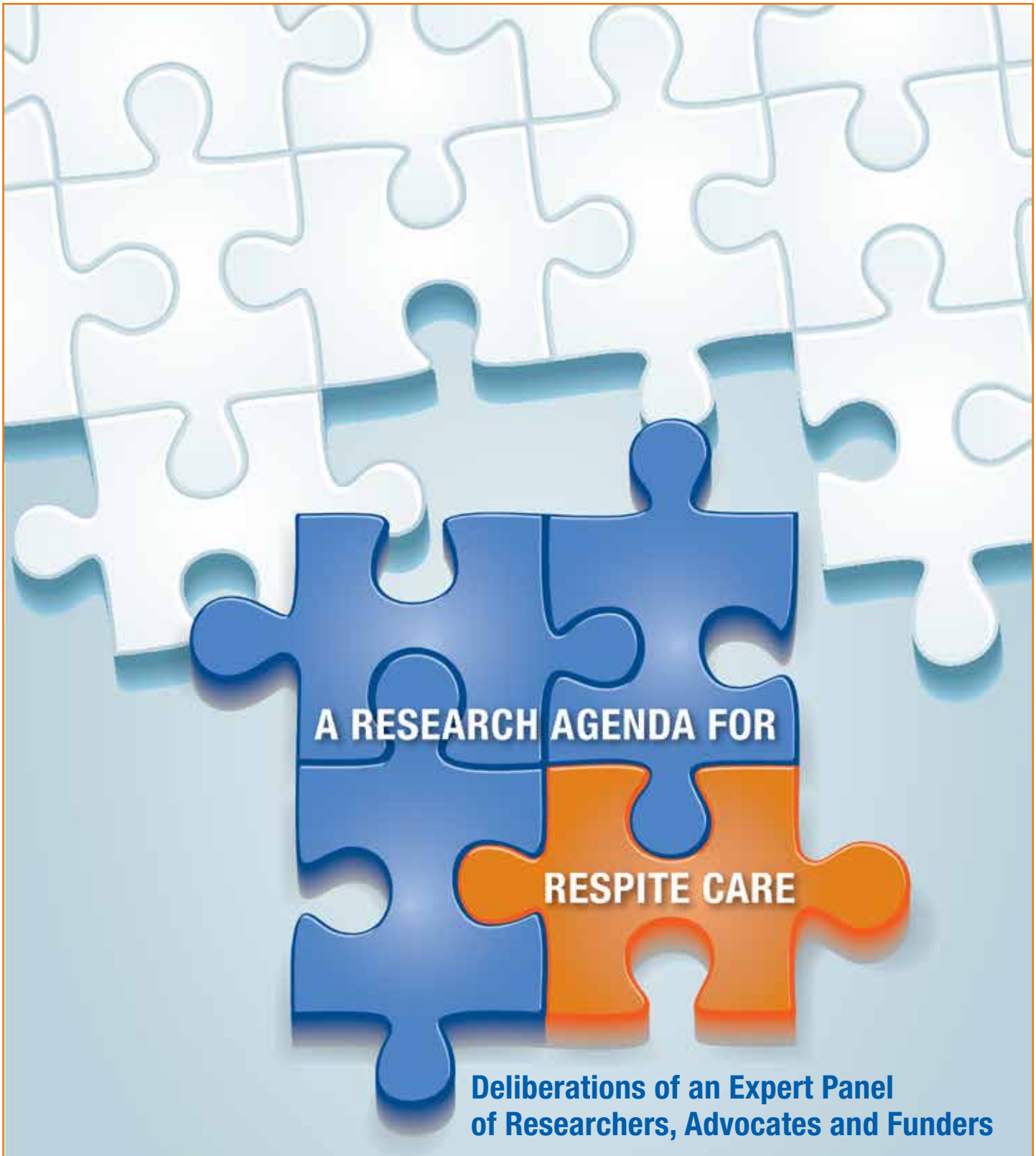
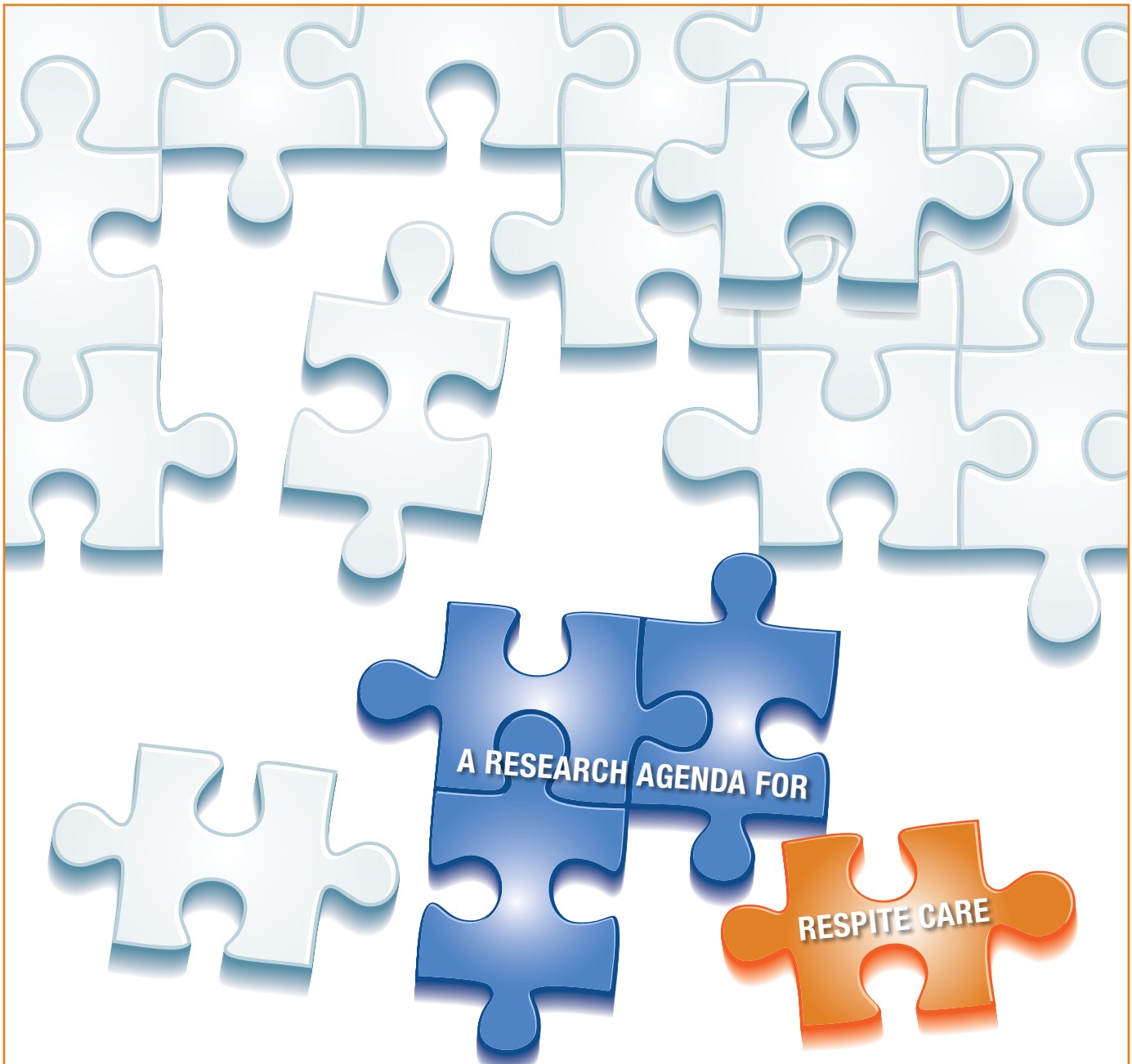


Deliberations of an Expert Panel of Researchers, Advocates and Funders

ARCH National Respite Network And Resource Center

Principal Authors:
Raymond S Kirk, PhD, RS Kirk and Associates and
Jill Kagan, MPH, ARCH National Respite Network and Resource Center



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ACKNOWLEDGMENTS

Principal Authors: Raymond S Kirk, PhD, RS Kirk and Associates, and Jill Kagan, MPH, ARCH National Respite Network and Resource Center

Editor: Susan Janko Summers, PhD

Layout and Design: Norma McReynolds

ARCH wishes to express thanks to the Association of University Centers on Disabilities (AUCD) for their collaboration and staff support for this initiative and for hosting the 2014 meeting of the Expert Panel on Respite Research in Washington, DC. ARCH is also grateful to the Wareheim Foundation and the National Multiple Sclerosis Society for their support in convening the 2014 Expert Panel meeting. We also want to acknowledge the ongoing support and guidance provided by Greg Link, federal project officer for the Lifespan Respite Technical Assistance Center in the Administration for Community Living/ Administration on Aging and offer our thanks to him. Without his foresight regarding the importance of building an evidence base for respite and caregiver support, and his advancement of this initiative, the work would never have come to fruition. Finally, ARCH is grateful for the expert facilitation of the Expert Panel by Ray Kirk, PhD, ARCH consultant and primary author of the report. The authors acknowledge the superb review of the report and the very helpful and substantive comments of Susan Janko Summers, PhD. The consistently creative and impeccable design work of Norma McReynolds is, as always, gratefully acknowledged and very much appreciated.

Most importantly, ARCH would like to thank the members of the Expert Panel on Respite Research for countless hours of deliberation, for their commitment of time and expertise to the effort, and for their final recommendations to advance a respite research agenda.

October 2015

This project was supported, in part by grant number 90LT0001, from the U.S. Administration for Community Living, Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

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Leisa Easom, PhD, RN
Executive Director
Rosalynn Carter Institute for Caregiving
Georgia Southwestern State University
Americus, GA

Elena M. Fazio, PhD
Office of Performance and Evaluation
Administration for Community Living
U.S. Department of Health and Human Services
Washington, DC

Lynn Feinberg
Senior Strategic Policy Advisor
AARP Public Policy Institute
Washington, DC

Tamar Heller, PhD
Director
Rehabilitation Research and Training Center
on Aging with Developmental Disabilities
University of Illinois
Chicago, IL

Raymond S Kirk, PhD
Panel Facilitator
RS Kirk & Associates
Chapel Hill, NC

Greg Link
Administration for Community Living
Administration on Aging
US Department of Health and Human Services
Washington, D.C.

Dale Lund, PhD
Professor and Chair
Department of Sociology
California State University at San Bernardino, CA

Michael Marcus
Program Director, Older Adults
The Harry and Jeannette Weinberg Foundation
Owings Mills, MD

Katie Maslow
Scholar-in-Residence
Institute of Medicine
Washington, DC

Mary Mittelman, DPH
Research Professor
Department of Psychiatry
NYU Langone Medical Center
New York, NY

Sue Peschin
Chief Operating Officer
Alliance for Aging Research
Washington, DC

Cordelia Robinson Rosenberg, PhD, RN
Professor
Pediatrics, Psychiatry and Preventive Medicine
JFK Partners
University of Colorado Denver
School of Medicine
Aurora, CO

Lisa Shugarman, PhD
Senior Consultant
Health Management Associates
Costa Mesa, CA

Carol J. Whitlatch, PhD
Assistant Director
Margaret Blenkner Research Institute
Benjamin Rose Institute on Aging
Cleveland, OH

Executive Summary

In 2014, more than 43 million caregivers[1] provided daily care for an adult with a chronic, disabling or serious health condition, or a child with special needs. The needs of care receivers[2] ranged from chronic mental or physical health problems and functional limitations, to cognitive and physical disabilities. Providing daily care is typically a ceaseless task, and while many caregivers report that they derive significant emotional and spiritual rewards from their caregiving experience, according to the American Psychological Association, many family caregivers also experience physical and emotional problems directly related to the stress and demands of daily caregiving responsibilities. Moreover, when a family caregiver experiences a decline in her own physical or emotional health, the person she or he has been caring for is at increased risk for hospitalization and institutionalization.

The growing respite field encompasses systems and services for persons of every age, with varying physical and mental health conditions, and it occurs in a variety of private and group settings. Across ages, needs and settings, respite is based upon the premise that providing caregivers periodic relief from daily, ongoing caregiving responsibilities will directly benefit them in terms of their physical health, immediate and long-term psychological health, and social-emotional relationships with family members. These benefits are assumed to result in secondary benefits for care receivers and even larger societal benefits in the form of cost benefits or improved employee productivity. Some research studies point to the merits of these assumptions. At this point in time, however, respite care is based primarily on practical ideas and good intentions. Evidence-based research supporting this premise—or going beyond it to demonstrate ***how*** to best provide respite care that results in maximum benefits to care receivers and their families, while maximizing invested resources—is largely lacking.

To understand the existing research base, and to make recommendations for how to structure and organize future research in ways that will improve understanding of respite care and maximize its benefits and resources, an Expert Panel on Respite Research[3] (the Panel) composed of academics, researchers, service providers, advocates, policymakers and administrators representing a range of age groups, disabilities and professional disciplines gathered over a period of 18 months in order to accomplish three tasks:

1. Explore in-depth the current status of respite research;
2. Propose strategies to overcome barriers to research; and
3. Develop a plan to encourage rigorous research in key areas that will translate to meaningful strategies and approaches to care.

A MODEL FOR RESPITE RESEARCH

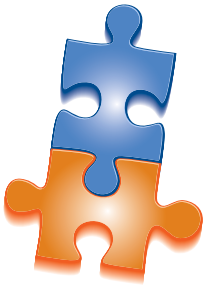
Respite care takes many forms in the United States, and the term "respite" is often used as a generic descriptor for a diverse range of services

1 In this document, *caregivers* and *family caregivers* (used interchangeably) refer to family members, neighbors, or friends who provide informal care to children or adults with one or more special needs, including, but not limited to, chronic mental, neurological or physical health problems; cognitive, intellectual or other developmental disabilities or delays; physical disabilities; and functional limitations.

2 *Care receivers* refer to children and adults with one or more special needs who are cared for by caregivers.

3 The initiative for this report, and the work of the Expert Panel on Respite Research, was supported by the Administration for Community Living in collaboration with the ARCH National Respite Network and Resource Center.

and supports. Respite care is funded by multiple sources, delivered by multiple persons, organizations and agencies, and intended for either, or both, a child or adult with a special needs and/or their caregivers, according to the particular eligibility requirements of funders and service providers. The multiplicity of funding sources and service delivery models resulting from a patchwork of persons and organizations serving different populations, each with their own service model, and many with their own categorical funding requirements, presents special challenges to researchers. Respite care research requires clarity and consistency of terms that allow researchers to examine which specific aspects of respite service, and the way it is delivered or used, lead to immediate, short-term or long-lasting benefits.



Respite care research requires clarity and consistency of terms that allow researchers to examine which of the specific aspects of the respite service, and the way it is delivered or used, lead to immediate, short-term or long-lasting benefits.

Even agreement about what constitutes respite, and for whom it is intended, differs among researchers. Research on respite care may focus on either, or both, caregivers and care receivers. Absence of a clear and cogent definition in published studies of respite care increases the difficulty of developing a base of evidence supporting, or failing to support, the efficacy of respite. Therefore, as a prerequisite for holding deliberations, and as a foundation for their work, by consensus the Panel set out by developing this concise definition of respite:

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

This definition is inclusive of caregiver and care receiver, but it places caregivers as the beginning point of respite research. The Panel agreed that no matter what else occurs during a period of respite, some benefit should accrue to the caregiver, and any research endeavor should identify and measure caregiver benefits. Acknowledging that benefits accruing to the care receiver or family may be equally important, and while specifying that research should start with the caregiver, the Panel recommends that research models should account for multiple variables, multiple beneficiaries, and multiple outcomes.

A FOCUS ON OUTCOMES

Human lives nested in family and community systems are inherently complex. Designing research agendas and studies that can parse out important aspects of services claiming to beneficially change those complex lives and relationships demands a taxonomy—or systematic classification—of aspects related to the intended beneficiaries of respite care. The Panel developed a taxonomy that focuses on outcomes that they sorted into "big bucket" categories according to the results they intend to achieve, such as improved relationships, better health, stable living status, and so forth. The taxonomy is based upon a presumption that researchers will track and record concomitant variables related to the design of the particular respite program including nominal, process and implementation, and consumer satisfaction variables. In addition to focusing on inclusive outcome categories, the Panel strongly advocates that whenever possible and appropriate, research addresses proximal outcomes (that are immediately observable) *and* distal outcomes (that emerge over time), related to individuals and families, and further identifies outcome categories at the societal level.

To allow translation of their taxonomy and model into practicable research, the Panel discusses methodological challenges associated with conducting research in fledgling, rather than established, services. Emphasizing the need for using

analytic techniques that increase the pace of program development toward the highest levels of evidence-based practice, the Panel identifies and defines four levels of model development and corresponding methodologies for research and evaluation of these: Level I: New Ideas, Novel Approaches; Level II: Emerging Practices and Models; Level III: Evidence-Informed Practices; and Level IV: Evidence-Based Practices.

RECOMMENDATIONS FOR FUTURE RESEARCH

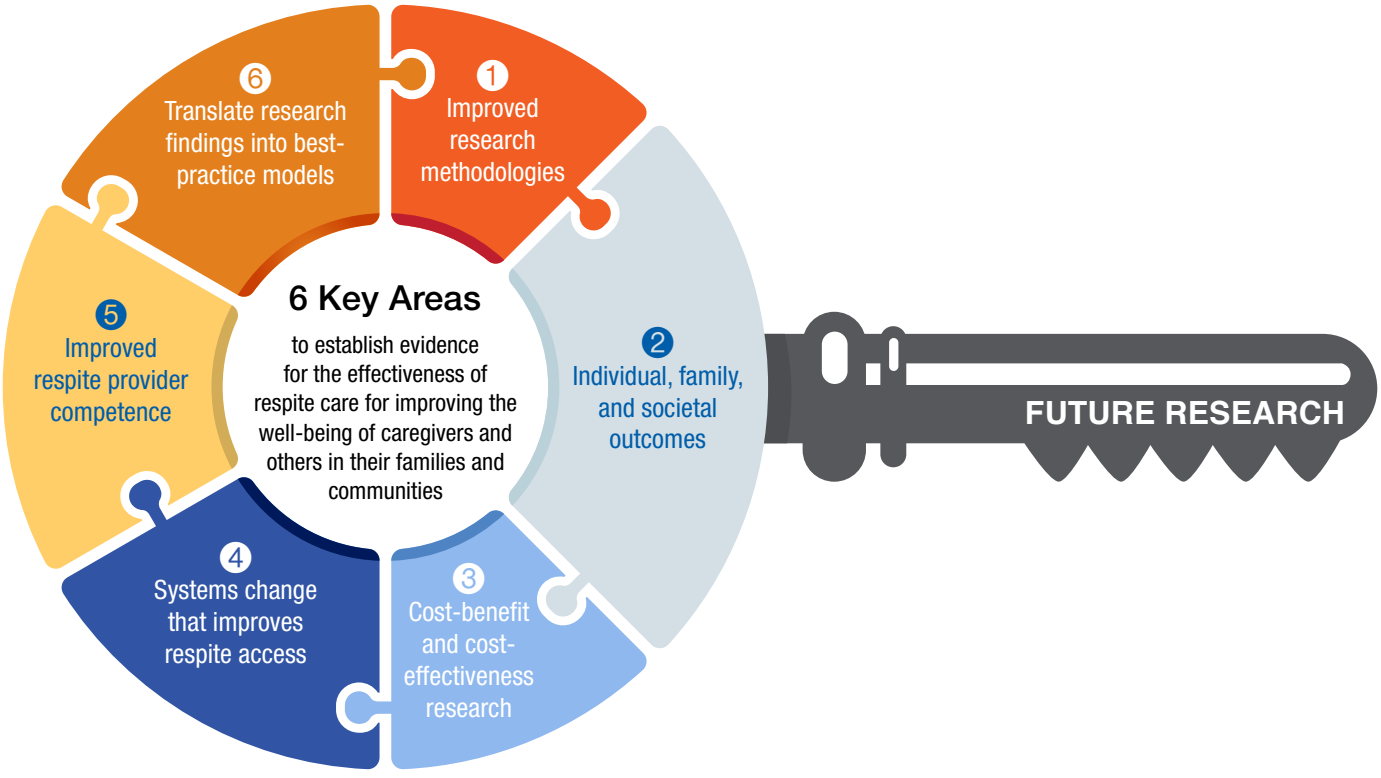
The Panel's foundational work, including crafting a proposed respite definition and research framework, guided the development of specific and practical recommendations in the following six categories:

1. **Address foundational methodological concerns.**

   From their review of the literature, the Panel ascertained the methodological shortcomings that have hampered current respite research. To address these issues, the Panel made specific recommendations to address these shortcomings from the perspectives of research design, construction of independent and dependent variables relating to respite services, and methods and statistical analyses.

2. **Research individual, family, and societal outcomes.**

   The Panel identified the family caregiver as the "portal of entry" for future respite research, and set the expectation that at least one outcome relating to caregiver well-being and quality of life be measured during any research study. However, the Panel specified that a focus on family caregiver outcomes does not negate the need to study additional outcomes. Recommendations reflect the Panel's recognition of benefits that may also accrue from respite to the care receiver, the family system, and society, and are therefore appropriate for inclusion in research studies.



