

# Advancing Respite Research: Findings from the 2020 Respite Research Summit

June 23, 2021  
Ray Kirk, PhD





# ARCH Goals for Advancing Respite Research

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



# Purpose of the Summit



Provide a forum for researchers and other research stakeholders

Committee for the Advancement of Respite Research (CARR)

# Brief Historical Review



Review of ARCH respite research-related activities



# Expert Panel Charges

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



# Expert Panel Recommendations

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

# Review of Summit Report and Findings

- Model definition: Describing the respite model under investigation  
*Define v. describe: Models, essential elements, populations, settings*
- Research funding  
*Identifying/obtaining funding; categorical funding driving services & designs*
- Measures and measurement  
*Qualitative/Quantitative; R&V; QoL; individualized v. generalizable; outcomes*
- Culturally appropriate research with hard-to-reach or serve populations  
*Culture, race, ethnicity, SE vars; overcoming distrust; research ambassadors*

# Review of Summit Report and Findings (con't)

- Rethinking cost-effectiveness and cost/benefit studies  
*Time-intensive; negative outcome avoidance; units of analysis; added value*
- Workforce development and access to respite  
*Workforce size, competencies, training, compensation, regulation*
- Utilizing research findings to inform and improve policy and practice  
*Provider acceptance/participation; partnerships; communities of practice across disciplines; being “research ready”*
- Impact of COVID-19 on respite and post-pandemic respite  
*Technology; access, utilization, satisfaction; Is it still respite?; returning to “normal”*

# Returning to the CARR



- 13 invited members, all of whom participated in the Summit
  - Help ARCH and researchers focus on issues we should be addressing?
  - Develop other ideas worthy of research interest?
  - Suggestions for prioritizing issues?



# Wrap up and Q&A

- Ray Kirk, PhD, Research Consultant
  - [rskirkassocs@gmail.com](mailto:rskirkassocs@gmail.com)
- Jill Kagan, MPH, Director
  - [jkagan@archresapite.org](mailto:jkagan@archresapite.org)
- Available at the ARCH website: [www.archrespite.org](http://www.archrespite.org)
  - Membership of the original Expert Panel on Respite Research
  - The final report of the Expert Panel: *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders*
  - Agenda and Presenters at the 2021 Respite Research Summit
  - Summit report: *Advancing Respite Research: Findings from the Respite Research Summit, September 2020*
- Search under “Publications”

This project was supported, in part by grant number 90LRLT0001, 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 ACL policy.