



Measuring the Value of Respite

*A White Paper
by the ARCH Committee
for Advancement of Respite Research*

Lead Authors

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

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

Jill Kagan, MPH
Director
ARCH National Respite Network and
Resource Center



Contents

3	Overview
4	Background
7	Measuring the Value of Respite
11	Redefining the Value of Respite
11	Figure A: The Value of Respite Model
15	Recommendations
17	Conclusion
18	References
20	Appendix A: ARCH Committee for Advancement of Respite Research (CARR)



Overview

Purpose

The purpose of this white paper is to provide an in-depth description of the current challenges related to measuring the economic value of respite and to offer a new framework for research and evaluation.

Key Points

- There is an urgent need to identify, expand, and develop evidence-based and evidence-informed respite that improves caregiver outcomes.
- Current research and evaluation methods do not adequately measure the economic value of respite.
- Caregivers need respite and accrue beneficial effects from respite, even if providing respite does not save money.

Acknowledgements

Special thanks to the Committee for Advancement of Respite Research (CARR) Members.

Joseph Caldwell, PhD

Thomas V. Caprio, MD, MPH, MS

Joseph E. Gaugler, PhD

Ken Genewick, MBA

Tamar Heller, PhD

Lauren J. Parker, PhD

Susan Peschin, MHS

Cordelia Robinson Rosenberg, PhD, RN

Rani E. Snyder, MPA

Sarah A. Sobotka, MD MSCP

Sarah Swanson, MPH

Rebecca L. Utz, PhD

Kim E. Whitmore, PhD, RN, CPN

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





Background

Respite is commonly referred to as a “break” from the demands of caregiving. The [ARCH Expert Panel on Respite Research](#) defined respite as “planned or emergency care that provides a family caregiver some time away from caregiver responsibilities, *and* results in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system.” The second half of the definition is a call to action to researchers and evaluators to ensure that outcomes of respite are measured. However, much of the current respite-related research focuses on identifying the need for respite among caregivers. Research articles that focus on outcomes can be found in the [Annotated Bibliography of Respite and Crisis Care Studies, 6th Edition](#), developed by the ARCH National Respite Network and Resource Center.

About ARCH

Mission

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.

Respite Research Initiative

ARCH has advanced efforts to enhance the respite evidence base to assist with sustainability, promote continuous quality improvement, and help grantees and others translate research into best practices through their [Respite Research Initiative](#). ARCH engages in strategies to collect, synthesize, disseminate, and stimulate research in the field of respite and family caregiver support. The ARCH Goals for Advancing Respite Research include:

- Improve access to and quality of respite services
- Identify aspects of respite services and models that make them exemplary
- Evaluate and replicate promising respite services
- Translate research findings into practice and policy
- Identify additional possibilities (e.g., funding opportunities for research)



Expert Panel on Respite Research

The [Expert Panel on Respite Research](#), convened by ARCH in collaboration with the Administration for Community Living, was key to helping advance this mission by engaging experts in the field in informed discussions of current respite research and possibilities for future investigation. A final report, including a respite research agenda, was released in October 2015. In the [Research Agenda for Respite Care](#), the Expert Panel identified six key areas to establish evidence for the effectiveness of respite for improving the well-being of caregivers and others in their families and communities:


- Improved research methodologies
- Individual, family, and societal outcomes
- Cost-benefit and cost-effectiveness research
- Systems change that improves respite access
- Improved respite provider competence
- Translate research findings into best-practice models

Respite Research Summit

On September 29 and 30, 2020, ARCH convened the virtual [Respite Research Summit](#) with more than 130 national and international participants, including researchers, philanthropic foundation representatives, representatives from the Administration on Community Living, policy analysts, advocates, Lifespan Respite grantees and partners, and respite program providers. The Summit was a capstone event to ARCH's initiative to advance the Expert Panel's respite research agenda. Researchers engaged in respite-related research were invited to present their research on respite and caregiving, with specific reference to the [six recommendations made by the Expert Panel of researchers, advocates and funders](#) convened by ARCH in 2015. The report [Advancing Respite Research: Findings from the Respite Research Summit](#) presents in detail the findings of studies presented, and summarizes recommendations and key themes from the deliberations of Summit participants. The emergent themes include defining and describing respite; research funding; measures and measurement; culturally appropriate research with diverse populations; rethinking cost-effectiveness and cost-benefit studies; workforce development and access to research; and utilizing research findings to inform and improve policy and practice. The recommendations made by both researchers and other Summit participants are used to advise ARCH on the current phase of advancing respite research.