3. **Conduct appropriate cost-benefit and cost-effectiveness research.**

   The Panel stated the necessity of cost-benefit and cost-effectiveness studies in order to justify funding, and discussed the importance of understanding costs and benefits in multiple contexts. Accordingly, the Panel recommends that studies of respite are specific to the contexts in which respite occurs, and that studies include measures relating to overall cost, costs that would reasonably be expected to occur in the absence of respite, costs borne by different parties associated with the respite model, and outcomes for both respite-receiving and non-respite-receiving caregivers.

4. **Research systems change that improves respite access.**

   During their review of existing research, the Panel recognized that an examination of the efficacy of the existing respite system—which includes a large variety of service models, and a large number of caregivers and care receivers who could potentially benefit from respite—must include large numbers of varied and culturally diverse caregivers receiving respite. At the same time, the Panel recognized that there are also large numbers of caregivers who might benefit from respite, but for whom respite is not available or accessible due to a number of reasons occurring across systems levels—such as lack of funding, lack of awareness of the service, limited understanding of how and where to access services and funding, and unavailability of services or trained providers or volunteers. The Panel therefore recommends studies occurring at multiple systems levels.

5. **Research improving respite provider competence.**

   Existing research led some panel members to question whether the provision of respite by providers who lacked training specific to the needs of care receivers might lead caregivers to be reticent about using respite. While acknowledging that not all respite must be provided by people with special training, if special training is needed, the Panel recommends conducting research on the quality of available training curricula and on the most appropriate credentialing criteria for respite providers.

6. **Conduct translational research that informs respite policy and practice.**

   The Panel acknowledges that while statistically significant findings are the end goal for any research study, they also acknowledge that these findings do not necessarily translate automatically to findings or models that can be broadly or easily implemented. The Panel recommends consideration of the multiple factors in the implementation environment including: contextual variables; an organization's readiness to change; implications for resources such as personnel requirements, training, record keeping, and accounting; and attention to details at the level of caregivers and the social and political contexts within which services are provided.

Detailed recommendations in each category can be found in the body of the report beginning on page 25. The research and deliberations upon which the Expert Panel based these recommendations also may be found in the full report. It is the Panel's hope that these recommendations will advance our collective understanding of how to best provide respite care that results in maximum benefits to care receivers and their families, and maximizes resources invested to accomplish these.

Introduction—Why Respite?

In 2014, an estimated 43.5 million adults in the United States provided unpaid care to a child or adult with a chronic, disabling or serious health condition (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015). The trend to provide long-term services and supports at home, driven by social, demographic, political and economic forces, is increasing.

Respite care in the U.S. is commonly seen as an issue related to care of the aging. And although the aging population in our nation is growing rapidly, and concerns about care for this population raise significant programmatic and policy issues, family caregiving is not just an aging issue. It is a lifespan issue. Respite care receivers' needs range from problems associated with chronic mental or physical health problems, to cognitive and physical disabilities as well as functional limitations of aging. In 2014, the majority of family caregivers were caring for someone between the ages of 18 and 75 (53%); with 14 percent caring for someone ages 18-49 and 39 percent caring for persons between the ages of 50-74 (NAC and AARP Public Policy Institute, 2015). According to the most recent National Survey of Children with Special Health Care Needs, 15.1 percent of children younger than 18 years-of-age in the United States, or approximately 11.2 million children, are estimated to have special health care needs. Overall, 23 percent of U.S. households with children have at least one child with special health care needs (U.S. Department of Health and Human Services, 2013).

While many family caregivers report that they derive significant emotional and spiritual rewards from their caregiving experience, many caregivers also experience physical and emotional problems directly related to the stress and demands of daily caregiving responsibilities (American Psychological Association, 2012; U.S. Department of Health and Human Service, 2013; The Arc, 2011). Moreover, when family caregivers experience a decline in their own physical or emotional health, the person they have been caring for is at increased risk for hospitalization and institutionalization (Elliot and Pezent, 2008; National Alliance for Caregiving, 2012; Spillman and Long, 2007).

There is evidence that respite helps reduce stress levels among family caregivers (Harper, Dyches, Harper, Roper, and South, 2013; Zarit, Kim, Femia, Almeida, and Klein, 2013; Zarit and Leitsch, 2001). Managing stress among caregivers is important because high levels of stress are often precursors to developing significant physical and mental health issues. National, state and local surveys show that respite is a frequently requested service by family caregivers (The Arc, 2011; National Family Caregivers Association, 2011). Other than financial assistance for caregiving through direct voucher payments or tax credits, respite has been identified as the most important national policy related to service delivery by family caregivers (National Alliance for Caregiving and AARP, 2009). A more recent survey found that caregivers providing higher hours of care are more likely to say respite services would be helpful. Respite services are especially appealing to higher-hour caregivers who live with their care receiver (National Alliance for Caregiving and AARP

When family caregivers experience a decline in their own physical or emotional health, the person they have been caring for is at increased risk for hospitalization and institutionalization (Elliot and Pezent, 2008; National Alliance for Caregiving, 2012; Spillman and Long, 2007).

Public Policy Institute, 2015). Some studies suggest caregivers believe that not enough respite is available (Institute of Medicine, 2012), and according to the National Alliance for Caregiving and AARP Public Policy Institute (2015), 85 percent of family caregivers of adults receive no respite services at all.

Respite is generally accepted as an important component of comprehensive strategies to support family caregivers and care receivers. To date, however, respite research confirming or supporting this premise has been limited in breadth and depth, and hampered by methodological shortcomings. Further,

One of the most important researchable questions about respite is whether to take into account the needs of all family members when determining eligibility or designing and delivering services.

providing long-term services and supports places demands not only on direct caregivers, but also on family members, neighbors and friends of caregivers and care receivers. Much more information is needed to document how, and to what extent, respite may impact the health and well-being of family caregivers and care receivers, and other variables of interest—such as family relationships and stability, family economic well-being, the rate and timing of out-of-home placements, and other possible health, social and economic outcomes. There is also much to learn about which types of respite family caregivers and care receivers prefer, which aspects of respite are important to improved outcomes, the role of respite in comprehensive caregiver support initiatives, and how to improve access to services.

THE COMPLEXITIES OF RESPITE CARE

Those reading this report likely have their own idea of what respite is. But respite takes many forms and the term "respite" is often used as a generic descriptor for a diverse range of services and supports. The preferred type of respite, the location, and the choice of provider or program can change for a family caregiver over time depending on the caregiver's own needs, the care receiver's needs, and the needs of other family members. Some of the variation among forms and services is important and needed in order to match services with caregivers' and receivers' needs, and make respite services truly helpful and useful. But these complexities also make challenging the task of defining a single service model or service system that can be subjected to fidelity testing. For example, some research suggests that respite is more effective when offered and provided as an adjunct to other important family caregiver services and supports (Gallagher-Thompson and Coon, 2007). However, there is no clarity about which specific aspects of respite service—or the way they are configured, delivered or used—lead to short-term or sustainable benefits.

Respite program eligibility requirements that differ among multiple providers and systems with different funding sources complicate the definition of respite by raising questions about the intended beneficiary of the service. The Lifespan Respite Care Act defines respite as "planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult" (Public Law 109-442). This broad definition makes clear that while the care is for the individual with a special need, the intended relief is meant for the family caregiver. However, many federal and state funding streams, including Medicaid Home and Community-Based Waivers (currently the largest source of federal funding for respite) link eligibility to the condition, age, and/or income of the care receiver. Differing eligibility criteria not only raise issues about the definition of respite, they also impose barriers to services for family caregivers trying to access respite. A notable exception is the Lifespan Respite Care Program that clearly directs services to the family caregiver. The National Family Caregiver Support Program and the relatively new Veterans Caregiver Support Program also recognize the family caregiver as the primary recipient of services, but they continue to impose some eligibility criteria for the care receiver. One of

the most important researchable questions about respite is whether to take into account the needs of all family members when determining eligibility, or when designing and delivering services.

Eligibility issues contribute to difficulties in defining respite, but the diverse range of respite service models, delivery mechanisms, and provider options further complicate efforts to define respite. Government agencies and local program practitioners often struggle to decide what constitutes a respite service and when it is appropriate to provide respite. For example, should a service be considered respite when it is used to allow family caregivers to work or attend training programs on a regular basis? Can a child's participation in a camp program be defined as a respite service if the primary goal of the camp is to provide recreation and socialization for a child with a disability? What about adult day programs in which therapeutic benefits for the care receiver are the primary purpose, or that serve individuals who do not rely on a family caregiver?

Researchers and policymakers may also face difficulties when trying to compare service use across states or funding sources. Each program or funding source may define respite differently based on the location of service delivery, the hours or units of service, the respite provider, the service model, and other factors (Houser and Ujvari, 2012; Reinhard, Bemis, and Huhtala, 2005). Clearly, in the absence of a clarifying definition of respite, it may be difficult for researchers to develop a base of evidence supporting, or failing to support, the efficacy of respite.

THE IMPORTANCE OF RESPITE RESEARCH

- ***Are respite services beneficial to family caregivers as well as care receivers and do they result in improvements to the quality of their lives?***
- ***Is a particular respite service being delivered in ways that help maximize benefits, accessibility and acceptance among family caregivers and their families?***
- ***Are public and private funds efficiently and effectively invested in respite care?***

Finding answers to foundational questions is among the multiple reasons that strengthening and expanding respite research are important. In addition, given current economic challenges, private and public funders are making funding requirements more stringent. Increasingly, funders want evidence that services are effective and accomplish intended goals, that they are meaningful to those using them, and that there is a value-added benefit in the form of reduced cost to public programs.

Research that demonstrates an evidence base for significant, beneficial, and long-lasting outcomes is essential to the advancement of certain programs and approaches. Although an evidence base does not exist on a broad scale, there are several examples of well-researched services that have resulted in increased or sustained funding following the development of an evidence base. These include the current federal expansion of home visiting services for vulnerable families of young children, and the expansion of caregiver assessment programs such as T-Care, and certain supports for family caregivers of individuals with dementia, among others.

Increasingly, funders want evidence that services are effective and accomplish intended goals, that they are meaningful to those using them, and that there is a value-added benefit in the form of reduced cost to public programs.

These programs point the way forward. Establishing evidence of efficacy based on sound research of a clearly defined service is essential to assure that, at a minimum, current respite funding is sustained, and that services meet standards of quality.

The Initiative for a Research Agenda

The extant state of research literature on respite, and a general lack of agreement among practitioners, researchers, policymakers and other stakeholders about basic features of respite, inspired the Administration for Community Living to undertake an initiative in collaboration with ARCH to offer guidance for the research community. The intention behind their initiative is to develop an evidence base for respite, thereby helping other stakeholders to better plan, deliver, and evaluate respite programs. Specifically, the initiative frames a research agenda for respite, and provides guidance to researchers interested in exploring the efficacy of respite.

Some studies suggest caregivers believe that not enough respite is available (Institute of Medicine, 2012), and according to the National Alliance for Caregiving and AARP Public Policy Institute (2015), 85 percent of family caregivers of adults receive no respite services at all.

In order to address intrinsic issues associated with the research agenda, this initiative also needed to address the inconsistent and often conflicting definitions of respite; examine and identify the common shortcomings in existing literature pertaining to respite; propose salient research questions that would help focus research activities so as to remediate the shortcomings; suggest research methods and approaches appropriate to the stage of development of various respite models, programs, and delivery mechanisms; and propose ways to generate interest among researchers to conduct respite research.

AN EXPERT PANEL

ARCH in collaboration with the Administration for Community Living convened an Expert Panel on Respite Research (the Panel) composed of researchers, academics, service providers, advocates, policymakers, and administrators to conduct a series of structured meetings to address each of these issues. The Panel was not tasked with establishing or focusing on a single programmatic definition of respite care that would limit how respite is delivered or accessed. Rather, their task was to understand and accept the complexities of a service that takes many forms and must be flexible to meet family caregivers' individual needs. The challenge for the Panel was to design a research agenda that embraces the inherently diverse nature of respite and translates it into the development and support of meaningful research strategies and approaches.

Panel members were selected from a known cadre of researchers and experts who had engaged in respite research previously, or were familiar with caregiving research overall. Recommendations for panel members were also solicited from the ARCH Lifespan Respite Technical Assistance Center Advisory Committee and from the national Lifespan Respite Data Workgroup that assisted ARCH in the development of performance metrics for Lifespan Respite grantees.[4] Every effort was made to ensure that members of the Expert Panel represented all age groups and disabilities, and came from a variety of disciplines including federal evaluation staff, academic researchers, foundations and nationally-recognized disability or aging organizations. Panel members were invited to voluntarily serve on the Panel with no financial compensation.

4 Lifespan respite grantees are state agencies which implement Federal Lifespan Respite Care Program activities to build and sustain statewide systems to improve access to respite resources for all caregivers.

PURPOSE AND GOALS

Fourteen panel members met from June 2013 to November 2014, via both teleconference meetings and one face-to-face meeting. The Panel, the Administration for Community Living, and ARCH began their work by agreeing upon seven project goals, which also comprised their final task plan:

1. Identify the current status of respite research broadly, including research gaps and limitations, taxonomical approaches used by past and current research on respite, methodological concerns and issues, and barriers to respite-focused research;
2. Craft a respite definition and framework for guiding the development of the research agenda;
3. Identify areas of respite research on which to focus the recommendations (e.g. family caregiver and/or care receiver outcomes; service satisfaction; economic impacts; improving service delivery and access);
4. Identify methodological approaches and other strategies to address identified barriers to respite research;
5. Identify strategies for supporting translation of these goals for use in practice settings;
6. Identify incentives to engage researchers in the respite research agenda developed by the Panel; and
7. Identify and encourage funders to support implementation of respite research recommendations promulgated by the Panel.

The Current Status of Respite Research

In order to inform their initial work—creating a working definition of respite and constructing a framework that would guide them as they developed a research agenda—the Expert Panel began by reviewing current research. To ascertain the current status of respite research, the Panel conducted a comprehensive literature review of all respite research published between 2001 and 2014. Their search focused primarily on studies that attempted to measure outcomes associated with the receipt of respite. A general review of respite research revealed that the number of available studies was small, and they were typically limited in scope, complexity or methodology (Appendix 1: Summary Matrix of Research Studies on Respite and Crisis Care).

The preponderance of existing studies are evaluations of one distinct model of respite and/or respite for a narrowly defined eligibility group. For example, Steven Zarit and colleagues documented the benefits of respite through adult day services for caregivers of older adults with Alzheimer's and other dementias (Zarit, Gaugler and Jarrott, 1999). A study of parents of children with autism spectrum disorders found that respite care was associated with reduced stress and improved marital quality (Harper, et al., 2013). While the findings from these studies inform the field, they may not relate to respite outcomes for individuals across the age and disability spectrum because of a narrow focus on population and/or intervention.

Research has found that consumer-directed respite produces the greatest level of family caregiver satisfaction (Feinberg and Whitlatch, 1996; Whitlatch and Feinberg, 2009). However, expression of satisfaction with the respite service alone, while important, does not necessarily correspond to long-term benefits for family caregivers, reductions in out-of-home placements, or other social, health or cost-related outcomes.

The review also revealed that much of what we know and believe about respite is a result of programs that assess family caregiver satisfaction with the services they have received. Not surprisingly, results are generally positive. For example, research has found that consumer-directed respite produces the greatest level of family caregiver satisfaction (Feinberg and Whitlatch, 1996; Whitlatch and Feinberg, 2009). However, expression of satisfaction with the respite service alone, while important, does not necessarily correspond to long-term benefits for family caregivers, reductions in out-of-home placements, or other social, health or cost-related outcomes. Those outcomes need to be studied specifically in addition to satisfaction, as exemplified by studies that have found that respite may reduce administrative burdens and reductions in facility-based placements, and improve maternal employment (Caldwell, 2007). Furthermore, very little has been studied about how the satisfaction of the care receiver influences family caregiver or other outcomes.

Research has only recently begun to explore other specific aspects of the service that may contribute to positive outcomes. Recent research has found that family caregivers are more likely to experience reduced stress levels for longer periods if they were satisfied with how they spent their respite time (Lund, 2011; Lund, Utz, Caserta and Wright, 2009). This same group of researchers has recently begun to develop and test programs that help respite providers and caregivers optimize the respite experience by contemplating and carefully planning how respite time will be spent (Lund, Utz, Caserta, Wright, Llanque, et al., 2014). Long-standing work

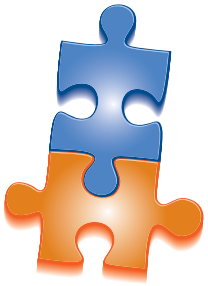
has shown that there may be a minimum number of hours of respite necessary each week to have a longer term impact on family caregiver stress levels, and that these respite hours should be available on a consistent and regular basis so that family caregivers can count on this time (Zarit, Stephens, Townsend, and Greene, 1998). Other researchers have shown that the earlier respite is received in the caregiving experience, the more effective it will be in preventing the onset of serious stress and the associated negative physical and emotional effects (LaSasso and Johnson, 2002; Gottlieb and Johnson, 2000).

As in many other fields of research, methodological limitations are prevalent. As an example, a 2007 meta-analysis conducted by researchers in England identified and reviewed relevant studies of various community-based respite care models for the frail elderly and their caregivers (Mason, Weatherly, Spilsbury, and Arksey, et al., 2007). The literature review provided evidence that respite for these caregivers has a small positive impact of reducing caregiver burden, and caregivers were generally very satisfied with the service. However, no reliable evidence was found that respite delayed entry to residential care. One of the study's authors, Hilary Arksey, presented at the 2009 ARCH National Respite Conference in Burbank, California. After summarizing a broad review of the literature across age and disability groups, she concluded, "It would be wrong to assume that lack of evidence of effectiveness means that respite care is ineffective. It's more about methodological weaknesses" (Arksey, 2009). These conclusions were affirmed by the identification of a preponderance of methodological limitations reported in the literature and summarized by the Expert Panel in an Annotated Bibliography of Respite and Crisis Studies (ARCH, 2014; Appendix 1: Summary Matrix of Research Studies on Respite and Crisis Care, page 45).

Taken as a whole, the present research base leaves unanswered questions relating to whether respite benefits family caregivers, has short-term benefits only, or has potential for more lasting positive outcomes.

IMPROVING FUTURE RESPITE RESEARCH

Caregiver satisfaction with services and reducing caregiver stress are important indicators of respite benefits. But exploration of other outcomes is very important in order to establish an evidence base for the efficacy of respite. The ways that respite influences family caregiver relationships and marital status, employment and family economic stability, family caregiver and care receiver social interactions, abuse or neglect prevention, and caregiver health status have not been well researched. Furthermore, it is increasingly important for policymakers and other funders to know if respite is cost-effective by examining such variables as reduction in care receiver hospitalizations, prescription drug use, nursing home utilization, foster care or other out-of-home placements. Research on the cost-benefits of respite has been mixed and fraught with methodological problems. Some promising work on the role of respite in reducing the risk of costly psychiatric hospitalization among children with autism offers new possibilities for research in this area (Mandell, Xie, Morales, Lawer, McCarthy, and Marcus, 2012), but by and large, the existing research is either silent or equivocal on these important questions.



The ways that respite influences family caregiver relationships and marital status, employment and family economic stability, family caregiver and care recipient social interactions, abuse or neglect prevention, and caregiver health status have not been well researched.

The Expert Panel's Deliberations

From the outset the Panel's literature review revealed that researchers define respite in a variety of ways. It was also noted that researchers used a variety of different terms to describe respite. The Panel added the task of developing a taxonomy for respite that would provide consistency of language when focusing on outcomes, discussing research designs, levels of scientific rigor of research designs, and ultimately for making recommendations regarding strategies, methods, and topics for future respite research.

DEFINING RESPITE

Acknowledging the lack of a working definition of respite, panel members recognized the problems this causes not only in conducting research, but also in holding conversations about respite across disciplines, and even from program to program. Requisite to their task of identifying areas of research, developing a working model, identifying outcomes, and specifying methodological strategies that would guide their recommendations, the Panel began by composing a working definition of respite.

Studies have shown that the earlier respite is received in the caregiving experience, the more effective it will be in preventing the onset of serious stress and the associated negative physical and emotional effects (LaSasso and Johnson, 2002; Gottlieb and Johnson, 2000).

The Panel's research review showed that in some cases respite was defined as a particular clinical or medical intervention on behalf of the care receiver, based on the care receiver's dependency characteristics related to conditions such as dementia, Alzheimer's, cerebral-vascular accident, developmental disability, or physical disability. Those services might, incidentally, also result in the family caregiver having a period of relief from the responsibilities of caregiving. However, the studies rarely quantified the duration of respite or captured information on how caregivers' spent time. In some cases, the type of respite service or how it was delivered was not described at all. In fact, it was common among the studies reviewed that in the discussion sections the authors themselves would decry the lack of a cogent and inclusive definition of respite. A common recommendation in these articles, accompanying the usual recommendations for future research, was for the field to generate such a cogent, inclusive definition.

This focus on the care receiver rather than the caregiver as the target of respite is most often dictated by the major funding streams, primarily federal, that define eligibility for reimbursable services based on the care receiver's condition, and that more narrowly define eligibility according to the guidelines of the funder, principally Medicaid. The Panel cited fragmented funding streams, restrictive criteria for eligibility, and lack of services or program models that focused primarily—if not expressly—on relief of caregiving responsibilities for the family caregiver.

