of activities used to implement the “process” component of the **Value of Respite Model**. These included:

- Marketing and outreach strategies designed to help the caregiver identify as a caregiver.
- Trust and relationship building activities designed to assist caregivers to accept respite.
- Flexibility in programming to assure that services provided met the family's needs.

Outcomes were measured through program satisfaction surveys and evidence-based caregiver assessment tools. The final report will also identify average cost per caregiver for each respite model.

It was challenging to develop an evaluation to understand the wide scope of services and innovations that were implemented. However, the reach of the programs has been great with more than 3,000 family caregivers served to date, 22% of whom were using respite for the first time. The expected long-term impacts and lessons learned from this initiative are noteworthy. The Massachusetts Lifespan Respite Coalition plans to include the findings in future grant planning and budget requests, and to leverage outcomes to build on networking and learning collaboratives initiated through the innovation grants. Specific results from the evaluation are detailed in the [presentation](#) and a final evaluation report will be forthcoming.

3. Evaluation of EXHALE, The Family Caregiver Initiative

- *Linda Weiss, PhD, Senior Researcher, Center for Evaluation and Applied Research, The New York Academy of Medicine*

EXHALE—The Family Caregiver Initiative, funds and supports collaborative projects in Western New York (WNY) and Southeast Michigan that offer respite and other programming for caregivers of older adults, primarily in rural areas. The Initiative was launched in WNY in 2019 and has provided support to 27 respite projects across 3 cohorts. Support included grants and resources for effective implementation, sustainability, and expansion. EXHALE is managed by The Philanthropic Initiative (TPI) and funded by the Health Foundation for Western and Central New York, the Ralph C. Wilson, Jr. Foundation, the Ann Arbor Community Foundation and others.

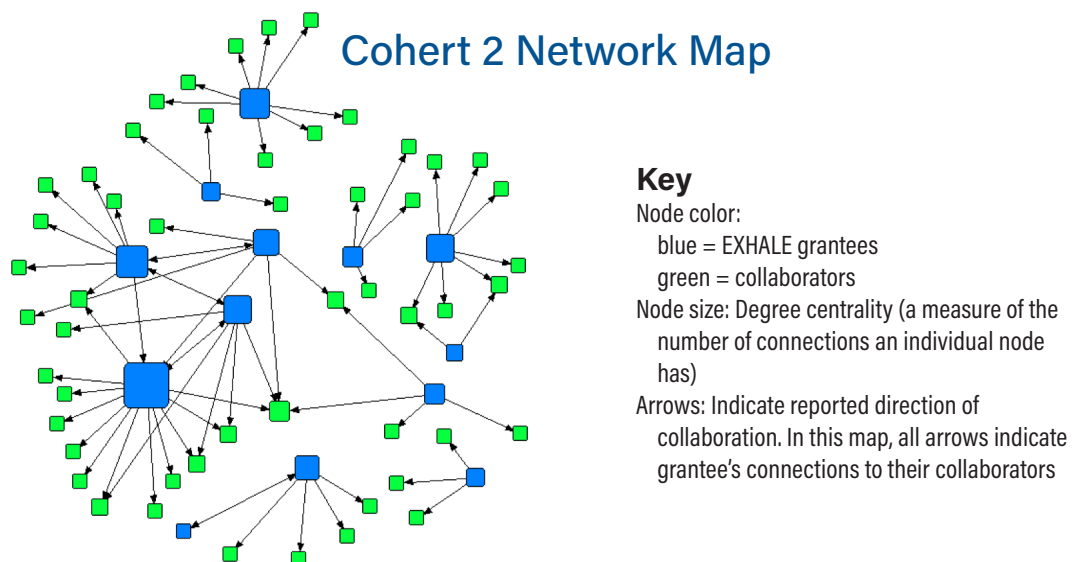
To qualify for funding through EXHALE, programs must use caregiver input in the design of respite programs and employ innovative respite service models. Examples of the innovations emerging from this work include: engaging the caregiver and care recipient in shared respite opportunities, individualized technology-based respite that is not bound by time or place, and offering a broad range of programs and services that may include music, household chores, wellness activities, and brief periods of respite.

The evaluation focuses on assessing changes in access to and use of respite among caregivers of older adults; building the evidence base to better support respite needs and innovative respite models; documenting the development, implementation and significance of new collaborative partnerships; and examining the EXHALE model and its component parts.