Committee for Advancement of Respite Research

ARCH convened a [Committee for Advancement of Respite Research](#) (CARR) [Appendix A]. The purpose of the CARR is to advise ARCH on the execution of its respite research initiative and help advance a respite research agenda that supports activities and innovations to develop an evidence base for respite care and related services. The CARR is comprised of some former members of the ARCH Expert Panel on Respite Research, research scholars and evaluators, and foundation representatives. The CARR is charged with taking the original work of the Expert



Panel and the findings from the Respite Research Summit to help tailor ARCH's next steps for advancing respite research. The CARR formed three work groups to address the following identified priority actions:

- Define and measure the value of respite
- Recommend the use of common data elements (CDE) for respite-related research
- Expand culturally appropriate respite-related research with historically underrepresented populations

Alignment to National Initiative

This work aligns with the [2022 National Strategy to Support Family Caregivers](#), which was created to support family caregivers caring for those of all ages, from youth to grandparents, and regardless of where they live or what caregiving looks like for them and their loved ones. There are five goals outlined in the National Strategy; goal 5 is to expand data, research, and evidence-based practices to support family caregivers. The following are the three outcomes for Goal 5:

- Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience.
- Outcome 5.2: Family caregiver research facilitates the development and delivery of programs and services that support and enhance the health and well-being of the family caregiver and the person receiving support.
- Outcome 5.3: Promising and evidence-informed practices are promoted, translated, and disseminated to support family caregivers in the delivery of health care and social services.

Current Context

Context matters. The current context in the United States includes an aging population; an increase in the number of individuals with disabilities, health care needs and functional limitations who require caregiving support; a direct care worker crisis; and widening disparities that limit equity of access among historically marginalized racial and ethnic groups, individuals identifying as LGBTQIA+, people living in rural areas, and those with lower sociodemographic status. Additionally, families and programs are still recovering and trying to find a "new normal" after the devastating impacts of the COVID-19 pandemic. Measuring the value of respite care is more important now than ever.



Measuring the Value of Respite

Despite ample evidence that respite has many benefits, limited research has been done to capture the economic value of respite. Often economic value is important to funders and decision makers, so it is important to be able to demonstrate value to these stakeholders. However, current methods used to measure value that use an economic framework are difficult and arguably inappropriate to use in the context of respite. Therefore, the purpose of this white paper is to provide an in-depth description of the current challenges related to measuring the economic value of respite and to offer a new framework for research and evaluation. We will first describe what we know about the value of respite based on current research that highlights the benefits of respite. Next, we will discuss the challenges with using current models of economic analysis. We conclude with a call to action for researchers and evaluators to redefine how we measure the value of respite using a new framework.

Current Respite Research

Current research highlights the many benefits of respite. Respite utilization has helped to delay or avoid facility-based placements (Gresham, et. al., 2018; Avison, et al., 2018), improve maternal employment (Caldwell, 2007), strengthen marriages (Harper, et. al., 2013), and reduce caregiver depression, stress and burden linked to caregiver health (Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014). While current research demonstrates many benefits of respite, these benefits are not always recognized as a “value,” especially from an economic perspective.

Current Methods for Measuring Economic Value


According to the [CDC](#), there are three traditional ways that we currently measure “value” in economic evaluation: return on investment (ROI), cost-benefit analysis (CBA), and cost-effectiveness analysis (CEA). In any economic analysis, it is crucial to define what counts as a cost or a benefit by defining the perspective (context matters).

Return on Investment

The formula for calculating ROI is the net gain – or the direct financial gain from an investment minus the cost of the investment – divided by the cost of the investment. This gives the return on investment, often shown as a percentage.

$$\frac{\$ \text{ Gained} - \$ \text{ Cost of Investment}}{\$ \text{ Cost of Investment}} = \% \text{ ROI}$$

According to the [CDC](#), ROI has limitations when applied to public health interventions, such as respite care. “Most public health programs are implemented because of their nonfinancial



benefits. These programs' benefits accrue to patients, communities, and society as a whole. Without taking into account all these benefits and focusing only on financial gains, the intervention may look as though it's not worth the cost (p. 9)." It's usually better to consider societal ROI in terms of cost-benefit analysis (CBA) or cost-effectiveness analysis (CEA).

Cost-benefit Analysis

A cost-benefit analysis (CBA) can be thought of like an ROI from a societal perspective and can assess whether the program's total societal benefits justify its costs. In CBA, all costs and benefits of a program are given a monetary value, not just the financial ones. Costs can include direct, indirect, and intangible costs. Benefits include a program's financial outputs and its non-financial, health and social benefits. However, selective monetization of benefits likely underestimates and devalues the monetizable benefits. According to the [CDC](#), there are two common measures used in a cost-benefit analysis: benefit-cost ratio and net benefit (shown below).

