



PARTICIPANT PACKET

September 29 and 30, 2020

ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER | ARCHRESPITE.ORG



A Project of the Chapel Hill Training-Outreach Project, Inc.

September 29, 2020

Dear Summit Participants:

Welcome to the first ARCH Respite Research Summit!

This event marks the culmination of an ARCH initiative to advance a respite research agenda first put forth in 2015 by the ARCH Expert Panel on Respite Research. The Panel's final report, [Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders](#), challenged us to stimulate high quality research that would translate into much needed support for family caregivers across the lifespan.


Over the next two days, we are convening a prestigious group of expert researchers in the respite and caregiving field who will share their timely research and help us evaluate the progress we have made in building an evidence base for respite. We will also explore the changing respite landscape resulting from the COVID-19 pandemic, as well as the broad diversity of family caregivers and care receivers, to ensure that future research and the services that result are as responsive as possible to families' needs.

We are excited that a diverse group of Summit participants from the U.S. and internationally, including academicians, policy makers, advocates, providers, and funders have come together to share their tremendous knowledge and experience. Most importantly, all of you will help us identify next steps in building a path to greater knowledge about the benefits of respite, improving strategies for making respite more acceptable and available to family caregivers, and replicating best practice models in respite innovation, safety, and quality.

Many thanks to our sponsors, the John A. Hartford Foundation and the Wareheim Foundation for their generous support of this event, and to the Administration for Community Living for ongoing guidance and support.

Thank you all for joining us. We look forward to a lively and worthwhile discourse that will help us lay the course for future knowledge and action in the respite and caregiving field.

Sincerely,


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

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**Note: All of the documents included in the Participant Packet are also available for download from the Respite Research Summit webpage at <https://archrespite.org/respite-research-summit>.*

Virtual Research Respite Summit September 29 and 30, 2020
ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER | ARCHRESPITE.ORG

AGENDA for VIRTUAL ARCH RESPITE RESEARCH SUMMIT

DAY 1 - September 29, 2020

With generous support from the John A. Hartford Foundation

1:00 – 1:30 PM*	Welcome	<ul style="list-style-type: none"> Jill Kagan, MPH, Director, ARCH National Respite Network and Resource Center (ARCH) Rani Snyder, MPA, Vice President, Program, The John A. Hartford Foundation Lori Stalbaum, Administration for Community Living, Administration on Aging, U.S. Department of Health and Human Services
1:30 – 1:45	Background on ARCH Expert Panel on Respite Research Report	Ray Kirk, PhD, ARCH Senior Consultant
1:45 – 2:00	Focus on Equity and Diversity in Respite Research	Kim Whitmore, PhD, RN, University of Wisconsin - Madison, School of Nursing
2:00 – 2:45	Aligning Research Agendas with Research Recommendations <ol style="list-style-type: none"> 1) Research Agenda of the National Adult Day Services Association 2) Scoping review of the evidence base on short breaks in the United Kingdom 3) BREAK Exchange 	<i>Moderated by Jill Kagan, ARCH</i> <ul style="list-style-type: none"> 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
2:45 – 3:00	Break	
3:00 – 4:15	Research on Respite Outcomes and Access <i>Moderated by Casandra Firman, MS, ARCH National Respite Network</i>	<ul style="list-style-type: none"> 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 Long-Term Care (LTC) and Aging & Professor, 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 Pediatric Programs, University of Chicago
4:15 – 5:00	Reactor Panel and Group Discussion <i>Facilitated by Kim Whitmore, PhD</i>	<ul style="list-style-type: none"> 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 Pediatrics and Psychiatry, University of Colorado School of Medicine