To fully inform the Panel's work on developing a respite definition that would lend itself to research efforts, the Panel reviewed existing definitions of respite in federal programs (Appendix 2: Federal Definitions of Respite) as well as the recent taxonomy of home and community-based services (HCBS) developed by the Centers for Medicare & Medicaid Services (CMS) (Lollar, Peebles, and Timmel, 2013; Peebles and Bohl, 2014). Currently, the CMS taxonomy applies to a wide array of Home and Community Based Services (HCBS),

including respite, covered under HCBS waivers as well as the State Plan HCBS benefits authorized by Section 1915(i). The utility of the taxonomy is that researchers can analyze HCBS use at the person-level rather than at the aggregate level, although respite is defined only as an in-home or out-of-home service under the broader taxonomy category of Caregiver Supports (Peebles and Bohl, 2014).

Panel members agreed that any definition of respite should focus on relief from caregiving responsibilities. However, Panel members also concluded that focusing only on the caregiver could have untoward consequences with respect to funding respite since funds are typically connected to the disability or condition of the care receiver. Furthermore, the Panel recognized that much of respite is delivered as part of a multi-service plan or program that usually includes some service for the care receiver.

Panel members also discussed whether or not a definition of respite should address, directly or indirectly, the intended outcomes of respite. Panel members wondered if there should be quid pro quo for the receipt of respite. Should a caregiver receiving respite be required to engage in certain activities, or use the time in certain ways, presumably defined by the funding source? Is it sufficient for the caregiver simply to rest? Is the provision of respite still "respite" if the caregiver spends respite time in the presence of the care receiver (such as a caregiver who accompanies a child with a developmental disability to a camp experience)?

The Panel agreed that the definition of respite should be inclusive, should focus primarily on the caregiver, but should also include reference to the care receiver and even the family system as potential beneficiaries. They also agreed that while the definition should not place arbitrary limits on how respite time is spent by the caregiver, that there should be some measurable or observable benefit that accrues to the caregiver in the form of well-being or quality of life.

Panel members bored deeply into the draft definitions, and were very precise with respect to their critiques and attempts to clarify. For example, several panel members argued that the word "temporary" should not appear in the definition at all, lest it be misconstrued as an adjective implicitly defining a limit on the term or duration of respite that a caregiver might receive, rather than more simply stating that an episode of respite provided temporary relief from the duties of caregiving. The Panel's conversations were essential to achieving clarity and purpose for the proposed definition.

Through their deliberative process, the Panel reached consensus and adopted a definition that includes explanatory language making clear that collectively the panel members recognize that there are many different models of respite. For example, some models provide regularly scheduled and recurring respite, while other models make respite available in response to emergencies or only on an as-needed basis.

Panel members note that specific definitions of a respite service are likely to vary as a function of care receivers' needs, as well as those of caregivers, among others. The Panel, therefore, drafted language that appended the definition in order to make it as inclusive as possible when applied. The Panel held particularly strong feelings about the addendum to the definition because their intention is that the definition serve as the cornerstone of their recommendations for conducting future research and testing the efficacy of respite.

A Concise, Inclusive Definition

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

The preceding definition is intended to make the family caregiver the starting point for planning any research endeavor relating to respite. It explicitly

states that while some benefit from respite should accrue to the caregiver, benefits may also accrue to the care receiver and to other family members. The care receiver or other family members may be the primary focus of the respite service research, but benefits accruing to the caregiver should also be identified and measured.

Appended to the respite definition is the following:

> *Services provided may be informal, formal or specialized, and they may be provided to either, or both, the caregiver and the care receiver. It is acknowledged that respite takes on various forms; may be of short or extended duration; may occur one time, multiple times as needed by the caregiver, or be regularly scheduled; may include paid or voluntary services; may involve different types of providers and services of varying degrees of formality; may be provided in-home or at some other location (such as a center or camp); may involve or require direct staff with varying degrees of experience or training, or who possess various credentials; and may be designed to address different chronic or disabling conditions, types of dependency, age levels of dependent persons, and levels of dependency. To the degree that one or more of these variables are suspected of or intended to affect the desired outcomes for either caregivers or care receivers, they should be so acknowledged, measures should be identified, and the measures should be tracked throughout the research project for analysis and model testing.*

AN "ENTRY PORTAL" FOR RESPITE RESEARCH

Once the Panel reached consensus on a practicable definition of respite, they began contemplating a model for respite research. Because the Panel's definition identified the caregiver as the primary reason that respite is provided, panel members agreed that any model of research should focus, at least initially, on benefits accruing to the caregiver. While acknowledging that benefits accruing to the care receiver or the family as a system may be equally important in terms of approaching respite research, the Panel agreed that the caregiver was the place to start. The term "entry portal" evolved in the Panel's discussions about the beginning point of any research endeavor. That is, no matter what else occurs during a period of respite, some benefit should accrue to the caregiver, and any research endeavor should attempt to identify and measure caregiver benefits. More simply stated, if you are not measuring some intended benefit to the caregiver, you are not conducting respite research; you are researching something else, such as a medical service or life experience for the care receiver.

TAXONOMY OF RESPITE RESEARCH

Having focused on "benefits accruing to the caregiver," the Panel began identifying outcomes that might logically be expected to accrue from, and that could be attributed to, respite. Stated in research parlance:

> ***If you provide a particular respite service (the independent variable), and the service is effective, what positive outcome (the dependent variable) would you expect to observe?***

Research is all about manipulating independent variables with some expectation that those manipulations will impact the dependent variable in some observable, measurable way. The Panel had already agreed that there were multiple variables defining possible respite models. Their next task was to define beneficial outcomes that might be expected to occur following respite.

The task of identifying caregiver outcomes is not as simple as it might first appear because the reported research studies did not always measure specific benefits to caregivers. When they did, outcomes were limited to just a few, such as reduced stress or depression levels. Therefore, no taxonomy of terms was readily available for the Panel to adopt in order to generate a more comprehensive list of outcomes potentially attributable to respite. The Panel

reviewed several different taxonomic approaches and ultimately categorized outcomes that might occur at three levels: individual caregiver, family, and society. For each level, the Panel identified *proximal outcomes* (those that might be observable during or immediately after a spell of respite, such as relief from depression), and *distal outcomes* (those that might take time to emerge or to be measured, such as delayed or avoided institutional care, or family continuity).

The original taxonomic schema the Panel developed focused on: *affective dimensions*, both positive and negative, such as depression, hopefulness, loneliness; *human capital*, such as competence as a caregiver or as an advocate for care receiver; and *major situational changes*, such as separation or divorce, decline of caregiver health status, care receiver hospitalization or institutionalization.

Based on panel members' comments, the schema was revised by labeling "big buckets"—or inclusive categories—of outcomes according to the results they were intending to achieve, such as improved relationships, better health, or stable living status. The revised schema that follows uses this approach and provides examples of both proximal and distal outcome measures for each "big bucket" category.

A FOCUS ON OUTCOMES

The revised schema focuses only on outcomes, and presumes that concomitant variables related to the design of the particular respite program will be tracked and recorded. These concomitant variables include *nominal variables* (such as the type of service or specifics of the model); *process variables* (such as the 'dosage' of service(s) or the frequency of service); and *implementation variables* (such as fidelity of model implementation, satisfaction with service(s) received, satisfaction with the service provider, or satisfaction with the location of service, among others).

The Panel strongly advocates that future respite research addresses proximal and distal outcomes when appropriate and possible. Tracking and maintaining contact with families throughout a long-term study can be expensive, and usually requires large sample sizes due to the likelihood of attrition. However, distal outcomes are very important because they reflect life-course trajectory changes in the caregiver, care receiver, or both. A focus on proximal outcomes is well-grounded and bolsters the logical arguments associated with particular proximal outcomes leading to more distal outcomes. When resources and research design permit the measurement of distal outcomes, which is essential to establishing the long-term efficacy of respite, the proximal outcomes provide the logic for causal attribution.

Related Proximal and Distal Outcomes

The taxonomic schema on page 16 is designed to relate both proximal and distal outcomes, which can be potentially attributed to the provision of respite, to the relationships and persons for whom respite is intended to benefit, and the individual, family and societal level contexts in which respite occurs. The outcomes presented here, both proximal and distal, are provided as examples, are not inclusive of all possibilities, and are not intended to limit future research.

TAXONOMIC SCHEMA OF RELATED PROXIMAL AND DISTAL OUTCOMES

Outcome Category	Proximal Outcomes (results of direct service)	Distal Outcomes (changes in well-being over time, following respite)
Individual and Family Level Outcomes		
Family Relationships	• quality of marital/partner relationship • perceived strength of relationships • relationship with other family members • relationship with care receiver • time available for non-care receiving family members • reduced risk of care receiver maltreatment • caregiver's positive attitude towards care receiver and other family members • care receiver's positive attitude towards care receiver and other family members • family's ability to develop and utilize social networks	• family continuity • relationship stability (separation and divorce) • family vacations, outings, events with or without care receiver • reduced incidence of care receiver maltreatment • long-term increase in family's social capital
Social Relationships (outside the family)	• frequency/duration/quality of social interactions (both caregiver and receiver) • maintenance of friendships (both caregiver and receiver) • accessing/utilizing support groups • family's ability to organize and utilize social support/social capital	• caregiver's sustained willingness to provide care • caregiver's sustained confidence and ability to provide care • long-term increase in family's use of social capital
Health and Mental Health Effects	• free time for caregiver to use as determined by caregiver • receipt of health care • resolution of health problems affecting caregiving • receipt of mental health counseling or other mental health services • measures of caregiver depression, frustration, sense of burden, stress, anxiety, chronic fatigue, guilt • disrupted or insufficient sleep • caregiver and care receiver risk of psychiatric hospitalization • eating disorders • anxiety about the future • anxiety about aging • anxiety about diminishing ability to provide care for dependent family members	• caregiver relief from stress, depression, frustration, anxiety • caregiver mental and physical health maintained/restored • care receiver mental and physical health maintained/restored • increase in coping behaviors and/or decrease in maladaptive behaviors
Living Status	• placement stability with caregiver • continuity of placement • successful transition into or out of institutional care or other placement • reunification of care receiver with caregiver (and family)	• institutional placement delayed • institutional placement avoided • institutional placement rescinded

Outcome Category	Proximal Outcomes (results of direct service)	Distal Outcomes (changes in well-being over time, following respite)
Quality of Life	• stress levels • sense of support • happiness • satisfaction with caregiving • care recipient academic achievement • confidence in provision of care • sense of freedom and self-care • time for recreation/leisure important for caregiver and care receiver quality-of-life	• improved/sustained quality of life for both caregiver and care receiver • perceived quality of life of both caregiver and care receiver • caregiver sense of well-being • caregiver maintains hobbies or other leisure activities
Experience of Care (perceptions of caregiver and care receiver)	• caregiver satisfaction • care receiver satisfaction • caregiver's perceptions of competence in providing care • caregiver self-efficacy	• long-term caregiver satisfaction • long-term care receiver satisfaction • maintenance of caregiver's perceptions of competence in providing care • long-term self-efficacy as caregiver
Community Participation and Involvement	• caregiver participates in community activities, volunteers, maintains community connections • care receiver participates in community activities and builds community connections	• caregiver avoids increasing sense of isolation from community • community benefits from caregiver participation in community activities and events • care recipient avoids increasing sense of isolation from community • community benefits from care recipient participation in community activities and events
Societal Level Outcomes		
Cost-Effectiveness and Cost/Benefit	• cost efficiencies (cost per outcome achieved) • degree of achievement of outcome per-unit cost • hospital costs/utilization • number of inpatient/outpatient days • emergency room visits • reduced societal burden of care	• cumulative program cost savings over time • benefits that accrue to society through taxes • avoidance of institutionalization/reduced societal burden of care
Employment	• caregiver participation and productivity in the workforce • caregiver maintenance/retention of employment • caregiver absenteeism and presenteeism in the workplace • ability to provide care to care receiver • maintain/increase household income • caregiver able to support the economy • employer productivity	• continued independence of caregiver • continued ability of caregiver to be employed and productive in the workplace • continued ability of caregiver to provide care to care receiver • income/household stability • taxes return to society by employed caregiver • long-term employer productivity and profitability

The outcomes presented here, both proximal and distal, are provided as examples, are not inclusive of all possibilities, and are not intended to limit future research.

A RESEARCH FLOW DIAGRAM

The Panel's focus on outcomes is noteworthy—particularly in the absence of a research literature that clearly specifies succinct categories of outcomes that have been studied previously. Embarking on a mission to study outcomes in the absence of a guiding body of research required an organizing framework to help guide the Panel's discussions, and to assist future researchers wishing to embrace the Panel's recommendations. To meet this need, the Panel constructed a research flow diagram (see page 20) that purposefully reflects the Panel's definition of respite, restated here:

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

The Panel derived the logic for constructing the Research Flow Diagram from the conceptual model of David Evans (2013). In an article titled *Exploring the Concept of Respite*, Evans began his exploration of respite by identifying the caregiver and the care receiver as a dyad, where the respite service is needed to engage both parties in the dyad and offer assistance. The logic in this concept is that if the parties were not engaged, then any subsequent assistance would not be accepted. In turn, if the assistance was not effective then the respite would be of little value. Within this model, therefore, assistance/engagement identifies the starting point for the delivery of respite.

Based on Evans' (2013) conceptual model, any respite service is the result of a negotiation and agreement between the respite service provider, the caregiver and the care recipient.

Continuing with Evans' postulation, assuming successful engagement and negotiation of assistance, respite should result in one or more of three general categories of outcomes: *freedom*, *support*, and *connection*. Recalling that the Panel's definition of respite is intended to make the caregiver the starting point for planning any research endeavor relating to respite, some benefit of respite should accrue to the caregiver. Therefore, the research idea, plan, or proposal flows first to the caregiver, and thereafter may remain focused solely on the caregiver, or it may branch out to include other beneficiaries, such as, the care receiver, other family members or the family system. Informal, formal or specialized services may be provided to the caregiver, the care receiver or other family members.

The Panel concluded that a generic research framework for respite based on Evans' conceptual model requires that any respite service is the result of a negotiation and agreement between the respite service provider, the caregiver and the care receiver. The agreement specifies the respite to be provided, and the elements of that service that relate to either *assistance or engagement* (see #1 following), or both, with the intention of producing one or more proximal outcomes for the caregiver, and possibly other beneficiaries, relating to *freedom, support, or connection* (see #2 following), and distal outcomes relating to *optimal well-being* of the caregiver, care receiver, or caregiver family (see #3 following). Therefore, the design of any respite research project would have to include *independent variables* (see #4 following) relating to assistance/engagement (the respite service), and *dependent variables* (see #5 following) relating to outcomes expressed in terms of freedom, support and well-being. The Respite Research Flow Diagram on page 20 illustrates how this framework provides a flow for a research endeavor on respite services.

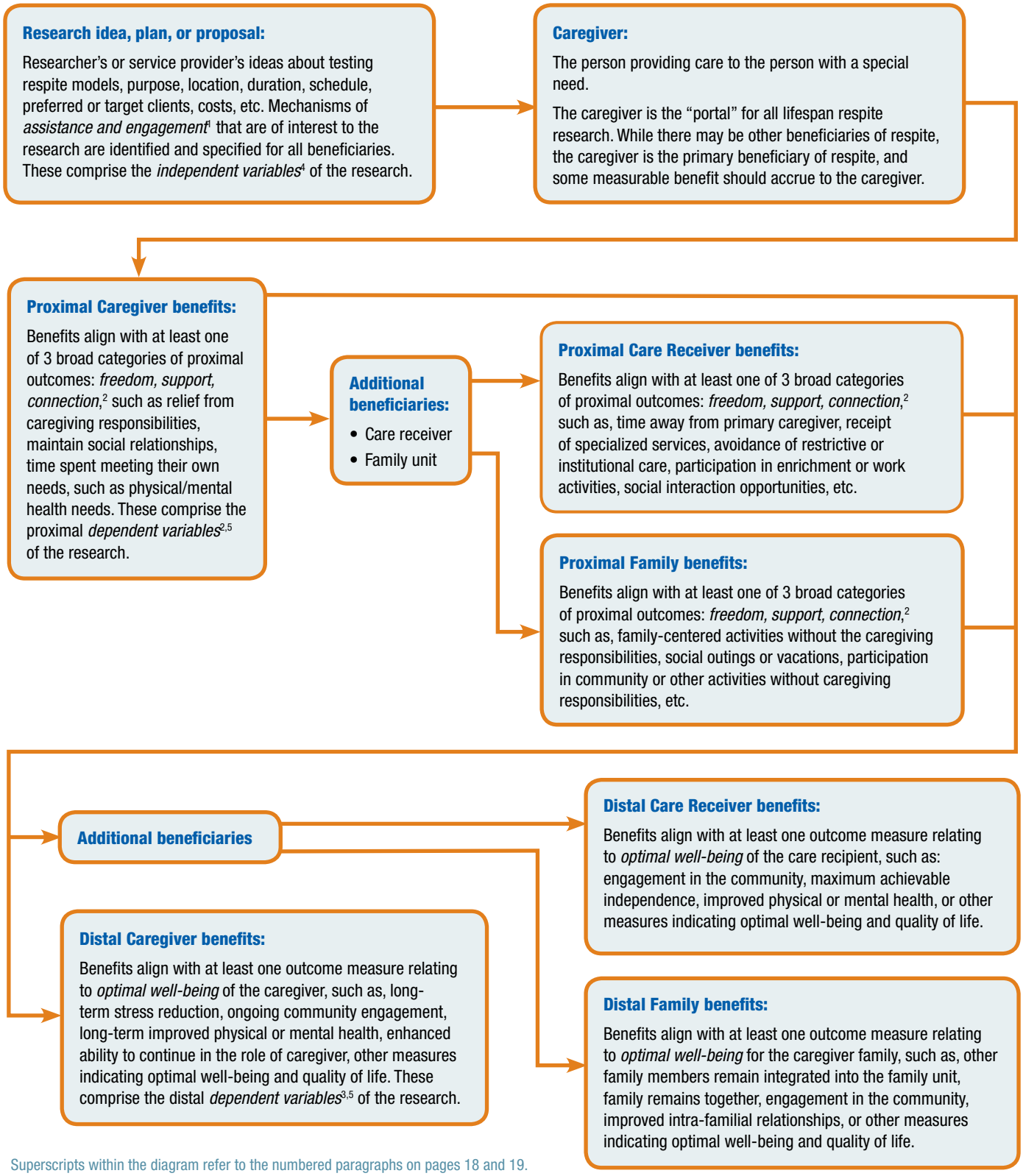
1. **Assistance and engagement.** Research studies should highlight:
   - **Assistance:** the manner in which care is provided, including the duties and mechanisms of providing care (location of services, type of services, dosage, and other

variables defining the specifics of the respite service provided); and

- **Engagement:** highlighting the mechanisms by which caregivers (and care receivers, if included in the research design) engage in respite, such as educational activities, health-related activities, social engagement, rest and relaxation, etc.

2. **Proximal outcomes—freedom, support, connection.** Research studies should highlight:
   - **Freedom** includes relief from caregiving responsibilities and from the stress of caregiving (for the *caregiver*) and freedom to use the respite time in any number of ways, including simple rest and relaxation. For the *care receiver* this might include time away from the traditional caregiver, or freedom to receive other services, supports or opportunities not available from the traditional caregiver, or freedom from more restrictive or institutional care. For family this might include freedom to engage in family-centered activities without the simultaneous responsibility of caring for the dependent family member.
   - **Support** for the *caregiver* normally involves participation in activities related to health, education, social activities, self-care (e.g., rest, relaxation, pursuit of personal goals), and employment. For *care receivers*, support may include respite provider's efforts to improve the quality of life, well-being, or to engage in activities that the traditional care provider cannot offer. For the *family,* the support may mean that the caregiver can attend to the needs of other family members without disabilities or participate in activities involving other family members.
   - **Connection**, for all three beneficiaries (*caregiver, care receiver, family unit*), includes continuity of the family unit, participation in social or community events, maintenance or pursuit of social relationships and social interactions.
3. **Distal outcomes—optimal well-being.** Research studies should highlight:
   - Improved physical health, improved mental health, improved stability of caregiver family life, improved intra-familial relations, and other measures relating to optimal well-being, where "optimal" means achieving the *best possible* outcomes in what may be difficult and/or demanding circumstances for the caregiver, care receiver, and family unit.
4. **Independent variables:**
   - Those measurable variables that the researcher manipulates in order to increase the availability and/or effectiveness of the respite services, decrease the costs of providing the respite services, or both.
5. **Dependent variables:**
   - Those measurable variables that the researcher intends to impact through manipulations of the independent variables. Using Evan's framework, proximal dependent variables (other than cost variables) should align with at least one of the following three categories of variables: freedom, support, and connection; and distal dependent variables should relate to the optimization of well-being of the caregiver, care receiver, or family unit.

RESPITE RESEARCH FLOW DIAGRAM



Superscripts within the diagram refer to the numbered paragraphs on pages 18 and 19.

Methodological Issues in Respite Research

Problems caused by an inadequate definition of respite present significant barriers to conducting research on respite programs and services. Although the definition proposed by the Expert Panel is intended to remove some of these barriers, an inadequate definition is not the sole problem that has affected respite research to date. A general lack of focus of much respite research suggests the absence of an organizing framework for respite research. Evans' article, and the Panel's work and discussions about focusing on benefits to the caregiver being of primary interest (and serving as a "portal of entry" to research), followed by benefits to the care receiver, led to the development of the framework and the flow diagram described above.