$\frac{\$ \text{ Value of all benefits}}{\$ \text{ Value of all costs}} = \text{Benefit-Cost Ratio}$

$\$ \text{ Value of all benefits} - \$ \text{ Value of all costs} = \text{Net Benefit}$

$\$ \text{ Value of all benefits} - \$ \text{ Value of all costs} = \text{Net Benefit}$

Cost-effectiveness Analysis

A cost-effectiveness analysis compares the cost of an intervention or program to its effectiveness as measured in health outcomes and is expressed as cost per health outcome (shown below).

$\frac{\$ \text{ Net Costs}}{\text{Net Effects}} = \text{CE in } \$ \text{ per Health Outcome}$


$\frac{\$ \text{ Net Costs}}{\text{Net Effects}} = \text{CE in } \$ \text{ per Health Outcome}$

This approach helps planners and payers to choose among different approaches to achieving a desired outcome by quantifying the value each proposed intervention or program is likely to produce. "When a set of programs do not necessarily save money but do produce positive health outcomes, cost-effectiveness analysis can help determine the best value by finding which one produces the most health benefit for its cost. ([CDC](#), p.13)."

Respite Research Using Economic Analysis

Economic analyses related to respite are limited. However, there are a few examples in the literature that have looked at multiple supports, which include respite.

[Mason, et. al., 2007](#) conducted a systematic review to determine the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their caregivers. They concluded that there was no reliable evidence that respite care delays entry to residential care for frail older people; however, they cite methodological issues as a likely reason for these findings and state that better-quality evidence is urgently needed.




In 2012, [Dr. Mandel and colleagues](#) conducted a retrospective cohort study reviewing 2004 Medicaid claims data of children aging from 5 to 21 diagnosed with autism spectrum disorder. They found that each \$1000 of increased spending on respite care during the preceding 60 days resulted in an 8% decrease in psychiatric hospitalization after adjusted analysis. The researchers evaluated the use of both therapeutic and respite services. They did not find the same association with therapeutic services. The researchers note that respite is not universally available or reimbursed and offer their study as evidence of the need to expand respite care.

Washington's [Medicaid Transformation Project](#) (MTP), which includes the Medicaid Alternative Care (MAC) and Tailored Supports for Older Adults (TSOA), has received a lot of national attention for the wide range of supports provided to family caregivers and the resulting ROI. Researchers used Medicaid medical/LTSS and Medicare claims between September 2017 and December 2019 to examine the outcome measures. Since comprehensive assessment and a broad range of support services, including respite, were used by caregivers, not all these outcomes can be directly linked to just the respite provided, but qualitative data from caregiver interviews identified respite as a very important part of the program.

Using data from the Ten-Year Long-Term Care Project (TLTCP) in Taiwan, a study by [Chan, et. al., 2022](#) examined the effects of multiple long-term care (LTC) services, such as home care, adult day care, home nursing care, in-home and institutional respite care, and meal delivery services on the health care utilization and cost among caregivers of service recipients with and without dementia. They concluded that providing multiple LTC services for people with dementia results in great benefit to their caregivers, including lower health care costs.

Challenges to Measuring the Economic Value of Respite

There are numerous challenges to measuring the economic value of respite using traditional cost analysis methods. First, general barriers to respite use often impact our ability to collect meaningful data and conduct quality research. Respite services can be provided formally through volunteer or funded programs or respite may be provided informally by family and friends, making it less likely to be "counted" in research and evaluation and even more difficult to attach a true economic cost of the service. There is a respite care workforce shortage (made worse by the COVID pandemic) and limited funding for respite, which make it hard to conduct studies with large sample sizes, which are needed for cost-benefit studies. Additionally, there is a lack of a consistent definition of respite, what constitutes a "unit of service," and hence, its cost, which makes it challenging to measure the amount of respite received, the subsequent "dose effect," and its economic value. While the primary benefit of respite is intended for the caregiver, it is often difficult to measure caregiver outcomes because respite is typically a service provided to the care receiver, rather than the caregiver, which makes it difficult to collect data on caregiver outcomes and attribute a cost to those outcomes. Another challenge is that individuals do not always identify themselves as a caregiver, making them less likely to respond to requests to participate in research studies. There are also no requirements for respite programs to collect consistent, standardized data which makes it difficult to compare data across programs or combine data to increase study sample size. Finally, respite programs



may be reluctant to invest the time and energy it takes to engage in more robust evaluation or research if the potential cost-benefits are reaped by another program or agency.