***Please note, all times are Eastern Daylight Savings Time**

DAY 2 - September 30, 2020

With generous support from the John A. Hartford Foundation

1:00 – 1:15 PM*	Welcome, Recap and Agenda for the Day	Kim Whitmore, PhD, RN, University of Wisconsin - Madison, School of Nursing
1:15 – 2:00	Using the Expert Panel Framework <i>Moderated by Ray Kirk, PhD, ARCH</i>	<ul style="list-style-type: none"> Tiffany Washington, PhD, John A. Hartford Geriatric Social Work Scholar, Associate Professor, University of Georgia School of Social Work
2:00 – 3:00	Practice Research and Evaluation <i>Moderated by Casandra Firman, MS, ARCH</i>	<ul style="list-style-type: none"> 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
3:00 – 3:15	Break	
3:15 – 4:15	Roundtable Discussions Summit participants will break into groups to address Expert Panel Key Recommendations: 1) Individual, family and societal outcomes research; 2) cost-benefits and cost-effectiveness research; 3) systems change research to improve access; and 4) competency and training needs of providers.	<i>Facilitated by Kim Whitmore, PhD, RN, University of Wisconsin – Madison, School of Nursing; Casandra Firman, MS, Ray Kirk, PhD, and Susan Janko Summers, PhD</i> Read More about Expert Panel Key Recommendations
4:15 – 4:45	Roundtable Reports and Recommendations for Future Research <i>Facilitated by Kim Whitmore, PhD, RN</i>	<ul style="list-style-type: none"> Joseph Caldwell, PhD, Senior Scientist and Director, Community Living Policy Center, Lurie Institute for Disability Policy, Brandeis University Ray Kirk, PhD, ARCH Susan Peschin, MHS, President and CEO, Alliance for Aging Research Cordelia Robinson Rosenberg, PhD, RN, Professor Pediatrics and Psychiatry, University of Colorado School of Medicine
4:45 – 5:00	Wrap-Up and Next Steps	Ray Kirk, PhD, ARCH

****Please note, all times are Eastern Daylight Savings Time***

This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



ARCH RESPITE RESEARCH SUMMIT PRESENTERS

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

Dr. Caldwell has over 25 years of experience in the fields of aging, disability and family caregiving as a researcher, policy expert, and family member. His research has focused on supports for aging caregivers of adults with developmental disabilities, outcomes of person and family-directed supports, and promising practices in family support across the lifespan and disability populations. Prior to Brandeis, he worked to advance federal long-term services and supports policy at the National Council on Aging, Association of University Centers on Disabilities, and as a Joseph P. Kennedy, Jr. Fellow on the Senate Health, Education, Labor, and Pensions Committee. Dr. Caldwell has served on the boards of the National Alliance for Caregiving and Consortium for Citizens with Disabilities. He currently is an appointed member of the RAISE Family Caregiving Advisory Council.



Thomas V. Caprio, MD, MPH, MS, FACP, AGSF, FAAHPM, Professor of Medicine, Psychiatry, Dentistry, Clinical Nursing, and Public Health Sciences, University of Rochester Medical Center, Rochester, New York

Dr. Caprio serves as the Chief Medical Officer for University of Rochester Home Care and the Medical Director for the hospice program. He serves as director of the Finger Lakes Geriatric Education Center at the University of Rochester and oversees the federally-funded HRSA Geriatric Workforce Enhancement Program which provides education and training related to geriatrics and dementia care for health care professionals and family caregivers. Dr. Caprio is Past-President for the National Association of Geriatric Education Centers and the National Association for Geriatric Education as well as the Past-President of the State Society on Aging of New York. In 2008, Dr. Caprio served as the project director for the Long-term Care Council New York Survey of Caregiver Support Services which implemented a statewide survey in partnership with the New York State Office for the Aging to identify gaps in services and make policy recommendations. Since 2012, he has served as the program evaluator for the federal Administration on Community Living-funded New York State Lifespan Respite Program, which implemented a statewide caregiver network, and develop a coordinated system and database of respite care to meet the needs of individuals and their family caregivers across the age and disability spectrum.



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

Joseph Gaugler is the Robert L. Kane Endowed Chair in Long-Term Care & Aging in the School of Public Health Division of Health Policy and Management. His research examines the sources and effectiveness of long-term care for persons with Alzheimer's disease and other chronic conditions. An applied gerontologist, Dr. Gaugler's interests include Alzheimer's disease and long-term care, the longitudinal ramifications of family care for persons with dementia and other chronic conditions, and the effectiveness of community-based and psychosocial services for older adults with dementia and their caregiving families. Underpinning these substantive areas, Dr. Gaugler also has interests in longitudinal and mixed methods.



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

Susan Jenkins is the Director of the Office of Performance and Evaluation for the Administration for Community Living, US Department of Health and Human Services. She has 25 years of program evaluation experience. She is ACL's Evaluation Officer, Chief Data Officer, and Performance Officer and is an officer of the Eastern Evaluation Research Society (EERS). She serves on the Federal Interagency Council for Evaluation Policy (ICEP), a task force the American Evaluation Association to advise the AEA Board on the future of funding in evaluation, and teaches a program evaluation class in the School of Public Administration at American University. In 2018-2019, she was on detail with OMB contributing to guidance and evaluation standards related to the Evidence Act of 2018. Previously, she was an evaluation program specialist with the US Peace Corps overseeing international evaluations. She has worked as government contractor conducting evaluation projects with the Office for Juvenile Justice and Delinquency Prevention, the Bureau of Justice Assistance, the Office of National Drug Control Policy, the Substance Abuse and Mental Health Services Administration and the National Cancer Institute.



