ADVANCING RESPITE RESEARCH
Findings from the Respite Research Summit
September 2020

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Executive Summary

On September 29 and 30, 2020, ARCH convened the virtual Respite Research Summit with more than 130 national and international participants in attendance, including researchers, philanthropic foundation representatives, representatives from the Administration on Community Living, policy analysts, advocates, Lifespan Respite grantees and partners, and respite program providers. The Summit was a capstone event to an eight-year initiative by the ARCH National Respite Network and Resource Center to advance a respite research agenda developed by an Expert Panel under the auspices of ARCH.

The purpose of the Summit was to review and assess the current state of respite research with the goal of advancing a respite research agenda to strengthen respite services. Researchers currently engaged in respite-related research were invited to present their research on respite and caregiving, with specific reference to six recommendations made by an Expert Panel of researchers, advocates and funders convened by ARCH in 2015. The six recommendations encouraged researchers to:

1. address foundational methodological concerns in respite research;
2. focus research on individual, family, and societal outcomes;
3. conduct appropriate cost-benefit and cost-effectiveness research;
4. conduct research on improving access to respite;
5. conduct research to improve respite provider competence; and
6. conduct translational research that informs respite policy and practice.

Two reactor panels contributed summative and interpretive comments on the presentations. Breakout discussion sessions provided an opportunity for Summit participants to discuss issues and ideas for research and mechanisms for continuing to advance the research agenda’s six recommendations. This report presents in detail the findings of studies presented, and summarizes recommendations and key themes from the deliberations of Summit participants. The emergent themes include defining and describing respite; research funding; measures and measurement; culturally appropriate research with hard-to-reach or serve populations; rethinking cost-effectiveness and cost-benefit studies; workforce development and access to research; and utilizing research findings to inform and improve policy and practice.

The recommendations made by both researchers and other Summit participants will be used to advise ARCH on the next phase of advancing respite research. ARCH will convene a Committee for Advancement of Respite Research charged with taking the original work of the Expert Panel and the findings from this Research Summit to help tailor ARCH’s next steps for advancing respite research.
Introduction

This report presents a summary of the proceedings and findings of the ARCH Respite Research Summit, convened to assess the progress made in implementing ARCH’s Expert Panel on Respite Research Agenda and to suggest next steps in advancing respite research. The virtual Summit held September 29 and 30, 2020, was both a capstone event representing the culmination of an ARCH long-term initiative to strengthen the evidence-base for respite, and a commencement of activities by the newly formed Committee for Advancement of Respite Research.

HISTORY AND RECOMMENDATIONS OF THE EXPERT PANEL

ARCH literature reviews and subsequent additional studies and national evaluations have attempted to address the essential research question: What does the research say about the efficacy of respite care? To date, a mix of findings has emerged. Among the positive general findings are:

- Respite is capable of reducing caregiver stress, depression, alleviating sleep deprivation, and reducing the sense of burden experienced by caregivers as a result of their caregiving responsibilities (Cowan & Reed, 2002; Empano, et al., 2011; Gaugler, et al., 2003; Owens-Kane, 2007; Zarit, et al., 2014a, 2014b; Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012).
- Respite may help delay or avoid facility-based placements (Gresham, 2018; Avison, et al., 2018), improve maternal employment (Caldwell, 2007), and reduce the odds of hospitalizations (Mandell, et al., 2012).
- Respite may support positive trends in quality of life indicators such as improved marital relationships (Harper, et al., 2013; Norton, 2016).
- Specific and regular doses of respite may be more effective in alleviating stress or burden than sporadic respite (Avison, et al., 2018; Zarit, et al., 1998)
- When caregivers plan their respite time to be most meaningful for them, greater benefits accrue (Lund, et al., 2009; Mensie & Steffen, 2010; Utz, et al., 2012).
- When the respite service focused on at-risk children there was evidence of a reduced risk of child abuse, neglect, and child abuse potential. (Cole, et al., 2005; Cole & Hernandez, 2008).

A similar number of studies revealed equivocal findings and a number of challenges in conducting respite research. A few of the methodological issues identified were:

- In a number of studies, there was a lack of clarity about the intended recipient of respite. Often the care receiver was monitored, but not the caregiver. In
addition, in many of the cost studies, the caregiver was not mentioned, the focus being entirely on cost and cost savings relating to certain undesirable outcomes such as care receiver placement or emergency medical services, seemingly due to eligibility for federal and state programs studied being limited to the care recipient, not the caregiver.

- In the majority of studies, there was a lack of model clarity and categorization. Respite ranged from occasional, irregular, infrequent use of in-home services provided by volunteers or family members, to formal, weekly, or even daily place-based respite with professional paid staff. The two models with the most apparent evidence were Crisis Care Nurseries and Adult Day Services.

- When respite models and components are not adequately described or documented, it is difficult to discern which aspects of an intervention are essential and contribute to positive outcomes.

- Typically, respite has been studied in combination with other caregiver services and/or supports making it difficult to isolate the impact of respite alone.

- There was a lack of objective, standardized outcome measures. Very few studies included pre- and post-measurement, relying most often on self-reports which tend to be highly subjective, and prone to response bias.

- There was weak efficacy testing or outcome evaluation. Very few comparison group studies had been conducted, and many studies did not include outcome measures relating to caregivers.

Evidence continues to mount that respite services are underutilized, despite an ever-increasing apparent need. The 2019 National Alliance for Caregiving and AARP national survey of family caregivers revealed that 86 percent of family caregivers of adults did not receive respite services at all, although 38 percent felt it would be helpful. Respite was especially underutilized or delayed among caregivers of persons with Alzheimer’s and other forms of dementia (NAC and AARP, 2020). Nearly half of family caregivers of older adults (44 percent) identified in the National Study of Caregiving were providing substantial help with health care tasks, yet, fewer than 17 percent used respite (Wolff, 2016). A significant proportion of parents of children with autism and other special needs also have documented unmet needs for respite (Cooke, et al., 2020; Neff, 2009; Sobotka, et al., 2020).

This disconnect between apparent need and respite utilization, limited evidence of efficacy, and other challenges evident in the peer-reviewed research literature on respite, led ARCH, with support from the Administration for Community Living, to begin the process of developing a prospective research agenda to see if positive research findings were replicable, challenges to research could be overcome, and efficacy for respite could be established. The underpinnings of this effort included recognition that:

- Model development along with concomitant Continuous Quality Improvement (CQI) indicators would be necessary in order to clarify
independent variables in prospective research and measure fidelity during research studies;

- Research that focused on outcomes associated with various well-defined models of respite was needed to test the efficacy of respite, and to build evidence for the value of respite care;

- Efficacy for respite needed to be based on measurable, observable improvements in the lives and well-being of caregivers and others involved in the respite care environment, including care receivers, families, and even the community; and

- An evidence base was necessary for successful advocacy for respite care as a service, for program expansion, for adequate funding, and perhaps even to encourage greater use of respite among family caregivers.

The ARCH initiative began in 2013 with the convening of the ARCH Expert Panel on Respite Research. Panel members included academic researchers, policy analysts and executives, representatives from philanthropic foundations, and respite providers. The Panel was charged to take a “deep dive” into the current status of respite research and make recommendations for advancing rigorous study of respite. They identified the following goals:

- Construct a definition of respite and a research framework based on that definition;

- Make specific recommendations to current and future respite researchers to guide research designs and content;

- Address and recommend appropriate methodological approaches and analytic strategies for respite research in order to assure scientific rigor and generalizable findings;

- Translate research findings into policy and action;

- Identify and engage researchers in respite research; and

- Identify potential funders to support respite research using the Expert Panel’s recommendations.

The Expert Panel’s work on these goals began with construction of an inclusive definition of respite that would assist the Panel in developing a meaningful research framework to guide future research. That definition of respite identifies the caregiver as the portal of entry to any outcome study on respite, based on the logic that respite is first and foremost a service provided to support the family caregiver. However, a number of collateral beneficiaries can and should also be included in the research design, as appropriate, with corresponding outcome measures. These may include the care receiver, other family members, and society at large. After much deliberation, the following definition was proposed:

**Respite is planned or emergency care that provides a family caregiver some time away from caregiver responsibilities, and results in some measurable improvement in the well-being of the caregiver, care recipient, and/or family system.**
With the definition in hand, the Panel addressed the other goals and ultimately made formal recommendations in six key areas. (See page 7.)

In addition to making these recommendations, the Panel developed a number of resources to assist in implementation of the recommendations. The Panel developed a research flow diagram providing a visual map to guide construction of research designs. To increase generalizability and precision of research findings, the Panel developed a taxonomy of terms recommended for use in respite research. Similarly, a compendium of standardized measures was assembled and guidance on the development of parochial measures was developed. To address the issue of imposing research methods suited for studying established respite models on studies of programs in their infancy or evolving towards maturity, the Panel developed a matrix of study designs and methodological approaches of increasing complexity and rigor along with appropriate measurement and data analysis strategies for use when conducting research on models of respite at varying stages of development. This information and resources, and the recommendations are presented in their entirety in _A Research Agenda for Respite Care._

In 2015, in order to help implement the Expert Panel’s recommendations, ARCH formed the Respite Research Consortium, an interested group of respite researchers and funders, as well as other service providers and advocates. ARCH identified potential funding for new research and helped connect researchers with those sources. Principals at ARCH began a dialogue with representatives of private foundations, the Patient-Centered Outcomes Research Institute (PCORI), and the National Institutes of Health in an effort to stimulate interest on their part in funding respite research relating to their designated service or treatment populations.

The Respite Research Summit was the capstone of the initial multi-year effort, designed to provide an opportunity to review progress made on the implementation of the Expert Panel’s six key recommendations and chart a course for the subsequent five years. Other ARCH activities (efforts to engage and encourage researchers, identify funding sources and encourage sources to provide funding, and to promote individual research endeavors) are ongoing.

To advise ARCH on the next phase of strengthening an evidence-base for respite, and to identify still outstanding or new research issues, ARCH has convened the Committee for Advancement of Respite Research (Appendix). The Committee will examine research that will help improve access to and quality of respite services; identify aspects of respite services and models that make them exemplary; encourage evaluation and replication of promising services; and help translate research findings into practice. Given the current effects of COVID-19 on respite service delivery, the Committee will also identify methods for evaluating the impact of alternative respite options developed to support family caregivers during and after the pandemic.
Recommendations from the Expert Panel on Respite Research in Six Key Areas

1. **Address foundational methodological concerns.** From their review of the literature, the Panel ascertained methodological shortcomings that have hampered current respite research. To address these issues the Panel made specific recommendations from the perspectives of research design, construction of independent and dependent variables relating to respite research, and methods and data 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 studies measure at least one outcome relating to caregiver well-being and quality-of-life. The Panel also 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 recommended 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 caregivers and caregivers not receiving respite.

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 would 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 reluctant about using respite. While acknowledging that not all respite must be provided by people with special training, if special training is needed, the Panel recommended 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.** Acknowledging that while statistically significant findings are the end goal of any research study, the Panel also acknowledged that these findings do not necessarily translate automatically to models or practices that can be broadly or easily implemented. The Panel recommended consideration of multiple factors in implementation environments, including contextual variables; organizational readiness to change; resources implications such as personnel requirements, training, record keeping, and accounting; attention to detail at the caregiver level; and the social, political and economic contexts within which services are provided.
Summit Agenda

DAY ONE, SEPTEMBER 29, 2020

Opening Remarks

- Jill Kagan, MPH, ARCH National Respite Network and Resource Center
- Rani E. Snyder, MPA, Vice President, Program, The John A. Hartford Foundation
- Greg Link, Director, Office of Supportive and Caregiver Services, Administration for Community Living, Administration on Aging, U.S. Department of Health and Human Services

Background on the ARCH Expert Panel on Respite Research and the Final Report

- Ray Kirk, PhD, Senior Research Consultant, ARCH National Respite Network and Resource Center

Focus on Equity and Diversity in Respite Research

- Kim Whitmore, PhD, RN, University of Wisconsin–Madison, School of Nursing

Aligning Research Agendas with Research Recommendations

- Bill Zagorski, Chair and Research Committee Chair, National Adult Day Services Association
- Emma Miller, PhD, Senior Research Fellow, School of Social Work and Social Policy, University of Strathclyde, Glasgow, Scotland
- Kim Whitmore, PhD, RN, University of Wisconsin–Madison, School of Nursing

Research on Respite Outcomes and Access

- Rebecca Utz, PhD, Associate Professor, Director of Graduate Studies, Department of Sociology, Director, Health Society & Policy Program, Co-Director, Consortium for Families & Health Research, University of Utah
- Joseph E. Gaugler, PhD, Robert L Kane Endowed Chair in the Long-Term Care and Aging, Professor and Director School of Public Health Center on Aging, Division of Health Policy and Management, University Of Minnesota
- Sarah A. Sobotka, MD, MSCP, Assistant Professor of Pediatrics, Developmental and Behavioral Pediatrics, Associate Program Director of Developmental and Behavioral Pediatrics, Medical Director, Comer Outpatient Developmental and Behavioral Pediatrics Programs, University of Chicago

An Equity and Diversity Lens

Throughout the Summit, a deliberate focus was maintained on the importance of using an equity and diversity lens on every aspect of research. This concept was thoughtfully laid out during the opening of the Summit by Dr. Kim Whitmore, Summit facilitator and a researcher in her own right.