The evaluation activities used in EXHALE mirror the elements of the **Value of Respite Model** and **Common Data Elements** with a focus on the collection of shared data using mixed methods (interviews and caregiver surveys), caregiver assessments at baseline and follow-up intervals, and triangulation of findings from multiple data sources. Specific data elements included:

- Demographics of the caregiver and care recipient;
- Information on the respite experience (prior respite experience, frequency of respite, satisfaction with services); and
- Outcome measures of caregiver and care recipient general health, mental health, emergency and hospital use, and caregiver intensity measured at baseline and follow-up.

Figure 9. Network Map of EXHALE Grantee Connections



Dr. Weiss also highlighted the impact of required collaborative activities among grantees participating in EXHALE, such as outreach/advertising, referrals, and shared resources, including volunteers, transportation, training, and space. The belief is that collaborative projects are more likely to be sustainable because of increased community support and efficiency. The extent of grantee collaboration was represented by a Network Map of Connections that extends awareness and delivery of respite services beyond the grantees (**Figure 9**).

Preliminary findings from the evaluation point to growth in access to an uptake in respite; multiple models demonstrating positive impact; and expanded networks of organizations supporting caregiver respite.

Day 2 of the Respite Research Summit concluded with questions and observations provided by conference participants.

Discussion Summary

This discussion focused on advancing respite evaluation through alignment, measurement, and caregiver voice. Stakeholders and evaluators working on a variety of national, state and local respite initiatives explored opportunities for alignment with the CARR **Value of Respite Model** and the use of **Common Data Elements** (CDEs). The conversation focused on improving evaluation practices, developing more caregiver-centered outcome measures, and broadening the understanding of what respite means in diverse caregiving contexts. The discussion emphasized both the promise and complexity of evaluating respite care in ways that are rigorous, meaningful, and responsive to caregivers' lived experiences.

Key Points

1. Alignment with the CARR Value of Respite Model

Current projects show retrospective alignment with the model, underscoring its relevance across varied settings. Participants expressed interest in modifying evaluation metrics to further strengthen alignment and promote consistency using CDEs.

2. Describing and Categorizing Respite Interventions

There is a recognized need to better define and categorize respite interventions in evaluation and research to facilitate comparison and improve communication across initiatives.

The tools developed by CARR—particularly those focused on capturing caregiver experience with respite and respite model descriptions—are seen as useful for standardizing definitions and enabling comparison across projects.

“We need to measure what matters and have those outcome measures informed by the caregivers.”

– Kim Whitmore, PhD, RN, Marquette University

3. Data Limitations in Linking Respite Type to Outcomes

Some evaluations aggregate data at the organizational level, making it difficult to connect specific types or doses of respite with individual caregiver outcomes.

4. Identifying Existing Models and Promising Practices

Upcoming reports from state-level and federal evaluations (e.g., Massachusetts innovation grants, CDRI project) aim to document effective and sustainable respite models. There is interest in compiling a compendium of promising practices.

5. Evaluating Fit and Family-Centeredness

Evaluators are increasingly focused on whether respite services are appropriate, and if they meet families' unique contexts and needs. Some projects incorporate open-ended questions and qualitative methods (e.g., focus groups) to capture this nuance, though sample size limitations may constrain quantitative analysis.

6. Challenges with Current Outcome Measures

Many standard outcome measures used in respite evaluations (e.g., stress, anxiety) are not specific to respite or adaptable to its goals, that may limit the ability to demonstrate impact.

There is a growing call to develop personalized, caregiver-informed measures that better capture the true impact of respite and what matters most to caregivers.

7. Need for Caregiver-Informed Measure Development

Caregivers should play a central role in identifying what outcomes matter and how they should be measured.

These measures should undergo validation and meet funders' needs for rigor and relevance, creating a necessary balance between scientific validity and caregiver voice.

8. Measuring Respite in Nontraditional Ways

Concepts like “goal attainment scaling” and single-subject research were proposed as innovative ways to track individualized outcomes over time.

Some caregivers view help with daily living tasks (e.g., lawn mowing, housework) as forms of respite, which challenges traditional definitions and calls for a broader lens in evaluating respite value.