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

Emma is a registered Social Worker, with ten years' experience working in area teams. Emma obtained her PhD in Sociology in 2004. Since then she has worked in research, policy and practice on developing and embedding personal outcomes in practice, ensuring that what matters to people who use services and carers is at the centre of decision-making, at individual and collective levels. Emma is a member of the Short Breaks Research & Practice Development Group, with members in Scotland and Wales. The group recently completed a review of evidence for respite and short breaks, hosting a video linked conference in May 2020 between the two countries to further progress the research agenda. Emma is also a member of the Eurocarers Research Working Group, connecting researchers and carer support organizations across many EU countries.



Susan Peschin, MHS, President and CEO, Alliance for Aging Research, Washington, D.C.

Susan Peschin, MHS, is president and CEO at the Alliance for Aging Research, the leading national non-profit organization dedicated to accelerating the pace of scientific discoveries and their application to improve the experience of aging and health. Since 2012, Ms. Peschin has been a driving force in the growth and success of the organization. As a thought leader on many aging-related issues, she has led the Alliance in efforts to: boost older adult immunization rates; increase NIH Alzheimer's disease and aging research funding; raise awareness of geriatric cardiac issues; develop *Talk NERDY to Me (NERDY-Nurturing Engagement in Research and Development with You)*, a PCORI-funded, older patient and family caregiver research engagement network; address costs of healthcare and value frameworks; and reform Medicare treatment access issues. She participates in major industry and policy symposiums around the country each year and has published opinion pieces in news outlets nationwide. Ms. Peschin currently serves on the Boards of Heart Valve Voice U.S. and the King Farm Neighbors Village; and on the National Advisory Council for the National Institute on Aging at the NIH. Ms. Peschin earned a B.A. in Sociology from Brandeis University, and a M.H.S. degree in Health Policy from the Johns Hopkins University Bloomberg School of Public Health.



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

From 1993 through June of 2015, Dr. Robinson Rosenberg was Director of JFK Partners, an interdepartmental program of Pediatrics and Psychiatry at the CU School of Medicine. In this role she was responsible for providing leadership and direction to an interdisciplinary professional staff of over 40 faculty members. She has worked in the field of early intervention for children with developmental disabilities as a clinician, researcher and educator of personnel from multiple disciplines since 1973. She has been the PI on over 40 federally funded demonstration, training or research projects in the field of Developmental Disabilities and Intellectual Disabilities.

Work since 2001 has been focused on Autism Spectrum Disorders. She is Co-Principal Investigator on the CDCP funded Colorado CADDRE and Surveillance projects. She is PI on the Colorado site of the SPARK study. She Co-chairs Colorado CANDO (Colorado Autism and Neurodevelopmental Disorders Options), an ad-hoc committee of the Colorado Developmental Disabilities Council. She also serves as the evaluator for Colorado Inclusive Higher Education Pilot Program. Most recently she has joined Colorado's Employment First Action Partnership.



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

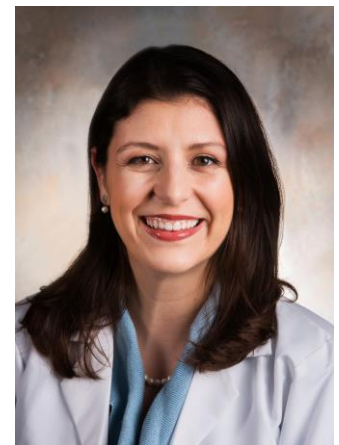
Rani E. Snyder, MPA, is Vice President, Program at The John A. Hartford Foundation. Ms. Snyder has over 25 years of experience working with preeminent health care institutions across the nation improving the care of older adults, identifying and guiding health care programs that have set the standard for medical best practices, increased medical education opportunities, and maximizing resources to improve health care broadly. She brings that experience to The John A. Hartford Foundation where she coordinates initiatives that foster collaboration among academic institutions, hospitals and health care providers to build Age-Friendly Health Systems, support family caregivers, and improve serious illness and end-of-life care. She is also chair of the board for Grantmakers in Aging, a membership organization comprised of philanthropies with a common dedication to improving the experience of aging, a fellow of the New York Academy of Medicine, and previously served as a Volunteer Long-Term Care Ombudsman for the State of Nevada Aging and Disability Services Division.