Having developed a general definition of respite, and also having tailored an organizing framework for respite research, the Panel turned to methodological issues that have challenged effective research. Methodological shortcomings call into question the credibility of study findings, limit their usefulness, and in many cases, seriously limit their generalizability. It is noteworthy that both methodologically weak designs, and overly rigorous designs (when applied to models in early stages of development) can result in equivocal findings or "non-findings." These studies fail to detect a result when one has actually occurred. (This is known as a classic Type-II error in the hypothetico-deductive scientific method.)

METHODOLOGICAL DESIGN CONSIDERATIONS

Methodologically weak designs are frequently the result of underfunded studies. A lack of adequate funding often translates into a lack of appropriate and reliable measures for those variables related to establishing the efficacy of respite. Adequate funding also needs to be commensurate with the state-of-the-art or stage of development of the respite program serving as the focus for the research or evaluation study. In other words, a research endeavor may suffer from a weak, ill-defined, or amorphous "independent variable"—that is, the lack of a clearly defined service model being implemented, in a clearly described context, to a clearly identified service population. When independent variables are not adequately described, and appropriate outcomes (dependent variables) are not identifiable, methodologically rigorous designs cannot be devised.

Zarit's (2014) recent research investigating the effects of adult day care use on caregiver care-related stressors measured by salivary biomarkers is "one of the few studies demonstrating an effect of a caregiving intervention on physiologic indicators of stress."

Perhaps equally problematic is the inappropriate application of highly rigorous research designs to models that are still under development. When the measurement system and the expected results of the intervention (i.e., the outcomes of the respite program being studied) are unrealistic, the sample size too small, implementation fidelity too weak, or the service model itself too loosely defined, the results of research are questionable. These overly rigorous methods—randomized controlled trials (RCTs), in particular—frequently fall victim to the false assumption that when conducted in varied practice settings, RCTs are truly capable of controlling for random sources of error variance. Many "post mortems" conducted on failed studies have found numerous sources of variance that

are not random after all, but rather are sources of variance that might be important intervening or confounding variables whose variance can and should be accounted for as part of the research. Examples of such intervening or confounding variables include unrecognized sample selection bias (either deliberate or inadvertent), which frequently occurs in real-world practice settings, or using measures only indirectly related to the outcome of interest. As a result, the study may be incapable of detecting treatment effects, leading to the conclusion that no treatment effects occurred.

The Panel recommends to those conducting research and evaluations of respite programs that the designs and scientific rigor of the studies be driven by the stage of development of the program, the fidelity of implementation, the availability of reliable and valid measures of specified outcomes, and the sample size available.

While RCTs may be considered by some to be the gold standard of efficacy testing, their premature use, or particularly their inappropriate use on developing models, may result in the loss of good ideas and good programs when RCTs fail to detect positive findings. Note that the use of the phrase "failed to detect" is deliberate. It is used in this instance to differentiate between studies in which an actual failure to detect positive outcomes occurs, as opposed to finding or "proving" (since this is an RCT) that a particular program does not work.

The overuse of RCTs is influenced by a trend among funders of research (including government sources of research funds) requiring highly rigorous research methods as an a-priori condition for funding. Recently, many state departments of finance have become increasingly unwilling to fund programs in the human services that do not rise to the level of "Evidence-Based Practice" as defined by at least two independently conducted random controlled trails showing statistically significant positive outcomes. When the use of a random controlled trial, itself, is the problem, the results are often a failure to detect positive findings. The requirement to impose very costly and overly rigorous research designs on developing programs has a stifling effect on creativity to develop new programs, improve existing models, or make other changes that may improve a model, even if that improvement causes a drift away from original model fidelity.

It is notable that in the field of medicine, which is often considered more grounded in science than human services, there is growing recognition that random controlled trials may sometimes be inappropriate in medical studies. In a recent article in the Journal of the American Medical Association, former Administrator of the Centers for Medicare and Medicaid Services, Donald Berwick, notes the difference between negative findings, inconclusive findings, and failure to detect positive findings (Berwick, 2008). He notes issues relating to "experimental contamination" of field studies in hospitals testing new models intended to improve medical care, such as the Medical Early Response Intervention in Therapy study. He identifies poorly implemented random controlled trials as nearly leading the medical community to reject a potentially beneficial program, even when the practice wisdom and the "accumulated experience of many hospitals that were adapting rapid response for their own use" indicated that the model was both meritorious and efficacious.

With this discussion as a backdrop, the Panel recommends to those conducting research and evaluations of respite programs that the designs and scientific rigor of the studies be driven by the stage of development of the program, the fidelity of implementation, the availability of reliable and valid measures of specified outcomes, and the sample size available. RCTs may be appropriate for highly evolved models being tested in essentially identical practice settings with homogeneous service recipients, and with a sufficient sample size to provide required statistical power relative to the expected (often only incremental) treatment effect size. However, RCTs are not appropriate for developing programs where less rigorous and

more affordable research and evaluation efforts are more likely to result in increased practice wisdom leading to improved programs or to a growing base of evidence. From this evidence base, more highly advanced and defined service models can be developed and tested with increasingly rigorous designs.

A most compelling example of this progression in respite is evidenced by two studies recently published by Zarit, et al. (2013; 2014). In the first study, the use of adult day services (ADS) by caregivers of individuals with dementia was qualitatively explored using survey methods, telephone interviews and secondary administrative data to study the effects of ADS on caregiver daily stressors, affect, and health symptoms. Zarit and colleague's second study (2014) replicated the first, but added a new dependent variable: a biological marker (i.e., Dehydroepiandrosterone-Sulfate [DHEA-S]) associated with the recovery from stress among the caregivers receiving the respite. Caregivers had higher DHEA-S levels following use of ADS and these higher levels may help ameliorate the stress that can lead to illness. Thus, the promise of this intervention was supported by the first study, and its efficacy established almost to a scientific certainty in the second. The phrase "almost to a certainty" is used because the design of the second study was not an RCT. However, the biomedical evidence of changes in biomarkers in the caregivers receiving respite is very convincing. Remember that even a well-conducted RCT would present a 5 percent probability that the findings are in error using conventional alpha levels and confidence intervals. One might ask, would an RCT be any more convincing, more likely to be correct, or even be necessary?

STATISTICAL AND ANALYTICAL CONSIDERATIONS

Different levels of scientific rigor and different properties of data (nominal, ordinal, interval, and ratio) require or permit different levels of analysis. Qualitative data are inductive, interpretive, grounded in context and largely descriptive. Qualitative data may include narrative responses to open-ended or semi-structured questions; descriptions of case studies; or groupings of similar respondents or study participants as a percentage of some variable, theme, or issue of interest. Qualitative data are particularly useful in the beginning stages of developing services or treatment, as in clinical observations and notes. Qualitative data are also useful in discovering how those participating in experiential phenomena make sense of their experiences, and for social validation of services or of researchers' interpretations.

Quantitative data, ordinal and interval data can be scaled and counted, and more interesting statistical approaches can be applied in order to conduct pre-post difference testing or group comparisons. Correlations among variables also are useful at these levels of analysis in order to identify variables that track meaningfully in the same or opposite directions. With interval and ratio level data, and even with ordinal data to which interval properties may be imputed, more advanced statistical models can be applied, including those frequently used to measure outcomes and to test efficacy in RCTs.

Measures utilizing each of these data levels can serve appropriate roles in the effort to build knowledge and increase the scientific evidence for the efficacy of respite. Appropriate use of these analytic techniques can increase the pace of program development toward the highest levels of becoming evidence-based, where appropriate use of group comparison studies or RCTs may provide the credibility that the major funders and empiricists want to see before declaring something to be "effective".

A METHODOLOGICAL/STATISTICAL CONTINUUM FOR RESPITE RESEARCH

The Panel posits that a continuum of approaches used to conduct research begin with the least rigorous and least demanding and advance to the most rigorous. Four levels of rigor are suggested, with the levels being identified by increasing

methodological rigor and sophistication of measurement and analysis. The Panel recognizes that this continuum is neither official nor inviolate. That is, there is plenty of room along the continuum for overlap with respect to the suggested methods, both qualitative and quantitative, at each level.

The first of the four levels is "New Ideas or Novel Approaches." As the name implies, the effort and methods a researcher would use to field-test a new idea or novel approach for the first time would demand a largely qualitative inquiry, with some administrative data to help identify interesting variables or groupings of participants, for example, as specified in the suggested methods. Following the "New Ideas or Novel Approaches" are, in order, Emerging Practices and Models, Evidence-Informed Practices, and Evidence-Based Practices. Again, as the names imply, increasing methodological rigor calls for increasing sophistication of design, measurement and analysis.

Level I of Model Development:	**New Ideas, Novel Approaches** (single site, single program)
Suggested Methods:	**Qualitative:** Interviews, surveys, consumer satisfaction, case studies, observational studies. **Quantitative:** Administrative data (e.g., service utilization; model compliance; incident analysis such as placement, maltreatment); standardized instruments (e.g., depression inventories, stress inventories, quality of life inventories).
Level II of Model Development:	**Emerging Practices and Models** (two or more pilot study sites)
Suggested Methods:	**Qualitative:** Interviews, surveys, consumer satisfaction, case studies, observational studies. **Quantitative:** Administrative data (e.g., service utilization; model compliance; incident analysis such as placement, maltreatment); standardized instruments (e.g., depression inventories, stress inventories, quality of life inventories); cost-effectiveness analysis. Samples of convenience, possible comparison to unserved caregivers/care receivers.
Level III of Model Development:	**Evidence-Informed Practices** (one or more sites, high fidelity implementation, comparison groups, quasi-experimental designs)
Suggested Methods:	**Qualitative:** Interviews, surveys, consumer satisfaction, case studies, observational studies, funder surveys, community surveys, fidelity checklist. **Quantitative:** Administrative data (e.g., service utilization; model compliance; incident analysis such as placement, maltreatment); quantitative outcome documentation such as standardized instruments (e.g., depression inventories, stress inventories, quality of life inventories); multivariate measurement systems (outcomes for both the caregiver and care receiver across a broader spectrum, including psychological, health, biomarkers if available); larger samples, comparison groups, matched if possible, multivariate analyses, advanced statistical modeling.
Level IV of Model Development:	**Evidence-Based Practices*** (i.e., one or more sites, high fidelity implementation, control groups, experimental or quasi-experimental designs, possibly randomized controlled trials; if multiple sites, focus on possible intervening variables and account for their variance).
Suggested Methods:	**Qualitative:** Surveys (e.g., consumer satisfaction, funder surveys, community surveys), case studies, fidelity checklist. **Quantitative:** Administrative data (e.g., service utilization; model compliance; incident analysis such as placement, maltreatment); quantitative outcome documentation such as standardized instruments (e.g., depression inventories, stress inventories, quality of life inventories); multivariate measurement systems (outcomes for both the caregiver and care receiver across a broader spectrum, including psychological, health, biomarkers if available); larger samples, randomized or matched comparison groups, multivariate analyses, advanced statistical modeling.

* The major difference between evidence-informed and evidence-based is that at the evidence-based level, studies should employ randomized trials, matched control groups, or other rigorous designs intended to test efficacy.

Recommendations for Future Respite Research

The ultimate purpose of convening the Expert Panel was to develop a set of recommendations for future research on respite. After defining respite, developing a taxonomic approach for its discussion, focusing on outcomes of future research endeavors, constructing a research flow model to guide the development of studies, and discussing resolutions to methodological and analytical deficiencies of the existing research literature, the Panel brought its collective wisdom to the task of applying this body of work to the development of the recommendations.

For background and to help initiate the process, the Panel reviewed the recommendations for future research on respite and caregiving put forth by researchers cited in the ARCH Annotated Bibliography. Publications from other experts in the field that laid out research agendas for family caregiving and related long term services and supports were also reviewed (Kaye & Harrington, 2015; MetLife Mature Market Institute and National Alliance for Caregiving, 2007; Rosalynn Carter Institute for Caregiving, 2010).

Panel members posed a series of questions to help structure and facilitate the process. They asked, for example: Should the Panel make recommendations that align respite outcomes at the level of measurement? Should they focus on outcomes that could be achieved in the shortest term? Should they focus on outcomes that have been largely overlooked in previous research, and/or prioritize research questions? Should they recommend new service models, or focus on developing evidence for existing models? Should they recommend research focused on identifying the added value of respite when being studied as part of a multiple component or multiple service intervention?

These questions elicited productive debate with the Panel deciding that just as they had identified "big buckets" of outcomes earlier in their deliberations, they needed to identify "big buckets" or global categories in which to organize their recommendations. Ultimately the Panel identified six broad categories of recommendations:

1. improved research methodologies;
2. individual, family, and societal outcomes research;
3. research on cost-benefits and cost effectiveness;
4. systems change research to improve access;
5. research on competency and training needs of providers; and,
6. translational research.

IMPROVED RESEARCH METHODS

A large portion of the Panel's work focused on the methodological shortcomings that have hampered studies to date and that have limited the usefulness of their findings. These shortcomings have been addressed from the perspectives of research design, construction of independent and dependent variables relating to respite services, and methods and statistical analyses. To address the methodological issues heretofore discussed, the Panel makes the following recommendations. The initial group of recommendations addressing research methods focuses on global methodological concerns.

Issue 1: Improving the Approach to Respite Research

1. Consistent with the Panel's definition of respite as a service or support designed to benefit the family caregiver, the caregiver should be the portal of entry and an important focus of any research study or evaluation of respite services. Benefits accruing to the caregiver, the

family unit, or to others are also important, but the caregiver should be the focus of at least one independent variable/dependent variable relationship.

2. The selection of research designs and the level of scientific rigor of studies should be driven by: the stage of the program's development; the fidelity of program implementation; and the availability of reliable and valid measures of specified outcomes.
3. Research studies should compare different types of respite, not just respite versus non-respite controls or comparison groups.
4. Qualitative methods should be employed to capture contextual information. This information is critical to data interpretation; for example, to determine why cultural differences, or study site differences, may have occurred; or why fidelity was achieved or not achieved.

Issue 2: Studying Respite as a Component of Comprehensive Caregiver Support Programs

The Panel noted that, typically, respite has been studied in combination with other services or supports for the caregiver making it difficult to isolate the impact of respite alone. The Panel views as critical determining the added value of respite in combination with other support services. In keeping with the Organizing Framework based on Evans' (2013) model previously described, which recognizes the essential dyadic relationship between the caregiver and the care receiver, the Panel recommends the following:

1. Research should include multiple level studies of respite, such as respite alone and respite in combination with other services to the caregiver and/or care receiver (e.g., medical services, skill building, support groups, education, or counseling) to determine the importance of respite alone or in combination with other support services.
2. Research studies should examine the relative impact of informal family and community support as compared to formal and/or paid respite services.

Issue 3: Examining Contextual and Measurement Variables

Through their review of current research, the Panel identified several issues affecting interpretation of research findings, and they noted that contextual and measurement variables were often at the heart of equivocation about findings. The Panel found that at times contextual variables—those variables not identified as independent variables, but likely to influence outcomes—were not discussed by researchers, or were only vaguely discussed. Further, the measures researchers frequently used were neither standardized nor validated; rather, they were based only on theory—or worse, on assumption. Sometimes unique measures constructed for an individual study were developed without reliability or validity testing.

A recent national study of caregivers conducted by the National Alliance for Caregiving (NAC) and AARP found considerable differences among caregivers related to their age, gender, and race as well as to the intensity and complexity of care provided. These and other variables could strongly affect the extent to which family caregivers use, need or desire respite, the extent to which they would benefit from respite, and the timing and procedures required to access respite services. For example, this caregiver survey found that the use of respite services is more common among Asian American, Hispanic (22% each), and African American (20%) caregivers than it is among White caregivers (12%), suggesting that research to determine the role of race and culture in accessing respite would be extremely telling. Caregivers in more complex care situations, such as requiring the provision of more hours of care or provision of nursing or medical care, often have more difficulty finding affordable support services. In addition, the same survey found that caregivers who felt they had no choice other than to assume a caregiving role were more likely to face complex

care situations, and experienced higher levels of emotional stress and strain. Respite services were especially appealing to high and medium burden caregivers (42% and 36%, respectively, vs. 24% low burden), co-resident caregivers (39% vs. 31% non-co-resident), those caring for someone with Alzheimer's or dementia (46% vs. 30% without), and those caring for someone with a mental health issue (39% vs. 32% without) (NAC and AARP Public Policy Institute, 2015).

The Panel strongly believes that the effectiveness of respite may be influenced in any given case by context and caregiver/care receiver characteristics. To address these issues the Panel recommends the following:

1. Demographic variables, such as age, income, gender and other context variables should be tracked as part of the measurement system in order to provide data for higher-order statistical analysis relating to differential effectiveness.
2. When examining the impact of respite on caregiver-centered variables, researchers should consider and endeavor to quantify different levels of care (e.g., care to multiple recipients; age/gender related care needs), and attend to the different number of caregiving hours and intensity of caregiving required to influence change.
3. Research on respite should consider the effects of racial and cultural differences, and approaches to caregiving, on access and receipt of respite, and how that might affect caregiver/care receiver outcomes. Researchers' cultural and racial awareness should also be reflected in the measures used, and in their interpretations of the data.
4. In addition to standardized instruments/measures, researchers and scholars should continue to develop and validate additional or new proximal outcomes specific to respite such as "feeling relief," and other subtle changes in caregiver status, health, or circumstances. New measures are intended to increase sensitivity to allow detection of changes attributable to respite.
5. Caregiver and family expectations of respite should be examined as well as the ability of respite care to meet those expectations (e.g., goal attainment scaling).

Issue 4: Additional Research on Specific Target Groups

The Panel recognizes that respite may be of value to caregivers providing care to a variety of care receivers whose characteristics are defined by a particular disability, disease, age, or unique form of dependency. Often the provision of respite is dependent on the characteristics of the care receiver. However, this sometimes results in a limitation of generalizability of results of research findings. The Panel further recognizes the difference between generalizability across populations (derived from quantitative studies making group comparisons) and generalizability across issues (derived from qualitative research and inquiry). The Panel does not discourage research on respite provided to caregivers within specific populations of care receivers, but calls for consideration of generalizability across populations and across issues during the design of research, and additional specific research on unique populations. Specifically:

1. Researchers should integrate findings from research conducted across disciplines on how research benefits caregivers, care receivers, families and society in different populations defined by age, disability and other variables, and apply this knowledge to the formulation of future research on respite and the design of new studies.
2. Research should be undertaken which identifies respite outcomes for typically underserved populations such as individuals with Multiple Sclerosis or ALS, adolescents or adults with mental health issues, certain cultural groups, military families, and others.

Issue 5: Longitudinal Studies to Ascertain Long-Term Impact of Respite

The Panel recognizes that longitudinal research is both more difficult to undertake and more expensive than shorter-term studies focusing solely on proximal outcomes. However, the Panel believes the potential long-term benefits of respite have not been adequately addressed in that a large portion of respite services are provided during times of crisis; and even when provided in caregiver/care-receiver dyadic circumstances that may be ongoing, the measurement intervals are brief and focus only on short-term benefits. To better understand the long-term potential of respite services to both caregiver and care receiver, the Panel recommends:

1. Long-term-term benefits to the well-being of caregivers and care receivers may take many months or even years to detect, study, and understand. When appropriate and possible, studies should employ longitudinal designs and long-term participant tracking.
2. The needs of both the caregiver and care receiver may not always follow a linear path, but may change over time. Therefore, longitudinal research studies need to differentiate between the testing of one model over time, versus the receipt of various types of respite or doses of respite over time as the families' needs change. Consistency of the independent variable is important for model testing, but different models may be required over time, in turn requiring a more general definition of the independent variable.

A study of parents of children with autism spectrum disorders found that respite care was associated with reduced stress and improved marital quality (Harper, Dyches, Harper, Roper, and South, 2013).

Issue 6: Effects of Dosage, Timing, and Service Delivery Modes on Outcomes

The term respite can encompass a wide variety of models and model parameters. Often, the provision of respite is predicated on the need for a particular number of hours per week, as opposed to the provision of respite on an as-needed basis. Unless the model parameters are specified and held constant within any particular study, these kinds of differences complicate the interpretation of data describing the impact or effectiveness of respite. It would also be extremely helpful to know if the amount of respite received, and when and how it was received, make a difference in determining long-term benefits of respite. To address this issue the Panel recommends:

1. In order to enable comparisons across studies, and to determine differential effectiveness due to differing model components or the addition of respite to "services as usual," respite research must include specific descriptions and determination of the services provided, the venue, the combination of services (as appropriate), whether the respite is consumer-directed or provider-directed, and other variables defining the model.
2. The dosage of respite, including amount and frequency of respite provided, may be a determining factor for achieving specific outcomes for caregivers or care receivers. Also, when respite was first accessed can be a determining factor in achieving desired outcomes. It may be that respite received earlier in the caregiving experience may have longer lasting benefits than respite first accessed late in the caregiving experience when families may be in crisis. At this point, if the caregiver has already suffered deterioration of physical and emotional health and may have reached a breaking point, the care receiver may be more likely to be placed out-of-home regardless of the receipt of respite or other caregiver supports. Research should examine the relation between respite dosage and timing (e.g., frequency, intensity, duration) and specific outcomes.