“The limited respite research that has been done with the Latinx population also reminds us that we need to understand the cultural context of respite and how we can ‘reframe’ respite and work to create culturally and linguistically appropriate services.”

Kim Whitmore, PhD, RN, on the need to use an equity and diversity lens on research.
Reactor Panel and Group Discussion

- Joseph Caldwell, PhD, Senior Scientist and Director, Community Living Policy Center, Lurie Institute for Disability Policy, Brandeis University
- Susan Peschin, MHS, President and CEO, Alliance for Aging Research
- Cordelia Robinson Rosenberg, PhD, RN, Professor of Pediatrics and Psychiatry, University of Colorado School of Medicine

DAY TWO, SEPTEMBER 30, 2020

Using the Expert Panel Framework

- Tiffany Washington, PhD, John A Hartford Geriatric Social Work Scholar, Associate Professor, University of Georgia School of Social Work

Practice Research and Evaluation

- Thomas V. Caprio, MD, Professor of Medicine/Geriatrics, Psychiatry, Dentistry, Clinical Nursing, and Public Health Sciences, University of Rochester Medical Center
- Sarah Swanson, MPH, Assistant Professor, Community and Family Resource Specialist, Munroe-Meyer Institute, University of Nebraska Medical Center
- Susan Jenkins, PhD, Director, Office of Performance and Evaluation, Center for Policy and Evaluation, Administration for Community Living, U.S. Department of Health and Human Services

Roundtable Reports and Recommendations for Future Research

- Joseph Caldwell, PhD, Senior Scientist and Director, Community Living Policy Center, Lurie Institute for Disability Policy, Brandeis University
- Ray Kirk, PhD, Senior Research Consultant, ARCH National Respite Network and Resource Center
- Susan Peschin, MHS, President and CEO, Alliance for Aging Research
- Cordelia Robinson Rosenberg, PhD, RN, Professor of Pediatrics and Psychiatry, University of Colorado School of Medicine

Wrap-Up and Next Steps

- Ray Kirk, PhD, Senior Research Consultant, ARCH National Respite Network and Resource Center

“Let the question guide the methodology.”

Tiffany Washington, PhD, speaking about the use of cross-sectional studies and the importance of considering the research aim and study phase rather than using randomized controlled trial research design prematurely.
Assessing the Current State of Respite Research

The aim of the subsequent panels on *Aligning Research Agendas with Research Recommendations*, *Research on Respite Outcomes and Access*, *Using the Expert Panel Framework*, and *Practice Research and Evaluation* was to assess the current state of respite research on issues relating to strategies for improving access to and best use of respite; best practices in respite program implementation, including respite voucher approaches; caregiver, care receiver and family outcomes resulting from respite; models and dosage of respite needed to achieve maximum benefits; and the value and quality of respite provider training.

Brief summaries of each of the formal presentations are presented in this section.
“You may have heard the phrase: ‘Nothing about us without us.’ It is really important that at all stages of the research process, we engage with those directly impacted by the work we are doing.”

Kim Whitmore, PhD, RN, speaking about equity in respite research

OPENING SESSION:
FOCUS ON EQUITY AND DIVERSITY IN RESPITE RESEARCH

Kim Whitmore, PhD, RN, University of Wisconsin–Madison, School of Nursing

Dr. Whitmore began her presentation by clarifying three important concepts – Diversity, or different perspectives; Inclusion, or feeling welcome; and Equity, or fairness – and by describing the broad array of social identifiers comprising social identity. She also emphasized that equality, or sameness, is different from equity or that which is fair apart from sameness, and pointed out that available community services influence equitable outcomes.

With regard to equity of respite care, Dr. Whitmore identified five rights – the right family needs the right type of respite, at the right time, for the right duration, and in the right location to help assure that respite is tailored to individual needs populations. In order for positive outcomes to occur – including decreased caregiver stress and increased family quality of life, it is important that respite care is equitably distributed and matches unique family needs. Attention to respite cost, location, safety, duration, timing, frequency, type and a trusting relationship between families and providers are essential, and without these, respite may yield the opposite of beneficial outcomes to caregivers that respite providers intend.

Applying an equity and diversity framework to the Expert Panel’s key recommendations includes strategies such as Conducting Inclusive Research Studies that: intentionally address disparities or inequities; focus on diverse populations; engage community partners in research; engage community advisory boards; and disseminate plain-language summaries of findings to relevant communities.

Dr. Whitmore presented the following five reflection questions to guide respite researchers as they incorporate an equity and diversity lens in their work:

1. Is your research team diverse, representative, and inclusive?
2. Are you cultivating authentic relationships with diverse stakeholders, including caregivers, care receivers, and respite providers?
3. Are you engaging stakeholders at all stages of the research process, including formulating research questions, study design/methods, recruitment, data collection, analysis, and dissemination?
4. What implicit biases do you/your team need to unlearn to avoid biased data collection and biased dissemination?
5. What inequities need to be prioritized in your work?

Resources to Ensure Diversity in Research Studies

- Wisconsin Network for Research Support (WINRS) and Community Advisors on Research Design and Strategies (CARDS) – For help to engage community members and increase the diversity in research samples.
- CLAS Standards – Culturally and linguistically appropriate services.
- Community Guidelines for Engaging with Researchers and Evaluators: A Toolkit for Community Agencies, Organizations and Coalitions by Evelyn Cruz, Director for Program Development and Evaluation at Centro Hispano, Madison, WI, and Dr. Lori Bakken, Professor, Civil Society and Community Studies Department and Evaluation Specialist for the Division of Extension at the University of Wisconsin–Madison.

CLAS Standards

• CLAS Standards  – Culturally and linguistically appropriate services.

Community Guidelines for Engaging with Researchers and Evaluators: A Toolkit for Community Agencies, Organizations and Coalitions by Evelyn Cruz, Director for Program Development and Evaluation at Centro Hispano, Madison, WI, and Dr. Lori Bakken, Professor, Civil Society and Community Studies Department and Evaluation Specialist for the Division of Extension at the University of Wisconsin–Madison.
ALIGNING RESEARCH AGENDAS WITH RESEARCH RECOMMENDATIONS

The panel on Aligning Research Agendas with Research Recommendations demonstrated that ARCH’s vision to advance a respite research agenda is well aligned with similar approaches by other organizations, and that opportunities for collaboration will enhance our collective efforts.

Mr. Zagorski, Dr. Miller, and Dr. Whitmore presented their current research and research initiatives, and explicitly linked their research methods and research initiative approaches to the recommendations advanced in the Expert Panel Report, with particular attention to creating a strong research culture in organizations. They emphasized that networking can result in translational research to improve practice.

Research Agenda of the National Adult Day Services Association

Bill Zagorski, Chair and Research Committee Chair, National Adult Day Services Association

Mr. Zagorski provided an overview of Adult Day Services (ADS), and highlighted the variability of settings in which those coordinated and structured services are offered. ADS historically has focused on care receivers (services to adults in need of supervised or assisting care during the day) through the provision of social and health-related services, outside of their residence. ADS also delivers respite for caregivers who would otherwise provide 24/7 care for their loved ones. Mr. Zagorski notes that ADS has increasingly placed an emphasis on evidence and research that includes outcomes for caregivers as well as care receivers.

The National Adult Day Services Association (NASDA), serving the more than 6,000 ADS centers, created a Research Committee to help align disparate data collection and research initiatives throughout the industry. The Research Committee has established an Outcomes Matrix; identified and standardized Uniform Outcomes Measures for ADS; developed a Research Statement and Five Year Plan with Domain Map; and compiled an Annotated Bibliography.

The Research Committee identified five domains that reflect a cycle of planning, implementing, evaluating, and translating research into practice, and are consistent with recommendations of the Expert Panel:

1. Standardize ADS outcomes and measures;
2. Metrics and data collection;
3. Data utilization and integration by ADS Stakeholders;
4. Translational research into innovation in adult day services; and
5. Implementation and evaluation of best practices.

Mr. Zagorski described challenges encountered by the Research Committee including standardization of ADS models in a heterogeneous industry; research participation that bridges the gap between an academic approach and practice-based and grass roots research; and executing data collection and analysis and retaining research partnerships. Two key takeaways from the Research Committee’s experiences include:

1. Ongoing implementation, evaluation and updates are essential to successful research implementation; and
2. Data from research and evaluation of Adult Day Services demonstrates that those services yield benefits for both care receivers and caregivers.
Respite Care/Short Breaks: Sharing an Evidence Review from Wales and Scotland (UK)\textsuperscript{24}

Emma Miller, PhD, Senior Research Fellow, School of Social Work and Social Policy, University of Strathclyde, Glasgow, Scotland

Dr. Miller introduced the Short Breaks Research and Practice Development Group\textsuperscript{25} (SBRPD), established in 2017 in the UK for the purpose of supporting a culture of research, and building research capacity across the short breaks (respite) sector. The group’s aim is to improve understanding of the role of short breaks/respite and to help structure future research in ways that support continuous improvement in policy and practice. The group maintains a strong focus on caregiver outcomes and caregivers in diverse caregiving circumstances, and recognition of the importance of broader family outcomes. The Research and Practice Development Group conducted a scoping review\textsuperscript{26} in order to better understand the research evidence about short breaks/respite and carer/caregiver outcomes. The various types of short breaks identified included: traditional (day-care, residential and in-home respite); and alternative breaks (supported holidays and access to leisure and arts).

Carer/caregiver outcomes identified in the review included: improvements in carer emotional well-being; enhanced sense of resilience; opportunity to attend to self-care needs; and retrospective necessity. Research confirmed that positive health and well-being outcomes for caregivers and care receivers are linked to the provision of personalized short breaks/respite. Evidence that was less clear about carer health and well-being include: some studies showed positive physical but not emotional outcomes, with positive benefits soon dissipating; and some caregivers reported feeling guilty, anxious, lonely or sad about being separated from their loved one. Negative effects mitigated carers’ view of respite as a legitimate need, and their appreciation of its preventative effects.

In recognition that short breaks/respite play a key role in supportive positive relations and enabling carers to continue caring, key policy priorities across the UK include supporting opportunities away from caring to pursue personal interests; thinking and relating to others in ways not linked to the caring role; taking short breaks that afford opportunities to undertake routine domestic chores and mundane tasks; and using short break time to pursue individual interests or be with family and friends – both activities that are associated with positive outcome and improved well-being.

Important features of short breaks include: the quality of the break as experienced by the carer and the duration of breaks with longer breaks (over 24 hours) having a greater positive effect for carers than shorter breaks. The review has resulted in a renewed focus for the SBRPD group on ensuring carers (and families) are engaged in defining the outcomes that matter to them in determining the right type of break of respite; that we monitor those outcomes as means of evaluation and use the information to continue to develop the sector. Dr. Miller shared a research article\textsuperscript{27} on a method for conducting meaningful qualitative research, the link to which is listed in the references.
The **BREAK Exchange**[^28]  

*Kim Whitmore, PhD, RN, University of Wisconsin–Madison, School of Nursing and ISBA Conference Chair*

The **BREAK Exchange**,[^29] which stands for **B**uilding **R**espite **E**vidence **A**nd **K**nowledge, is an international group of researchers, respite providers, agencies, and individuals committed to building a culture of evidence-based respite care. Founding partners include ARCH National Respite Network and Resource Center, Shared Care Scotland, the School of Nursing, University of Wisconsin-Madison, and the International Short Break Association (ISBA).

The Expert Panel's **Six Key Recommendations**[^30] to establish evidence for the effectiveness of respite care form the foundation of the BREAK Exchange, and the BREAK Exchange encourages members to use these recommendations to inform their work and translate it into research practice.