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 Pediatric Programs, University of Chicago

Dr. Sarah Sobotka is Assistant Professor of Pediatrics in the Section of Developmental and Behavioral Pediatrics, Department of Pediatrics at the University of Chicago. Dr. Sobotka is also Associate Program Director of the Developmental and Behavioral Pediatrics Fellowship Training Program at the University of Chicago and Associate Director of the IL Leadership Education in Neurodevelopmental and Related Disabilities (IL-LEND) program.

Dr. Sobotka's research utilizes mixed methodology to study patients whose disabilities are a sequelae of medical complexity, particularly after prolonged critical illness. She studies trends and is interested in creating efficient and effective healthcare service models which minimize hospitalizations and provide support for families of children with mechanical ventilation dependency. As a Developmental Pediatrician, she is primarily interested in how to enable children at risk for severe disabilities to reach their developmental potentials. Dr. Sobotka is committed to creating innovative care coordination models to support high risk children and complex care teams.



Dr. Sobotka received her medical degree and a master's degree in public health sciences for clinical professionals from the University of Chicago. Her clinical training includes pediatric residency at Children's Memorial Hospital, now Lurie Children's Hospital/Northwestern Feinberg School of Medicine, and fellowship training in Developmental and Behavioral Pediatrics at the University of Chicago. Dr. Sobotka has received research funding from the National Institutes of Health (NIH): the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the Health Resources and Services

Administration (HRSA), as well as several internal awards at the University of Chicago. In 2019, the University of Chicago Department of Pediatrics selected Dr. Sobotka to receive the Early Career Peter Huttenlocher Award for Scholarly Excellence.

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

Sarah Swanson is an Assistant Professor at the University of Nebraska Medical Center's Munroe-Meyer Institute, the state's federally-designated University Center for Excellence in Developmental Disabilities (UCEDD). She has her Master's in Public Health and has two children with special healthcare needs. Sarah is interested in conducting translational research and engaging people with disabilities and families to shape programming and drive policy changes. She has worked with state leadership to evaluate the impact of respite programs, created a training program for respite providers, and developed programming to educate employers on the needs of working family caregivers and how they can best support these employees. Finally, she manages a program that places Family Navigators (parent leaders who have children with disabilities) in primary care clinics to connect families to early intervention services and help them navigate medical systems, school systems, and community resources in order to improve supports to family caregivers and overall health outcomes. In 2019, she served as a virtual fellow at the Association of University Centers for Disabilities (AUCD) where she partnered with their policy team to create a policy brief on "Best Practices and Innovations in Medicaid Managed Long-Term Services and Supports"- which provided specific examples of states who have created innovative programs to support family 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

Rebecca Utz is an Associate Professor in the Department of Sociology at the University of Utah, where she is also a faculty affiliate in Gerontology and Nursing, Director of the "Health, Society & Policy" program (undergrad interdisciplinary major), and Co-Director of the "Consortium for Families & Health Research" (C-FAHR). She is an interdisciplinary life course scholar committed to the study of health and aging, with particular research interests related to how aging families cope with end-of-life transitions such as bereavement, caregiving, and palliative care planning. Currently, she is PI on an R01 project funded by the National Institute on Aging (NIA) to develop and test an online intervention to maximize dementia caregivers' use of respite time.



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

Dr. Tiffany Washington joined the University of Georgia School of Social Work faculty in 2013 after completing her PhD at the University of North Carolina at Chapel Hill. She publishes in aging, health/minority health, and caregiving. In the area of chronic kidney disease, Dr. Washington's research examines the relationship between psychosocial factors and self-management behaviors. In addition, her work is concerned with factors that facilitate and impede the uptake of health promotion intervention in dialysis facilities. In the area of caregiving, Dr. Washington designed and pilot-tested a caregiver respite program in which student volunteers deliver in-home respite visits to caregivers of persons with dementia. Recently, Dr. Washington was awarded a grant from the Health Foundation for Western & Central New York to examine the relationship of respite dose to psychosocial factors in caregivers. Dr. Washington is the recipient of numerous awards and honors including the Gulf South Summit Outstanding Faculty Contributions to Service- Learning in Higher Education Research Award and the National Institutes of Health Loan Repayment Award for health disparities research.