INDIVIDUAL, FAMILY AND SOCIETAL OUTCOME RESEARCH

The Panel's identification of the caregiver as the "portal of entry" for any research study on respite is deliberate. At least one outcome relating to the caregiver's quality of life, well-being, competence or self-efficacy should underpin the study. However, this focus on the caregiver and on family caregiver outcomes does not negate the need to study additional outcomes. In addition to recognizing the caregiver as the primary focus of respite, the Panel's definition of respite and the organizing framework for research recognizes the care receiver, the family system, and society as being possible beneficiaries of respite, and therefore appropriate for inclusion in research studies. Although the Panel acknowledges that the cost of conducting research increases as the complexity of the studies and the sample sizes increase, the Panel also recognizes the value of including measures on all persons affected, or potentially affected, by the provision of respite. To this end, the Panel recommends:

1. Respite research should include at least one measurable outcome for caregivers. Care receiver outcomes, family outcomes, and societal outcomes should also be measured whenever possible, relevant, and appropriate.
2. Outcomes selected for inclusion in research measurement systems should reflect the program's specific goals and objectives and should be related to the program's service model by previous research findings and/or strong theoretical/logical argument. The theoretical and logical underpinnings of the study should be clearly stated.
3. Standardized measures should be used whenever possible and available (e.g., depression inventories, health status inventories, caregiver self-efficacy), in order to operationalize the desired outcomes. However, given that outcomes such as the elimination of burden and alleviation of depression, may be difficult to measure directly, tools that measure subtler changes or temporary benefits (e.g., feeling relief for a few hours each day because of respite) may also be informative and should be developed.
4. Research should examine how the dyadic relationship between caregiver and care receiver is affected by receipt of respite (e.g., the diminishing feeling of being a burden to the caregiver that the care receiver may feel following the receipt of respite; the enhanced feelings a caregiver may experience toward the care receiver as a result of respite).

Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every $1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization ((Mandell, Xie, Morales, Lawer, McCarthy, and Marcus, 2012).

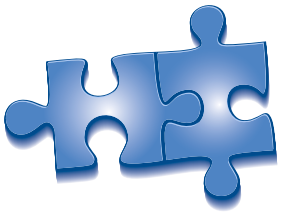
COST BENEFITS AND COST EFFECTIVENESS OF RESPITE

The Panel recognizes that while a substantial portion of respite care is provided voluntarily, the greater goal is the provision of respite as an adequately funded service that is more broadly available across multiple populations. This goal can only be achieved and sustained if respite can be shown to result not only in the improvement of well-being of the caregiver and care receiver/family, but also if respite is demonstrated to be cost-effective and/or provide a cost benefit. In short, cost-effectiveness and cost-benefit studies are necessary in order to justify funding. But cost findings are only meaningful in light of demonstrated outcomes of respite when compared to the counterfactual condition. Rather than merely calculating total expenditures, cost studies should be context-specific, as context can have a substantial impact on cost, and should include measures relating to all of these domains: overall cost, costs that could reasonably be expected to occur in the absence of respite, costs borne by different

parties associated with the respite model, outcomes for both respite-receiving and non-respite-receiving caregivers. Cost-effectiveness and cost-benefit demonstration is considered paramount by both policymakers and funders when determining the worthiness of human service programs for funding.

Much of the existing research on respite posits, but often fails to adequately measure potential cost savings due to delayed or avoided institutional placements, loss of employment by caregivers who must choose between work and providing care for their loved ones, and other societal costs and benefits. Recognizing the need to examine the value of respite in relation to other services, the Panel recommends the following:

1. Research studies should examine broadly accepted and desired outcomes that may be related to cost-savings, (e.g., the delay or avoidance of premature or inappropriate institutionalization; reductions in abuse, neglect, or exploitation of dependent persons) across different types of respite, and with respect to different types of care receivers.



Much of the existing research on respite posits, but often fails to adequately measure potential cost savings due to delayed or avoided institutional placements, loss of employment by caregivers who must choose between work and providing care for their loved ones, and other societal costs and benefits.

2. Research studies should determine if respite helps avoid or delay institutional placement or hospital use of the care receiver, or the duration and level of care needed during spells of institutionalization or hospitalization. However, not all cost savings are necessarily associated with institutional or hospital care. Therefore, any associated savings to patients/families (e.g., of out-of-pocket costs) as well as savings to Medicare/Medicaid, should also be determined.
3. Research studies should determine if respite alone, or in combination with other services, results in cost benefits attributable to improvements in care receiver health status, reduced emergency room use or reduced prescription drug use.
4. Research studies should determine if respite alone, or in combination with other services, results in cost benefits attributable to improvements in caregiver health status, reduced emergency room use, reduced hospitalizations, or reduced prescription drug use of the caregiver for health conditions resulting from caregiving.
5. Research studies should determine if respite alone, or in combination with other support services, can improve employee productivity of caregivers (e.g., reduced absenteeism, improved work productivity, sustained labor force attachment).

SYSTEMS CHANGE RESEARCH TO IMPROVE ACCESS

During their review of existing research, the Panel recognized that in order to examine the efficacy of respite, large numbers of varied caregivers must receive respite. The "large numbers" requirement is driven in part by the large variety of service models and the large number of caregivers and care receivers that could potentially benefit from respite. In research parlance, as the number of variables increases, sample sizes must also increase in order to provide statistical power during data analysis. At the same time, it is apparent that there are large numbers of caregivers who might benefit from respite but for whom respite is not available or accessible.

Lack of availability and accessibility may be due to any of a number of reasons such as lack of funding, lack of awareness of the service, limited understanding of how and where to access services and funding, unavailability of the service, or questions about service efficacy. Each of these

concerns relates to the overarching system of care for persons with illness or disabilities for whom respite may be of value. Is the service available? Is the service affordable? Is the service accessible? Is the service perceived as valuable? To address some of these system-level questions, the Panel recommends the following:

1. Research should ascertain the level of public awareness of respite; the best ways of increasing awareness of and access to respite; and how to improve communication about service availability to caregivers. Research should determine if increased public awareness increases access to and use of respite.
2. Research should examine how to assess caregiver expectations associated with receiving respite, and whether those expectations are met.
3. Research should identify the features of respite that produce the greatest consumer satisfaction.
4. Research should identify the mechanisms whereby employers can assist workers to access respite for dependent family members, as an aid to workforce continuity for the caregiver.
5. In order to overcome identified barriers to respite and improve access, factors affecting how and when caregivers access respite should be studied. The effects of variables such as caregiver and/or care receiver age, gender, income, race, or culture on access to respite should be studied.
6. Additional variables that might affect ease of access to and use of respite services, such as condition of the care receiver, complexity of care required, hours and intensity of care provided, caregiver/care receiver relationships, and whether or not the caregiver felt they had a choice in providing care should be studied.

RESEARCH ON COMPETENCY AND TRAINING NEEDS OF PROVIDERS

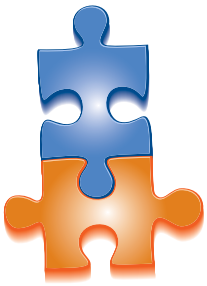
Existing research and practice led some panel members to question whether the provision of respite by persons with inadequate training might lead caregivers to be fearful of using respite. Depending on the needs of the care receiver, not all respite must be provided by people with special training. However, if special training is needed, there is a limited body of research on the quality of available training curricula and the most appropriate credentialing criteria for respite providers. To address these issues the Panel recommends:

1. Research should focus on the assessment of individuals providing respite, including their ability to provide safe and appropriate care; the education and training requirements in relation to care receivers' needs; cultural competence; ability to participate in a multiservice team, and other core competencies. In addition, competencies that define the standards of adequate care need to be determined empirically.
2. Research should focus on the most efficacious methods for training respite providers, including training content; delivery mechanisms for training respite providers (e.g., in-person, online self-paced); tiered training leading to credentialing or licensing; and training currency requirements.
3. Policy analysis is needed to inform the process of credentialing and licensing respite providers, including volunteers, paid professionals or paraprofessionals.

TRANSLATIONAL RESEARCH TO IMPROVE POLICY AND PRACTICE

The translation of positive research findings into practice models is a challenge across all disciplines in human services. The practice community may become comfortable with certain practice models, and embrace those models, even if there is scant evidence that the models are effective. Service programs may succumb to the development of "institutional inertia" in which even the most compelling evidence suggesting changes in program design is resisted by administrators, practitioners, or both.

Sometimes the resistance to change is stubbornly anchored in public policy or the funding streams associated with the provision of service under certain strictures or to certain service populations, even when research suggests that those strictures should be lifted or the service populations redefined. A recent article by Gitlin, Marks, Stanley and Hodgson (2015) on the translation of evidence-based caregiving interventions for persons with dementia illustrated many of these issues. The authors noted that among the biggest impediments to translating research into practice were funding mechanisms, gaps in underlying theory (a responsibility of researchers or model progenitors to remedy), and a basic lack of understanding by otherwise well-intentioned persons of Implementation Science. Implementation Science makes very clear the predictable resistance to systems change that occurs when the status quo



Sometimes the resistance to change is stubbornly anchored in public policy or the funding streams associated with the provision of service under certain strictures or to certain service populations, even when research suggests that those strictures should be lifted or the service populations redefined.

practice is challenged, or even when a new practice model is simply being added to existing services. Implementation Science describes, explains and offers both technical and adaptive solutions to these research-to-practice implementation problems. For more information about Implementation Science and a review of the seminal Implementation Science literature by its progenitors, see Fixsen, Naoom, Blase, Friedman & Wallace (2005).

Assuming that future respite research studies provide evidence that respite is effective, and both cost effective and cost beneficial, the task remains to translate those research findings into "best practice models" for respite care. Statistically significant findings, while representing the goal line for any research study, do not necessarily translate automatically to findings or models that can be broadly or easily implemented. Implementation Science tells us that translating research findings into practice models requires consideration of multiple factors in the environment of implementation: attention to contextual variables; an organization's readiness to change; implications for resources such as personnel requirements, training, record keeping, and accounting; and attention to details even to the level of personalities of caregivers and the social and political contexts of communities within which the services are to be provided.

Statistical findings may be subject to interpretation within the context of probability, and assuming that computations are accurate, the statistics typically stand firm. However, more general and contextual interpretation of findings requires attention to qualitative data and more social and contextual interpretation of those data than is typical of statistical findings. To maximize the probability of accurate translation of research findings into practice models, and to maximize successful implementation of practice models across the panoply of respite models and providers, the Panel recommends the following:

1. Whenever possible and appropriate, research endeavors should include qualitative inquiry in order to enhance the understanding of the impact of respite through the experience of those receiving the service.
2. Respite model fidelity and implementation context are essential for replication of respite models after effectiveness has been established. Therefore, research studies should include attention to fidelity of the model and contextual variables defining or describing the implementation setting in order to assist those involved in the translation of research to practice.
3. Translation of research findings into practice requires fidelity to the practice model. Standardized protocols of models under

investigation should be developed as part of the research if they are not already developed by model progenitors. Deviations from standardized protocols in an attempt to improve effectiveness or generalize a model to a different setting or service population must be described in detail.

4. For those implementing evidence-based respite services or programs in the field, ongoing measurement of program effectiveness is necessary for sustainability and continuous quality improvement. Ongoing technical assistance is critical.
5. Research should explore how current determinations of eligibility for government funding (e.g., Medicaid, National Family Caregiver Support Program) for respite services may affect how respite is perceived, accessed and used, and to what extent respite impacts caregiver, care receiver, family and societal outcomes.
6. When discussing evidence-informed and evidence-based respite, researchers should consider addressing the abilities of professionals in other disciplines, as well as providers in the field of respite, to implement research findings in order to maximize outcomes.
7. Policy analysis and treatises should define target audiences (e.g., service providers, funders, politicians, professionals across multiple disciplines, academics across multiple disciplines) for translational research, and should tailor discussions accordingly.
8. Implementation Science dictates that successful implementation requires a balance between technical work of program implementation and adaptive work within the organization or community to accept the implementation. Research is needed on how to determine which organizations are ready to implement best practice models, and even which caregivers are ready to accept and benefit from respite.

Incentivizing Research, Identifying Funding Sources

The preceding chapters in this report highlighted the Expert Panel's call for well-designed research studies focusing on the provision of respite for caregivers of dependent persons, with an emphasis on examining outcomes intended to accrue not only to caregivers, but also to care receivers and to society. Outcomes have been categorized as being caregiver-centered, care receiver-centered, or community/society-centered, and generally have been further categorized as relating to maintenance or improvement of health status, family status, and well-being of both the caregiver and the care receiver in the respite dyad.

The Panel presented ideas for applying appropriate designs to research studies examining programs at various stages of development and across different caregiver and care receiver populations. The Panel takes a position supporting methodologies that emphasize the practical application of research results to establish program efficacy, improve service delivery, and improve outcomes to caregivers and care receivers. The Panel also provides a list of recommendations of topics for research and the formulation of research questions.

The Expert Panel believes that well-conducted studies will enlighten caregivers, care receivers, providers and health care and other program administrators, as well as employers, and policymakers, with respect to benefits that respite can provide to caregivers, care receivers and to society. However, the Panel also recognizes that research on a scale and at a level of rigor that establishes credibility, and which can be generalized across different service populations, requires significant funding and requires researchers interested in pursuing appropriate lines of inquiry. The Panel recognizes the need to adequately fund meaningful research on respite, and to engage academics and other researchers to conduct those research studies.

To date, sources of funding for this kind of research have been limited, and infrequently sustained. Occasionally, studies have been funded on an individual basis, but there have been only a few research efforts that have conducted serial studies with the intent of specifically building evidence or establishing the efficacy of respite as a stand-alone service or as a component of a comprehensive package of caregiver or family support services (e.g., Lund, et al., 2009; Lund et al., 2014; Zarit et al., 2013; Zarit et al., 2014). As an incentive for researchers and providers to develop an interest in a particular area of research and for participating in research studies, the Panel identified potential funding sources for developing funding opportunities for scholars and other researchers interested in conducting outcome-based research on respite. The following entities have funded respite research in the past, or have mandates aligned with the Panel's recommendations that might predispose them to funding new respite research.

FEDERAL FUNDING OPPORTUNITIES

National Institute on Aging

Although the provision of respite to caregivers transcends all age groups, disease processes, and disabilities, the dependent elderly comprise a major share of the population associated with respite care. The National Institute on Aging (NIA) conducts extramural research in four focus areas of interest to respite researchers: biology, social and behavioral aspects of aging, geriatrics and clinical gerontology, and neuroscience (including Alzheimer's disease). Within the Division of Behavioral and Social

Research, there are two clusters of research interests: Individual Behavioral Processes (IBP), and Population and Social Processes (PSP).

The Individual Behavioral Processes cluster comprises six focus areas. The Behavior Change and Behavioral Interventions Section funds projects relating to disease recognition, coping and management (including physiological consequences of life stresses and burdens) as well as social, behavioral and environmental interventions for health promotion, disease prevention, and disability postponement.

The Family and Interpersonal Relationships Section focuses on family and interpersonal relationships at an individual and dyadic level. Also included is an interest in associations between marital and other interpersonal relationships with health and well-being; the role of family and social networks on individual health behavior and compliance; the role that friends and siblings play in healthy aging; and the development of interpersonal relationships over the lifespan.

The Population and Social Processes (PSP) cluster comprises four focus areas: Demography and Epidemiology, Economics of Aging, Population Genetics of Aging, and Health Systems. The PSP branch focuses on research on the effects of public policies, social institutions and health care settings on the health, well-being, and functioning of people, both over their life course and during their later years. This branch also promotes interdisciplinary and multi-level research.

The Demography and Epidemiology Section funds projects relating to interactions between health and socioeconomic status over time and across generations; interrelationships between work, family and health; the intersection between demographic processes and social outcomes, including intergenerational relationships; and cohort analyses of aging, among others.

The Economics of Aging Section funds research on allocation of family resources across generations; the impact of care arrangements for the elderly on labor supply; determinants of retirement, family labor supply, and savings; evaluations of the impact of changes in federal programs including Medicaid, Medicare, supplemental security income and Social Security policies; and cost-effectiveness of interventions to improve the health and well-being of the elderly, among others.

The Health Systems Section focuses on formal health care and long-term care systems and settings and their impact on the health and well-being of older persons. Their current research (circa 2014) focuses less on efficacy of treatments and more on provider-level variation in health expenditures, services, and outcomes for older persons.

NIA also funds groups of Centers that might offer collaboration possibilities for other researchers, particularly new researchers, interested in respite. These are the Edward R. Roybal Centers, and the Centers on the Demography and Economics of Aging. The *Edward R. Roybal Centers for Translation Research in the Behavioral and Social Sciences of Aging* focus on the development and piloting of innovative ideas for translation of basic behavioral and social research findings into programs and practices intended to improve the lives of older people, and the capacity of institutions to adapt to societal aging. Currently there are 13 Roybal Centers whose mission is to build a research infrastructure to enhance basic research, and to facilitate collaboration among academic researchers and commercial interests, including the recruitment of new researchers to aging and translational research, among others.

The *Centers on the Demography and Economics of Aging* support the infrastructure and pilot data necessary for larger research projects, the development of research networks, the development of analytical methods (including longitudinal methods), among others. There are 11 Centers currently funded by NIA that focus on a variety of topics, among which are several that closely align with research recommendations in this

report, including: the role of social, economic, and behavioral determinants of health outcomes over the lifespan; and the economics of health care provision for the elderly including health care costs.

Information about extramural research opportunities and how to apply for NIA funds can be found at www.nia.nih.gov/research.

National Institute of Mental Health

Research at the National Institute of Mental Health (NIMH) tends to focus on particular disease processes, such as autism, schizophrenia, bipolar disorder, and other mental health conditions. However, NIMH also funds mental health-related research in four priority areas: promoting discovery in the brain and behavioral sciences relating to the causes of mental disorders; charting mental illness trajectories to determine intervention timing and strategies; developing interventions that incorporate diverse needs and circumstances of people with mental illnesses; and strengthening the public health impact of NIMH-supported research.

Among the more likely divisions in which to generate interest in respite is the Division of Services and Intervention Research (DSIR), which takes a lifespan view of services organization, delivery, and related health economics at the individual, clinical, program, community and systems levels.

Additional information about NIMH funding opportunities may be found at https://www.nimh.nih.gov/funding/index.shtml.

National Institute of Nursing Research

The National Institute of Nursing Research (NINR), within the National Institutes of Health, emphasizes in their mission statement funding for clinical and basic research to improve palliative and end-of-life care. While the provision of respite care is a lifespan issue, there can be no argument that caregivers of persons requiring palliative and end-of-life care account for a large proportion of respite care provided throughout the country.

Although focusing primarily on nursing care per se, the NINR strategic plan states: "The Institute supports and conducts clinical and basic research and research training on health and illness across the lifespan to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care." Further, the plan acknowledges that health promotion requires exploration of behaviors at multiple levels of society, including individuals, families, clinicians, healthcare organizations, communities, and populations.

Current funding announcements and recently funded research projects focus largely on delivery of medical care. However, several of these projects focus on "community partnerships to advance research," "novel technologies for healthy independent living," "family-centered self-management of chronic conditions," and "interventions for individuals with cognitive impairment or dementia." As well, NINR has a history of reviewing and funding a small number of unsolicited proposals.

The Panel's recommendations include the examination of the provision of respite care as an adjunct to the provision of other services to the care receiver. None of the agencies listed above are known to have funded this kind of research, although NINR and NIA have co-funded research on models where the addition of respite might have great added value. For example, they co-funded research on the REACH (Resources for Enhancing Alzheimer's Caregiver Health) model, which tested strategies for helping caregivers of those with dementia manage their own stress and emotional burden. The model included education of caregivers on dementia, training on specific caregiving skills, and techniques for physical and emotional self-care. Results of this research were positive and REACH is now being implemented through both the Veterans Administration (VA) and the Administration on Aging (AoA). It seems that adding respite to the model as a concomitant service to the caregiver to help manage and reduce stress and emotional burden would be both logical and researchable.

More information about the National Institute of Nursing Research can be found at their website: http://www.ninr.nih.gov

National Institute on Disability, Independent Living, and Rehabilitation Research

The National Institute on Disability, Independent Living, and Rehabilitation Research is a major federal funding source for research. The Institute recently transitioned from the Department of Education to the Administration for Community Living (ACL). Acknowledging the enactment of the Workforce Innovation and Opportunity Act of 2014 which moved the Institute to ACL, Director John Tschida, stated,

> *"Our colleagues at ACL share the same commitment to inclusion and full societal participation for individuals with disabilities. Philosophically, we are cut from the same cloth. ACL has been an agency with a strong program and policy focus. With the addition of NIDRR, it will now have research capacity. This creates immediate opportunities for alignment where we have strong common interests, including work in the areas of family support and outcome measurement for home and community-based services" (National Institute on Disability, Independent Living, and Rehabilitation Research, undated).*

While the Institute's historical focus has been on persons with disabilities, a large proportion of caregivers receiving respite are providing care to adults and/or children with disabilities. Therefore, research findings from well-conducted studies on the impact of respite for families in which one or more family members have a disability should be reasonably generalizable to caregivers in other care-receiver defined populations.

Grant funds awarded by the Institute are done so on a competitive basis involving peer review of proposals submitted in response to announced funding priorities. In 2014, the Institute funded 61 new grants, raising the total number of ongoing grants to more than 300.