9. Broadening the Definition of Respite

Caregivers define respite in deeply personal ways—from formal services to moments of peace or practical support.

Evaluations should capture this range of interpretations, recognizing that what constitutes meaningful relief varies widely.

10. Tools and Resources Sharing

Participants were encouraged to share surveys, tools, and evaluation instruments with ARCH to support knowledge exchange and replication.

11. Specific Tools and Measures Discussed

Examples included standardized tools like the Desire to Institutionalize scale and the Caregiver Intensity Index, as well as several short-form and non-proprietary measures featured in the CDE white paper.

12. Importance of Community-Engaged Research

Future efforts should ensure that measures reflect the unique voices of caregivers in different communities, and individualized definitions of need and relief.

“It is so heartening to see so many innovative respite approaches not only being funded, but also evaluated, so that we will have the best information to provide what family caregivers truly prefer and benefit from. The ultimate goal is to be able to sustain and replicate promising practices and your work moves us in that direction.

- Jill Kagan, MPH, ARCH

Conclusion

The conversation underscored the need to evolve respite care evaluation by centering the caregiver perspective, adopting shared frameworks like the CARR **Value of Respite Model**, and developing outcome measures that reflect the actual impact of respite in caregivers' lives. There is strong interest in working collaboratively to share tools, develop new caregiver-informed metrics, and ensure evaluation approaches are both rigorous and meaningful. As the field moves forward, success will depend on balancing formal evaluation standards with the lived realities of caregivers—measuring not just what is easy to count, but what truly matters.



DAY 3: RESPITE RESEARCH AND EVALUATION THAT ENGAGES FAMILY CAREGIVERS AND COMMUNITIES



The final day of the Summit focused on respite research and evaluation that engages family caregivers and communities in order to address unmet needs and highlighted the important role of philanthropy in supporting these vital initiatives.

The introductory remarks for Day 3 presented by Dr. Kim Whitmore called attention to the lens a person brings to their work and the importance of understanding the needs of caregivers, families, and the community from their perspective in order to best meet their needs. Dr. Whitmore reviewed the multiple components of the **Value of Respite Model** designed to guide person- and family-centered program delivery, evaluation, and research. These include:

- Understanding individual, family, community, and cultural contexts as risk and protective factors;
- Developing person/family-centered respite programs that are tailored to meet the unique needs of individuals and families; and
- Recognizing that context varies and changes over time and across the life course.

Dr. Whitmore also addressed the importance of community engagement of family caregivers and care recipients in respite research through the use of Community Advisory Boards, community validation of findings, and dissemination of research results in a ways that are most useful to communities through use of short summaries, fact sheets or briefs in plain language.

“ *Respite care is a part of this work...which means awesome opportunities for studying and learning and making sure that we get this right—so that there's payment for respite, so that there's widespread availability of respite.*

– Rani Snyder, Vice President for Program, John A. Hartford Foundation

Philanthropy's Role in Advancing a Respite Research Agenda that Addresses the Diverse Needs of Family Caregivers

1. The John A. Hartford Foundation

- *Rani Snyder, MPA, Vice President, Program, The John A. Hartford Foundation*

The John A. Hartford Foundation (JAHF) uses a multi-tiered approach to inform grant-making and program development with a focus on national initiatives of Age-Friendly Health Systems, Family Caregiving, and Serious Illness & End of Life.

Ms. Snyder reviewed how an idea becomes a grant, with judgments made related to settings, models, scalability, and sustainability. She discussed the importance of philanthropy investing in respite services and how evaluation and research are important to guide the funding of the most effective programs, to inspire researchers to look at respite as a model, and to help implement models.

A few of the initiatives supported by the Foundation that are specific to respite include [Best Programs for Caregiving](#), further support for the [CMS GUIDE model](#), and efforts by the National Academy for State Health Policy (NASHP) to enhance access to respite through respite workforce training; to facilitate federal-state dialogue to implement respite actions within the National Strategy to Support Family Caregivers; and conduct state scans on respite and direct care workforce policy activity. The Foundation has also supported the National Alliance for Caregiving in its advocacy for policy changes that promote community-based support for caregivers.

Ms. Snyder emphasized JAHF's commitment to supporting person-centered care; partnering across sectors and disciplines; and leveraging research and community input to improve and scale caregiving models—especially in the context of respite care for older adults and their families.