There are also numerous methodological challenges that affect respite research generally, but also make it difficult to conduct cost-benefit studies. Many of these were cited in the ARCH [Research Agenda for Respite Care](#), including:

- Limited quantitative respite-related studies
- Difficulty measuring avoidance of negative outcomes (e.g., out-of-home placements, abuse and neglect)
- Difficulty monetizing quality of life measures
- Many studies focused more on measuring the need for respite, rather than on caregiver outcomes
- Failure to focus on caregiver as primary beneficiary of respite
- Comparing to and/or combining with those who need respite to those who do not need respite
- Selection bias in who has access to respite
- Difficulty attributing benefits to a specific component (i.e., respite) in a bundled intervention/program
- Limited waitlist control studies
- Lack of standard definition of respite
- Studies do not consistently define the “dose” of the respite intervention or adequately describe the model
- Lack of reliable and validated measures
- Inconsistent use of measures across studies limits comparability between studies
- Failure to define, measure, and account for informal supports that may serve as confounding variables
- Limited attempts to measure the human costs and value
- Limited longitudinal studies that are necessary to document meaningful economic benefits

Redefining the Value of Respite

The CARR has developed *The Value of Respite Model*, a multi-dimensional conceptual model as a framework for researchers and evaluators interested in measuring the value of respite (Figure A). The model was influenced by the [Individual and Family Self-Management Theory](#), the [Life Course Framework](#), and the [Social-ecological Model](#).