In FY 2014, the Institute funded the Family Support Research and Training Center (FSRTC) to be operated by the University of Illinois at Chicago and the National Council on Aging. The focus of the FSRTC is to enhance family support policies and programs across disabilities and the lifespan. Their first order of business is developing a national strategic plan for family support research in the U.S. The ARCH National Respite Network and Resource center is one of 22 organizations on the National Advisory Council to the FSRTC, presenting possibilities for collaboration on promotion of a respite research agenda.

More information about the National Institute on Disability, Independent Living, and Rehabilitation Research funding opportunities may be found at their website: http://www.acl.gov/Programs/NIDILRR/Grant-Opps/Grant-Forecast.aspx

National Science Foundation

The National Science Foundation (NSF) has, in the past, funded doctoral fellowships and graduate schools of varying disciplines. Occasionally, persons who have studied respite outcomes or access to respite as part of their doctoral dissertation research have received NSF fellowships. In several cases those dissertations and companion research studies have been published in scholarly journals. Some of these articles are included in the annotated bibliography conducted as part of the activity supporting the Expert Panel's deliberations.

More information about National Science Foundation funding may be found at their website: http://www.nsf.gov/funding

Administration for Community Living

While the Administration for Community Living (ACL) does not fund research, it has a history of funding competitive grants that directly support respite care through the National Family Caregiver

Support Program, and the Lifespan Respite Care Program, and, that indirectly support respite care through initiatives such as the Alzheimer's Disease Supportive Services Program. To varying degrees, each of these initiatives results in at least minimal reporting on grantee-identified outcomes. Currently, a national evaluation of the National Family Caregiver Support Program is underway. The outcome evaluation portion of the study will attempt to answer the question: *Do NFCSP caregiver experiences differ from non-NFCSP caregivers?*

Department of Veterans Affairs

The US Department of Veterans Affairs, Office of Research and Development, has an active research program focusing on caregivers of both aging veterans, and younger veterans returning from recent deployments with various war-related mental health issues (such as PTSD), illnesses, and trauma-related disabling injuries. Recent examples include the 2007 adaptation of NIA's REACH program to reduce stress on caregivers for veterans with Alzheimer's disease and other dementias. Work on this project led to the development of a home-safety toolkit intended to make home environments safer for persons with Alzheimer's disease. More recently, the 2010 Family and Caregiver Experiences (FACES) study focused on caregivers of veterans with severe injuries. The FACES study led to the development of a variety of resources for caregivers of injured veterans, including the VA's National Caregiver Support Line.

Current VA-sponsored research includes caregiver support for veterans with heart failure and those undergoing chemotherapy for cancer. The VA's future research agenda includes studying the impact on family members who immediately become caregivers after a loved one has been injured or incapacitated, and also on caregivers who provide long-term care for both war-injured and frail elderly veterans.

Information on VA-sponsored research on caregivers, including information on joining ongoing studies, and a calendar for research proposal applications and procedures for submitting proposals for VA-funded research projects can be found in the following web link: http://www.research.va.gov/topics/caregivers.cfm

NONPROFIT AND PRIVATE FUNDING OPPORTUNITIES

Federal governmental institutes and research programs are by no means the only potential sources of funding for respite research. State government, independent research centers or institutes, private foundations and corporate entities have funded respite research studies or have the potential to fund such efforts.

Patient-Centered Outcomes Research Institute

The Patient-Centered Outcomes Research Institute (PCORI) is a nonprofit, nongovernmental organization established by Congress through passage of the Patient Protection and Affordable Care Act of 2010. PCORI's mandate "...is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policymakers make informed health decisions. The goal of PCORI's work is to determine which of the many healthcare options available to patients and those who care for them work best in particular circumstances."

In a description of why PCORI was created, and in a discussion of PCORI's strategy, the website states: "For patients [in respite, this is the equivalent of the caregiver/care receiver dyad], this strategy means we must provide information about which approaches to care work best, given their particular concerns, circumstances, and preferences. For clinicians, it means we must focus on providing evidence-based information about questions they face daily in practice. For insurers, it means we must provide evidence that can help them make the best decisions on how to improve health outcomes for their members. For researchers, it means we must support studies designed to build a badly needed base of

useful evidence for improving outcomes in high-burden, hi-impact conditions."

Some of PCORI's funding opportunities relate specifically to clinical research on patients, but several funding programs may be appropriate for research on respite and perhaps other non-clinical healthcare modalities. In fact, Gail Hunt, President and CEO of the National Alliance for Caregiving and a member of PCORI's Board of Governors, and Sue Sheridan, MBA, MIM, DHL, Director of Patient Engagement for PCORI recently wrote, "At PCORI, through our comparative effectiveness research agenda, we are dedicated to learning how to work with caregivers to help them be more effective, reduce their stress, and improve their satisfaction… Through our research funding, we at PCORI are looking for ways to improve the experience and efficacy of caregivers, which would result in improving the quality of life of the patients they care for. What kinds of support are most effective? Respite care? Time off from paid work? Education and training? Online information?" (Hunt & Sheridan, 2013)

PCORI's first funding cycles included projects that studied a range of questions on caregiving. In spring, 2015, PCORI announced a funding opportunity in the area of Improving Healthcare Systems. In the announcement for this funding opportunity, PCORI states that they want to "…study the comparative effectiveness of alternate healthcare systems intended to optimize the quality, outcomes, and/or efficiency of care for patients they serve…" And recognize that healthcare systems "…encompass multiple levels (e.g., national, state and local health environments, organization and/or practice settings, family and social supports, and the individual patient) and include entities organized to deliver, arrange, purchase, and or coordinate healthcare services. PCORI seeks to fund studies that will provide information of value to patients, their caregivers, clinicians, and healthcare leaders regarding which features of delivery systems lead to better patient-centered outcomes…"

Additional information about the Patient-Centered Outcomes Research Institute funding may be found at: http://www.pcori.org/funding/opportunities

Private Foundations

Although foundations generally have a history of funding research or capacity building in particular areas of interest (and these areas are frequently stated in their charters), they also are more likely to have more flexibility to respond to emerging needs and trends than government agencies where their missions are often defined in statute. The challenge facing researchers interested in conducting research on respite care is to locate foundations where that type of research is permitted within their charters, and to convince those foundations to develop a research initiative that might have some measure of longevity, including the ability to fund a series of studies in sequence where knowledge and evidence continues to emerge with each study.

To date, foundations have not participated in respite research to the degree necessary to develop an evidence base on the efficacy of respite care. However, part of the challenge, indeed the responsibility, of those wishing to conduct research is to promote their interests to likely foundations and engage in a dialogue that excites the foundations to participate. Researchers and advocates for respite care are encouraged to identify foundations that would be likely to support respite research and to describe the Panel's recommendations in terms that align with each foundation's charter and history of previously funded research.

Corporations and Corporate Foundations

With increasing numbers of family caregivers in the workplace, employers are recognizing the need to acknowledge as well as support them to ensure their continued employment and work productivity. The cost to society and businesses of employed family caregivers who have limited support in their caregiving roles has been documented to be significant (MetLife Mature Market Institute &

National Alliance for Caregiving, 2006; MetLife Mature Market Institute, National Alliance for Caregiving, & University of Pittsburgh Institute on Aging, 2010; Witters, 2011). In addition, an increasing number of family caregivers who have primary responsibility for purchasing medical devices and supplies, pharmaceuticals, adaptive equipment, and interacting with insurance companies on behalf of the individual with a disability or chronic condition in their care are seen as important consumers. As a result, the importance and value of family caregivers is not lost on the corporate world. Corporate entities or corporate foundations are very often sponsors of caregiver survey research or studies documenting the current status and needs of the nation's caregivers. Exploring the continued role of corporate sponsorship in this context and expanding it to funding future respite research would be a worthy endeavor.

Summary

An Expert Panel of researchers, policy analysts, providers and advocates was assembled by ARCH in collaboration with the Administration for Community Living to determine the state of the art of research on respite care, for the purpose of formulating recommendations to guide future research on respite.

The Panel conducted a comprehensive literature review on research relating to outcomes attributable to respite. The review, covering the period from 2000 to 2013, revealed a body of research with few definitive studies. The majority of studies presented equivocal findings or findings of a highly parochial nature. The studies were fraught with methodological and statistical/analytical concerns. There appeared to be little commonality across studies with respect to the definition of respite, the research questions under investigation, the measures employed by researchers, or even a basic agreement on the target recipient of respite services.

The Panel established goals, objectives, and set the agenda they would follow in order to be able to make firm recommendations to ACL, and to the broader community of respite providers and researchers interested in respite, on requirements and guidelines for future research.

The Panel developed a research-oriented, inclusive definition of respite care. This definition clearly identifies caregivers as the primary recipients and beneficiaries of respite. However, it also acknowledges that others (the individual with a disability or dependent care receiver), other members of the caregiver's family, and even society at large might benefit concomitantly when a caregiver receives respite. This is most likely to occur when respite service is part of a more comprehensive service plan to the caregiver, care receiver and family. However, very few studies have been conducted to date that examine such multiple-component, multiple-recipient service plans.

The Panel also established an organizing framework for respite research based on its definition of respite. The organizing framework flows directly from the Panel's definition of respite, identifying the caregiver as the primary focus of research, and recommending that any research study should record at least one measure relating to improved well-being of the caregiver. Other measures that are relevant to the caregiver or other persons affected by the delivery of respite may be important and should be included in any research endeavor. However, improved well-being of the caregiver should be the primary focus.

The Panel constructed recommendations for focused, prospective research across the panoply of respite models. The recommendations focus on six areas that comprise general areas of weakness in the current literature and which, if executed, would provide a basis for establishing evidence for the effectiveness of respite care for improving the well-being of caregivers and others in their families and communities. The six areas include: improved research methodologies; individual, family, and societal outcomes; cost-benefit and cost-effectiveness research; systems-level changes required to improve availability, accessibility and affordability of respite care; improving respite provider competence; and, the translation of research findings into best-practice models.

The Panel reviewed the current status of funding on respite research, including the sources of funding and the magnitude of funding in relation to the need for well conducted research, and the burgeoning need for respite services as the population of family caregivers and care receivers increases, due to demographic trends in the population at large. Panel members agree that there is an urgent need for well-constructed and well-executed prospective research studies on the efficacy of respite care, and encourage potential funding sources, public or private, to consider the potential value of respite to caregivers of numerous populations of dependent children and adults, and to consider engaging with researchers to test the efficacy of respite and to determine the most programmatically effective, most cost-effective, and most cost-beneficial models.

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Appendix 1: Summary Matrix of Research Studies on Respite and Crisis Care

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
I. Studies of the Outcomes of Respite Care Targeted to Children			
1. Aniol, K., Mullins, L.L., Page, M.C., Boyd, M.L., & Chaney, J.M. (2004). The relationship between respite care and child abuse potential in parents of children with developmental disabilities: A preliminary report. *Journal of Developmental and Physical Disabilities*, 16(3): 273-285.	To examine the longitudinal impact of short-term inpatient respite care services on child abuse potential and family relationships among parents of children with developmental disabilities.	*Outcomes:* • Child abuse potential • Family relationships • Parenting stress *Key findings:* Neither respite nor short-term hospitalization + therapy resulted in significant effects on child abuse potential or family relationships, although "there were trends in the direction of reduced child abuse potential and improved family relations." At each of the three time points, "strong interrelationships" were found between the three primary outcomes measured child abuse potential, quality of family relations, and parenting stress.	• Small sample size • Sample represents parents who were specifically seeking out certain types of services • Use of self-report measure of abuse potential • Design did not allow for assessment of other mediating or moderating variables
2. Bernard-Brak, L. and Thomson, D. (2009). How is taking care of caregivers of children with disabilities related to academic achievement? *Child Youth Care Forum*, 38: 91-102.	Summarizes research conducted using longitudinal national survey data to examine the association between receipt of respite care and academic achievement of children with disabilities.	*Outcome:* Academic achievement of child with disabilities *Key findings:* Statistically significant positive association (at the 0.05 level) between receiving respite care services and academic achievement across time.	• Distinguishing characteristics between families who did and did not receive respite care services not found. • Parental satisfaction or caregiver stress not examined. • Other data relevant to family characteristics which might affect academic achievement were not collected.
3. Cole, S.A., Wehrmann, K.C., Dewar, G. and Swinford, L. (2005). Crisis nurseries: Important services in a system of care for families and children. *Children and Youth Services Review*, 27 (9): 995-1010.	To describe the program participants and services and to examine the impact of crisis nurseries for children and families in Illinois.	*Outcomes:* • Caregiver stress • Parenting skills • Caregiver perception of reduced risk of child maltreatment *Key findings:* In the first year of the study, 79% of caregivers using crisis nursery services reported decreased stress. In year 3, 90% of reported decreased stress after crisis nursery use. Similarly, 73% of caregivers in year 1 reported improved parenting skills after crisis nursery use; 96% of the year 3 group reported a similar improvement. Caregiver perception of risk of maltreatment improved from 73% of year one caregivers to 96% reporting the same decrease in year 3.	Study used only aggregate data routinely reported to IL Dept. of Human Services—case level information was protected and unavailable for analysis.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
4. **Cole, S.A. and Hernandez, P.M. (2008). Crisis nursery outcomes for caregivers served at multiple sites in Illinois. *Children and Youth Services Review*, 30: 452-465.**	To assess the effects of crisis nursery services on individual caregiver service recipients using aggregate administrative data from the Illinois Department of Human Services (IDHS).	*Outcomes:* • Caregiver stress • Risk of child maltreatment • Parental skills *Key findings:* Stress reduction, potential for abuse and neglect and parenting skills were all positively affected by use of crisis nursery services. Regression analyses found that among exit survey respondents, caregivers who were single parents, had a Caucasian child, had a higher rather than lower income, had a child four years of age and older, and those who sought crisis nursery services due to a home crisis, mental health issues, or family violence were significantly more likely to report greater stress reduction compared to caregivers with other characteristics who sought crisis nursery assistance for other reasons.	African Americans, caregiver households with income below $10,000, and those with lower education levels were underrepresented in the sample of survey respondents.
5. **Cole, S.A. and Hernandez, P.M. (2011). Crisis nursery effects on child placement after foster care. *Children and Youth Services Review*, 33: 1445-1453.**	To investigate the effect of crisis nursery services on the length of stay of infants and young children in foster care and other differences in placement outcomes when child welfare services were terminated.	*Outcome:* Child reunification with biological family members *Key findings:* Children whose families received crisis nursery services prior to foster care placement were twice as likely to be reunited with their biological families (birth or extended family members) when compared to children whose families received only foster care services. The difference in the length of stay in foster care was not statistically significant.	Other data on caregivers and child variables of interest, "such as prenatal substance exposure of the infant, pre-maturity, substitute care, and child development data" unavailable.
6. **Collins, M., Langer, S., Welch, V., Wells, E., Hatton, C., Robertson, J., Emerson, E. (2013). A Break from Caring for a Disabled Child: Parent Perceptions of the Uses and Benefits of Short Break Provision in England. *British Journal of Social Work*, 26(4): 271-83.**	To examine perspectives of parents of children with disabilities on the provision of respite services through the Aiming High for Disabled Children Short Breaks Pathfinder Programme in England. The purpose of the study was to explore how parents talk about and use the program in the context of caring for their disabled child to better understand the need for respite and how this national program can best meet those needs.	*Outcome:* Parents perceptions regarding enhanced ability to continue to provide care *Key findings:* Parents who took part in the program wanted and needed breaks from caring for their children with disabilities and the "short breaks" were crucial in helping parents with children with disabilities continue to provide care for them, and for others in their family.	Qualitative, exploratory study based on interviews with a convenience sampling of parents "not intended to be statistically representative."

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
7. **Cowen, P., Reed, D. (2002). Effects of respite care for children with developmental disabilities: evaluation of an intervention for at-risk families. *Public Health Nursing*, 19 (4): 272–283.**	To examine the effects of respite care on parental stress and the relationships between levels of respite service use, parental stress, and other parental characteristics on their children's foster care placement and maltreatment rates.	*Outcomes:* • Parental stress • Risk of child maltreatment *Key findings:* Parental stress was found to be "above the high range" before and after respite use. Comparison of matched pre-respite and post-respite PSI scores found significant decreases in Total Stress scores, Parent Domain scores and Child Domain scores, but not Life Stress Domain scores. Multiple logistic regression analysis found significant correlation between Life Stress scores and social support and occurrence of child maltreatment during enrollment. Odds of maltreatment occurring during enrollment were found to be highest for families receiving a medium amount (not high or low amounts) of respite services.	Not a true experimental design; no control group of nonserved children with developmental disabilities for comparison.
8. **Davies, B., Steele, R., Collins, J., Cook, K., and Smith, S. (2004). The impact on families of respite care in a children's hospice program. *Journal of Palliative Care*, 20 (4): 277-286.**	To describe how parents viewed the strengths and limitations of the respite component of a children's hospice program (Canuck place in Vancouver British Columbia) during its first 30 months of operation.	*Outcomes:* • Parental perceptions of enhanced child social benefits, learning, and independence; • Caregiver reports of benefits including freedom, time for themselves, learning opportunities *Key findings:* Parents of ill children greatly value respite care and perceive a range of benefits to the child and siblings, including the opportunities for relaxation and enjoyment, learning, socialization, and independence. Parental benefits included: a break from routine, freedom from responsibilities and worries, time for themselves and other family members, and learning from staff and talking to other parents with children at the hospice. Parents also reported valuing the opportunity to prepare for child's death. While majority of parents were satisfied with the respite experience, some said they did not receive enough time, families from rural areas cited time and transportation barriers, and some parents wanted more flexibility in respite scheduling.	Limitations of exploratory qualitative research, but none cited by the authors.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
9. **Harper, A., Dyches, T.T., Harper, J., Roper, S.O., 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): 2604-2616.	To examine the relationship between receipt of respite care and quality of marriage for couples with a child with autism spectrum disorders (ASD), with wife and husband stress and daily uplifts as potential mediating variables.	*Outcomes:* • Uplift and parental stress • Marital quality *Key findings:* Number of hours of respite care was positively related to improved marital quality for both husband and wives, such that a one hour increase in weekly respite care was associated with a one-half standard deviation increase in marital quality. This relationship was significantly mediated by perceived daily stresses (hassles) and uplifts in both husbands and wives. There was also a direct association found between more respite care and increased uplifts and reduced stress; increased uplifts were associated with improved marital quality; and more stress was associated with reduced marital quality for both wives and husbands. The authors also found that having more than one child with ASD was associated with greater stress, reduced relationship quality, and daily uplifts	• Not a true experimental design. • Participants were not randomly selected. • Population may not generalize to other geographical areas.
10. **Mandell, D.S., Ming Xie, M.S., Morales, K.H., Lawer, L., McCarthy, M., and Marcus, S.C. (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.	To examine whether increasing outpatient respite and therapeutic services resulted in reduced use of psychiatric hospitalizations among children with autism spectrum disorders (ASDs).	*Outcome:* Risk of psychiatric hospitalization *Key findings:* 2.4 percent of the sample experienced at least 1 hospitalization during the study year associated with a diagnosis of ASD. Analysis of the adjusted odds of hospitalization associated with respite use in the preceding 60 days found that "each $1000 increase in respite expenditures in the preceding 60 days was associated with an 8% decrease in the odds of hospitalization." No association was found between use of therapeutic outpatient services and risk of hospitalization.	• Accuracy of Autism Spectrum Disorder diagnosis in Medicaid claims is unknown. • Process used for categorizing procedure codes has not been validated.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
11. McConkey, R., Gent, C., and Scowcroft, E. (2013). Perceptions of effective support services to families with disabled children whose behavior is severely challenging: A multi-Informant study. *J Appl Res Intellect Disabil*, 26 (4): 271-83.	To identify how "specialist short break and community support services programs" administered by Action for Children in three United Kingdom cities were perceived to meet the needs of families whose children are disabled and have severely challenging behaviors. "Family support services from these programs consist mostly of "overnight breaks in a small residential home for 2-7 days at a time." In addition, "staff will come to the family home and accompany the child at activities within the local community while also providing advice and training to the family in managing behaviors."	*Outcome:* Family perceptions of family and child benefits *Key findings:* Emergence of core themes: 1) complexity of family issues and perceived complexity of services available from different agencies; 2) negotiations required to implement; 3) positive relationships forged between program staff and families and the children; 4) benefits to children and families; and 5) concerns about planning for an uncertain future.	• Lack of a longitudinal perspective • Absence of quantitative measurement of changes in children and parents
12. Meltzer, J. and Bennett Johnson, S. (2004). Summer camps for chronically ill children: a source of respite care for mothers. *Children's Healthcare*, 33 (4): 317-331.	To examine the psychosocial benefits for mothers of a one-week overnight summer camp for chronically ill children. This authors note that "this study is the first to empirically examine camp as overnight respite care for mothers of children with chronic illnesses. In addition, the large sample size and longitudinal design provide a new contribution to the empirical literature on the benefits of respite care."	*Outcomes:* • Maternal caregiving demands • Maternal perception of overload • Maternal distress and depression-anxiety levels *Key findings:* Level of mothers' caregiving demands were relieved during camp, but returned to pre-camp levels once the child returned home. Despite this return to pre-camp levels of demands, mothers' perceived overload level decreased significantly below baseline for children with all types of illnesses during camp and remained at levels lower than baseline after camp. While maternal distress and depression-anxiety levels were also reduced during camp, they were not significantly below baseline even one week after camp.	• Measures of caregiving demands and psychological factors based on mothers' self-reports alone. • Study design did not include control group.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
13. **Mullins, L.L., Aniol, K., Boyd, M. L., Page, M.C., and Chaney, J.M. (2004). The influence of respite care on psychological distress in parents of children with developmental disabilities: a longitudinal study.** *Children's Services: Social Policy, Research, And Practice*, 5 (2): 123-138.	To examine the benefits of inpatient respite services for children with developmental disabilities and their parents.	*Outcomes:* • Parental psychological distress • Parenting stress • Child functional ability *Key findings*: 1) parental psychological distress was significantly lower at discharge and 6-month follow-up for the respite group and equal to that of the comparison group; 2) parenting stress was significantly lower at discharge, but at 6-month follow-up had returned to admission levels for both groups; and 3) both groups of children demonstrated improved functional ability from admission to discharge.	• Study design did not include control group. • Parental distress measures relied solely on self-reports. • Data sources did not allow for measurement of mediating or indirect factors.
14. **Olsen, R. and Maslin-Prothero, P. (2001). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation.** *Journal of Advanced Nursing*, 34 (5): 603-610.	To examine parent responses and effects of a nurse-led in-home respite support service for parents of young children with complex health care needs.	*Outcome:* Family well-being *Key finding:* While the majority of the 18 families described moderate or significant improvements in family well-being over the study period, only 5 of those said respite played a role.	Limitations of exploratory qualitative research