“The need for respite—and the need to build respite informed by caregivers—spurred three very robust pilots....We believe these models will lead to even more robust evaluation on not only the caregiver respite program, but on the memory café model itself.

– Ken Genewick, MBA, Vice President of Programs, Health Foundation for Western and Central New York

“So good to hear all you wonderful researchers with passion and a heart for our family caregivers.

– Summit Participant

2. Health Foundation for Western and Central New York

- *Ken Genewick, MBA, Vice President of Programs, Health Foundation for Western and Central New York*

Ken Genewick, from the Health Foundation for Western and Central New York, provided a regional perspective on supporting family caregivers and advancing respite care, emphasizing the Foundation’s strong commitment to community-driven solutions. The Health Foundation for Western and Central New York (HFWCNY), founded in 2002, strives to prioritize meeting the unique needs of all individuals to achieve health outcomes. This work is guided by experts and grassroots organizations with a focus on advocacy for policy change that reduces unfairness in healthcare.

He opened by reflecting on how the discussions throughout the convening resonated with the Foundation’s work—particularly the need to define respite based on caregivers’ voices and lived experiences, and to adapt approaches for different communities. Mr. Genewick emphasized the importance of compensating community partners, honoring their time and contributions. He discussed the importance of co-designing respite services with caregivers and committing to evaluating and scaling innovative, community-based models.

The Foundation supports cross-sector collaboration guided by the principles of trauma-informed care with a strategic focus on family caregivers. Their work gained momentum in 2017 through a partnership with the Ralph C. Wilson, Jr. Foundation, allowing for expanded initiatives to support family caregivers. Examples specific to respite include the Exhale Family Caregiver Initiative, which used community-based creative problem solving to develop tailored respite solutions. One standout was the *Musical Memories Café*; a memory café model now expanded into an 11-member *Western New York Memory Café Collective*.

The Foundation is active in New York’s Master Plan for Aging and is helping bolster state-level advocacy efforts around caregiving and respite. Their work is rooted in a belief that robust, and fairly distributed local implementation—paired with rigorous evaluation—can shape impactful policy and future research.

Mr. Genewick underscored the Foundation’s commitment to advancing equity-informed, community-rooted caregiver support and how local evaluations can fuel broader, evidence-based innovation in respite care.



Discussion Summary

The discussion following this session emphasized the importance of deep community engagement and intentional work to promote fairness in funding and program development, acknowledging that such efforts require extra time, resources, and sustained commitment.

Key Points

1. Recognizing Community Differences

Funders discussed the motivation behind prioritizing social justice, noting that meaningful differences across communities must be recognized and addressed to improve health outcomes and quality of life.

The COVID-19 pandemic was cited as a turning point that magnified existing disparities, prompting some organizations to intensify their inclusion-focused initiatives that had already begun pre-pandemic.

2. Overcoming Funding Challenges

Despite limited staff capacity and logistical challenges, some foundations are finding alternative methods to maintain meaningful engagement with different communities. This includes rethinking application processes to reduce barriers for grassroots organizations.

A key strategy involves shifting away from transactional relationships to build authentic, bi-directional, and trusting partnerships with community-based organizations. The need to remain humble, listen, and defer to local expertise was underscored.

Participants stressed that fairness should not be treated as afterthoughts or “check-the-box” activities. Instead, these principles must be embedded in the core structure of programs and initiatives—“baked into the cake,” not added on top.

Conclusion

The session concluded with an invitation for attendees to reflect on their own work with racially and ethnically diverse communities in respite research and share their accomplishments via chat, as the group transitioned into a break before the next presentations.

Respite Research and Programs that Engage Family Caregivers and Communities In Order to Address Unmet Needs

The programs and research activities described in these presentations demonstrate the application of the **Value of Respite Model** and offer suggestions for future efforts.

1. *Cultural and Contextual Adaptations of Adult Day Services: Enhancing Inclusivity and Relevance in Respite Care.*

- *Lauren J. Parker, PhD, MPH, Associate Scientist, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD*

Adult Day Services (ADS) provide daytime care and supervision for older adults, serving as an alternative to nursing home care. These services enhance wellbeing for individuals with dementia and support family caregivers through education and skill-building. ADS centers serve approximately 286,300 participants nationwide and approximately 60% of the clients identify as racial/ethnic minorities.