Benefits of BREAK Exchange membership include: **Connecting** with a global network of more than 130 members from 13 countries; **Learning** about evidence-based respite care practices and research occurring around the world; **Sharing** one’s own evidence-based practices or research with international partners and featuring one’s work on the BREAK Exchange website, e-newsletter or social media platform, or presenting in a quarterly webinar; and **Collaborating** with other researchers conducting similar research, identifying potential partners for future projects, creating a member profile, and searching for partners in the Member Database.

The BREAK Exchange received funding from the Global Health Institute to leverage and enhance respite capacity by building technical infrastructure and furthering recruitment activities. This funding also supported the administration of the **COVID-19 Pandemic Survey**[^31] with respite partners and programs in 15 countries in order to better understand key challenges experienced by respite programs and practitioners, to discover how programs adapted and innovated, and to generate resources that could be broadly used by respite programs and providers.

Dr. Whitmore and the BREAK Exchange also collaborated with ARCH in generating national guidelines for respite care agencies, providers, family caregivers and respite care receivers, *Providing and Receiving Respite Care Safely during the COVID-19 Pandemic.*[^32]
RESEARCH ON RESPITE OUTCOMES AND ACCESS

In the panel on Research on Respite Outcomes and Access, Dr. Utz, Dr. Gaugler, and Dr. Sobotka presented their research and research syntheses related to individual and societal outcomes across age groups and conditions, improving respite access, and translating research into best practice models. The presenters shared research measures and methods well suited to capturing respite outcomes, including protocol papers that describe the procedural details of interventions, mixed methods including quantitative and qualitative data, and goal attainment scaling to capture individual progress on person-centered outcomes.

Respite Time Use: Research Findings Lead to Novel Intervention to Maximize Benefit of Respite for Caregivers

Rebecca Utz, PhD, Associate Professor, Director of Graduate Studies, Department of Sociology, Director, Health Society & Policy program, Co-Director, Consortium for Families & Health Research, University of Utah

Dr. Utz and colleagues conducted a study focusing on how caregivers use respite time, and on an intervention to support caregiver use of respite time in ways that maximize caregiver benefits. In their work over the past decade, Dr. Utz and colleagues found that about half of caregivers reported being “not satisfied” with their respite time, despite identifying respite as their most needed and desired service. In a pilot study to better understand how caregivers spend their respite time and to identify which activities were most beneficial to them, Dr. Utz discovered that caregivers spent less than the desired time doing their most desired activities. To help caregivers increase the amount of time doing the activities they most wished to do, the research team developed an intervention to maximize respite time using a trained facilitator to coach caregivers in setting goals for respite time use, identifying barriers to meeting those goals, and reviewing outcomes after receiving respite. The study also focused on treatment fidelity, assuring each caregiver received the same intervention as other participating caregivers. Those caregivers participating in the pilot study experienced lower levels of anxiety and caregiver burden, and higher levels of well-being based upon meeting their stated goals for specified, desired activities. However, the researchers also realized that the trained facilitator model was labor intensive and not feasible or cost efficient for broader application – in keeping with the Expert Panel’s recommendation for translating research findings into best practice models.

The research team developed Time for Living and Caring (TLC), a technology delivered intervention, via APP or computer, using virtual coaching to maximize the benefits of respite and to increase caregiver satisfaction with respite time use. The APP has three components: (1) Information and Education (defining respite); (2) Virtual Coaching (creating a virtual break, planning activities, and reviewing activities with a dashboard that tracks progress); and (3) Resource and Referral (finding more formal and informal respite resources). The APP is being field tested for feasibility and initial efficacy with 150 dementia caregivers (although this intervention is intended for any caregiving population) for 16 weeks using a randomized control trial with a waitlist control. The APP design was developed with the guidance and participation of a 15-member community advisory board to help insure relevance to caregivers from diverse communities.

Because the pilot study is occurring during COVID-19, the researchers are supporting caregivers in identifying creative alternatives to respite by creating additional modules with the APP. Post COVID-19, the researchers plan to pilot the model on a broader national scale to demonstrate its feasibility and to provide evidence of its efficacy across settings and populations.

“When caregivers are doing what they want to do, they have lower levels of caregiver burden and higher levels of caregiver well-being.”

Rebecca Utz, PhD, speaking about research on caregiver goal setting and review of respite time use
"Often times in research, the key respondent is an individual caregiver, for example, a primary caregiver... (but) often care occurs within a network... I don’t think the methodology has caught up yet to effectively analyze the effects of respite on care networks."

Joseph Gaugler, PhD, speaking about logical matching of methodologies to research inquiry.

Research on Respite Outcomes and Access

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

Dr. Gaugler spoke about the alignment of the Expert Panel report with recommendations from dementia summits on how to improve dementia care, and how that relates to respite care. He also spoke about the utility of the Key Recommendations in taking stock of respite research and identifying future questions and research areas that need addressing.

The Expert Panel report framed the challenge of identifying beneficiaries of respite, and the importance of incorporating levels of analysis in research designs. Dr. Gaugler pointed out that traditional research methodologies on the whole do not capture broad or nuanced change within a network of caregivers. Rather, research typically focuses on a few commonly used signifiers of change, such as caregiver stress or burden, accruing to a single, primary caregiver. This singular focus fails to capture change related to significant policy issues, such as the “family care gap,” that is, the critical shortage of available, unpaid persons to care for individuals with significant health needs in the upcoming decades.

Another challenge to respite research cited by Dr. Gaugler is the way in which studies define respite intervention. Respite services when operationalized encompass many variations in who utilizes and benefits from respite, who delivers respite, how and where it is delivered, intensity or dose of services, etc. Understanding this complexity is important in clarifying what does and does not constitute respite, and in allowing comparison of studies (or meta-analyses) that claim respite as intervention, but may be measuring very different things within a generally defined respite intervention. Improved reporting of the components/elements that comprise respite services through the use of classification taxonomies would allow detailed reporting of respite interventions across delivery characteristics (such as mode, materials used, location, duration and intensity, scripting, interventionist characteristics). These kinds of analyses are essential to understanding whether respite works, and using research results to inform policy and practice.

Another characteristic of current approaches to respite research described by Dr. Gaugler is an over-reliance on deficit-oriented outcome measures such as caregiver stress. Strengths-based measures or indicators, such as resilience, and using person-centered outcome measures, such as Goal Attainment Scaling, would allow researchers to capture well-being and changes defined by and meaningful to caregivers and care receivers.
Dr. Sobotka spoke about the pediatric population that qualifies for respite care; the distinct opportunities and challenges for pediatric respite care; the current barriers to respite care for families of children with medically complex conditions; and planning for future respite research. Dr. Sobotka’s study of children with medically complex conditions has focused primarily on children requiring home mechanical ventilation (HMV), the majority of whom have primary respiratory or neurological conditions. Unique to respite care for caregivers of children, compared to caregivers for adults, are the commonly shared presumptions that the parent is the primary caregiver, and that having young children limits the time caregivers have available away from caregiving responsibilities. These presumptions may carry with them judgments about caregiving, and feelings of guilt among parents for taking time away. In addition, medically complex children require not just caregiving, but complicated, high-level skilled caregiving that requires equipment, training, and 24-hour skilled care. Respite care models for medically complex children may deliver care in either of two forms: additional hours of home care nursing beyond baseline hours, and respite care provided in a specialized facility where the child stays for a period of time instead of the family home.

To understand barriers to respite care, Dr. Sobotka’s research included three key informant groups: parents of children with chronic, medically complex conditions (family caregivers are the “portal of entry” to research individual, family and societal outcomes); home care nurses; and care coordinators from the University of Illinois Department of Specialized Care for Children (providing a representative sample). In a mixed methods study which focused on respite care, she combined findings from these semi-structured interviews with care coordinators statewide with the National Survey of Children with Special Healthcare Needs (NS-CSHCN), which is a national survey of parents. About half of survey respondents said they needed respite care, and about half of those needing respite reported receiving all the respite care they needed. About 41 percent of the half not receiving all the respite care they needed, received some of the respite care they needed. Sixty percent did not receive any respite care. Qualitative data collected from care coordinators confirmed that respite was underutilized, but when available and used, often helped families meet essential needs (rather than providing a regenerating break from caregiving). The lack of availability of home health providers, and bed space in respite care centers were barriers to respite use – despite data showing that respite was helpful in preventing respite-related hospital readmissions.

Unmet Respite Needs of Children with Medical Technology Dependence

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

“This is a beautiful illustration of why qualitative methods are important, because the (response) choices (on the survey we used) are not all correct.”

Sarah Sobotka, MD, speaking about methods that allow discovery of perspectives that may differ from response options the researchers thought important to include in a survey.
USING THE EXPERT PANEL FRAMEWORK

Dr. Washington presented an example of a study deliberately designed, and specifically funded by the Health Foundation for Western and Central New York, to use the Expert Panel’s proposed framework for advancing respite research. As a work in progress, Dr. Washington was able to raise for discussion methodological issues and emerging challenges imposed by COVID-19, and present strategies she is using to address these challenges. Her mixed methods approach is in line with the Expert Panel’s recommendations to identify the caregiver as the portal of entry and to examine respite dose and its relationship to caregiver burden, family well-being, and care recipient quality of life. She also addressed the importance of her early phase study in informing her future respite research.

Respite Research: Using the Expert Panel Framework

Tiffany Washington, PhD, John A. Hartford Geriatric Social Work Scholar, Associate Professor, University of Georgia School of Social Work

In her presentation on respite dose (i.e., frequency, duration, and intensity of respite) and its relationship to caregiver burden, family well-being, and care recipient quality of life, Dr. Washington described the importance of understanding contextual factors influencing caregivers’ access to and desire for respite. Using a mixed-methods research design including telephone interviews with caregivers who currently or recently used respite and a subset of that population who participated in focus groups, Dr. Washington sought to answer the following qualitative questions related to caregivers’ access to desire for respite: **What services do you consider to be respite services? How did you decide to use respite services? How satisfied were you with the service? What would you change about respite services? What more would you like for me to know about respite services?**

Dr. Washington explained the importance of qualitative methods in capturing contextual information critical to data interpretation, including the reasons why cultural, or study site differences may have occurred, or why fidelity was, or was not, achieved. She described recruitment challenges she encountered during the various phases of her study, including lack of diversity of sample populations, and recent Covid-19 related challenges.

Dr. Washington’s preliminary data showed that a proportion of caregivers were themselves experiencing a number of defined chronic conditions. Preliminary themes included caregivers’ expression of feeling more freedom in their lives for self-directed activity; increased flexibility in scheduling activities; personal and structural barriers to respite, including cost; burdens including personal exhaustion and burnout; cultural factors, including notions that caregiving should be accomplished only by family members; motivation to use respite; and the nature and limitations of social supports.

Future research will include: a bi- and multivariate examination of the relationship between independent variables (demographic characteristics and dose) and dependent variables (caregiver burden family well-being, and caregiver recipient quality of life); and a thematic analysis to identify the relationship of contextual factors (cultural factors, environment, care situation, nature of social support) to caregivers access to and desire for respite. In future, Dr. Washington also plans to more fully examine proximal and distal outcomes, consistent with the framework described in *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates, and Funders* (p. 20).

Challenges to Recruiting Caregivers for Research

Dr. Tiffany Washington identified an important methodological issue in her current research – the difficulty in recruiting caregivers for participation. She identified the following barriers to caregiver recruitment:

- Limited funding for participant incentives
- High advertisement costs
- Lack of culturally-tailored strategies
- Limited geographic scope
- Miscommunication with partnering organizations/stakeholders

Summit participants added the following:

- Caregivers are overwhelmed
- IRB hurdles
- Caregivers don’t self-identify
- Partner agencies are overwhelmed and hesitant to participate
- Survey fatigue!
- Limited time and conflicting priorities
- COVID has decreased an already depleted pool of candidates
- Staff turnover at recruitment sites, and lack of a champion
PRACTICE RESEARCH AND EVALUATION

The Lifespan Respite Care Program and the National Family Caregiver Support Program are two federal programs designed to meet the respite and support needs of growing numbers of family caregivers. In order to assess the value of these efforts and the benefits to family caregivers, the purpose of the panel was to present evaluation processes and results from real life applications of services and provider training offered by state Lifespan Respite grantees, and to learn about respite outcomes from ACL’s national evaluation of the National Family Caregiver Support Program.

Expanding a Volunteer Respite Workforce to Provide Support to Caregivers in New York State 39

Thomas V. Caprio, MD, Professor of Medicine/Geriatrics, Psychiatry, Dentistry, Clinical Nursing, and Public Health Sciences, University of Rochester Medical Center

Forming unique partnerships with federal, state, aging services and community groups, Dr. Caprio conducted an evaluation of New York’s collaborative effort to build a statewide, sustainable Lifespan Respite Program that is fully integrated into the New York long-term services and supports system.