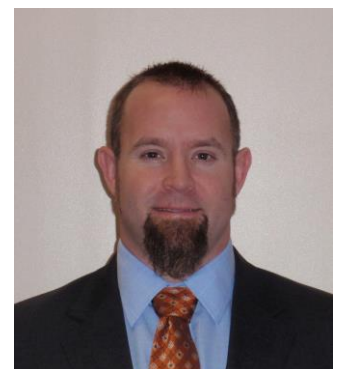
Kim E. Whitmore, PhD, RN, CPN, Assistant Professor, School of Nursing and Master of Public Health Program Faculty, School of Medicine and Public Health, University of Wisconsin - Madison*

Dr. Kim Whitmore, PhD, RN, CPN has more than 15 years of progressive leadership experience working with communities as a home-care nurse manager, private duty nurse, local Health Officer, Policy Section Chief and State Health Plan Officer for the Wisconsin Division of Public Health, educator and research scientist. Currently, Dr. Whitmore is an Assistant Professor in the School of Nursing at UW-Madison where she helps to cultivate the next generation of nurse leaders who will transform the healthcare system. The overall goal of her research program is to inform the development of a care delivery system that promotes family self-management in families of children with special healthcare needs in order to optimize individual and family outcomes. Kim is also an American representative of the International Short Break Association Committee.



Bill Zagorski, C.E.O. of American Senior Care Center, Inc., and Chair and Research Committee Chair, National Adult Day Services Association

Bill Zagorski is the C.E.O. of American Senior Care Center, Inc. overseeing Centennial Adultcare Centers, three Adult Day Health Care centers, home care, and transportation services, serving more than 100 adults each day throughout middle Tennessee. Bill is a Nashville native, who completed his undergraduate degree at Xavier University, and his graduate degrees in Cancer and Cell Biology, and Molecular Genetics, Biochemistry, and Microbiology at the University of Cincinnati, College of Medicine in Cincinnati Ohio where he split his career in academic research in cancer biology and molecular genetics.



He and his family returned to Nashville in 2011 and have expanded American Senior Care Centers, Inc. which his parents began more than 20 years before. In addition to his role with American Senior Care Centers, Bill is the President of the Tennessee Association of Adult Day Services, the Chair of the Tennessee

Coalition for Better Aging, and Chair of the Research Committee and Chair of the Board for the National Adult Day Services Association.

ARCH Staff/Consultants and Summit Facilitators

Cassandra Firman, MS

Susan Janko Summers, PhD

Ray Kirk, PhD

* Kim Whitmore, PhD, RN - Presenter and Summit Facilitator



This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



PRESENTATION INFORMATION

All presenter slides are available for download online at <https://archrespite.org/respite-research-summit>. The following presenters have additional handouts that are also available:

Bill Zagorski

- [*NADSA Research Positioning Statement and 5 Year Plan: August 2019*](#)
- [*NADSA Research Statement, Domain Map, September 2019*](#)

Emma Miller

- [*Short Breaks for Carers: A scoping review, September 2019*](#)

Sarah Sobotka

- [*Unmet Respite Needs of Children with Medical Technology Dependence Abstract*](#)

Sarah Swanson

- [*Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families 2015-2017*](#)

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Committee for Advancement of Respite Research (CARR)
serving in a research advisory capacity to the ARCH Lifespan Respite TA and Resource Center

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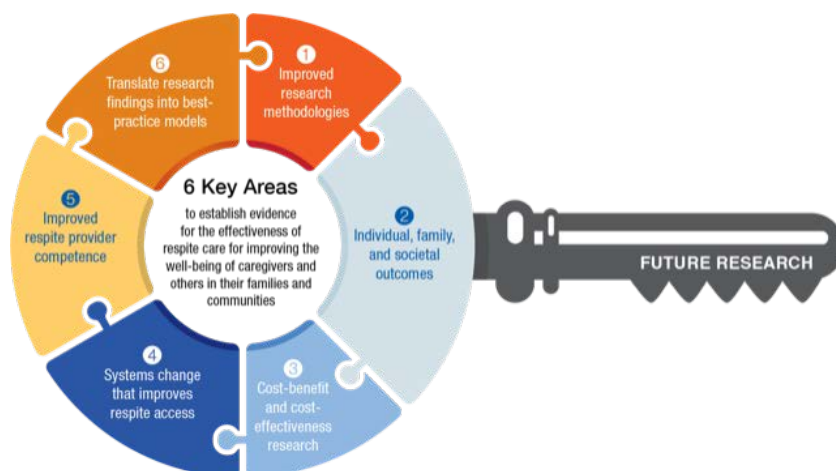
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RECOMMENDATIONS FOR FUTURE RESEARCH