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
15. **Owens-Kane, Sandra. (2007). Respite Care: Outcomes for Kinship and Non-Kinship Caregivers. *Journal of Health & Social Policy*, 22 (3/4): 85-99.**	To examine the outcomes associated with use of formal respite care services by kinship, foster, and adoptive caregivers of children with special needs involved in the child welfare system in a large urban area of a western state.	*Outcomes:* • Caregiver stress • Time for attending to caregiver's personal health needs • Attitude toward children • Feelings of objective burden • Caregivers' feelings of support and ease • Caregiver frustration • Perception of family member relationships *Key findings:* Majority of caregivers reported reduced stress, increased time for attending to own health needs, improved positive attitude toward their children, a significant increase in "feeling at ease and supported," and significantly decreased feelings of objective burden after receiving respite care. While most caregivers reported feeling frustrated about caring for their special needs child prior to respite, they were significantly less frustrated after receiving respite. At the same time, the authors found that caregivers felt less equipped to care for their child after receiving respite care and there was a statistical reduction in the number of caregivers who perceived that their family members got along well.	• Lack of a comparison group of caregivers who did not receive respite care • Lack of standardized scales measuring outcomes such as caregiver depression levels and other psychiatric symptoms of the caregivers
16. **Pascuet E., Cowin L., Vaillancourt R., Splinter W., Vadeboncoeur C., Dumond L.G., Ni A., and Rattray, M. (2010). A comparative cost-minimization analysis of providing pediatric palliative respite care before and after the opening of services at a pediatric hospice. *Healthcare Management Forum*, 23 (2): 63-66.**	To analyze changes in costs for the Children's Hospital of Eastern Ontario (CHEO) (a regional pediatric health care system in Canada) resulting from the provision of palliative hospice respite care for children with life-limiting illness (provided at a new 8-bed pediatric residential hospice adjacent to the hospital, called Roger's House).	*Outcomes:* • In-patient and outpatient hospital days • Emergency room use • Hospital costs *Key findings:* Mean number of monthly hospital inpatient days and outpatient days significantly decreased after the child's first respite visit, though number of monthly emergency room visits was not affected. The key study finding was: a mean decrease in the monthly in-patient hospital costs attributable to lower costs of respite, calculated as a $4,252 in savings per month per patient.	• Lack of standardized cost calculation • Cost for care at home not considered. • Comparisons of quality of care not included.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
II. Studies of the Outcomes/impacts of Respite Care Targeted to Older Adults			
1. Carretero, S., Garces, J., and Rodenas, F. (2007). Evaluation of the Home Help Service and its impact on the informal caregiver's burden of dependent elders. *Int J Geriatr Psychiatr*, 22 (8): 738-49.	To describe the characteristics of users and services received from and satisfaction with the Home Help Service (HHS), a respite program serving elders in Comunidad Valenciana in Spain, and to measure the impact of Home Help Service use on the burden of care among informal caregivers.	*Outcomes:* • Burden of care • Self-perceptions of caregiving competence *Key findings:* Although mean burden overall was higher among carers of non-HHS users than for carers of HHS users, difference was not statistically significant. Both groups have a "rather strong perception of the negative repercussions of caregiving," with no significant differences between the two groups. Both groups report low feelings of incompetence to continue in their caregiving role, with carers of non-HHS users having significantly higher feelings of incompetence.	None cited.
2. Empeño, J., N.T. Raming, S.A. Irwin, R.A. Nelesen, and L.S. Lloyd. (2011). The hospice caregiver support project: Providing support to reduce caregiver stress. *Journal of Palliative Medicine*, 14 (5): 593–597.	To measure the impact and level of hospice respite benefits used in the Hospice Caregiver Support Project, designed to provide in-home support services to unpaid, primary, at-home informal caregivers of hospice patients.	*Outcomes:* • Caregiver stress • Caregiver safety and comfort *Key findings:* After receiving respite services, mean self-reported caregiver stress levels decreased by 52%. Most common reported benefit was that respite "allowed the caregiver to get out of the house or take a break." Other benefits cited by multiple caregivers included: "relieved stress", "allowed caregiver to sleep/relieved exhaustion", and "felt safer/comforted." Fifteen of the 23 caregivers provided mixed (positive and negative) or negative comments about the quality of the service provided.	None cited.
3. Fernia, E.E., Zarit, S.H., Stephens, M.A., and Greene, R. (2007). Impact of adult day services on behavioral and psychological symptoms of dementia. *The Gerontologist*, 47 (6): 775-788.	To examine short-term (2 month) effects of adult day services (ADS) participation by individuals with dementia on their behavioral and psychological symptoms of dementia (BPSD) immediately after ADS use and on days when not using ADS.	*Outcomes:* • Care recipient nighttime sleep problems • Care recipient depressive symptoms • Care recipient agitated behavior *Key findings:* ADS use group showed significantly greater decline in duration of night-time sleep problems than comparison group, although the occurrence of those problems was similar in both groups. Effects for the ADS group on duration of sleep problems were stronger on ADS use days vs. non ADS use days. No significant cross-group differences were found for either occurrence or duration of depressive symptoms or agitated behavior. However, within-group analysis for the ADS group found that occurrence of depressive symptoms and incidence of agitated behaviors were all significantly lower over time on ADS days compared with non-ADS days.	• Short-term nature of study • Lack of reporting on specific domains or missing data from caregiver logs • Limitations of quasi-experimental design to evaluate treatment options

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
4. **Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M-A.P. Townsend, A., and Greene, R. (2003). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. International *Journal of Geriatric Psychiatry*, 18 (1), 55–62.**	To determine whether adult day service (ADS) use and its related reductions in primary caregiving hours would positively impact caregivers' negative emotional appraisals (i.e. exhaustion and fatigue, feeling of being trapped in the caregiving role) and levels of psychological distress.	*Outcomes:* • Caregiver negative emotional appraisals (i.e. exhaustion and fatigue, feeling of being trapped in the caregiving role) • Caregiver psychological distress *Key findings:* Caregivers using ADS who reported decreases in hours spent helping with memory problems were more likely to report decreases in "role overload" than comparison group of non-ADS-users. An opposite interaction effect occurred for change in worry and strain among a subgroup of non-ADS users: non-ADS users who reported greater decreases in relative's ADL dependencies over three-month study period were more likely to report decreases in worry than were ADS users.	• Due to quasi-experimental design, unknown variations in treatment and control group characteristics at baseline may have influenced the robustness of the findings. • Reliance on self-reporting may have increased potential for recall error.
5. **Gitlin, L.N., Reever, K., Dennis, M.P., Mathieu, E., and Hauck, W.W. (2006). Enhancing quality of life of families who use adult day services: short- and long-term effects of the Adult Day Services Plus Program. *The Gerontologist*, 46 (5): 630-639.**	To examine the short and long-term effects of the Adult Day Service Plus (ADS Plus) program, which integrates care management within usual adult day center services with the goal of "helping family caregivers develop problem-solving and coping skills, improve social and instrumental support, and enhance perceived competence in managing the difficult behaviors of their impaired elder."	*Outcomes:* • Caregiver depression • Caregiver burden • Caregiver confidence in behavior management • Caregiver well-being • Time for healthy behaviors • Nursing home placement *Key findings:* At 3-month follow-up, caregivers of ADS Plus participants reported less depression, improved confidence managing behaviors, and enhanced well-being compared to the basic ADS group. Long term effects analyses (6 and 12months) showed that, compared with controls, ADS Plus participants continued to report less depression and enhanced confidence managing behaviors. Additionally, mean use of ADS services was 37 days longer for ADS Plus participants than controls and ADS Plus users had fewer nursing home placements than those who received basic ADS.	• Unable to control for potential confounders such as the quality and number of staff-family interactions that may have differed across sites. • Attrition rate was substantially different between groups, which may have impacted the analyses of long-term effects.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
6. **Hancock, P.J., Jarvis, J.A., and L'Veena, T. (2007). Older Carers in Ageing Societies: An Evaluation of a Respite Care Program for Older Carers in Western Australia.** *Home Health Care Services Quarterly*, 26 (2): 59-84.	To describe the Older Carers Program in Western Australia administered by the Australian Red Cross and whether it met its stated objectives and carried out its intended activities. This 22-month older program at the time of the research was designed to provide help for older carers of adults with disabilities through home visits, development of integrated care plans, encouragement of regular planned respite, referrals to needed service providers, and access to a database of volunteers.	*Outcomes:* • Caregiver satisfaction • Self-perceptions of caregiving role *Key findings:* Older carers reported most useful aspects of the program were: 1) visit/support from program staff, 2) respite, and 3) information. Overwhelming majority of older carers provided high positive rating on quality of program and satisfaction, and said program had a positive impact on role as caregiver. However, rural older carers reported lower satisfaction with the program, lack of respite services, staffing problems, and only 28% of carers in rural areas said their needs had been met, compared to 80% of the metropolitan carers.	Small sample size
7. **Lee, D., Morgan, K., and Lindesay, J. (2007). Effect of institutional respite care on the sleep of people with dementia and their primary caregivers.** *J Am Geriatr Soc*, 55 (2): 252-8.	To evaluate the impact of two weeks of institutional respite care provided in four community hospital units in East Midlands, United Kingdom on sleep patterns of patients with dementia who normally live at home.	*Outcomes:* • Care recipient and caregiver sleep patterns *Key findings:* For caregivers, total sleep time per night increased significantly, subjective sleep quality improved, and total time in bed per night increased during respite. Comparing caregivers who shared a bedroom with the patient to those who did not, the former group showed less change in total sleep. For patients, respite was associated with increased sleep onset latency, reductions in total sleep time per night, and weakening of circadian activity rhythm compared to baseline. All outcomes were not sustained	• Randomized, controlled trial could provide more vigorous test of respite care effect. • Short follow-up period • Absence of serial measures of caregiver mood

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
8. LaVela S.L., Johnson, B. W., Miskevics, S. and Weaver, F. M. (2012). Impact of a multicomponent support services program on informal caregivers of adults aging with disabilities. *Journal of Gerontological Social Work*, 55: 160-174.	To evaluate the impact of a multi-component support program for caregivers of adults with aging Veterans with disabilities, implemented through a Veterans Administration site in Tampa, Florida. The program included 24-hr in-home respite care, caregiver group support, and education/ skills training. Caregivers had the option to receive services for 14 consecutive days.	*Outcomes:* • Caregiver service satisfaction • Caregiver mental and physical health • Perceived positive aspects of caregiving • Caregiver burden *Key findings:* Caregiver mental health improved significantly from pre to post-test. While mean caregiver burden did not show statistically significant improvement, bivariate analyses comparing "clinically meaningful improvement in burden (4 points on the Zarit scale) versus no clinically meaningful improvement showed that a statistically greater proportion of women experienced a clinically meaningful improvement in caregiver burden than women who did not." Multivariate analyses found that worse physical health of the care recipient at program onset was significantly associated with the caregiver experiencing a clinically meaningful improvement in burden. There was also a trend toward a clinically meaningful improvement in burden for caregivers who had provided care for a long duration of time. Other measures did not differ significantly from pre to post-test.	• Lack of control group • Small sample size • Short follow-up period
9. Lund, D.A., Utz, R., Caserta, M.S., and Wright, S.D. (2009). Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology*, 28 (1): 109-131.	To describe and analyze consistency between family caregivers' desired and actual use of their time while their relatives were receiving adult day services. The study then sought to examine the relationship between this level of consistency (or inconsistency) and caregivers satisfaction with respite time use, their feeling of burden, depression and satisfaction with caregiving.	*Outcomes:* • Satisfaction with respite time-use • Caregiver burden • Caregiver depression • Caregiver satisfaction with caregiving *Key findings:* A strong association with respite satisfaction and how consistent caregivers were in doing activities they wanted to do during respite time. Caregivers who were very satisfied with their respite time also had significantly lower depression scores than those who were not very satisfied. Likewise the high consistency group (i.e. highly consistent in actual vs. desired activities) had significantly lower depression scores compared to those who were not as consistent in their time-use during respite. Depression scores were highest among group of caregivers who had both low consistency in use of respite time (actual vs. desired) and low satisfaction with their respite time.	• One-week data collection period • Small, homogenous sample size • Limited age of caregivers included

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
10. Mavall, L. and Thorslund, M. (2007). Does day care also provide care for the caregiver? *Arch Gerontol Geriatr*, 45 (2): 137-50.	To investigate whether day care programs in Sweden positively impacted caregivers of relatives with dementia, with specific regard to feelings of worry, burden, overload and depression, physical difficulties, and psychological well-being.	*Outcomes:* • Caregiver's perceptions of role captivity, worry, burden and overload • Caregiver depression • Caregiver physical difficulties • Caregiver psychological well-being *Key findings:* Feelings of role captivity, worry and overload significantly decreased for all groups of caregivers after 4 months of day care. Continuation of day care had no significant association with changes in the depression scores for all caregivers; however, among subgroup of caregivers who did not reside with family member with dementia, depression levels were reduced among those who continued with day care compared to those who discontinued day care.	Small sample size
11. Neville C.C. and Byrne, G.J. (2006). The impact of residential respite care on the behavior of older people. *Int Psychogeriatr*, 18 (1): 163-70.	To examine the impact of residential care on disruptive behavior displayed by older adults, particularly those with dementia.	*Outcome:* Short-term disruptive behavior in individuals receiving residential respite care *Key finding:* Respite had a short-term impact on the frequency of disruptive behavior in older people with dementia, but no enduring impact on behavior.	• Homogenous sample with no ethnic diversity • Possible inconsistency between evaluators • Not a randomized controlled trial
12. Perry, J. and Bontinen, K. (2001). Evaluation of a weekend respite program for persons with Alzheimer Disease. *Can J Nurs Res*, 33: 81–95.	To explore family caregivers' experience with a pilot weekend respite program in western Canada. The program provided respite care in a homelike environment for persons with Alzheimer's Disease.	*Outcomes:* • Self-reports of improved caregiver well-being • Self -reports of relief from stress and worry *Key findings:* Through qualitative assessment, study found that caregivers frequently reported that respite provides time for them to maintain their own health, maintain family and social relationships, catch up on sleep and rest, and relief from stress and worry. Caregiver relief was found to be largely tied to their perception that family members enjoyed the respite care experience and that they were safe and comfortable there, although transitioning family member to the program was difficult.	• Small sample size • Lack of generalizability

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
13. Schmitt, E.M., Sands, L.P., Weiss, S., Dowling, G., and Covinsky, K. (2010). Adult Day Health Center Participation and Health-Related Quality of Life. *The Geronotologist*, 50(4): 531-540.	To assess the association between participation in an adult day health center (ADHC) in the San Francisco Bay Area and quality of life for the participants who suffer from multiple chronic conditions and functional limitations.	*Outcome:* Care recipients' quality of life *Key findings:* Adult Day Health Care (ADHC) participation was associated with perceived reductions in the extent to which participants' physical and emotional health problems affected their regular daily activities. Secondary analyses showed that changes in daily physical functioning, depressed affect, or cognitive functioning did not explain the improvements found in the two quality of life domains for the ADHC participants.	• Not a randomized controlled trial • Although many factors likely to predict quality of life were measured and controlled, unmeasured differences, such as aspects of the individuals living situation or receipt of services other than home care, could have over- or under-estimated the increases in quality of life attributable to ADHC participation.
14. Smeets, S.M., vanHeugten, C.M., Geboers, J.F., Visser-Meily, J.M., Schepers, V. P. (2012). Respite care after acquired brain injury: The well-being of caregivers and patients. *Arch Phys Med Rehabil*, 93: 834-41.	To investigate caregiver and patient satisfaction with respite care provided by adult day-care centers for individuals with acquired brain injury (ABI) in the Netherlands, and patient and caregiver factors related to caregiver well-being.	*Outcomes:* Caregiver and patient satisfaction with respite and effects on life satisfaction and emotional functioning and caregiver well-being. *Key findings:* Satisfaction with the day-care activity center care was high for caregivers and patients. Caregiver satisfaction with care was found to be unrelated to the measures of life satisfaction or emotional functioning for either caregivers or patients. Caregiver well-being was positively associated with a high sense of mastery over one's life among caregivers and patients and low measures of passive coping among the patients, but not with the patient's acquired brain injury (ABI) or the day-care activity center characteristics.	• Lack of information on patient or caregivers use of other services • Cross-sectional study design limits generalizability • Purposive exclusion of aphasia patients from the study sample • Caregiver and patient received questionnaires in the same envelope which may have influenced their responses.
15. Tompkins, S.A. and Bell, P.A. (2009). Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an Alzheimer's caregiver. *Journal of Geronotological Social Work*, 52: 89-104.	To examine whether and how receipt of a psychoeducational training program called the Savvy Caregiver Program (SCP), receipt of a respite voucher-type grant, and receipt of a combination of both services impacted caregivers and their use of other support services beyond the intervention. (Both types of interventions were conducted by the Alzheimer's Association Colorado Chapter.)	*Outcomes:* • Caregiver depression • Caregiver health status • Support service use and support group usage *Key findings:* Average caregiver depression scores decreased significantly regardless of treatment group. Overall caregiver health significantly improved with significant correlations between overall health and average depression scores. Support service use and support group usage increased among participants in the respite grant group and the group that participated in both SCP and the respite grant program. Participants in the combined treatment group showed positive findings for the three outcomes with no significant advantage over the SCP or respite grant group regarding depression scores or support group usage.	• Absence of random assignments to the treatment groups • Absence of a control group • Homogenous sampling (lack of ethnic diversity) • Constraints in the format of the questions used at intake because they were questions required by the federal grant program funding these interventions

