Resources to help expand culturally and linguistically competent respite research
Prepared by the ARCH Committee for Advancement of Respite Research

An environmental scan was conducted by the ARCH Committee for Advancement of Respite Research (CARR) to identify resources for expanding culturally and linguistically competent and responsive research with diverse populations. The following is a list of resources, stakeholders (individuals and organizations), articles, and webinars that were generated to help researchers who are interested in learning more about how to engage in more culturally appropriate research with diverse, marginalized and underresourced groups. We will continue to update this list as new resources are identified. If you are aware of any additional resources that should be considered, please email them to ARCH at info@archrespite.org.

Resources:

1) **BOLD Public Health Center of Excellence on Dementia Caregiving**
   - Health Equity Task Force - https://bolddementiacaregiving.org/about/team/

2) **Diverse Elders Coalition (DEC)**
   - Cultural Competency Training Curriculum “Caring for those who Care” -
   - What Providers Should Know (about diverse family caregiver), Factsheet Series - https://diverseelders.org/caregiving/

3) **Equitable Evaluation Initiative (eef)**
   - The Equitable Evaluation Framework - developed by Jara Dean-Coffey and Dr. Marcia Cone. This tool can be used to develop Equitable Evaluation practitioners by providing specific steps and considerations to incorporate equity into evaluation practices.

4) **Family Voices Anti-Racism Toolkit**
   - https://familyvoices.org/famu/

5) **Generations United**

6) ICI’s Research and Training Center on Community Living (RTC-CL), University of Minnesota
• Impact: *Engaging Communities Underrepresented in Disability Research* - This special issue of Impact highlights critical disability research questions derived from a State of the Science meeting at RTC-CL. https://publications.ici.umn.edu/impact/35-3/a-cultural-framework-for-idd-research

7) Mathematica
• *Culturally Responsive and Equitable Evaluation (CREE) for Federal Evaluation Staff* - To help navigate complex challenges of incorporating CREE in evaluations, this guide shares activities federal evaluation staff and others might consider as they decide on research objectives, how to fund evaluations, and how to support evaluations. https://www.mathematica.org/publications/culturally-responsive-and-equitable-evaluation-for-federal-evaluation-staff
• *Leading Practices to Advance Equity and Support of Underserved Communities throughout Health and Human Services Programs* - In an effort to increase collaboration and share promising practices, the HHS Office of the Assistant Secretary for Planning and Evaluation has made these tools available for both public and private partners. Tools include an *Equity Assessment Tip Sheet, In-Depth Equity Assessment Guide*, and more. https://www.mathematica.org/publications/leading-practices-to-advance-equity-and-support-of-underserved-communities

8) National Alliance for Caregiving (NAC) Reports
ENVIRONMENTAL SCAN


9) National Center on Cultural Competence – Georgetown University
   - Developing for ARCH 1) a self-assessment tool for cultural and linguistic competence for respite providers, Lifespan Respite grantees and partners; and 2) a guide for respite researchers on Ensuring Cultural and Linguistic Competence: A Guide for Respite Researchers. https://nccc.georgetown.edu/
   - Community of Practice Racial Equity Learning Community: Resources for Advancing Racial Equity. This toolkit includes resources designed to increase information sharing, knowledge, and advance racial equity in the intellectual and developmental disabilities (IDD) space, including a series of video narratives featuring the voices of persons with lived experience of IDD and family members on the meaning of equity, racial equity, and racial equity in the IDD space. https://nccc.georgetown.edu/resources/equity-learning-community.php

10) National Aging Resource Consortium for Racial and Minority Seniors
    - Association Nacional Pro Personas Mayores (ANPPM) https://anppm.wordpress.com/
    - National Asian Pacific Center on Aging, Inc. (NAPCA) https://www.napca.org/
    - National Caucus and Center on the Black Aged, Inc. (NCBA) https://ncba-aging.org/

11) Nell Hodgson Woodruff School of Nursing Emory University
    - Research on African American caregivers and dementia Contact: Fayron Epps, Assistant Professor - https://www.nursing.emory.edu/faculty-staff/fayron-epps

12) Office of the Assistant Secretary for Planning and Evaluation, USDHHS

13) Older Adults Equity Collaborative maintained by the New York Academy of Medicine
    - Cultural Competency Resources https://www.nyam.org/center-healthy-aging/advising/oaec-resource-library/
14) **RISE – Research Inclusion Supports Equity**
   - RISE is a research study being conducted by Emory University, the University of Nevada, Las Vegas, and the University of Tennessee, Knoxville. RISE stands for Research Inclusion Supports Equity. The RISE study includes a research registry created to help ensure the LGBTQIA+ community is represented in Alzheimer’s research.  [https://www.theriseregistry.org/](https://www.theriseregistry.org/)

15) **SAGE – Advocacy & Services for LGBTQ Elders**
   - Caregiver Resources  
     [https://www.sageusa.org/resource-category/caregiving/](https://www.sageusa.org/resource-category/caregiving/)
   - Cultural Competency Resources  
     [https://www.sageusa.org/resource-category/cultural-competency/](https://www.sageusa.org/resource-category/cultural-competency/)
   - National Resource Center on LGBTQ+ Aging  

16) **University of Wisconsin Madison**
   - Community Guidelines for Engaging with Researchers and Evaluators -  