The evaluation focused on implementation of the partners’ efforts to develop volunteer respite pools statewide using a train-the-trainer model. Importantly, this effort was preceded and supported by significant planning efforts that included: Stakeholder Engagement of community, government and academic partners; Infrastructure Building to increase capacity; and Sustainability Planning to diversify financial resources.

Evaluation methods and measures corresponded to stated goals and objectives.

1. **Train-the-Trainer Courses** to increase competence among respite providers. Measures used to evaluate this strategy included: (1) Enumerating trainers and master trainers (6 master trainers and 262 REST trainers across the state); and (2) a Post-Training Participant Survey resulting in high ratings across categories.

2. **Respite “Companion” Volunteer Training** to strengthen the workforce. Measures used to evaluate this strategy included: (1) Enumerating volunteers trained (N=242); and (2) a participant pre-post Course Evaluation Survey documenting statistically significant mean change scores in a number of areas related to providing for care recipient needs.

3. **Grow “Mini-Grant” Drop-in Respite Sites** to increase access. Measures used to evaluate this strategy included: (1) number of hours provided; and (2) a caregiver post-respite survey with 100 percent of respondents reporting a reduction in stress.

Dr. Caprio cited three lessons learned including: (1) the importance of leveraging new and existing state and community partnerships; (2) reconciling the focus on implementation by partner organizations with the need for data management and outcome assessment; and (3) working with academic institutions to enhance evaluation, measurement and outcome reporting.
Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families 2015-2017

Sarah Swanson, MPH, Assistant Professor, Community and Family Resource Specialist, Munroe-Meyer Institute, University of Nebraska Medical Center

Nebraska’s Department of Health and Human Services in partnership with University of Nebraska Munroe-Meyer Institute conducted a comprehensive evaluation using surveys and qualitative methods over three years that examined: caregiver outcomes as a result of receiving respite service; aspects of systems change that improve respite access; and respite provider competence.

Caregiver outcomes included stress levels, health, mental health, relationships, employment and finances. In brief, of 176 survey respondents, 78 percent were satisfied with respite services, although 47 percent reported that they had difficulty finding respite services. The majority of caregivers reported that stress levels and health and related outcomes improved with respite, but worsened significantly when respite ended. Respite providers surveyed (N=80), including those from agencies and independent providers, identified challenges including low wages, gaps in services in rural versus urban areas, and the need for training and strategies to address challenging behaviors.

Based on evaluation findings, State respite leaders made changes to Nebraska’s respite subsidy program including increasing financial allocations for crisis respite to meet exceptional circumstances; and addressing identified workforce challenges by developing (1) an interactive on-line training program with testing questions; (2) a structured practicum in recreational therapy programs, supplemented by mentorship with trained staff, and (3) a practicum in family homes with family caregiver coaching. State leaders also hired a respite employer engagement coordinator and established a website to reach, inform and educate employers about the needs of working family caregivers and the ways employers could support working family caregivers.

It is notable that Nebraska has developed a Respite Data Dashboard that tracks in real time: respite use across programs, the number and demographics of families using respite, the duration of services used, and funding sources. The Data Dashboard generates data for accountability and decision-making, and creates resources and opportunities for further research.
National Family Caregiver Support Program: Evaluation Findings

Susan Jenkins, PhD, Director, Office of Performance and Evaluation, Center for Policy and Evaluation, Administration for Community Living, U.S. Department of Health and Human Services

The National Family Caregiver Support Program (NFCSP) provides grants to states and territories to help informal caregivers care for older adults in their homes and includes five types of services – information to caregivers about available resources; assistance to caregivers in gaining access; individual counseling, support groups and caregiver training; respite care; and supplemental services. The purposes of the national evaluation of the National Family Caregiver Support Program (NFCSP) described by Dr. Jenkins were: to help ACL understand which kinds of services are most helpful to caregivers and to identify unmet needs and gaps in support; to assess service impact on caregiver ability to continue providing home-based caregiving; and to examine the relationship between caregiver outcomes and the Area Agencies on Aging management and provision of NFCSP services. ACL uses evaluation data to improve TA and grantee support, and to continue monitoring outcomes.

The evaluation methods included survey data collected from a nationally representative sample of NFCSP clients and comparison group of caregivers, and coupled with data about how programs operate to shed light upon organizational structures, approaches and strategies associated with optimal caregiving outcomes. Interviews with caregivers were conducted three times at six-month intervals.

Among the 1500 caregivers surveyed (mean age 66 years), 43 percent received an average of 6 hours of respite in their homes during the previous six months. On average, caregivers who received respite of 4 or more hours per week experienced a decrease in self-reported burden over time. Caregivers who did not receive at least four hours of respite reported an increase in self-reported burden over time indicating that burden may be sensitive to the amount of respite care received, and there may be a minimum amount of care needed to reduce caregiver burden.

Caregivers responded more favorably to providing continuing care to loved ones according to the amount of respite they received, increasing 4.7 percent with each hour of respite. Ninety-eight percent of caregivers surveyed found respite to be very or somewhat helpful. Caregivers receiving NFCSP services relied less on support from friends and families, prompting questions about possible second order effects of respite accruing to the larger caregiving community.
Observations and Reflections, Day One

THE DISCUSSANTS

At the end of the first day of the Respite Research Summit, a panel of expert leaders in respite research shared an overview of their work as it pertains to the Respite Research Agenda, identified key takeaways from the day’s presentations, and shared observations about the ways COVID-19 may influence respite practices and research.

Moderator:

• *Kim Whitmore*, PhD, RN, University of Wisconsin - Madison, School of Nursing

Panel Members:

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

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

• **Cordelia Robinson Rosenberg**, PhD, RN, Professor of Pediatrics and Psychiatry, University of Colorado School of Medicine

**Dr. Caldwell** spoke about his service on the federal RAISE Family Caregiving Advisory Council established by law to develop a national strategy to support family caregivers. The RAISE Council includes 15 federal agency and 15 non-federal members and is working on two products: (1) An initial report to Congress provides a framework with five major goals, each with five or six supporting recommendations, and modeled on the National Alzheimer’s Project Act (NAPA) Council and National Alzheimer’s Plan. Dr. Caldwell reported that respite has been at the forefront of all discussions and is a priority recommendation. The initial report includes a specific recommendation for long-term services and supports across all populations that aligns with the Summit’s first day of discussions, and includes a specific recommendation around research. (2) The second product Dr. Caldwell mentioned is a Strategic Plan to support family caregivers that will have very specific actions within the overarching goals. Dr. Caldwell challenged Summit participants to think about the importance of specific actions that funding and administrative organizations, including government agencies and the private sector, can and should take related to research.

**Ms. Peschin** introduced to Summit participants the Alliance for Aging Research, a national non-profit in existence since 1986 with a mission to promote research as a way to enhance aging and health. Ms. Peschin served as a member of the Expert Panel, bringing a patient advocacy perspective. She noted that since the time the Expert Panel started work on the report, it has occurred to her that
“You can't do a lot of research on something you don't put a lot of funding into. We’re trying to make the case for more funding based on research, but you can’t do research without sufficient funding for both the services and research.”

Sue Peschin, CEO, speaking about the challenges of reaching a certain threshold of evidence.

Dr. Robinson Rosenberg spoke about her professional history over the past four decades in nursing and developmental psychology at a University Center for Excellence in Developmental Disabilities (UCEDD) and Maternal Child Health, and talked about her particular interest in early intervention with children with complex medical conditions and care coordination. More recently her work has centered on advocacy for persons with dual diagnoses, autism and behaviors that increase risk to self or others. Dr. Robinson Rosenberg said she was struck by the pertinence of the discussions occurring during the Summit to populations across the age range, and across care settings, noting that when one “peels away the details, the basic core needs are the same.” She also noted that this view could help us create common cause across populations. She observed a critical intersection between care coordination and family navigation, and the role respite could play in moving the research agenda along. She also stated that she has been struck over the years about how bureaucratic requirements affect services like respite care, and noted the importance of being prepared to deal with these. She reflected that she has encountered these themes throughout the past 45 years.

KEY TAKEAWAYS

Dr. Caldwell stated that he found the ARCH Annotated Bibliography very useful, and in the updated 2020 version, was able to get a sense of where new studies were occurring, and where large gaps remained. He observed that most new studies represented respite services for older adults, especially those with dementia, and the second most represented area was respite research on caregivers of children. He noted a persistent gap in respite research for caregivers of adults with disabilities or developmental disabilities. Dr. Caldwell also noted that another common theme during the first day of the Summit was related to person- and family-centered services, especially with respect to the right type of respite, at the right time, in the right amount. He noted increased interest in caregiver assessments and efforts to identify what caregivers truly need as part of person- and family-centered services, which present a fruitful area for research.

Ms. Peschin expressed excitement about Dr. Utz’s NIH-funded research on caregiver coaching, and commented that there may be many opportunities for NIH to fund similar studies. She was struck by Dr. Utz’s finding that half of caregivers were not satisfied with their respite time. Ms. Peschin related this finding to the second part of the Expert Panel definition stating that respite...
interventions should result in measurable improvement. Ms. Peschin noted the need to better define the threshold for significance when studying respite outcomes because so few meet the criteria for being “evidence-based.” She described a recent review of non-pharmacological interventions for people with Alzheimer’s conducted by the Agency for Healthcare Research and Quality (AHRQ), and noted that the study did not find sufficient evidence of positive outcomes for most of the interventions they studied, which she found very disheartening. She observed that most respite and caregiving interventions do not meet the randomized control trial (RCT) level necessary to be considered evidence based, so Dr. Utz’s work is particularly important in producing a new level of meaningful evidence. She also noted the need for new definitions for what constitutes statistically significant outcomes, and the importance of defining measures used to provide evidence of outcomes.

**Group Discussion**

- **Rani Snyder**, The John A. Hartford Foundation, noted that the vast majority of researchers and providers believe cost data is what funders and policy makers wish to know. However, she described a project at Benjamin Rose Institute that developed a database of evidence-based, replicable caregiver support programs and noted that while they do not include randomized control trial data, they have sufficient evidence to be considered intervention approaches that have established merit.

- **Jill Kagan**, ARCH Director, cited the Expert Panel recommendation that a continuum of approaches be used to conduct research, beginning with the least rigorous and least demanding and advancing to the most rigorous. The panel felt strongly that multiple levels and types of evidence were necessary in order to make a case to support policy that advances specific interventions.

**Dr. Robinson Rosenberg** observed that Dr. Utz’s work about making respite person-centered goes to the core of what needs to happen. “Over the years,” Dr. Robinson Rosenberg noted, “we have heard about parents’ hesitancy to use respite care around adequacy of provider training.” She remarked that it is important to allow parents to define what is important to them. She stated that she especially liked the taxonomy of respite care programs and the importance of creating ways to assess accountability across programs and program variations. She commented on the acute issue of who is going to deliver respite, and the importance of assessing what personnel capacity we have as respite grows.

**COVID-19 RESPITE-RELATED RESEARCH**

**Dr. Caldwell** remarked that the use of remote technologies is an important area of research in light of COVID-19, including testing the efficacy of remote or online versions of interventions. He stated that he wished we had timely national data describing how caregivers are doing during the pandemic, including information about how much more care they are providing, and the racial/ethnic impact on amount of care needed and provided. He suggested that

“The research needs to continue with a broader focus on outcomes that reflect the breadth of the caregiver experience.”

Summit participant
existing national health and other surveys include questions about respite. Dr. Caldwell noted that he had observed increased flexibility and the allowance of self-direction options during the pandemic to allow families to control who they hire and to control their budget, and stated these changes in service delivery flexibility and self-directed models are worthy of study.

Ms. Peschin noted increased interest at NIH in pragmatic studies, and stated that if opportunities for funding were available, and if the pandemic persisted six months or a year, pragmatic studies of respite would be a good approach.

Dr. Robinson Rosenberg stated that in her research on Autism, she has noticed mixed reactions from families with regard to COVID-19. She observed that some are relieved that their child’s anxiety about school is reduced and mentioned current survey research that is studying the impact of the pandemic on families. She remarked that inequity in terms of internet access is an area worthy of study. She shared an example of a cable provider in Denver providing no-cost services in order to increase access, and stated that it would be good to know if and how this helps families.