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



- 1) **Address foundational methodological concerns.** From their review of the literature, the Panel ascertained the methodological shortcomings that have hampered current respite research. To address these issues, the Panel made specific recommendations to address these shortcomings from the perspectives of research design, construction of independent and dependent variables relating to respite services, and methods and statistical analyses.
- 2) **Research individual, family, and societal outcomes.** The Panel identified the family caregiver as the “portal of entry” for future respite research, and set the expectation that at least one outcome relating to caregiver well-being and quality of life be measured during any research study. However, the Panel specified that a focus on family caregiver outcomes does not negate the need to study additional outcomes. Recommendations reflect the Panel’s recognition of benefits that may also accrue from respite to the care receiver, the family system, and society, and are therefore appropriate for inclusion in research studies.
- 3) **Conduct appropriate cost-benefit and cost-effectiveness research.** The Panel stated the necessity of cost-benefit and cost-effectiveness studies in order to justify funding, and discussed the importance of understanding costs and benefits in multiple contexts. Accordingly, the Panel recommends that studies of respite are specific to the contexts in which respite occurs, and that studies include measures relating to overall cost, costs that would reasonably be expected to occur in the absence of respite, costs borne by different parties associated with the respite model, and outcomes for both respite-receiving 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 could potentially benefit from respite— must include large numbers of varied and culturally diverse caregivers receiving respite. At the same time, the Panel recognized that there are also large numbers of caregivers who might benefit from respite, but for whom respite is not available or accessible due to a number of reasons occurring across systems levels—such as lack of funding, lack of awareness of the service, limited understanding of how and where to access services and funding, and unavailability of services or trained providers or volunteers. The Panel therefore recommends studies occurring at multiple systems levels.

- 5) **Research improving respite provider competence.** Existing research led some panel members to question whether the provision of respite by providers who lacked training specific to the needs of care receivers might lead caregivers to be reticent about using respite. While acknowledging that not all respite must be provided by people with special training, if special training is needed, the Panel recommends conducting research on the quality of available training curricula and on the most appropriate credentialing criteria for respite providers.
- 6) **Conduct translational research that informs respite policy and practice.** The Panel acknowledges that while statistically significant findings are the end goal for any research study, they also acknowledge that these findings do not necessarily translate automatically to findings or models that can be broadly or easily implemented. The Panel recommends consideration of the multiple factors in the implementation environment including: contextual variables; an organization's readiness to change; implications for resources such as personnel requirements, training, record keeping, and accounting; and attention to details at the level of caregivers and the social and political contexts within which services are provided.

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

Excerpted from Research Agenda for [Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders](#), ARCH National Respite Network and Resource Center



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ARCH ANNOTATED BIBLIOGRAPHY

This updated bibliography is intended to inform ARCH's efforts to continue to strengthen the evidence base for research through its new Committee for Advancement of Respite Research. Studies were included if they documented outcomes of respite care for family caregivers, care recipients, families or communities, including cost-benefit studies. Ten new journal articles were added since the 4th edition in 2018 that highlight promising new research findings, especially in the area of informal respite supports. The bibliography also identifies research gaps and limitations where they exist that will help ARCH and the Committee formulate recommendations for future investigation and improved methodologies.

You can access the updated annotated bibliography online at:

[https://archrespite.org/images/docs/Bibliographies/Annotated Bibliography Web 2020 FINAL.pdf](https://archrespite.org/images/docs/Bibliographies/Annotated_Bibliography_Web_2020_FINAL.pdf)

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Roundtable Discussion Guide

Group 1: Individual, family, and societal outcomes research

Overview of the Key Recommendation

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

Overarching question

What is needed to advance respite-related outcomes research?

Equity lens reminder

In our discussion, consider how we can ensure respite-related outcomes research represents the broad diversity of family caregivers and care-receivers across the lifespan.