17) **National Academies of Sciences, Engineering, and Medicine**
   - Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups, 2022 -  

**Articles/Reports:**

1) **A seat for all: Advancing racial equity in scholarly publishing of health policy and health services research**

2) **Adult Day Service Use Among Minority Older Adults: Facilitators, Barriers, and Outcomes from an Updated Integrative Literature Review Between 2010 to 2021.**
3) Caregiving Burden Among Caregivers of People With Dementia Through the Lens of Intersectionality

4) Caregiving Status and Health of Heterosexual, Sexual Minority, and Transgender Adults: Results From Select U.S. Regions in the Behavioral Risk Factor Surveillance System

5) Culturally Responsive Evaluation Theory, Practice, and Future Implications

6) Culturally Responsive Approaches to Evaluation

7) “Dismantling the Master’s House”: New Approaches to Studying Racial/Ethnic Diversity in Gerontological Research


9) Family Matters: Cross-Cultural Differences in Familism and Caregiving Outcomes
10) Greater Inclusion of Asian Americans in Aging Research on Family Caregiving for Better Understanding of Racial Health Inequities

11) Improving Hispanic Family Caregiver Projects: Identifying How Unique Barriers and Cultural Values Influence Service Utilization and Caregiver Roles

12) It’s More Than Language: Cultural Adaptation of a Proven Dementia Care Intervention for Hispanic/Latino Caregivers

13) Key Determinants of Physical and Psychological Health-Related Quality of Life over Time among Midlife and Older LGBTQ and Sexual and Gender Diverse Caregivers
   - Karen Fredriksen-Goldsen, PhD, Sarah Jen, PhD, Charles A Emlet, MSW, PhD, Hyun-Jun Kim, PhD, Hailey H Jung, PhD (2022). Key Determinants of Physical and Psychological Health-Related Quality of Life over Time among Midlife and Older LGBTQ and Sexual and Gender Diverse Caregivers. *The Gerontologist*; gnac112, https://doi.org/10.1093/geront/gnac112

14) Paid Help and Caregiving Experiences of Black Caregivers of Community-Dwelling Older Adults

15) Participatory and Inclusive Approaches to Disability Program Evaluation
16) **Promoting Caregiver Mastery in Black American Dementia Caregivers**

17) **Racial Differences in Respite Use Among Black and White Caregivers for People Living with Dementia**

18) **Stressors and Acceptability of Services Among Black Caregivers of Persons With Memory Problems**
   - Deborah Ejem, PhD, MA, Ghislaine C. Atkins, PhD, Martinique Perkins, PhD, Darby J. Morhardt, PhD, LCSW, Ishan C. Williams, PhD, FGSA, Fawn A. Cothran, PhD, RN, GCNS-BC, FGSA, Fayron Epps, PhD, RN, FAAN, Cathy Scott, PhD, Mary Mittelman, DrPH, and Olivio J. Clay, PhD, FGSA (2022). *Journal of Gerontological Nursing*, Vol. 48, No. 6 [https://journals.healio.com/doi/full/10.3928/00989134-20220505-01](https://journals.healio.com/doi/full/10.3928/00989134-20220505-01)

19) **Use of Critical Race Theory to Inform the Recruitment of Black/African American Alzheimer’s Disease Caregivers into Community-Based Research**
   - Lauren J Parker, PhD, MPH, Joseph E Gaugler, PhD, Laura N Gitlin, PhD, FGSA, FAAN, Use of Critical Race Theory to Inform the Recruitment of Black/African American Alzheimer’s Disease Caregivers into Community-Based Research (2022). *The Gerontologist*, Volume 62, Issue 5, June 2022, Pages 742–750, [https://doi.org/10.1093/geront/g](https://doi.org/10.1093/geront/g)

20) **Using a Multiple-Case Study Design to Explore the Worship Experiences of Black Families Affected by Dementia**
21) **Who’s Helping Whom? Examination of Care Arrangements for Racial and Ethnic Diverse People Living With Dementia in the Community.**


**Webinars:**

1) **Public Health Center of Excellence in Dementia Caregiving**
   - [https://bolddementiacaregiving.org/resource-filter/?_sft_category=culture-equity&_sft_format=webinars-recordings](https://bolddementiacaregiving.org/resource-filter/?_sft_category=culture-equity&_sft_format=webinars-recordings)
   - Experiences of Diverse Older Adults Living with Dementia
     [https://www.youtube.com/watch?v=JJoFgncl7A8](https://www.youtube.com/watch?v=JJoFgncl7A8)
   - Cultural Adaptation in Dementia Caregiving, Part I
     [https://www.youtube.com/watch?v=MF-AeN1Z1jA&t=8s](https://www.youtube.com/watch?v=MF-AeN1Z1jA&t=8s)
   - Cultural Adaptation in Dementia Caregiving, Part II
     [https://www.youtube.com/watch?v=qaXoIJoQq8k8](https://www.youtube.com/watch?v=qaXoIJoQq8k8)
   - Cultural Adaptation in Dementia Caregiving, Part III
     [https://www.youtube.com/watch?v=zjM6_m95cks](https://www.youtube.com/watch?v=zjM6_m95cks)

*Prepared with ARCH CARR by Dr. Kim Whitmore, Marquette University College of Nursing, Updated August 2023.*

This publication is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $1,647,597 with 75 percentage funded by ACL/HHS and $549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.