The Value of Respite Model – A Multi-level, Life Course Perspective

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

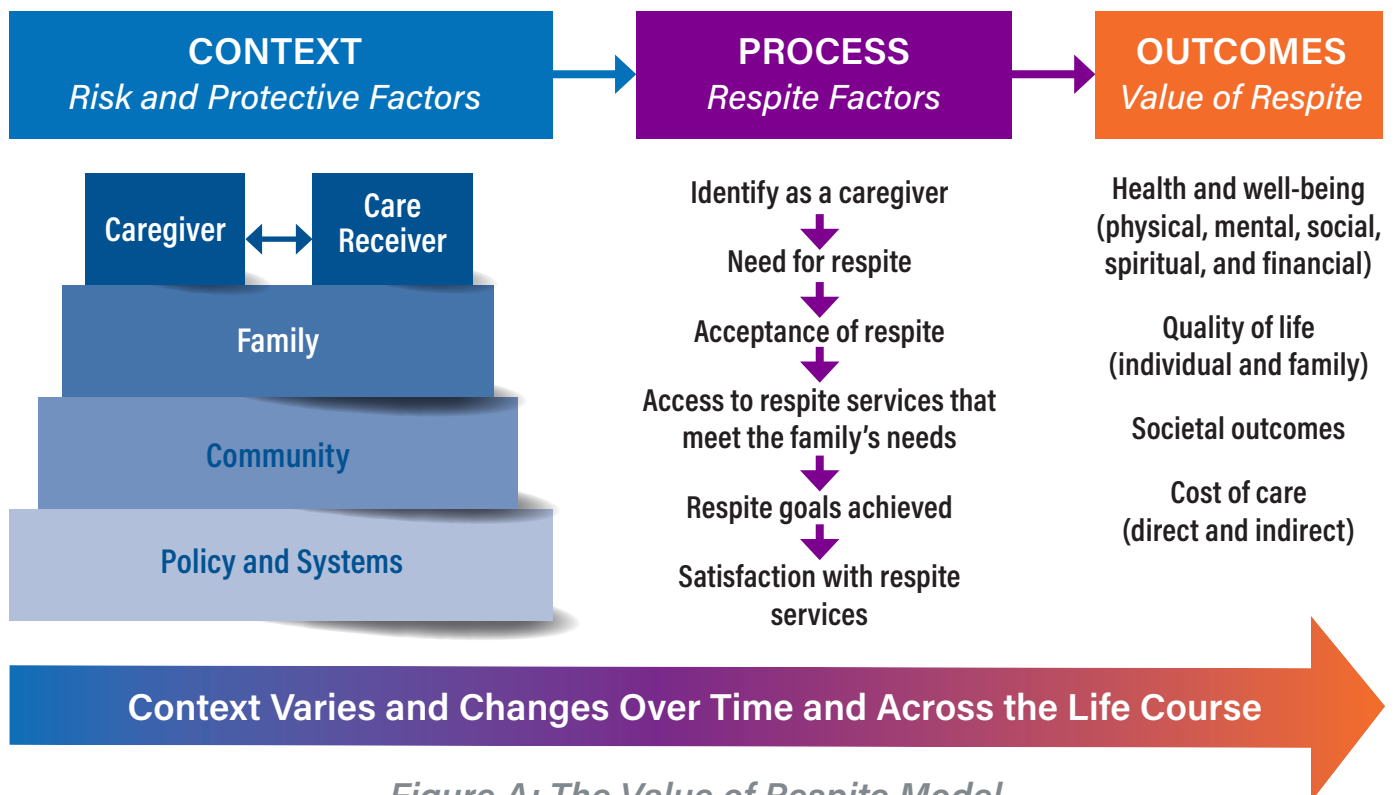


Figure A: The Value of Respite Model



Context

Context matters. The caregiver is the main beneficiary of respite. However, the caregiver is interconnected with the care receiver at the individual level. Both the caregiver and care receiver are situated in the context of their family, community, and policy and systems as illustrated by the layered circles on the left side of the model. The family level includes anyone the caregiver defines as part of their family, which may include their spouse or partner, their children, siblings, grandparents, or other individuals. The community level may include the caregiver's neighborhood, schools, employers, community-based organizations, and the faith community. The policy and system level is the broader socio-political context that is a result of laws, rules, regulations, and funding. Following is a list of potential contextual factors to consider at each level. These contextual factors can help protect the caregiver or put them at risk for negative outcomes.

Caregiver factors

- Caregiver culture and language
- Age and developmental level of caregiver
- Caregiver health (physical, mental, social, spiritual, and financial)
- Relationship to care receiver
- Time as a caregiver
- Income/financial stability
- Employment factors (employed, employer flexibility, paid time off, benefits)
- Educational level
- Knowledge
- Competence
- Confidence in caregiving (caregiver self-efficacy)
- Race/ethnicity
- Other stressors
- Competing demands
- Stress tolerance
- Learned coping skills
- Faith and spirituality
- Self-care tendencies
- Attitude towards caregiving
- Resilience

Care receiver factors

- Care receiver culture and language
- Age and developmental level of care receiver
- Age of onset/diagnosis
- Type of condition(s)
- Number of conditions
- Complexity/severity of condition(s) (including health, cognitive, physical, and behavioral)
- Condition stability
- Functional status
- Insurance status
- Caregiving needs (skilled vs. companion care)
- Duration of caregiving needs

Family factors

- Marital/partner status
- Family structure
- Living situation
- Family functioning
- Family support
- Family culture and language
- Other family stressors



Community factors

- Community culture
- Community support
- Faith community
- Available resources
- Transportation
- COVID-19 pandemic impact
- Worker shortage
- Medication and supply shortage
- Setting of care

System factors

- Political climate
- Accessibility of respite care
- Affordability of respite care
- Funding for respite care
- Policies and laws

Process

Identify as a caregiver. The caregiver goes through a process that begins with recognizing a need for assistance and that it is beneficial to ask for help, whether or not they identify as a caregiver. However, if a caregiver does not self-identify as a caregiver, they may not consider accessing or receiving caregiving supports, such as respite. However, caregivers often struggle with this important foundational step in the process. Instead many caregivers identify as simply a parent, spouse, or child who cares for a loved one. Caregivers may need the professionals who assist them to help them understand and recognize their important role as a caregiver.

Need for respite. Next, caregivers must have access to information about the benefits of respite that allows them to recognize their need for respite. Respite may be needed preventatively or on an emergency basis.

Acceptance of respite. Not all caregivers who recognize they need respite are willing to accept respite services. Cultural or social stigma related to asking for or receiving help may limit a caregiver's willingness to accept respite.

Access to respite services that meet the family's needs. If a caregiver is willing to accept respite, they next need to have access to respite services that meet the unique needs of the family. Important factors to consider include:

- Is respite culturally and linguistically appropriate?
- Is it the right "type" of respite (i.e., at-home vs. community based vs. facility, paid provider vs. volunteer, skilled vs. companion-care)
- Is the respite provider appropriate (i.e., properly trained, experienced, trusted by caregiver)
- Is the location respite is provided appropriate, safe, and accessible?
- Is the timing of respite appropriate (i.e., planned/preventative vs. crisis/emergency respite; waitlist, day/time offered)
- Is the duration of respite appropriate?
- Is the frequency of respite appropriate?
- Is respite affordable?



Respite goals achieved. The caregiver also needs to identify and achieve their goals for respite, including how they plan to spend their respite time.

Satisfaction with respite services. Finally, caregivers need to have an overall feeling of satisfaction with the respite services they receive.

If all respite factors in this process align, positive outcomes can occur. If any of these factors are not in alignment, it is possible that the caregiver will not use respite or may have a negative experience, which could lead to negative outcomes and foregoing future respite care services. These factors should be considered as potential moderating variables in this model.