Group Discussion

- **Kim Whitmore** stated that in the global study of COVID-19 she is conducting, it wasn’t only access to technology that presented barriers, it was also possessing the skills to use technology.
- **Marisa Bueno** asked, “If we may have to make a case to our governor and legislature, what are the core arguments?”
- **Susan Peschin** responded, “Delayed institutionalization.”
- **An unidentified participant** asked, “Is there good research around cost-benefits? Workforce impact?”
- **Jill Kagan** responded that there is not as strong evidence in the literature as we would like to see, and commented that this is methodologically difficult to study. She noted that as a field, we do have good data supporting that respite services result in reduced stress among caregivers that can positively affect health and well-being, and increased social relationships and decreased social isolation.
- **Ray Kirk** stated that focusing on cost-benefit research may present unanticipated risks, noting that until evidence of the impact of respite on cost measures is clearer, there is a risk in promoting services on the basis of being cost-cutting or cost-saving. Programs may be deemed ineffective even when other important benefits accrue to caregivers if the programs do not also reduce costs. Quality of life improvements may be worth added costs, Dr. Kirk noted, which reframes the conversation from how much things cost and what costs can be cut to what is important to society with respect to quality of life for caregivers and care receivers. He observed that this is a difficult conversation to have within a contentious political environment.

“One of the questions I have asked in focus groups to family caregivers is ‘What would happen if you DIDN’T get respite care?’ as a way to help understand how important it is to them. The responses were incredible. Sadly, there are many who are now learning what it is like without respite because of the pandemic.”

Kim Whitmore, PhD, RN

“(There is) a possible disconnect between traditional research and need for evidence (time, study design, outcomes) versus need for speed and tangible results to inform policy.”

Summit participant
Another speaker asked, “Is there an opportunity to capitalize on COVID-19 to leverage respite care rather than institutional congregate care.”

Ms. Peschin responded that home care companies have done this for safety reasons, and added that this is also an issue with Medicaid home and community-based waiver programs. Many tout HCBS services as much less expensive than facility-based care, but it in fact may be more expensive on paper to keep people in communities, she observed, and there are other benefits.

Proposed COVID Research Questions

Summit participants shared their research questions related to respite during the pandemic. They are grouped here by general topic of inquiry.

Virtual Services
- What practices utilized during the pandemic could be positively utilized post pandemic (e.g., virtual options)?
- What is the impact on caregivers of virtual respite that is offered in lieu of respite offered in congregate settings?
- How have access/barriers to technology been addressed in providing respite virtually, especially through the lens of equity?
- What successful virtual models have been tried/developed, and which models have been the most effective, and with which populations?

Caregiver Burden
- Did COVID make it more difficult to take short breaks? If so, what were the factors?
- What are some of the current issues related to COVID that caregivers are facing and how is respite care helping with those challenges?
- Are there additional burdens caregivers are facing? Does this provide new opportunities to explore?
- According to the CDC, mental health issues are rising among adults during the COVID-19 pandemic, including death by suicide. Have death-by-suicide numbers risen for primary caregivers or care recipients during this time?
- Post-COVID, what alternatives to a physical respite break have an emotional/mental health benefit? What impact do measures to reduce social isolation have on out-of-home respite use, need, and effectiveness?

- As COVID continues, how can families and caregivers feel comfortable while receiving and providing care? What do we need to keep in mind regarding the after effects of isolation caused by COVID?
- What is the financial impact of COVID on respite care and caregivers? In spite of COVID, does respite positively impact a caregiver’s well-being, and allow them to continue working or worker longer? Or, do costs associated with respite care during COVID lead to additional financial stress?
- What are the considerations regarding potential abuse with individuals in close quarters for lengthier periods?
- Does the current research presented on high stress levels among caregivers associated with respite no longer being available due to COVID provide insights into the possible impact of COVID and fewer available services?

Service Impact
- What are the preferred types of respite/short breaks during the pandemic and is this different from pre-COVID preferences?
- To what extent has COVID impacted respite services sustainability and what might this mean in terms of future availability (and choice)?
- How many respite care providers were out of work due to centers closing and how many returned to the profession? Were they successfully employed in different industries?
- Have there been positive changes in caregiving/respite as a consequence of COVID? If so, what are they? Do they have implications for future respite services?
Summit Participants Share Resources and Ideas

University Programs that Address Provider Workforce Issues

On the practice evaluation panel, issues emerged regarding the workforce shortage that results in limited respite opportunities. Several Summit participants discussed and shared resources on model initiatives at universities that use student volunteers to provide respite.

- In Wisconsin we will be working on developing a university-based volunteer service learning model that we look forward to disseminating broadly. This will be based on a project I led at another university called Project REACH (Respite Events Allowing Caregivers Hope). You can check out a video from an event [here](#).45

- I’m also doing service-learning46 engaged scholarship-based respite programming (at the University of Georgia). We frame it around training the future workforce and recently received funding to grow this program.

- This may be of interest (from Ohio): [Ohio University Respite Volunteer Program](#)47

- We also have a service-learning program48 (in Virginia) in which nursing students provide respite care for CSHCN. There is a sister program49 for older adults. Both programs are also offered through the university’s HR department to offer university employees these resources.

Research Considerations for Employed Family Caregivers

Nearly two-thirds of family caregivers are employed. Participants raised important issues for service needs and research considerations that are specific to working family caregivers.

- In the secondary analysis I conducted using data from the National Survey of Children with Special Healthcare needs, 3/4 of parents reported having to cut back or quit work to care for their children!!!

- Excellent highlighting the experience of working caregivers among your study respondents! We need more policy initiatives to support working caregivers (e.g., paid leave for ALL workers).

- The evaluation of working caregivers of children with special health care needs is complicated because often mothers of newborns/young children have intentionally decided to pause working or education, because of the birth of children with disabilities. This is not captured by measures that focus on missed work (they may self-identify as stay-at-home mom).

- In Scotland we have a Carer Positive kite mark50 for businesses that have carer friendly employment policies. This is sponsored by Scottish Government. Are there similar initiatives in the States?
Roundtable Summaries

Four virtual roundtable sessions were convened to provide a forum to discuss four of the six Key Respite Research Recommendations included in the Expert Panel Report. They include: Individual, Family, and Societal Outcomes Research; Appropriate Cost-Benefit and Cost-Effectiveness Research; Research Systems Change that Improves Access; and Research Improving Respite Provider Competence. The remaining two recommendations from the Expert Panel – Improve Research Methods and Translate Research Findings into Best Practice Models – were embedded in the list of open-ended questions posed by roundtable discussion leaders.

Although each roundtable focused on a different topic, all employed the same set of guiding questions, and used the same format for convening and facilitation of the discussions. The intent of this format and process was to make efficient use of the limited time available for the breakout sessions and to make the results of the sessions comparable across sessions.

The following summaries are based on notes taken during the roundtable sessions by note-takers trained in advance. These notes were supplemented by notes taken by discussion leaders and group participants, by chat transcriptions, and by session recordings. The summaries are a synthesis of key themes, and ideas are attributed to “roundtable participants” rather than to individual participants. The theme descriptions are based upon our best understanding of what was said. Ideally, when analyzing qualitative data, one would return to participants to ask for clarification of one’s understandings and interpretations. Because this was not possible, these summaries present important issues, but do not exhaust their multiple meanings and implications. They are the authors’ summaries of material in the referenced sources, but we may have missed information or misconstrued participants’ intentions. Therefore, please view these summaries as an indication of some important issues, but not as a definitive exploration or discussion of those issues.
ROUNDTABLE 1:
INDIVIDUAL, FAMILY, AND SOCIETAL OUTCOMES RESEARCH

Discussion Leader: Ray Kirk, PhD, ARCH Senior Research Consultant

What is needed to advance respite related outcomes research?

• Use a consistent definition of respite. Concern about a consistent definition was expressed across all of the groups, and in this session was discussed with respect to service delivery settings – camp for a child with disabilities, or adult day services for an older adult, for example. According to the Expert Panel Definition (see page 5), if caregivers receive some time away from caregiver responsibilities, and results in some measurable improvement in the well-being of the caregiver, care recipient, and/or family system, the time away is considered to be respite. However, as Dr. Gaugler pointed out in his formal presentation, defining and describing respite are both important. Descriptions of respite interventions will differ across programs and research studies, and are important to document and understand the effects of our interventions (see page 17). The importance of consistency in respite definitions across core programs, such as Aging, Maternal Child Health, and Centers for Medicare and Medicaid, was also noted.

• Identify innovative and supportive practices, promote these to programs, build upon these at the state level, and advocate for these to funders. This suggestion was consistent with one made by Dr. Robinson Rosenberg regarding the importance of cataloguing what we do know from respite programs and states’ efforts about the benefits of respite. She explained that this is important so that agencies, programs and providers have access to that information, and can speak with authority about the merit of respite services when delivered in ways consistent with what we know to be beneficial practices.

• Build upon existing data collection and tracking systems. One roundtable participant suggested incorporating quality of life measures in existing measurement efforts across programs and agencies, using or refining online data collection systems (like the Nebraska Data Dashboard) to collect key data elements, and requiring State Lifespan Respite grantees to collect common data elements using similar measures across programs.

If resources were not an issue, what are the respite-related outcomes research/evaluation questions that you would want answered?

• Measure Quality of Life. Participants emphasized the importance of measuring the financial burden assumed by caregivers; neglect of caregiver self-care; the experiences of care receivers and how these effect caregivers; and the quality of life of primary and other caregivers, such as grandparents and siblings, and the family system. Examples of quality of life measures include stress levels of caregiver and care recipient; health measures; employment
impact; sibling school attendance; marital/partner relationships; social supports; resiliency; caregiver self-efficacy; and satisfying social relationships. Standardized measures of quality of life, especially those standardized on the majority population, “are not meeting the mark” according to multiple roundtable participants. Mixed methods and community-based participatory research with caregivers, care receivers and families, involved from beginning-to-end of the research process, were recommended. Measurement processes sensitive to the transitory nature of change and situational influences over time were cited as a need. Process outcomes documenting engagement; the extent to which caregivers and family felt respected; and the extent to which caregivers and families were encouraged and supported in respite care planning should be included when measuring outcomes. It was also suggested that the best measures are based upon what families need, what they wish to change, and their expectations for life after respite. (See Dr. Gaugler’s description of Goal Attainment Scales, page 17.) It was suggested that peoples’ feelings and fundamental human values are best captured through narrative.

- **Measure outcomes related to the human ecology.** Roundtable participants acknowledged that caregiver measures should never be overlooked, but that the focus of inquiry should be broadened to include multiple generations, spouses, siblings and other caregivers as they are understood by the family. The focus of inquiry should also include the impact of caregiving beyond caregiver stress, including, for example, the ways caregiving for a child with a disability may affect caregiving parents’ ability to care for their aging parents, or in a second example, the ways early and intense support for families of children with behavioral challenges may prevent crises at home that precipitate out-of-home placements. Roundtable participants also pointed out that standardized measures capturing a moment in time do not adequately capture the transitory experience of caregiving day-to-day and overtime or the diverse experiences that define one’s well-being. Measures constructed for pre/post or repeated measurement can be helpful for addressing this issue. Roundtable participants stressed the importance of using methods that are culturally appropriate and sensitive to the populations participating. Person-centered research that uses mixed methods can be useful for documenting meaningful change by showing caregivers’ lived experience and how they adapt over time. Concern was expressed about whether person-centered measures would be considered important by decision makers and funders.

**What are the major barriers to conducting high quality respite-related outcomes research and how can we work together to overcome them?**

- **Conduct participatory studies.** Roundtable participants strongly advocated that researchers spend extended time in research settings in order to build trust with study participants, and discover and understand issues from their perspectives – involving caregivers in research “from the ground up.” To facilitate trust building, roundtable participants suggested involving cultural brokers: community leaders and stakeholders, particularly of
underrepresented groups (including families living in rural areas or experiencing poverty, racial/ethnic/cultural minorities, those with language differences). While investing in extended time to build relationships between researchers and caregivers and families was cited as important, roundtable participants cautioned that research measures need to be quick and efficient in order to decrease burdens on caregivers. Acknowledgement of the burden that complicated research measures may place on caregivers led to suggestions of ways researchers could give back to caregivers and families including paying caregivers for their participation and expertise; simplifying surveys and measures; and attending to ways that caregivers may receive a return on their investment and feel ownership in respite research.

- **Use qualitative and ethnographic methods.** A number of roundtable participants suggested the use of ethnographic and other qualitative methods in order to address issues related to person-centered and participatory issues described above. Qualitative research is conducted in familiar and comfortable settings, and it involves participants from the very beginning. Open-ended questions at the beginning of a study allow participants the opportunity to contribute to the content and direction of the study, rather than relying on a priori assumptions of what researchers believe is important to those receiving respite services. Qualitative research allows for, and is strengthened by, relationships between researchers and participants, and can help to overcome cultural barriers.

