Welcome!

Visit the ARCH website for the Summit Agenda, Discussion Guides, Speaker Bios and PowerPoints, and Background

https://archrespite.org/respite-research-summit
This project is 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.
Summit Planning Team

- Ray Kirk, PhD, ARCH; Facilitator, Expert Panel on Respite Research
- Kim Whitmore, PhD, RN, University of Wisconsin-Madison, School of Nursing
- Susan Janko Summers, PhD, ARCH
- Casandra Firman, MS, ARCH
- Notetakers: Aleta Embrey, Jane McCoy, Natalie Leek Nelson, and Monica Uhl
- Marcia O’Malley, Mindful Media Services
- Adam Todd, ZOOM
## Summit Objectives

<table>
<thead>
<tr>
<th>Provide</th>
<th>Provide an overview of the current status of respite and related research;</th>
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<tbody>
<tr>
<td>Highlight</td>
<td>Highlight respite and promising practice-based research with reference to the Expert Panel research framework;</td>
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<tr>
<td>Review</td>
<td>Review progress made in implementing the Expert Panel's six recommendations; and</td>
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<tr>
<td>Identify</td>
<td>Identify gaps in and barriers to respite research, the translation of research into practice, and steps to address these.</td>
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Committee for Advancement of Respite Research

- Promote research to:
  - Examine how to improve access to and quality of respite services; and
  - Identify aspects of respite services and models that make them exemplary, especially for culturally diverse groups.

- Charged with:
  - Encouraging evaluation and replication of promising services;
  - Translating research findings into practice; and
  - Identifying evaluation methods to assess impact of alternative respite options during the pandemic.

https://archrespite.org/CARR
# Day 1 Agenda

<table>
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<tr>
<th>Time</th>
<th>Session</th>
<th>Speakers</th>
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| 1:00 – 1:30 PM* | Welcome                                                                | • 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                | Moderated by Jill Kagan, ARCH                                              |
|               | 1) Research Agenda of the National Adult Day Services Association       | • Bill Zagorski, Chair and Research Committee Chair, National Adult Day Services Association |
|               | 2) Scoping review of the evidence base on short breaks in the United Kingdom | • Emma Miller, PhD, Senior Research Fellow, School of Social Work and Social Policy, University of Strathclyde, Glasgow, Scotland |
|               | 3) BREAK Exchange                                                       | • Kim Whitmore, PhD, RN, University of Wisconsin - Madison, School of Nursing |
| 2:45 – 3:00   | Break                                                                   |                                                                          |

* All times are EDT
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<th>Speakers</th>
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| 3:00 – 4:15 PM* | 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 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, Corner Outpatient Developmental and Behavioral Pediatric Programs, University of Chicago |
| 4:15 – 5:00    | 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 Pediatrics and Psychiatry, University of Colorado School of Medicine |

* All times are EDT
ARCH Respite Research Summit
September 29, 2020

Rani E. Snyder, MPA
Vice President, Program
The John A. Hartford Foundation
A private philanthropy based in New York, established by family owners of the A&P grocery chain in 1929

$625,000,000 in grants authorized since 1982 to improve aging and health

- Building the field of aging experts
- Testing and replicating innovation
Mission & Priorities

DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

PRIORITY AREAS

- Age-Friendly Health Systems
- Family Caregiving
- Serious Illness & End of Life
Family Caregiving

- Engaging family caregivers through shared access to the electronic health record
- Helping states support families caring for an aging America
- "Families Caring for an Aging America"
- Best Practice Caregiving: Online resource for comparing evidence-based dementia caregiving programs
- Addressing unmet family caregiving needs in diverse older communities
- CARE Act & Home Alone resources
- RAISE Act implementation
- UCLA Alzheimer's and Dementia Care program replication

DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS
Families Caring for an Aging America (2016)

• Focus needs to be on person- and family-centered care

• Support of family caregivers needs to be an integral part of the nation’s responsibility for caring for older adults

• 4 recommendations, one of which calls for a National Family Caregiver Strategy
CHCS: Helping States Support Family Caregivers Caring for an Aging America, Phase II

Supporting the scale, spread and execution of state actions that strengthen policies and programs to support family caregivers

• technical assistance to six states
• facilitation of peer-to-peer learning
• dissemination of promising practices and lessons learned

chcs.org/project/helping-states-support-families-caring-for-an-aging-america
NASHP: The RAISE Act Family Caregiver Resource and Dissemination Center

Supporting the work of the RAISE Act Advisory Council assembled by the Administration for Community Living

- research policies and evidence-based programs, convene experts, and provide information to the public
- test the Advisory Council’s recommendations for family caregiving policies and programs in select states

Diverse Elders Coalition: Addressing Unmet Family Caregiving Needs in Diverse Older Communities, Implementation Phase

Launching a training curriculum to educate health care and social service providers who want to better meet the needs of diverse family caregivers

- Educate and train practitioners, health and social service agency leadership and front-line workers
- Provide evidence-based information, resources and support to caregivers and diverse older adults, and
- Educate national and local policy makers

diverseelders.org/what-we-do/current-campaigns/family-caregiving
Thank You!

Rani.Snyder@johnahartford.org

WWW.JOHNAHARTFORD.ORG

Dedicated to improving the care of older adults