Outcomes

The value of respite can be measured by a variety of outcomes at the individual, family, community, or policy and systems level. Outcomes occur in four main domains:

Health and well-being

- Physical health and well-being
- Mental health and well-being
- Social health and well-being
- Spiritual health and well-being
- Financial health and well-being

Societal outcomes

- Relationships
- Socialization
- Inclusion
- Community connectedness
- Employment

Quality of life (as defined by the individual)

- Individual quality of life
- Family quality of life

Cost of care

- Direct costs
- Indirect costs
- Caregiver time cost equivalent
- Healthcare utilization
- Social services utilization

Life Course Perspective

A life course perspective implores researchers to reframe health outcomes as the reflection of an underlying multidimensional developmental trajectory. An important aspect of the model is the recognition that context varies and changes over time and across the life course of both the caregiver and care receiver. This is illustrated by the large arrow along the bottom of the *Value of Respite Model*.



Recommendations

Following is a set of key recommendations from the CARR related to measuring the value of respite care.

Common Data Elements


To adequately measure the value of respite, it will be important to identify and consistently use common data elements that align with variables in the *Value of Respite Model*. According to the [National Institutes of Health](#), a common data element is a standardized, precisely defined question that is paired with a set of specific allowable responses, that is then used systematically across different sites and studies to ensure consistent data collection. In other words, common data elements are developed so that data can be collected in the same way across multiple research studies. The CARR is working on developing a list of recommended common data elements for respite-related research that align with the *Value of Respite Model*.

Invest in Respite

We need to invest in respite. The value of respite cannot be quantified merely by financial measures. Caregivers need respite even if providing respite does not save money. As important as financial measures may be, we need to ensure that other conditions, such as caregiver health, family quality-of-life, and ability to retain employment are included in economic evaluations of respite policies, programs, and services. In addition to healthcare organizations, insurers, and government agencies, we believe employers should be investing in respite. Investing in respite for employees who are caregivers as part of a standard employee benefit could save money and valuable productivity time. We should also consider the consequences of not investing in respite, which may include poor caregiver health, poor family outcomes, workplace absenteeism/quiet quitting, reduced employability, reduced financial stability, and increased reliance on social services.

Focus on the Caregiver

We propose that the primary value proposition for respite is: **Respite results in positive outcomes for caregivers**. While outcomes for the care receiver and the family are very important and should be considered, it is critical that respite-related research include a focus on caregiver outcomes. Much of the current research being conducted is focused on the care receiver. Additionally, "value" should be *defined* by the caregiver to ensure we are measuring person-centered outcomes that are culturally and contextually appropriate. The [2022 National Strategy to Support Family Caregivers](#) describes the need to investigate and determine "person-centered outcomes, especially the totality of outcomes that truly reflect the end users' or the



caregivers' perceived value of a particular intervention, not only the financial incentive (p.31-33)." [PCORI](#) equires that patients be engaged in the research it funds – not as participants but as partners who help determine what to study and how. One way to ensure respite-related research is caregiver-centered is to establish a diverse caregiver community advisory board that can be engaged throughout the research process. [Community-Based Participatory Research and Community-Engaged Research](#) are two approaches that researchers should consider when conducting respite-related research. The [Developing a Community Advisory Board for Research Toolkit](#) may also be a helpful resource.

Research Implications

Researchers should utilize the *Value of Respite Model* and common data elements to enhance the ability to compare outcomes across studies. A set of specific value-based questions for consideration in respite-related research should be developed. The questions would be related to the actual costs of respite in relation to savings in such areas as work-force productivity, increased caregiver satisfaction, delayed institutionalization, and improvements in the health and well-being of caregivers. Once those questions are identified, efforts should be made to insert them into existing studies or studies under development.

Evaluation Implications

Respite programs should collect core common data elements (at a minimum) as part of their evaluation plan.

Guidelines for how to use common data elements for ongoing evaluation should be developed.

Policy Implications

Funding opportunities should be created that encourage researchers to use common data elements and the *Value of Respite Model* as a framework for respite-related research. Funding is needed to create a unified repository or database of common data elements (similar to [PROMIS Measures](#)). Additionally, policies that incentivize data collection among respite programs should be explored. Investments should be made in longitudinal studies and population-based studies to capture all the ways respite might be beneficial to the caregiver, care receiver, family and society, or incorporate questions about caregiving and respite in ongoing longitudinal studies such as the Health and Retirement Survey or the Baltimore Longitudinal Study of Aging.




Conclusion

The purpose of this white paper was to provide an in-depth description of the current challenges related to measuring the economic value of respite and to offer a new framework for research and evaluation. The recommendations provided should be used as a guide to enhance research and evaluation methods which, ultimately, may lead to increased access to evidence-based respite that improves caregiver outcomes.