Question 1

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

- If you work with a respite program, what outcomes matters most to you?
- If you are a researcher, what research design and methods you would use to measure outcomes?
- Are there questions you would want answered related to a specific racial or ethnic group or other under-represented group?
- What aspects of caregiver well-being and quality of life should we be measuring?
- What outcomes related to the care receiver, the family system, and society should we be measuring?
- How should we measure these outcomes? Do you have any recommended survey tools or instruments we should consider?

Question 2

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

- What are the barriers to conducting outcomes research that represents the broad diversity of family caregivers and care-receivers? Consider specific racial and ethnic groups or other underrepresented groups you work with.
- How can we overcome recruitment and retention barriers for family caregivers?
- How can we overcome funding barriers for respite-related outcomes research?

Question 3

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

- What methods of dissemination should we consider? What is the best way to share research findings with practice partners, funders, and policymakers?
- What are effective strategies for engaging respite providers, family caregivers, and care-receivers in the research process?

Summary

We now want to take a few minutes to reflect on the overall conversation. Consider the following questions:

- What key themes did you notice?
- What stood out to you as key ideas from our conversation?
- What questions do you still have?
- What do you feel is the most important thing we can do to advance respite-related outcomes research?

Roundtable Discussion Guide

Group 2: Conduct appropriate cost-benefit and cost-effectiveness research

Overview of the Key Recommendation

The Panel stated the necessity of cost-benefit and cost-effectiveness studies in order to justify funding, and discussed the importance of understanding costs and benefits in multiple contexts. Accordingly, the Panel recommends that studies of respite are specific to the contexts in which respite occurs, and that studies include measures relating to overall cost, costs that would reasonably be expected to occur in the absence of respite, costs borne by different parties associated with the respite model, and outcomes for both respite-receiving caregivers and caregivers not receiving respite.

Overarching question

What is needed to advance respite-related cost-benefit and cost-effectiveness research?

Equity lens reminder

In our discussion, consider how we can ensure respite-related outcomes research represents the broad diversity of family caregivers and care-receivers across the lifespan.

Question 1

If resources were not an issue, what are the respite-related cost-benefit and cost-effectiveness research/evaluation questions that you would want answered? Consider:

- If you work with a respite program, what costs and benefits matters most to you?
- If you are a researcher, what research design and methods you would use to measure costs and benefits?
- Are there questions you would want answered related to a specific racial or ethnic group or other under-represented group?
- How should we measure these costs and benefits? Do you have any recommended survey tools or instruments we should consider?

Question 2

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?

- What are the barriers to conducting cost-benefit and cost-effectiveness research that represents the broad diversity of family caregivers and care-receivers? Consider specific racial and ethnic groups or other underrepresented groups you work with.
- How can we overcome recruitment and retention barriers for family caregivers?
- How can we overcome funding barriers for respite-related cost-benefit and cost-effectiveness research?

Question 3

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

- What methods of dissemination should we consider? What is the best way to share research findings with practice partners, funders, and policymakers?
- What are effective strategies for engaging respite providers, family caregivers, and care-receivers in the research process?

Summary

We now want to take a few minutes to reflect on the overall conversation. Consider the following questions:

- What key themes did you notice?
- What stood out to you as key ideas from our conversation?
- What questions do you still have?
- What do you feel is the most important thing we can do to advance respite-related cost-benefit and cost-effectiveness research?

Roundtable Discussion Guide

Group 3: Research systems change that improves respite access

Overview of the Key Recommendation

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

Overarching question

What is needed to advance respite-related systems research?

Equity lens reminder

In our discussion, consider how we can ensure respite-related systems research represents the broad diversity of family caregivers and care-receivers across the lifespan.

Question 1

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

- What are the various systems and issues that impact respite access?
- If you work with a respite program, what questions or concerns do you have about existing respite systems or models? How do respite systems influence your program's work? What's working/not working?
- If you are a researcher, what research design and methods would you use to conduct studies at multiple systems levels?
- Are there questions you would want answered related to a specific racial or ethnic group or other under-represented group? Do certain groups face unique systems-related challenges to accessing respite?
- How should we measure these systems issues? Do you have any recommended survey tools or instruments we should consider?

Question 2

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

- What are the barriers to conducting systems research that represents the broad diversity of family caregivers and care-receivers? Consider specific racial and ethnic groups or other underrepresented groups you work with.
- How can we overcome recruitment and retention barriers for family caregivers?
- How can we overcome funding barriers for respite-related systems research?