- **Rethink the influence of existing institutional funding frameworks on respite.** This discussion focused on the importance of studying respite outcomes in the context of Medicaid Waivers, the largest source of federal funding for respite, that require the need for an institutional level of care as a criterion for eligibility, presenting barriers and opportunities for respite and respite research. Issues of interest cited by roundtable participants include paying caregivers for care provision in lieu of institutionalization; quantifying caregiver provided services and service impacts; caregivers’ ability to use self-direction in choosing and paying for respite; differences between agency and independent providers; documenting workforce insufficiencies; documenting provider rates of pay; caregiver access and ability to use and self-direct respite services; and measuring resilience and self-efficacy among caregivers.

**How can we make respite-related outcomes research more relatable and transferrable to respite practice?**

- **Involve stakeholders in the conversation.** One roundtable participant stressed the importance of involving caregivers and families in agency policy recommendations and decisions that would affect those caregivers and families. Another participant suggested that it is important to build cross-sector coalitions (local chapters of The Arc, AARP, etc.) in order to advance sound and coherent respite-related policies. A third suggestion focused on integrating respite measures into existing systems, including Medicaid home and community-based services, and other long-term services and supports so that respite data would be viewed as relevant and important to those systems.
If resources were not an issue, what are the respite-related cost-benefit and cost-effectiveness research/evaluation questions that you would want answered?

- **Collect longitudinal data.** Roundtable participants cited the need for longitudinal data in order to better understand prevention of negative outcomes (such as visits to the ER or hospitalizations, employment issues, difficulties in family relationships, continuity of care) related to the time of the onset of respite services; the periodicity and duration of services; costs and value in terms of quality of life; proportional costs and savings related to keeping people in the home and community compared to placement in facility-based settings; and cost to businesses/employers employing caregivers or being able to employ someone with a disability for a longer period of time. Research typically captures a moment in time, and respite projects are often funded for only three to five years. However, it was noted by one participant that the impact of respite cannot be really understood without looking at outcomes occurring over longer periods – as much as 15 to 20 years. One strategy suggested for collecting meaningful and useful longitudinal data was creating data registries that track a person’s services and progress over time, starting data collection prior to the onset of long-term services and supports, such as respite, and collecting data on those caregivers who never received respite services. Incorporating sub-studies of respite into ongoing longitudinal studies was also suggested.

- **Coordinate data collection across systems.** Roundtable participants cited a tendency among researchers and evaluators to look at costs associated with a particular respite intervention in a single setting, which limits the generalizability of findings to other populations and settings. Participants also noted a tendency for agencies to focus on care receivers, who receive categorical services supported by categorical funding rather than on caregivers as the recipients and beneficiaries of respite. Roundtable participants stressed the importance of collecting data within and across agencies and systems, and noted the challenges of accomplishing this given: the different definitions, funding sources and data collection procedures used by those agencies and systems; existing boundaries around data sharing; and the perceived burden of data collection by program and agency personnel. The involvement of health economists in research and evaluation was cited as important to capturing cost effectiveness data. To overcome silos and centralize and broaden data collection efforts, recommendations were made to conduct a demonstration cross referencing electronic medical records with respite outcomes and adding respite questions to broader national population-
based studies, such as the Health and Retirement Study and the Baltimore Longitudinal Study.

- **Collect data on underrepresented populations and services.** Conducting respite research in the contexts of varying cultural beliefs and norms, and finding caregivers not already connected with respite services, were cited as important reasons for involving caregivers in research, and for designing respite research that would advance understanding of respite and its benefits among diverse consumers. Roundtable participants noted that informal respite services, and at times community-based services, are missed by existing data tracking systems. It was further noted that studies should include cost-benefits directly related to caregivers and families, as they are experienced and understood by caregivers and families.

- **Collect data with the intention of informing policy.** Roundtable participants advocated collecting data with the intention of informing policymakers about what services result in care receiver benefits; what cost benefits accrue to caregivers as well as care receivers, who are most often the eligible program participants; the worth of caregiver education in helping to make respite accessible and effective; the extent to which respite services prevent care recipient placement in long-term congregate care settings; and avoidance of emergency room visits and hospitalizations of both care receivers and caregivers. One participant noted the difficulty in understanding what data research studies need to collect in order to capture cost benefits. A number of participants commented on the difficulty of monetizing respite-associated outcomes such as quality of life, family resilience, or family choice about place of residence, and the difficulty of demonstrating that these changes are causally affected by having received respite, but noted that ways to monetize these outcomes should be explored. One participant warned that before proceeding, it was important to ensure that data collected be as accurate as possible and that measures be well defined and comparable across systems.

**What are the major barriers to conducting high quality respite-related cost-benefit and cost-effectiveness research and how can we work together to overcome them?**

- **Reconcile bureaucratic and categorical funding barriers.** Roundtable participants noted the inherent problems of figuring out and documenting the beneficiaries of respite and describing the essential components of respite in our complex system (these definitional problems are cited elsewhere in this document); clarifying for whom data are collected if the funding agency differs from the provider agency (who benefits and who pays); and the risk of collecting data that may have unwanted consequences for clients (if data do not show significant positive effects, for example) or for programs (if data show increasing costs, for example). Agencies may be reluctant to invest in data collection for the benefit of a partner agency, and accurate data collection and reporting across programs and agencies is challenging. Savings and costs documented in one partner program may not be similarly documented in another partner program.
• **Measure in human terms.** Roundtable participants noted that focusing on monetary savings as a primary goal, or seeing savings as having greater value than quality of life benefits accruing to caregivers, care receivers and families may lead to unintended negative consequences. Some participants advocated for quality of life studies on community and individual benefits – such as physical and mental health, social relationships, and economic/employment – even though these may be difficult to monetize. At the same time, suggestions were made to attempt to find ways to monetize quality of life and other related outcomes.

_How can we make respite-related cost-benefit and cost-effectiveness research more relatable and transferrable to respite practice?_

• **Involve study participants in research design and throughout the research process.** Roundtable participants advocated for the inclusion of stakeholders – including caregivers, care receivers, family members, providers, employers, and community members, as appropriate – throughout the research process, beginning with the study design and continuing through the dissemination of data written in inclusive and culturally appropriate, plain or jargon free language. One roundtable participant noted the importance of setting, suggesting planning meetings occur “over lunch” so that the process is more collaborative and less institutional and intimidating. Another participant recommended including stakeholders in reviewing research findings (known as “social validation” in qualitative research), and using jargon-free language in written documents in consideration of agency and government neophytes, “So that if a policymaker started the job yesterday, they would understand the significance of what was shared.”

• **Use research designs that capture the complexity of and relationships within the human social ecology.** Roundtable participants noted the importance of making sure that research methods employed in a study logically fit the human-social ecology being studied. For example, because rural and tribal populations are difficult to reach and track, strategies to connect with the community and open lines of communication are a prerequisite to meaningful and accurate data collection and interpretation. Note that this recommendation is a natural extension of involving participants in developing research designs from the outset.

• **Use academic partnerships and peer reviewed publications to leverage broader support.** Roundtable participants noted the importance of university publications for conveying an understanding of the benefits of respite and supporting these with empirical data. They also noted the importance of using publications to draw broader national interest, elevate awareness, and educate and advocate for respite.

• **Foster greater federal collaboration to broaden meaningful data collection.** Participants suggested that federal agencies such as the Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS), build on current efforts to create common data points for collection across multiple funding streams. It was recommended by
two participants that to ensure that caregiver and care recipient needs are considered when conducting and translating research, and even quantifying quality of life outcomes, ACL should consider involving the Patient-Centered Outcomes Research Institute (PCORI) in respite research given their focus on patient-centered outcomes.

**ROUNDTABLE 3:**
**RESEARCH SYSTEMS CHANGE THAT IMPROVES ACCESS**

_Discussion Leader: Susan Summers, PhD, ARCH_

**If resources were not an issue, what are the respite-related systems research/evaluation questions that you would want answered?**

- **Coordinate data across programs, agencies and systems.** Roundtable participants noted that data collection systems across programs and systems range from basic to sophisticated. There are numerous definitional and information gaps within and across programs and agencies making it impossible to know with certainty: how various programs define eligibility for respite services and how data collected reflect those varying definitions; whether eligible caregivers are being reached; whether caregivers are sufficiently supported in locating, receiving and retaining respite services; or whether there are sufficient numbers of respite providers available. To address these definition and information gaps, participants advocated bringing together all stakeholders at administrative levels to reconcile differences in respite definition; to identify recipients of respite services; to identify important data elements to collect across programs and systems; to identify gaps in services and key descriptive information about services from all stakeholders; and to assess the extent to which current efforts to track outreach and service delivery are effective and efficient.

- **Use “Ambassadors” to reach and better understand underserved populations.** States often use one state-level system to identify and funnel potential respite recipients to local level programs. However, some programs and populations are not connected with those systems and are un-served or underserved. For populations in rural areas, tribal areas, areas with little access to technology, and other underserved populations, participants advocated a focus on public awareness and outreach using “Ambassadors” to champion respite and to learn about local needs. Roundtable participants noted the need to assess and identify gaps in training for paid and unpaid volunteers, and for paid respite providers, and to document the kinds of respite they provide. Roundtable participants also noted the need to better understand the demographics of caregivers (spouses, parents, grandparents, youth) within service and geographic communities.
What are the major barriers to conducting high quality respite-related systems research and how can we work together to overcome them?

- **Capture baseline data and take stock of what exists.** Roundtable participants stressed the importance of understanding respite in total (definitions used, populations participating, services offered, for example) and in context (across funders and settings). Participants noted that programs and agencies need dedicated staff to collect baseline data, inventory populations and services, track processes, and document outcomes. One participant noted the importance of including respite among the array of key services case coordinators use to generate referrals for clients so that opportunities for support aren’t missed at critical junctures. Related to improving and documenting access to respite, it was noted that emergency respite services may not be connected with service systems so may be overlooked by referring agents, and may be undocumented in data collection efforts.

- **Identify and remedy structural barriers to access.** Roundtable participants spoke about the need to examine and further knowledge about structural barriers that make certain populations invisible to the respite system, or make them difficult to reach and serve. Participants noted that funding rules may influence service access, and that available funding for individual respite services may be based upon categorical eligibility requirements, resulting in narrowed options or exclusion of some populations. Some respite service options seem misaligned with the unique needs of populations in rural areas, for example, or with cultural norms of a particular community. Roundtable participants noted that respite is not recognized as a “key service” in some systems, and may be overlooked as a caregiver resource by referring agents. Participants also discussed the need to identify all possible respite service access points in order to locate and study populations needing or desiring respite, but who are invisible to the respite system, and to better understand barriers to access. Roundtable participants suggested that at these access points, or “touch points,” human “connectors” should be educated and supported so that they know about respite resources and know how to access and use respite resources and data collection systems. One participant noted that a lack of awareness may be a barrier to access in rural areas when caregivers don’t self-identify as caregivers. To better understand access to the respite system, and to help to build and evaluate a strong, equitable and accessible respite systems, one participant advocated making a concerted effort to raise awareness with doctors, nurse practitioners, nurses, and others in the health care system who could, in turn, educate and advocate for underserved populations, such as Asian-Americans and African-Americans, who are less likely to be asked by the medical community what they need to help care for their care recipient. Participants noted the need to collaborate in building and evaluating respite access through the private sector (insurance companies, for example) who may be willing to pay for respite in high risk populations to help correct disparities in health care, and to collaborate in building and evaluating respite access through doctors and clinics providing direct service.
• **Advocate for respite as a key service across diverse populations.**
  Roundtable participants noted that respite services tend to be undervalued among the array of services offered to persons with chronic mental and physical health conditions and disabilities, and noted further that undervalued services also tend to be underfunded for research. Participants believe, therefore, that educating and advocating funders about the importance and value will likely increase funding for research.

  *How can we make respite-related systems research more relatable and transferrable to respite practice?*

• **Form strong academic-program/agency partnerships.** A number of roundtable participants advocated forming and formalizing partnerships with academic researchers and institutions in order to design and conduct research and evaluation studies. One participant noted that it is important to include community colleges as partners because they may have a strong role in the provision of respite services and could create opportunities to build and expand respite systems by helping to train respite providers. Roundtable participants also advocated forming research partnerships with faith communities that recruit providers and address workforce issues, and research partnerships with health care systems and providers as essential to strengthening and evaluating access to respite systems. Participants suggested that information about the need for respite and access to respite services be collected by using additional billing codes in existing medical record keeping systems and encouraging the collection of accurate, high quality data.