References

- ARCH National Respite Resource Center. (2022). Annotated Bibliography of Respite and Crisis Care Studies, 6th Edition. <https://archrespite.org/library/arch-annotated-bibliography-of-respite-and-crisis-care-studies-6th-edition-2022/>
- Avison, C, Brock, D, Campione, J, Hasell, S, Rabinovich, B, Ritter, R, Severynse, J, & Yang, D-H (2018). *Final Report prepared for the U.S. Administration for Community Living: Outcome Evaluation of the National Family Caregiver Support Program*. Washington, D.C.: Westat.
- Broady, T. and Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *Journal of the Australasian Rehabilitation Nurses' Association*, 20(2), 5-11.
- Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability & Society*, 22(6) 549-562. <https://doi.org/10.1080/09687590701560139>
- Center for Health Systems Effectiveness (2020). *Medicaid Transformation Project Evaluation, Interim Report*. Prepared for the Washington State Health Care Authority. <https://www.hca.wa.gov/assets/program/mtp-interim-report.pdf>
- Chan, S.-Y., Yu, H.-W., Yang, M.-C., Lee, Y.-C., & Chen, Y.-M. (2022). The Impact of Multiple Long-Term Care Services Use on Dementia and Nondementia Caregivers' Health Care Utilization and Costs. *Journal of Applied Gerontology*, 41(11), 2341-2352. <https://doi.org/10.1177/07334648221114110>
- Chapel, J. (2016). *Economic Evaluation: Alternatives to ROI to Show Societal Benefits* [Webinar], Division for Heart Disease and Stroke Prevention, Applied Research and Evaluation Branch, Centers for Disease Control and Prevention. https://www.cdc.gov/dhdsp/pubs/docs/cb_march2016.pdf
- Crawford, M., (2020). Ecological Systems Theory: Exploring the Development of the Theoretical Framework as Conceived by Bronfenbrenner. *J Pub Health Issue Pract* 4(2):170 <https://doi.org/10.33790/jphip1100170>. <https://gexinonline.com/uploads/articles/article-jphip-170.pdf>
- Gresham M., Heffernan, M., and Brodaty, H. (2018). The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 30(11):1697-1706. doi: 10.1017/S1041610218000686.
- Harper, A; Dyches, TT; Harper, J; Roper, SO; and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43(11):2604-16. doi: 10.1007/s10803-013-1812-0
- Kirk, R., Kagan, J. (2015). A Research Agenda for Respite Care. Deliberations of an Expert Panel of Researchers, Advocates and Funders. https://archrespite.org/wp-content/uploads/2022/04/ARCH_Respite_Research_Report_web.pdf
- Kirk, R., Summers, S. (2020). Advancing Respite Research: Findings from the Respite Research Summit. <https://archrespite.org/library/advancing-respite-research-findings-from-the-respite-research-summit>
- Lopez-Hartmann, M., Wens, J., Verhoeven, V., and Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers or community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12, e133. doi: [10.5334/ijic.845](https://doi.org/10.5334/ijic.845)



Lund DA, Utz R, Caserta MS, & Wright SD. (2009). Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology*, 28(1), 109-31. <https://doi.org/10.1177/073346480832348>

Lund DA, Utz RL, Caserta MS, et al. (2014). Time for Living & Caring: An intervention to make respite more effective for caregivers. *International Journal of Aging & Human Development*, 79(2), 157-78. doi: 10.2190/AG.79.2.d

Mandell, David S. ScD, Xie, Ming, MS; Morales, Knashawn H., ScD; Lawer, Lindsay, MA; McCarthy, Megan, MA; Marcus, & Steven C., PhD. (2012). The Interplay of Outpatient Services and Psychiatric Hospitalization among Medicaid-Enrolled Children with Autism Spectrum Disorders. *Arch Pediatr Adolesc Med*, 166(1), 68-73. doi: 10.1001/archpediatrics.2011.714.

Mason, A., Weatherly, H., Spilsbury, K, Golder, S., Arksey, H., Adamson, J., & Drummond, M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. *Journal of Am Geriatr Soc*, 55(2): 290-299. doi: 10.1111/j.1532-5415.2006.01037x

National Institutes of Health, Library of Medicine. (2023). Common Data Elements: Standardizing Data Collection. [https://www.nlm.nih.gov/oet/ed/cde/tutorial/03-100.html#:~:text=A%20common%20data%20element%20\(CDE,to%20ensure%20consistent%20data%20collection](https://www.nlm.nih.gov/oet/ed/cde/tutorial/03-100.html#:~:text=A%20common%20data%20element%20(CDE,to%20ensure%20consistent%20data%20collection)