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
16. **Utz, R.L., Lund, D.A., Caserta, M.S., and Wright, S.D. (2012). The Benefits of Respite Time-Use: A Comparison of Employed and Nonemployed Caregivers. *Journal of Applied Gerontology*, 31: 438-461.**	To describe and compare how employed and non-employed caregivers of older adults spend their time and are satisfied with their use of time while their family members are in adult day respite center care. The benefits caregivers received from their respite time use as well as how they thought they might be able to use this time more effectively was were described and compared.	*Outcomes:* Satisfaction with respite time-use of employed and nonemployed respite users *Key Findings:* Employed caregivers were generally more satisfied with respite time-use than nonemployed respite users and employed caregivers were also more likely to do activities that they desired to do. On the other hand, 40% of the nonemployed group felt they could have used their respite time more effectively. Nonemployed caregivers wanted to use their respite time better to reduce feelings of "wasted time and opportunity." Employed and nonemployed caregivers reported similar levels of caregiver burden. As a result, caregiver burden did not confound the relationship between employment status and time-use patterns during respite.	• Small sample size • Lack of generalizability Strength of study's qualitative and exploratory nature including personalized accounts of caregivers' time-use patterns and perceptions of the benefits of respite time should be noted.
17. **Warren, S., Kerr, J.R., Smith, D., and Schalm, C. (2003). The impact of adult day programs on family caregivers of elderly relatives. *J Community Health Nurs*, 20(4): 209-21.**	As part of a broader evaluation of 14 adult day programs in Alberta, Canada, study sought to measure the impact of the programs on the caregivers of elderly relatives and the degree of caregiver satisfaction with the program.	*Outcomes:* • Caregiving burden • Caregiver quality of life • Caregiver perceived health • Caregiver opinion on institutionalization • Caregiver program satisfaction *Key findings:* Caregiver burden, quality of life, and perceived health status remained stable over time. Caregivers' opinions on institutionalization remained negative and satisfaction with the programs high. Caregivers reported that client socializing and improved health were what they liked best about the program, followed by respite for themselves.	• Lack of a control group limits generalizability • Some tools used to measure family caregiver outcomes were not sensitive enough to detect improvements over time. • Low moderate burden scores, moderate quality of life scores and good health scores of caregivers at baseline may not have allowed for room for improvements sufficient to detect significantly.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
18. **Whitlatch, C.J. and Feinberg, L.F. (2009). Family and Friends as Respite Providers, *Journal of Aging & Social Policy*, 18 (3-4): 127-139.**	To compare the in-home respite experiences of caregivers using the direct pay mode of California's Caregiver Resource Centers (CRCs) respite program to pay family or friends to provide respite with caregivers who hired respite aides from a homecare or other agency. This is a consumer-directed model that gives caregivers vouchers to hire and manage their own respite workers.	*Outcomes:* • Caregiver satisfaction with consumer-directed respite • Caregiver health status • Respite cost comparisons *Key findings:* Caregivers who hired family and friends as respite aides were found to be very similar in their demographic characteristics and levels of mental health and distress to caregivers who hired respite aides from agencies, with a few exceptions: caregivers who hired family and friends were slightly more likely to report worse current health than five years previously, to report "health problems getting in the way of doing things," to have slightly higher levels of satisfaction with the respite assistance they received, and to have exercised more control and choice in the day-to-day management of their in-home respite aides. The study findings also indicate that hiring family and friends was less costly per hour of service than hiring service providers.	None cited.
19. **Zarit, S.H., Kim, K., Femia, E.E., Almedia, D.M., Savla, J. and Molenaar, P.C.M. (2011). Effects of Adult Day Care on Daily Stress of Caregivers: A Within-Person Approach. *J Gerontol B Psychol Sci Soc Sci*, 66 (5): 538–546.**	To examine the effects of adult day service (ADS) programming in New Jersey on exposure to and emotional response to stressors for family caregivers of individuals with dementia.	*Outcomes:* • Caregiver exposure to stressors • Behavior problems and sleep patterns for the person with dementia *Key findings:* After one and two months of ADS use, mean total exposure of caregivers to stressors stayed approximately the same on non-ADS days, while exposure on ADS days went down from just over 2 hours each day to 75 minutes at one month and to 52 minutes at two months. Most of the difference was accounted for by the time the person with dementia was away from the caregiver, but there were also significant reductions in behavior problems for the person with dementia during the evening and improved sleep immediately following ADS use. Additionally, the average reported length of caregiver upset per behavior problem decreased significantly across all days over the two-month period.	• Small sample size • Sample had higher levels of education and income than the population of the state as a whole • Daily assessments did not include measures of caregivers' own emotional distress or health symptoms • Effects of order of ADS and non-ADS days or lagged or cumulative effects of ADS use were not able to be tested *Strengths:* "within-person withdrawal design" is a strong study design for examining the effects of an intermittent intervention such as respite.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
20. Zarit, S.H., Kim, K., Femia, E.E., Almedia, D.M., and Klein, L.C. (2013). The Effects of Adult Day Care Services on Family Caregivers' Daily Stress, Affect, and Health: Outcomes from the Daily Stress and Health (DaSH) Study. *Gerontologist*, 54(4), 570-579.	To examine the effects of adult day service (ADS) programming in New Jersey on reported daily stressor exposure, affect, and health symptoms of caregivers of individuals with dementia (IWD).	*Outcomes:* • Caregiver exposure to stressors • Caregiver depressive symptoms, anger, and anxiety symptoms • Caregiver health symptoms *Key findings:* Caregivers reported significantly lower care-related stressors on ADS days compared with non-ADS days. Caregivers' experiences of noncare stressors were significantly higher on ADS days as were their experiences of positive events on ADS days. Both types of stressors were associated with more depressive symptoms, anger, anxiety and health symptoms. Positive events were associated with fewer of these daily affects and health symptoms. Among caregivers who reported higher care-related stressors, ADS use had a buffering effect on depressive symptoms.	Potential selection bias in a study sample that includes only volunteers who already used ADS. *Strengths:* "within-person withdrawal design" and measures of daily ADS use and daily stress, affect and health are components of a strong study design for examining the effects of an intermittent intervention such as respite.
21. Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almedia, 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.	To examine the effects of adult day service (ADS) use on caregiver relatives living with individuals with dementia (IWD) on the caregivers' level of a salivary biomarker (DHEA-S) of stress reactivity as well as the association of the biomarker levels with variability in reported symptoms of positive mood and depression.	*Outcomes:* • Caregiver care related stressors measured by salivary biomarker of stress reactivity • Association of the biomarker levels with variability in reported symptoms of positive mood and depression. *Key findings:* Care-related stressors were lower on days the IWD attended ADS and that ADS use was associated with increased DHEA-S levels on days after ADS use (whether or not the person used ADS or not on those "days after ADS use"). The effect size was small but significant. They also found that days with positive moods were associated with the higher daily DHEA-S, though daily ADS use was not associated with reported positive moods. At the same time, total ADS days used was significantly related to higher mean positive moods. Daily depressive symptoms were not associated with daily DHEA-S.	• Volunteer sample who were already using ADS may be selectively those who experience a positive response to ADS • Lack of measurement of duration of caregiver exposure to stressors • Short study period • Predominance of women in the sample *Strengths:* • "Within-person withdrawal design" is a strong study design for examining the effects of an intermittent intervention such as respite. • This is "one of the few studies demonstrating an effect of a caregiving intervention on physiologic indicators of stress."

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
III. Studies of the Outcomes of Respite Targeted to Adults with Developmental Disabilities			
1. **Caldwell, J. and Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme.** ***Journal of Intellectual Disability Research*****, 47 (4/5): 252-366.**	The study had two main objectives. First, it sought to explore associations between the amount of family control in the management of paid respite/ personal assistance services for families of individuals with developmental disabilities (DD) and five outcomes: caregiving burden, caregiving satisfaction, caregiving self-efficacy; satisfaction with the service, hours of weekly employment of the mother, and community involvement of the individual with DD. Second, the study sought to compare outcomes for families who hired relatives to provide respite/personal assistance to those who hired non-relatives.	*Outcomes:* • Caregiving burden • Caregiving satisfaction • Caregiving self-efficacy • Maternal employment • Community involvement of the individual with DD *Key findings:* Statistical associations were found between more control by families in the management of their respite/personal assistance services and 1) increased service satisfaction; 2) increased community involvement of individuals with DD; and 3) increased employment of mothers.	Low reliability of measures for caregiving self-efficacy and community involvement.
2. **Chou, Y.C., Tzou, P.Y., Pu, C.Y. Kroger, T. & Lee, W.P. (2008). Respite care as a community care service: Factors associated with the effects on family carers of adults with intellectual disability in Taiwan.** ***Int Journal of Intellectual and Developmental Disability*****, 33 (1): 12-21.**	To describe the use of publicly funded respite care in Taiwan, caregivers' satisfaction with those services, and measure the effects of respite use on caregivers' burden and factors that may contribute to positive effects of respite.	*Outcomes:* • Caregiver level of social support • Caregiver psychological stress level • Caregiver life satisfaction • Caregiver overall burden • Family interaction/relationships • Access to information and resources *Key findings:* After using respite care, majority of participants responded that their life was 'somewhat better' or 'very much better' for each outcome with the most common improvements in social support, psychological stress, life satisfaction, and overall burden. Respite users who reported having a religious belief and lived in a metropolitan city were more likely to have overall burden of care relieved, improved family interaction, and better access to information and resources than users who had no religious belief and lived in non-metropolitan areas.	Caregivers interviewed only once to collect pre and post-respite information, with reported level of burden prior to respite use based on their ability to recall that information.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
IV. Literature Reviews/Meta-Analyses of Respite Care Studies			
1. **Ingleton C, Payne S, Nolan M, & Carey I. (2003). Respite in palliative care: a review and discussion of the literature.** *Palliat Med*, 17(7):567-75.	To consider the definitions and assumptions that underpin the term respite and its impact on the physical, psychological and social outcomes of carers in palliative care contexts.	*Outcomes:* Carers physical, psychological and social outcomes *Key findings:* No empirical studies assessing the effects of specialist palliative respite care intervention on carer well-being. Insufficient evidence to draw conclusions about the efficacy of offering respite care to support carers of patients with advanced disease.	• Definitional issues • Applicability of findings from the wider care-giving literature • Pre-eminence of stress coping/burden model Conceptual and methodological problems with studies on the effects of palliative respite care on carer well-being: • Applying outcome indicators to evaluate the effectiveness of respite in palliative care necessitates clear definitions of the content and model of services, yet there is little known about these features beyond that respite is delivered in a wide range of settings and there are wide variations in the pattern of specialist and nonspecialist and voluntary and statutory services. • Research in the family care giving literature has focused on the negative or pathological aspects of care to the relative while disregarding sources of satisfaction and reward. • Little attention has been devoted to examining the impact of respite on the carer rather than the patient.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
2. **Jeon, Y., Brodaty, H., Chesterson, J. (2005). Respite care for caregivers and people with severe mental illness: Literature review.** ***Journal of Advanced Nursing*****, 49 (3): 297-306.**	To review research literature on respite for people affected by severe mental illness (SMI) and identify implications for nursing practice.	*Outcomes:* • Caregiver satisfaction with respite • Impact on family caregivers • Impact on care recipients • Impact on long-term institutionalization of care recipients. *Key findings:* Significant lack of controlled empirical studies examining the effectiveness of respite care services for people with SMI and their families was found. Evidence of respite effectiveness for respite for the elderly on these outcomes is inconclusive.	Despite the large number of studies on respite for caregivers of persons with dementia and Alzheimer's disease, "Studies examining outcomes and effectiveness of respite series are either scarce or lack rigor. The authors stress that the differences in respite care needs between carers of people with SMI and those with dementia have not been adequately addressed in respite care research to date."
3. **Mason A., Weatherly H., Spilsbury K, Golder S., Arksey H., Adamson, J., and Drummond M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people.** ***J Am Geriatr Soc*****, 55 (2): 290-9.**	To conduct a systematic review of the literature on the effectiveness and cost-effectiveness of community-based respite care for caregivers of frail older people. The authors found 22 effectiveness and 5 cost studies that met inclusion criteria. Of the former group, 10 used randomized controlled study designs, were quasi-experimental studies, and 5 were uncontrolled studies included because no controlled study was identified for the type of respite or patient group studied. Of the cost studies, 2 conducted cost-effectiveness analysis and 3 analyzed costs or cost differences of respite vs. different or no care.	*Outcomes:* • Cost-effectiveness • Caregiver burden • Caregiver mental and physical health • Caregiver satisfaction with respite *Key findings:* Evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn. For all types of respite, effects on caregiver burden and caregiver mental and physical health were generally small, with better controlled studies finding modest benefits only for certain subgroups and "no reliable evidence that respite care delays entry to residential care or adversely affects frail older people." At the same time, the authors found many studies that reported high levels of caregiver satisfaction with the respite they received.	"The existing evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn" for two principal reasons. First, there are serious problems with the methodological quality of many studies underpinning the evidence base…. Second, where better-quality evidence exists, the implications for other populations are unclear. Furthermore, they note that the "relative effects found in these studies are highly dependent on how the intervention and comparator (non-intervention) services were configured, resourced, delivered, and accessed."

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
4. **Pinquart, M. and Sorensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18:4, 577-595.**	This meta-analysis sought to improve upon findings from extant evaluations of various interventions serving dementia caregivers by pooling the samples and analyses of intervention effects from studies that generally use small sample sizes and measuring more reliable mean effects.	*Outcomes:* • Caregiver burden • Caregiver depressive symptoms Indicators of positive subjective well-being (e.g. life-satisfaction, happiness) • Knowledge and/or coping abilities of the caregiver • Care receiver symptoms or outcomes • Institutionalization *Key findings:* Interventions had statistically significant, but small immediate effects on caregiver burden, depressive symptoms, subjective well-being, caregiver abilities/knowledge, and care receiver symptoms. Studies with follow-ups showed significant positive effects on caregiver burden, depressive symptoms and ability/ knowledge after 11 mos. No significant effect of intervention was found on risk of institutionalization. Studies on respite interventions had small significant effects, specifically on caregiver burden, depression and subjective well-being. "Structured" multi-component interventions did not show significant effects on most outcomes, but were significantly related to delayed institutionalization for the care receiver.	Insufficient research on sustained or long-term consequences of caregiver interventions exists. Few studies focus on the positive aspects of caregiving, such as caregiver well-being or finding benefits in the caregiving role. Lack of studies on mediators that may be causing the observed effects of the interventions, such as caregivers' beliefs, coping strategies, or a reduction in the amount of care they need to provide.
5. **Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S. (2011). The impacts of short break provision on families with a disabled child: an international literature review. *Health and Social Care in the Community*, 19(4): 337-371.**	To assess the existing research evidence concerning the impacts of short breaks on families with disabled children. Sixty articles and reports were identified for inclusion in the review. The majority of these studies were cross-sectional studies, with only 8 studies using quasi-experimental pre/post or longitudinal designs.	*Outcomes:* • Impacts of respite on carer well-being • Impacts on child with disability receiving respite • Impacts on siblings • Impacts on family functioning • Impacts on seeking permanent out-of-home placement. *Key finding:* Research consistently reports positive impacts of short breaks on the well-being of most (but not all) children with disabilities and their families.	"Quality of evidence included in this review is low in terms of widely accepted hierarchies of evidence (GRADE Working Group 2004), with only one randomized controlled trial and a predominance of qualitative studies. Nonetheless, the consistency with which some findings have been reported lends weight to evidence for the effectiveness of short breaks in impacting upon particular aspects of the well-being of disabled children and their families." For studies reviewed, some of the methodological problems cited were: 1) limited use of quantitative outcome measures; 2) confounding factors in the comparison of short break users and non-users; 3) lack of a control group who did not use short breaks; 4) small sample sizes; and 5) the provision of short breaks in conjunction with other interventions.

Study Title and Citation	Study Purpose	Outcomes Studied and Findings	Study Limitations (as cited by the authors)
6. **Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., Myles, S., O'Mahony, S., Roe, B., and Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment*, 13: 20.**	To provide a systematic review of published studies up through 2008. The review includes quantitative studies on the effectiveness and cost-effectiveness of respite on the well-being of informal caregivers of frail and disabled adults aged 65 years and older who live in the community. The review also summarizes findings of qualitative studies on these caregivers' needs and views related to respite services and perceived barriers to utilizing respite.	*Outcomes:* • Caregiver burden • Caregiver depression • Caregiver anxiety • Caregiver moral • Caregiver anger and hostility *Key findings:* Impact on caregivers: 1) Caregiver burden reduced at 2-6 months' follow-up in studies with single samples, but not in randomized control (RCT) or quasi-experimental studies. 2) Caregiver depression reduced in the short term in RCTs but only for respite home care, not for out-of-home day care. 3) No effect found on caregiver anxiety. However, respite did have positive effects on morale, anger and hostility. Single-group studies suggested that perceived quality of life may have been worse after respite use.	• Lack of good-quality larger trial studies • Respite interventions studied varied greatly from one another. • Limited process measures with "poor descriptions of the characteristics of the respite that was provided" • Limited provision and uptake of the respite services offered • Lack of economic analyses of respite
7. **Strunk, J.A. (2010). Respite care for families of special needs children: A systematic review. *J Dev Phys Disabil*, 22: 615-630.**	To identify the common findings of quantitative and qualitative studies of respite care for families of children with disabilities, the authors synthesized findings from 15 articles.	*Outcomes:* • Parental stress • Parental psychological distress • Child abuse prevention *Key findings:* 1) Family characteristics that may influence respite use include level of family stress, access to informal support networks, family size, and marital status. 2) Respite care use is associated with significant reductions in parental stress. 3) Implementing any form of more structured respite appears to have a positive impact compared to no support or the receipt of standard services. 4) Respite offers important short-breaks to families caring for children with multiple disabilities. 5) Respite care appears to result in reductions in psychological distress among parents of children with developmental disabilities. 6) Respite care may be considered an intervention for child abuse prevention, especially for those children suffering from challenging behaviors.	• Use of tools not tested for validity and reliability • Small sample sizes • Samples of parents not representative of larger population of parents of children with developmental disabilities • Some designs did not allow for assessment of other mediating or moderating variables • Studies without control groups; • Lack of longer-term follow-up data • Lack of inclusion of process measures.

Source: ARCH National Respite Network and Resource Center (2014). *Annotated Bibliography of Respite and Crisis Care Studies, 3rd Edition.* Chapel Hill, NC: Author.

Appendix 2: Federal Definitions of Respite

1. **Lifespan Respite Care Program** (Title XXIX of the Public Health Service Act – Public Law 109-442)

   Respite Definition: Planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

2. **Older Americans Act** (As Amended In 2006 – Public Law 109-365)

   - **Section 102 (a) (30) refers to respite in its definition of "in-home services."**

     The term "in-home services" includes—

     (A) services of homemakers and home health aides;

     (B) visiting and telephone reassurance;

     (C) chore maintenance;

     (D) in-home respite care for families, and adult day care as a respite service for families;

     (E) minor modification of homes that is necessary to facilitate the ability of older individuals to remain at home and that is not available under another program (other than a program carried out under this Act);

     (F) personal care services; and

     (G) other in-home services as defined—

     (i) by the State agency in the State plan submitted in accordance with section 307; and

     (ii) by the area agency on aging in the area plan submitted in accordance with section 306.

   - **National Family Caregiver Support Program** (Title III-E of the Older Americans Act)

     There is no specific definition of respite in the Act. However, when listing support services that the state should provide under this title, respite is described as "care to enable caregivers to be temporarily relieved from their caregiving responsibilities."

3. **Community-Based Child Abuse Prevention Programs** (Title III of the Child Abuse Prevention and Treatment Act – Public Law 111-320).

   Respite Definition: The term "respite care services" means short term care services, including the services of crisis nurseries, provided in the temporary absence of the regular caregiver (parent, other relative, foster parent, adoptive parent, or guardian) to children who—

   A. are in danger of child abuse or neglect;

   B. have experienced child abuse or neglect; or

   C. have disabilities or chronic or terminal illnesses.

4. **Medicaid 1915 (C) Home and Community-Based Waiver Application**

   In the technical guidance[5] from CMS accompanying a Medicaid 1915(c) Home and Community-Based Services Application for states, a core definition of respite is provided. However, states are instructed to supplement or modify the core definition to incorporate specific service elements under the waiver.

5 Centers for Medicare& Medicaid Services. (2015). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5, includes changes implemented through Nov 2014]. Instructions, Technical Guide and Review Criteria. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/Technical-Guidance.pdf

Respite Care Core Service Definition: Services provided to participants unable to care for themselves that are furnished on a short-term basis because of the absence or need for relief of those persons who normally provide care for the participant. Federal financial participation is not to be claimed for the cost of room and board except when provided as part of respite care furnished in a facility approved by the state that is not a private residence.

Waiver Application Instructions:

- Supplement or modify the core definition as appropriate to incorporate specific service elements under the waiver.
- The service definition must specify the location(s) where respite care is provided.
- These locations may include (but are not limited to):
  - Participant's home or private place of residence
  - The private residence of a respite care provider
  - Foster home
  - Medicaid certified Hospital
  - Medicaid certified Nursing Facility
  - Medicaid certified ICF/IID
  - Group home
  - Licensed respite care facility
  - Other community care residential facility approved by the State that is not a private residence.
- Specify the types of these facilities where respite is provided.
- The service definition must specify the location(s) (if any) where FFP is claimed for the cost of room and board. FFP may not be claimed for room and board when respite is provided in the participant's home or place of residence.

5 Veterans Respite

- 38 USC. Ch. 17: Hospital, Nursing Home, Domiciliary, And Medical Care - Title 38. Veterans' Benefits. Part Ii—General Benefits

  §1720B. Respite care

  (a) The Secretary may furnish respite care services to a veteran who is enrolled to receive care under section 1710 of this title.

  (b) For the purpose of this section, the term "respite care services" means care and services which—

  (1) are of limited duration;

  (2) are furnished on an intermittent basis to a veteran who is suffering from a chronic illness and who resides primarily at home; and

  (3) are furnished for the purpose of helping the veteran to continue residing primarily at home.

  The Millennium Health Care and Benefits Act of 1999, P.L. 106-117 amended 38 USC Chapter 17 to substitute "the term 'respite care services' means care and services" for "the term 'respite care' means hospital or nursing home care."

- **Definitions Section of the VHA HANDBOOK 1140.02.** Department of Veterans Affairs, Veterans Health Administration, Washington, DC, November 10, 2008

  Respite Care. Respite care is a distinct VA program with the unique purpose of providing temporary relief for unpaid caregivers from routine care giving tasks, thus supporting caregivers in maintaining the chronically ill veteran in the home. Respite care services may include various VA and non-VA programs or contracts. In all cases, respite care remains distinct from usual Geriatrics and Extended Care (GEC) services in that the focus and purpose of respite care is providing relief for the caregiver.

- **Caregivers and Veterans Omnibus Health Services Act of 2010** (PL 111-163)

  There is no definition of respite in Title I of the Act: Caregiver Supports. However, the law does stipulate in Title 1 that "Respite care provided under subparagraph (A)(ii)(III) shall be medically and age-appropriate and include in-home care." Also stipulates that:

  The support services furnished to caregivers of covered veterans under the program required by paragraph (1) shall include the following:

  ``(iii) Respite care under section 1720B of this title that is medically and age appropriate for the veteran (including 24-hour per day in-home care).

ARCH National Respite Network And Resource Center

ARCH is a project of the Chapel Hill Training Outreach Project, Inc.

Website: www.archrespite.org

Email: jkagan@archrespite.org

Phone: 703-256-2084