• **Inform, educate, and advocate.** Roundtable participants noted the importance of designing and using research and evaluation studies to inform and educate within programs for quality improvement and informed decision-making; with the broad population to increase general awareness; with overlooked populations such as youth or grandparents who may be in caregiving roles; and with key decision makers who hold influence over policy changes within programs and systems.

**ROUNDTABLE 4: RESEARCH IMPROVING RESPITE PROVIDER COMPETENCE**

*Discussion Leader: Casandra Firman, MS, ARCH*

1. **If resources were not an issue, what are the respite-related provider competence questions that you would want answered?**

• **Define competence and identify core competencies.** Roundtable participants noted the importance of developing a working definition of competence. To develop a definition and identify core competencies, participants recommended gathering information from stakeholders using qualitative methods, such as focus groups. It was noted that qualitative methods are well suited to learning stakeholder perspectives, including
caregivers and providers, to understand individual values and beliefs, and to understand community, culturally, and regionally held values and beliefs. Participants also noted the importance of defining competence in ways that allow application of the definition and the core competencies to accommodate varying levels of care. For example, respite homecare training need not necessarily meet stringent state training mandates applicable to certified home health care providers in order to adequately meet caregiving needs in other caregiving settings. Roundtable participants noted that in identifying competencies, it is important to know critical information about care receivers including medical conditions; behavioral conditions; intellectual and developmental needs; and age, ethnicity, and racial background.

- **Explicitly link competencies with training efforts and work settings.** Roundtable participants noted the importance of becoming aware of all respite training efforts available in a state or region, and working to assure that some uniformity exists across provider training programs in order to measure competency across provider groups. Participants noted that working conditions and individual personal attributes also affect job performance, and that these are considerations to include in training.

**What are the major barriers to conducting high quality respite-related provider competence research, and how can we work together to overcome them?**

- **Explicate roles and responsibilities related to training.** Roundtable participants noted the importance of identifying where the responsibility for training lies across settings, across time, and across populations of caregivers, and populations of paid and volunteer providers. Participants noted that because caregivers possess unique knowledge of the care receivers’ strengths, preferences and needs, the caregiver’s role in training and coaching care providers is essential, and that role should be respected by providers. One participant noted that in a number of ways, caregiver/family training has shown better results than costlier professional training. Participants stressed the importance of articulating the caregiver’s role in training care providers, and of describing how this role and associated responsibilities and boundaries should be developed, promoted, and protected. The demands accompanying these roles and responsibilities should also be considered in the context of caregivers who frequently are already burdened by time-intensive caregiving tasks and who may be experiencing physical or emotional exhaustion. It was also noted that caregivers may have historical experience of interactions with professionals who were dismissive of the caregiver’s knowledge and experience. Participants noted that caregivers may not wish to take a primary role in training and should have autonomy in making that decision. Apart from the caregiver role in training, participants noted the importance of differentiating between paid and volunteer providers, and of considering the inherent demands associated with the roles when attempting competency evaluations. One participant noted that in Canada, a distinction is made in amount of training for volunteers and paid professionals, and that distinction may impose limits on volunteer training.
• **Take language and cultural differences into account.** Roundtable participants stated the importance of better understanding language and literacy barriers to recruitment, retention and training of a respite workforce. Participants also noted the importance of understanding how cultural barriers to the use of professional jargon and research-related terminology may exist and influence the efficacy of dissemination of research findings, and on teaching and learning.

**How can we make respite-related provider competence research more relatable and transferrable to respite practice?**

• **Create Communities of Practice.** Roundtable participants advocated creating and using Communities of Practice engaging in Action Research (research that occurs simultaneously with practice and is linked by critical reflection) that are inclusive of direct service programs and providers, caregivers and families, and academics/researchers/evaluators. To increase communication and coordination, Communities of Practice may engage in and evaluate the effectiveness of the following activities related to improving respite provider competence: training; dissemination of information; development and distribution of training videos; and establishing standards of competency families may use to screen, interview and hire potential caregivers. Communities of Practice, when they are inclusive, would also allow the development and dissemination of complementary materials, such as complementary training materials for caregivers and care providers that assure caregivers and providers “receive the same messaging.” It was noted that when care providers are also family members or friends, sharing competency requirements with them may be awkward or difficult, and that using videos to share information about competencies, or about health or disability conditions may be useful and should be evaluated.

• **Link competencies with funding and accountability.** Roundtable participants noted that using family participation and caregiver/family-generated data is essential in gauging the extent to which training goals, objectives, and outcomes are reached. To increase accountability, participants recommended that researchers and evaluators: design and use consumer satisfaction surveys to identify training issues; explicitly tie competencies to outcomes; monitor staff training issues through annual satisfaction surveys from employed and volunteer direct support staff, and through incident reports; invite families to participate in data monitoring in order to discover families’ understandings and interpretations that could improve provider competence; and collect longitudinal data to monitor staff retention. In order to increase the return of useful and meaningful data, participants recommended creating incentives that would tie the amount of data returned from programs to the amount of funding they receive.
Next Steps to Advance Respite-Related Research

At the conclusion of the roundtable discussions, the reactor panel presented key ideas discussed by each of the four groups. These ideas are incorporated in the summaries presented above. The reactor panel discussants also recommended one or two next steps researchers could take to advance the respite research agenda.

**Roundtable 1: Individual and Societal Outcomes**

Dr. Kirk shared that Roundtable One participants conveyed the importance of engaging, or re-engaging, with communities receiving respite — to know their needs rather than impose preconceived research dispositions or agendas upon research participants. Roundtable One participants recommended including more qualitative measures that would allow researchers to engage with research participants, to discover their perspectives and needs, and to help researchers have a better understanding of context and what the numbers derived from quantitative measures mean.

**Roundtable 2: Cost-Benefits and Cost-Effectiveness**

Ms. Peschin reiterated that Roundtable Two’s primary recommendation was to pursue longitudinal and population-based studies to best conduct cost-benefits studies, or to integrate respite information into electronic medical records. However, numerous policy and programmatic barriers to conducting cost-benefit studies are in play. For example, a reluctance to engage in cost-benefits research arises when one government agency funds the service, but the cost-benefits are reaped by another. Roundtable participants recommended that researchers seek and form partnerships, such as between the Administration for Community Living and PCORI, that can elevate research, and locate funding sources to support research.

**Roundtable 3: Systems Change Research to Improve Access**

Dr. Caldwell identified themes emerging from Roundtable Three that provide opportunities for research. One theme centered around the questions of who has access to respite and where service gaps exist. To advance research in this area, roundtable participants suggested that despite the different definitions of respite used by each government system, it would be beneficial to find at least a few common questions that could be asked about respite across various state funding streams and programs. Dr. Caldwell noted that a lot is currently being accomplished in outreach and improving access to respite, and those efforts could be enhanced through research partnerships with colleges and universities, and in particular with University Centers of Excellence in Developmental Disabilities, and through private sector partnerships, including insurance companies and physicians.

**Roundtable 4: Provider Competency and Training Needs**

Dr. Robinson Rosenberg stressed, in addition to the need for increased funding for research, the importance of compiling and organizing the information we currently have available regarding care provider competence, and identifying not only what skills and approaches to skill building work best to engage and create a workforce, but also what values and beliefs are important to provider competence.
Summary Findings and Research Considerations

This final section of the Research Summit Report presents general findings and considerations from the information presented throughout the two-day Summit. Information was gathered from the oral presentations made during the topical sessions, the chat thread that was live throughout the entire Summit, comments from members of the reactor panels responding to each day’s series of presentations, and the breakout roundtable discussions on day two, presented in detail in two other sections of this report. In this section, we identify common threads from all presentations and discussions throughout the Summit.

As previously noted, this Respite Research Summit was originally intended to be a daylong, in person meeting. However, the COVID-19 pandemic necessitated canceling the in person meeting and replacing it with two one-half day virtual sessions. Reliance on online technology provided an opportunity to document in real time the participation of Summit attendees by recording the chat thread that was live throughout the Summit. Posted chats demonstrated that researchers and other participants assimilated information presented during the Summit and used their own and each another’s knowledge in ways that broadened and deepened discussions and understanding of respite research issues.

The breakout roundtable sessions provided additional opportunities to address in greater depth one of four issues presented in the Expert Panel’s Report that served as the foundation for convening the Research Summit. A burgeoning recognition of the value of respite research on developing better models of respite and of the responsibility to demonstrate evidence of the value of respite was evident among Summit participants.
**Progress in Advancing the Respite Research Agenda**

Presenters shared how their ongoing research is consistent with the recommendations of ARCH's Expert Panel, influenced by those recommendations, or both, and demonstrated that progress is being made to enhance a meaningful evidence base for respite. While some researchers focused on particular subgroups of caregivers and care receivers (e.g., older adults with dementia and their caregivers, medically fragile children and their caregivers), many shared concerns affecting respite use and quality emerged across all types of caregivers, care receivers and families. These shared concerns include limited access to respite; ensuring meaningful use of respite time; engagement; respite provider competence; the need for strengths-based outcomes research; racial, cultural, ethnic sensitivity of available respite; and adapting respite service models during a pandemic, among others. Some of the researchers are focused directly on addressing challenges, such as increasing provider competence through innovative training approaches; applying technology to improve access to and quality of respite; assisting caregivers with paying for respite; and the resultant positive effects of using respite on caregiver health, family stability, and other quality of life measures. Some researchers are focused on basic questions such as direct connections between respite and caregiver well-being; between provider competence and caregiver well-being; and determining the “effective dose” to produce a measurable outcome attributable to respite. In addition, we learned that other organizations such as the National Adult Day Services Association, Shared Care Scotland and the BREAK Exchange at the University of Wisconsin-Madison School of Nursing are pursuing respite agendas that align with the agenda of ARCH’s Expert Panel on Respite Research, providing promising opportunities for national and international collaborations.

**Defining and Describing Respite**

Permeating many conversations throughout the Summit was the issue of defining respite. Throughout the entire Summit and across all four breakout topical sessions, presenters and participants discussed the fact that definitions of respite may differ by particular service populations, the mechanisms by which respite is delivered, and the funders supporting respite services. The Expert Panel definition acknowledges the parochial interests of respite providers and programs using different models and serving different or varying service populations across the lifespan, and across all types of service and mechanisms for service delivery. According to that definition, any caregiver’s time away from caregiving responsibilities is considered to be respite, and respite is still a service primarily delivered to and for the caregiver. Additional beneficiaries of respite can and should be included in research studies of respite. This construction is made clear in the Expert Panel’s definition of respite. However, Summit participants struggled to reconcile existing definitions used in categorically funded settings and with respite service delivery partners. Participants also frequently used the term *define* respite when citing the need to *describe* the essential components of a given respite model. Dr. Gaugler’s presentation provides support for the importance of describing essential elements of respite models in respite research in addition to defining respite.

**Funding Research**

The large majority of attendees were cognizant of the difficulties of obtaining funding to conduct high-quality prospective research on respite. There was general agreement that potential funders in both government and the private sector should be identified and encouraged to fund respite program development and attendant respite research. Focused advocacy should be applied to funders when respite programs or models have been identified as being innovative and effective so that they can be advanced to
their next level of development by sufficient funding on appropriate research.

Discussions about support for respite research included not only ways to increase available funding, but also how institutionalized funding has influenced the provision of respite and respite research designs, sometimes to their detriment. It was noted that funding sources may require that certain measures be tracked (e.g., cost savings) or drive decisions about the respite services themselves (e.g., limiting who can provide respite, where it can be provided, and how much can be provided at a given level of funding, etc.). The result can be the stifling of inquiry and independent thinking, and inadvertent (or even deliberate) restrictions on what can be studied. Thus, even if the studies have sufficient funding, institutional funding frameworks can diminish the value of the studies and limit their generalizability.

**Measures and Measurement**

Regardless of the complexity of a research question, or the methods employed to address that research question, the selection of measures is quintessential to conducting research. There were numerous comments on the appropriateness of measures, both traditional and innovative, and not surprisingly, there were numerous deliberations and suggestions about how and when to measure outcomes associated with respite.

There was general agreement that researchers should focus on Quality of Life measures (for caregivers, and for care receivers/families as appropriate) and that positively worded or strengths-based Quality of Life measures need to be identified and tracked during respite research. Similarly, there was agreement on avoiding deficit-based measures that have been routinely employed. It was further argued by some that these measures should relate to the ways that caregivers (as well as care receivers/family members, as appropriate) define quality-of-life, rather than applying instrument-driven measures that may be relevant to some, but not all caregivers. Goal attainment scaling (GAS) was mentioned as a measurement strategy that might be used, in part, to address this issue. GAS is a measurement technique wherein the caregiver specifies an individualized outcome that he or she wants to achieve, and then measures progress towards that outcome/goal using a Likert-type subjective scale. GAS has very high content and face validity to the caregiver, the trade-off being generalizability across caregivers and/or across respite research studies.