National Institutes of Health, Office of Strategic Coordination-The Common Fund. (2023). Patient Reported Outcomes Measurement Information System (PROMIS). [https://commonfund.nih.gov/promis/index#:~:text=The%20PROMIS%20\(Patient%20Reported%20Outcomes,a%20variety%20of%20chronic%20diseases](https://commonfund.nih.gov/promis/index#:~:text=The%20PROMIS%20(Patient%20Reported%20Outcomes,a%20variety%20of%20chronic%20diseases)

Patient-Centered Outcomes Research Institute (PCORI). (2023). Principles for the Consideration of the Full Range of Outcomes Data in PCORI-Funded Research. <https://www.pcori.org/research/about-our-research/patient-centered-economic-outcomes/principles-consideration-full-range-outcomes-data-pcori-funded-research#Principle1>

Ryan, P. A., & Sawin, K. J. (2023). Individual and Family Self-Management Theory. University of Wisconsin. <https://uwm.edu/nursing/centers-institutes/self-management-science-center/theory/>

Southern California Clinical and Translational Science Institute. (2023). Developing a Community Advisory Board for Research Toolkit. <https://sc-ctsi.org/resources/developing-a-community-advisory-board-for-research-toolkit>

U.S. Department of Health and Human Services, Administration for Community Living (2022). *National Strategy to Support Family Caregivers*. <https://acl.gov/CaregiverStrategy>

Utz RL, Lund DA, Caserta MS, & Wright SD. (2012). The Benefits of Respite Time-Use: A Comparison of Employed and Nonemployed Caregivers. *Journal of Applied Gerontology*, 31(3), 438-61. doi: 10.1177/0733464810389607

University of Wisconsin. (2012). The Lifecourse Framework Factsheet. Maternal Child Health Program. <https://www.dhs.wisconsin.gov/mch/earlychildhoodsystems/lcframework.pdf>

Wallerstein N, Oetzel JG, Sanchez-Youngman S, Boursaw B, Dickson E, Kastelic S, Koegel P, Lucero JE, Magarati M, Ortiz K, Parker M, Peña J, Richmond A, Duran B. Engage for Equity: A Long-Term Study of Community-Based Participatory Research and Community-Engaged Research Practices and Outcomes. *Health Educ Behav*. 2020 Jun;47(3):380-390. doi: 10.1177/1090198119897075. PMID: 32437293; PMCID: PMC8093095.

Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almeida, D.M., Rovine, M.J., & Klein, L.C. (2014). Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and Dehydroepiandrosterone-Sulfate. *Am J Geriatr Psychiatry*. 22(12),1592-602. doi: 10.1016/j.jagp.2014.01.013



Appendix A

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

Joseph Caldwell, PhD
Director, Community Living Policy Center
Lurie Institute for Disability Policy
Brandeis University
Waltham, MA

Thomas V. Caprio, MD, MPH, MS
Professor of Medicine/Geriatrics, Psychiatry,
Dentistry, Clinical Nursing, & Public Health
Sciences
Director, Finger Lakes Geriatric Ed Center
Medical Director, University of Rochester Geriatric
Assessment Clinic
Chief Medical Officer, UR Medicine Home Care &
Hospice
Rochester, NY

Joseph E. Gaugler, PhD
Robert L. Kane Endowed Chair in Long-Term Care
and Aging & Professor
Director, Center for Healthy Aging & Innovation
Division of Health Policy and Management
School of Public Health, University of Minnesota
Minneapolis, MN

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

Tamar Heller, PhD
Distinguished Professor, Department Head
Director – DHD, Disability and Human
Development
College of Applied Health Sciences
University of Illinois at Chicago
Chicago, IL

Lauren J. Parker, PhD
Assistant Scientist, Department of Health,
Behavior and Society
Johns Hopkins Bloomberg School of Public Health
Baltimore, MD

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

Cordelia Robinson Rosenberg, PhD, RN
Professor Emeritus of Pediatrics and Psychiatry
University of Colorado School of Medicine
Aurora, CO

Rani E. Snyder
Vice President, Program
The John A. Hartford Foundation
New York, NY

Sarah A. Sobotka, MD MSCP
Assistant Professor
Section of Developmental and Behavioral
Pediatrics
The University of Chicago
Chicago, IL

Sarah Swanson, MPH
Assistant Professor & Family Support Coordinator
UNMC Munroe-Meyer Institute
University of Nebraska Medical Center
Omaha, NE

Rebecca L. Utz, PhD
Associate Professor, Department of Sociology
Director, Health Society & Policy Program
Co-Director, Consortium for Families & Health
Research
University of Utah
Salt Lake City, UT

Kim E. Whitmore, PhD, RN, CPN
Assistant Professor
University of Wisconsin-Madison
School of Nursing
Madison, WI