Question 3

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

- What methods of dissemination should we consider? What is the best way to share research findings with practice partners, funders, and policymakers?
- What are effective strategies for engaging respite providers, family caregivers, and care-receivers in the research process?

Summary

We now want to take a few minutes to reflect on the overall conversation. Consider the following questions:

- What key themes did you notice?
- What stood out to you as key ideas from our conversation?
- What questions do you still have?
- What do you feel is the most important thing we can do to advance respite-related systems research and improve respite access?

Roundtable Discussion Guide

Group 4: Research improving respite provider competence

Overview of the Key Recommendation

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

Overarching question

What is needed to advance respite-related provider competence research?

Equity lens reminder

In our discussion, consider how we can ensure respite-related provider competence research represents the broad diversity of providers across the lifespan.

Question 1

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

- If you work with a respite program, what questions or concerns do you have about provider competence and training?
- If you are a researcher, what research design and methods you would use to conduct provider competence research?
- Are there questions you would want answered related to a specific racial or ethnic group or other under-represented group? Do certain groups of providers face unique training/competence challenges?
- How should we measure provider competence and training? Do you have any recommended survey tools or instruments we should consider?

Question 2

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

- What are the barriers to conducting provider competence research that represents the broad diversity of respite providers? Consider specific racial and ethnic groups or other underrepresented groups you work with.
- How can we overcome recruitment and retention barriers for respite providers?
- How can we overcome funding barriers for respite-related provider competence research?

Question 3

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

- What methods of dissemination should we consider? What is the best way to share research findings with practice partners, funders, and policymakers?
- What are effective strategies for engaging respite providers, family caregivers, and care-receivers in the research process?

Summary

We now want to take a few minutes to reflect on the overall conversation. Consider the following questions:

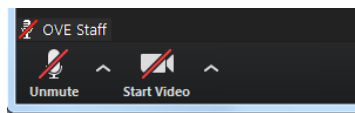
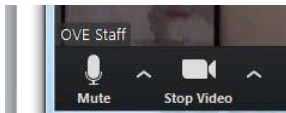
- What key themes did you notice?
- What stood out to you as key ideas from our conversation?
- What questions do you still have?
- What do you feel is the most important thing we can do to advance respite-related provider competence research?

ZOOM TIP SHEET – THE BASICS, FOR PARTICIPANTS

You do not need a Zoom account to use Zoom on a computer or laptop. For a tablet/smart phone, download the Zoom (free) app.

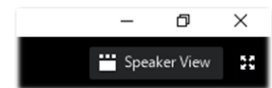
MUTE, VIDEO ON/OFF, SPEAKERS and MICROPHONES

- Move your mouse to the bottom of the black Zoom frame. A ribbon will appear – magic! On the far left corner, you will find “Mute/unmute as well as Video stop/on. For smartphones, touch your photo.
- To test your speaker and microphone in advance, click the up arrow next to the mic icon. Select Test Speakers and Microphone and follow the instructions. For a smartphone, test **before** joining the Zoom meeting by searching “How to test microphone and speaker on (my phone type).”



VIEW: The Whole Group or The Speaker

- Move your mouse to the top right corner of the black Zoom frame to see SPEAKER VIEW or GALLERY/GRID view.
- Click on both - the Gallery and the Speaker view - to see the various options .



- Smart phones: swipe the screen side to side to see the speaker or others. Swiping on a smartphone may take you into Safe Driving Mode - the microphone is muted and video is stopped. Tap the screen to speak.



CHAT

- From the bottom ribbon, open your “chat” function. (In tablets/phones, this feature may be inside the Participants option. Click “more” at the three dots, lower bottom right.)
- Select “Everyone” in the drop down menu of chat to say hello to everyone.
- If you wish to send a private message to someone, select their name in the dropdown menu of the chat feature. Private messages are not captured in the Zoom recordings.

RENAME YOURSELF

- To rename yourself, move the mouse onto your own image. In the upper right corner of your own “frame” are three dots . Click on the three dots to rename yourself.

TIPS:

- Bring a pair of earbuds that you can use with your device, in case you have trouble hearing/being heard.
- If you cannot hear or be heard online, call into the meeting using the number on your invite. You will still be see the action on the computer screen. **If calling in and staying online, remember** to turn your speakers down on your device **and** mute yourself on the Zoom black frame. Otherwise, you will cause an unfriendly noise for all.
- Create a zoom account at www.zoom.us. It’s free. Now you can host your own zoom meetings. Have fun!