Key components of adaptations to respite models that match population specific customs, beliefs, and preferences include:

- Language accessibility includes interpreters and outreach materials tailored to individuals and communities.
- Activities and programs are tailored to individual preferences and community traditions.
- Staff receive training from families and communities to learn about their caregiving practices.
- Nutrition services offer meal options tailored to individuals and communities.

This model of care exemplifies the **Value of Respite Model**, supporting caregiver wellbeing by making respite services relevant and accessible, enhancing sustainability across caregiving relationships, addressing caregivers' specific beliefs and practices, and fostering stronger social networks to increase utilization of respite and other community resources. Future directions include implementation of research using the **Value of Respite Model** to assess the efficacy of community relevant ADS programs, development of relevant metrics and tools, and continued advocacy for funding policies to assure fair access to quality respite care that meets the unique needs of all individuals and communities.

“I work with a lot of tribal communities in Northern Nevada and over years of building relationships we are beginning to see more respite uptake among these populations. I would say it takes time, but keep at it! Our respite program offers an option for the caregiver to be reimbursed for paying a private caregiver for respite. This has been a popular option among these communities as they can hire people they may already know and trust to provide care, while it can also be more flexible and cost less.

- Summit Participant

2. Understanding the Respite Care Experience of Latinx Families of Children With Special Health Care Needs (CSHCN)

- *Kim Whitmore, PhD, RN, Assistant Professor, College of Nursing, Marquette University, Milwaukee, WI*

This presentation reported findings from a [mixed-methods pilot study](#) guided by the variables recognized in the **Value of Respite Model** in collaboration with PADRES E HIJOS EN ACCIÓN, a non-profit supporting Latinx families and Loyola University Chicago. Access to respite was primarily provided in-home and funded by public sources with almost half of the respondents indicating there was a waitlist for services. Common barriers to respite care included lack of knowledge about respite, citizenship issues, language barriers, and long waitlists.

This study employed two measures validated in Spanish (APGAR and PSS-10) and the Global Family Quality of Life Scale that is not currently validated for use by members of the Spanish-speaking community. Future efforts include validation of this tool and use of findings to develop respite interventions that meet the unique needs of Latinx families of CSHCNs.

3. Community-Engaged Research

- *Kadijha Marquardt-Davis, MSW, ECCHO Program Director/Director of Advocacy & Civic Health, ECCHO—Engaging Communities to Change Health Outcomes, Madison, WI*

The final presentation from this panel provided a rich description of efforts to improve health outcomes through civic participation and community-based research initiatives. ECCHO focuses on civic engagement training for BIPOC women and non-binary individuals to address systemic racism. Local Program Coordinators oversee cohorts and provide compensation and necessary training resources to participants.

The vision for these efforts aligns with the Context—Risk and Protective Factors (Policy and Systems) and Outcomes (Health and Wellbeing) of the **Value of Respite Model**. The goals of this work include:

- Improve overall health and mental health of participants.
- Increase hope and civic participation levels.
- Enhance confidence and leadership skills among participants.
- Strengthen civic infrastructure to improve health outcomes.

The call to action shared by Ms. Marquardt-Davis was to:

- Encourage radical dreaming for a better world.
- Utilize Community-Based Participatory Research (CBPR) methods.
- Prioritize people and their experiences.
- Emphasize that initiatives are not about individual interests.

Discussion Summary

The closing session discussion emphasized the importance of centering community voices and lived experience in respite care research and program development. There was a strong call to recognize and value community members as experts, approach the work with humility, and move beyond institutional constraints that often overlook relationship- and trust-building as legitimate academic or professional contributions.

Key Points

1. Overcoming Resource Challenges in Community-Engaged Research

Speakers discussed the persistent funding challenges faced by community-based organizations trying to provide respite care, especially for underserved populations. They acknowledged the need for specialized training and staffing, which increases costs, and emphasized the ethical tension between dreaming big and the reality of limited resources. A key recommendation was to collect and share both data and personal caregiver stories to demonstrate the value and impact of respite care for advocacy and policy change.

“Thanks to all the organizers, presenters and panelists for the entire summit. As a caregiver of a young adult, and a teen aged who will need supports as they both continue into adulthood, I am inspired by this work. I am also thinking about support my husband and I will have to provide as our parents age.