An issue closely related to measurement is the cost of conducting research in the first place. Obtaining reliable, valid and meaningful person-centered data can be very expensive. It was suggested that paying caregivers and even care receivers for their participation in the research study would likely increase the reliability of the data. As well, it was suggested that caregivers and care receivers can and should be engaged (and possibly remunerated) to offer their expertise or opinions during the interpretation of the data, quite likely increasing the validity and meaningfulness of the findings.

Another suggestion to improve the reliability of respite research data is to strive for automated data collection whenever possible, and to place a very low-burden on programs and participants when it is not possible. Asking caregivers receiving respite to participate in data collection is a “big ask” given their caregiving duties. Emergency respite services (e.g., crisis nursery childcare) present even greater challenges to collection of reliable data, in part due to the caregiver likely being in a state of crisis or physical/emotional distress.

“Goal Attainment Scaling is a way to get to ‘What Matters’ to people in regard to their care.”
Rani E. Snyder, MPA

“**Our outcomes approach includes strengths-based personalised outcomes for both caregivers and cared for persons. It’s about engaging with the family to find out what matters to them and what they hope for and then reviewing over time.”**
Emma Miller, PhD
Culturally Appropriate Research with Hard-to-Reach or Serve Populations

Many Summit participants expressed concern about the need for researchers to address cultural, racial, ethnic, economic and other variables that often inhibit “inclusiveness” in research. It was suggested that reaching these populations, and thereby broadening the evidence base for respite, might be achieved in part if researchers endeavored to improve access to research by involving caregivers and care receivers in the design of studies, and by engaging them to participate in data collection rather than simply serving as research subjects. Others suggested that inclusiveness could be improved by increasing the use of more qualitative methods and participatory approaches to respite research in order to better understand and describe respite, per se, as perceived by hard-to-reach or serve populations. It was argued that results from studies employing these methods and approaches may also better enable respite researchers to conduct more meaningful quantitative research studies.

In addition to cultural, racial, ethnic and economic variables, a discussant raised the issue of too little research focusing on adults with disabilities and their caregivers. Adults with physical or intellectual/developmental disabilities may require care for many years from family caregivers for whom respite may be one of only a few ameliorative services. Yet too little is known about this population of care receivers or the needs of their caregivers.

Summit participants representing provider communities suggested that researchers should work with participating respite programs to develop research “ambassadors” who can readily access members or groups of hard-to-reach populations to inform and educate them about both respite and respite research. Informing and educating needs to be done in terms and language that are accessible, respectful, and not off-putting to members of these populations. This is especially important in settings or situations where cultural norms suggest that caregivers may not be likely to self-identify as caregivers, thereby rendering the very idea of respite vague or confusing.

Rethinking Cost-Effectiveness and Cost-Benefit Studies

Cost studies, particularly cost-benefit studies, frequently rely on longitudinal data. In prospective research it may be necessary to track caregivers and care receivers for months if not years in order to obtain measures typically used to attribute costs and cost savings to selected respite services and outcomes. Historically, outcomes associated with incurring or avoiding cost have also been associated with negative outcomes. For caregivers these might include negative physical or mental health outcomes, deterioration of quality-of-life, or loss of employment, among others. For care receivers these negative outcomes might include emergency room utilization, institutional placement, and some of the same negative outcomes experienced by caregivers relating to health, mental health, quality-of-life, etc. In fact, the only slightly broader issue of general health care utilization by caregivers and care receivers, perhaps even analyzed as dyadic units of analysis, should be undertaken. Methodologically these studies can be problematic due to the requirement to detect and measure the absence of occurrence of a negative outcome, and they often rely on the tenuous logic of attributing the absence of the negative outcome to the presence of respite. Though many studies have attempted to establish these connections, few have provided meaningful or convincing evidence. Looking at health care utilization by caregiver and care receivers as a dyadic unit of analysis might shed new light on these issues of cost and well-being of dyadic partners.

“In the pediatric complex care world there have been anecdotal shared experiences with hospitalizations because of caregiver health (which is an important natural experiment for why respite is essential for sustained caregiving).”

Sarah Sobotka, MD
While systems level cost savings due to respite might be nice to achieve, much of the conversation about cost studies involved rethinking the basis and focus of cost studies to include monetary cost to the caregiver and family required to enable the provision of in-home or non-institutional care (e.g., out-of-pocket costs related to caregiving such as transportation, loss of income, or even the cost of non-reimbursed respite services). A number of Summit participants suggested that monetary savings should not supplant quality of life benefits, even when quality-of-life may be difficult to monetize. It was suggested that improving or maintaining the quality-of-life of caregivers and supporting their resiliency has intrinsic value that may well be worth the costs incurred, irrespective of any potential cost savings due to the provision of respite. However, given the persistent demand among policymakers for documentation of cost-benefits, others suggested that pursuing strategies to monetize quality of life and other outcomes should be investigated by researchers as long as we can assure that the data collected are accurate and that study parameters are well-defined.

Historically respite has been viewed, if not marketed, as a mechanism to reduce systems-level costs of providing government-funded care to dependent populations. It may be difficult to disassociate respite research quickly or completely with this premise. But future cost studies should at least include attention to caregiver- and family-centered costs associated with providing respite as a counterbalancing argument to a desire to decrease healthcare costs.

Workforce Development and Access to Respite

Although it is generally acknowledged that the efficacy of respite is directly linked to the competencies of the respite providers, there is scant research available on respite provider competence, and how the acquisition of competencies relates to quality of care, access to care, compensation, and even regulatory issues such as credentialing and licensure. Clearly this is an area of need for respite research. Other research questions related to acquisition of competencies and workforce development relate to the availability of training curricula, and even the fundamental question of whether or not training provided by the caregiver and family is sufficient or even more (or less) effective than other methods, formal or otherwise.

It was noted that questions relating to cultural and language issues raised in other content areas are also highly relevant to research on training and the acquisition of competencies needed to provide good respite care.

Utilizing Research Findings to Inform and Improve Policy and Practice

Summit chat threads and roundtable conversations revealed an increased understanding among non-researcher attendees of the importance of well conducted research studies appearing in peer reviewed, reputable journals, in that strong research findings increase the credibility of recommendations for supporting or changing policy and practice. After all, the prerequisite for declaring a service model to be “evidence-based” is having multiple, peer reviewed journal articles demonstrating efficacy. This growing understanding and acceptance of the need for high quality research on respite is likely fueled by the simultaneously increasing understanding that government agencies only want to fund evidence based practice models. The only way to establish an evidence base is to conduct the requisite research.

In a broader sense, contributing to the evidence base of respite requires studies that are well designed and conducted, and designing and conducting studies require specialized skills and talents. Several established researchers suggested that respite programs interested in participating in respite research studies, or even conducting their own respite research, should affiliate with academic researchers or research centers where methodologist’s and statisticians can assist in the design and execution of those studies.
Another suggestion to improve not only the ability to conduct respite research but to disseminate findings was borrowed from other disciplines: develop communities of practice across disciplines, respite programs and providers, caregivers/care receivers and families, researchers/evaluators; and assist programs and providers to be “research-ready.” These communities of practice not only can provide broad support and advocacy for funding of research, they can also facilitate execution of research studies by being ready to participate. After studies are completed, the same communities of practice can be marshaled to disseminate research findings in order to improve policy and practice. Consistent with suggestions in other topical areas, a number of Summit participants emphasized the need to include caregivers and families in these communities of practice because recommendations derived from research may directly affect their access to respite and their satisfaction with respite care.

**The Impact of COVID-19 on Respite**

COVID-19 has had an ongoing and serious impact on the delivery and receipt of in-person respite. There is a critical need for research on the impact of COVID-19 on respite access, utilization, satisfaction, caregiver/care receiver/family outcomes, and the practicality of traditional respite services.

Technology made the Summit possible, and several presentations discussed the use of technology for training and supporting caregivers, respite providers and respite programs. The potential for technology to enhance or simply make possible the provision of respite during the current COVID-19 pandemic, or future epidemics or pandemics, was a constant and recurring theme. It was suggested that respite researchers should examine the full breadth of technological options for delivering respite to caregivers, some of whom due to COVID-19 cannot or will not receive in-person respite. Consistent with conversations and other topic areas, but perhaps even more important with respect to accessing technology, the issues of culture, ethnicity, race, social and economic circumstances, rurality, and other factors may well limit the application of technology to solving some of the problems in the delivery of respite caused by the pandemic. Depending on the issues, technology may facilitate the ability to conduct research, or inhibit and complicate it as it has sometimes complicated the delivery of respite.

Besides issues of technology, there are fundamental questions that can be addressed by research such as: How are caregivers doing now, compared to pre-pandemic? Are there features of “remote respite” that should be retained after the pandemic eases? Are there other types of alternative respite, such as weekly phone check ins, outside visits at the family home, care packages, etc., that are having the desired impacts on caregiver and care recipient well-being? Can we identify specific barriers to remote or alternative or non-traditional respite options, and develop strategies to overcome these? It was suggested that researchers should explore the counterfactual: are there features of online/remote or alternative respite that may increase access and utilization; affect costs in positive ways; positively affect quality-of-life or other indicators in ways as yet unknown and unanticipated? And, since congregate and facility-based care increases the likelihood of COVID-19 or other disease transmission, is there a case to be made for increasing the focus of respite research on alternatives to in-person respite?

“The unintended outcomes are often as important as those that are anticipated which is why we need to stay open minded."

Emma Miller, PhD
Conclusion

The 2020 ARCH Respite Research Summit was convened to gauge the progress made in implementing the recommendations of the ARCH Expert Panel on Respite Research to develop a research agenda for respite, and to review the current status and activity level of respite research.

Although researchers must carve out certain areas of inquiry or certain features of respite in order to focus their research, there was general agreement among researchers and other participants that focusing on the outcomes attributable to respite is essential for developing effective respite models, improving funding for both respite research and service delivery, and for improving the well-being of caregivers, care receivers and their families, in addition to informing public policy. Many attendees from without the community of researchers expressed a new appreciation for the value of well conducted research studies to the development of an evidence base for respite.

The Findings section organizes key ideas shared by presenters, and by roundtable participants, into categories that readers will find familiar when discussing respite research or respite effectiveness: funding, measures and measurement, culturally appropriate research, costs, among others. No attempt has been made to organize the findings in order of presumed importance, ease of conducting research, imputed value-driven or other, perhaps biased, strategies. Some of the findings will likely lead to easily identifiable research questions; others may be more complex, or address interconnected variables of interest that require a series of studies to gain understanding. We have presented them so that readers can be informed and appreciate the breadth of findings that can and should be part of the respite research agenda going forward. The findings, derived from both the active research community and all other constituencies represented at the Summit are gratefully received, and they will inform the work of the newly formed Committee for Advancement of Respite Research (CARR). Using these findings to stimulate and guide serious deliberations, the CARR will advise ARCH on the execution of its respite research initiative going forward.

ARCH is grateful to all who participated in the Summit, contributing their time, sharing their ideas, their wisdom, their questions and their experiences relating to respite research. Knowledge gained by ARCH during this Summit is invaluable to our efforts on behalf of the respite community.
Resources

3. archrespite.org/respite-research-summit/videos
4. https://archrespite.org/respite-research-summit/videos#Welcome
5. https://archrespite.org/respite-research-summit/videos#Background
6. https://archrespite.org/respite-research-summit/videos#Focus
7. https://archrespite.org/respite-research-summit/videos#Aligning
8. https://archrespite.org/respite-research-summit/videos#Outcomes
11. https://archrespite.org/respite-research-summit/videos#Practice
12. https://archrespite.org/respite-research-summit/videos#Future
14. https://winrs.nursing.wisc.edu/
15. https://thinkculturalhealth.hhs.gov/clas
23. https://www.nadsa.org/research/

References to Internet websites (URLs) were accurate at the time this report was written. If you find an inoperable link, please notify ARCH.
29. https://breakexchange.wisc.edu/
30. https://archrespite.org/expert-panel-respite-research-recommendations
34. http://tlc.gslc.utah.edu/
42. https://nrrs.ne.gov/respite/data/index.php
45. https://www.youtube.com/watch?v=i_6x6NKWmuo
47. https://www.ohio.edu/chsp/rehab/communication-sciences/respite-program
48. https://www.iihhs.jmu.edu/precioustime
49. https://www.socwork.jmu.edu/Caregivers/
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Appendix

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