- Summit Participant

2. Practical Steps to Success in Engaging Communities

The conversation highlighted the difficulty service providers and researchers face in reaching underrepresented communities. Practical suggestions included attending local events, partnering with trusted community leaders, and engaging authentically without expectations of immediate outcomes—likened to a “dating” process of building relationships. Funders were encouraged to require and support these engagement efforts explicitly in grant proposals and budgets.

Panelists stressed the importance of ensuring programs and services are responsive to community identity, values, and communication styles—rather than using a one-size-fits-all approach. They emphasized the need to design and deliver respite care that reflects and respects the varied backgrounds, languages, traditions, and lived experiences of those being served.

Conclusion

The session concluded with expressions of gratitude and a collective call to action for program planners, evaluators, researchers, and policy makers: to sustain the momentum, take concrete next steps, and remain committed to improving caregiver supports through research, collaboration, and systems change.



V. Report Conclusion

The 2024 Respite Research Summit provided a timely and critical forum for advancing the national dialogue on respite care and caregiver support through the lens of evidence, innovation, and equity. The discussions and presentations reaffirmed the urgency of centering caregivers in research, strengthening the infrastructure for data collection and use, and addressing systemic barriers that hinder access to high-quality, meaningful respite. The Summit underscored the importance of the **Value of Respite Model** and the **Recommended Common Data Elements** as guiding frameworks for evaluation, service delivery, and policy development.

“We hope you leave this summit with practical action steps, renewed energy, and inspiration to keep advancing respite research—because in doing so, we’re ultimately strengthening support for family caregivers and improving lives.

*– Kim Whitmore, PhD, RN,
Marquette University*

Participants from across sectors demonstrated that collaboration—among researchers, program providers, funders, and family caregivers—is essential to building a sustainable ecosystem for respite care that is effective, inclusive, and informed by lived experience. The examples shared throughout the Summit reflect a growing national momentum to generate better data, develop caregiver-defined measures, and scale promising practices that are responsive to real-world challenges.

As the ARCH National Respite Network and Resource Center and the Committee for the Advancement of Respite Research (CARR) move forward, the insights and recommendations from this Summit will inform a shared research agenda and drive continued alignment with the *National Strategy to Support Family Caregivers*. Together, these efforts will help ensure that respite services are not only available, but truly valuable—improving the wellbeing of caregivers, families, and the communities they support.

Appendix

ARCH Committee for Advancement of Respite Research (CARR) serves in a research advisory capacity to the ARCH Lifespan Respite Technical Assistance and Resource Center.

Joseph Caldwell, PhD, Senior Scientist and Director of the Community Living Policy Center, Lurie Institute for Disability Policy, Brandeis University

Thomas V. Caprio, MD, MPH, MS, Professor of Medicine/Geriatrics and Chief Medical Officer, UR Medicine Home Care & Hospice, University of Rochester Medical Center

Joseph E. Gaugler, PhD, Distinguished McKnight University Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging; Director, Center for Healthy Aging & Innovation, University of Minnesota School of Public Health

Ken Genewick, MBA, Vice President of Programs, Health Foundation for Western and Central New York

Tamar Heller, PhD, Distinguished Professor, Disability and Human Development Director, Institute on Disability and Human Development, University of Illinois Chicago

Lauren J. Parker, PhD, MPH, Associate Scientist, Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health

Susan Peschin, MHS, President and CEO, Alliance for Aging Research

Cordelia Robinson Rosenberg, PhD, RN, Professor Emerita, University of Colorado School of Medicine

Rani E. Snyder, MPA, Vice President, Program, The John A. Hartford Foundation

Sarah A. Sobotka, MD, MSCP, Associate Professor of Pediatrics, Department of Pediatrics, Section of Developmental and Behavioral Pediatrics, University of Chicago

Sarah Swanson, MPH, Assistant Professor, Munroe Meyer Institute, University of Nebraska Medical Center

Rebecca L. Utz, PhD, Associate Dean of Research and Graduate Education and Professor, Department of Sociology, College of Social and Behavioral Science, University of Utah

Kim E. Whitmore, PhD, RN, CPN, Assistant Professor, College of Nursing, Marquette University