

ENVIRONMENTAL SCAN

*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, 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”
 - Resources for Providers: Meeting the Needs of Diverse Family Caregivers Toolkit - <https://diverseelders.org/wp-content/uploads/2021/03/DEC-Toolkit-Final-R2.pdf>
 - *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**
 - Diverse Intergenerational Programs Initiative – <https://www.gu.org/projects/diverse-intergenerational-programs-initiative/>
 - *Latino Grandfamilies: Helping Children Thrive Through Connection to Family and Cultural Identity* - <https://www.gu.org/resources/latino-grandfamilies-helping-children-thrive-through-connection-to-family-and-cultural-identity/>
 - *American Indian & Alaska Native Grandfamilies: Helping Children Thrive Through Connection to Family and Cultural Identity* - <https://www.gu.org/app/uploads/2020/07/AIAN-Toolkit-WEB.pdf>

ENVIRONMENTAL SCAN

- *African American Grandfamilies: Helping Children Thrive Through Connection to Family and Culture* - <https://www.gu.org/app/uploads/2020/07/AA-Toolkit-WEB-2.pdf>

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

- *When Communities Lead: Tips for Conducting Equitable and Culturally Responsive Research* – A toolkit of best practices for researchers to help integrate equity, and a focus on cultural responsiveness in research and evaluation work. [https://mathematica.org/features/tips-for-conducting-equitable-and-culturally-responsive-evaluation?utm_source=acoustic&utm_medium=email&utm_campaign=evidence_insights&utm_content=Evidence%20and%20Insights%2001%2026%2023%20\(1\)](https://mathematica.org/features/tips-for-conducting-equitable-and-culturally-responsive-evaluation?utm_source=acoustic&utm_medium=email&utm_campaign=evidence_insights&utm_content=Evidence%20and%20Insights%2001%2026%2023%20(1))
- *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

- *Supporting Diverse Family Caregivers: A Guide For Patient Advocacy Groups* - NAC, March 2023 - <https://www.caregiving.org/guidebook-supporting-diverse-caregivers/>
- *Family Caregiving in Diverse Communities - Addressing the Needs of Diverse Family Caregivers for Older Adults*, Diverse Elders Coalition and the National Alliance for Caregiving, December 2021 - <https://www.diverseelders.org/wp-content/uploads/2021/12/DEC-Caregiving-Report-Final.pdf>

ENVIRONMENTAL SCAN

- *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*, NAC, November 2021 - <https://www.caregiving.org/caregiving-in-a-diverse-america-beginning-to-understand-the-systemic-challenges-facing-family-caregivers/>

9) National Center on Cultural Competence – Georgetown University

- In development 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/>
- National Indian Council on Aging (NICOA) <https://www.nicoa.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

- *Guide on Advancing Equity through Quantitative Analysis* - explores opportunities to advance equity in quantitative analysis. <https://aspe.hhs.gov/reports/guide-advancing-equity-qa>

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/>

15) SAGE – Advocacy & Services for LGBTQ Elders

- Caregiver Resources
<https://www.sageusa.org/resource-category/caregiving/>
- Cultural Competency Resources
<https://www.sageusa.org/resource-category/cultural-competency/>
- National Resource Center on LGBTQ+ Aging
<https://www.sageusa.org/what-we-do/national-resource-center-on-lgbt-aging/>

16) University of Wisconsin Madison

- Community Guidelines for Engaging with Researchers and Evaluators -
<https://ictr.wisc.edu/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 -
<https://www.nationalacademies.org/our-work/improving-the-representation-of-women-and-underrepresented-minorities-in-clinical-trials-and-research?s=09>

Articles/Reports:

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

- Vabren L. Watts, Patti Sweet, Patrick Odai-Afotey Watts, V.L., Sweet, P., Odai-Afotey, P., Ashby-Rosellon, A. and Dey, A. (2023), A seat for all: Advancing racial equity in scholarly publishing of health policy and health services research. *Learned Publishing*, 36: 85-93. <https://doi.org/10.1002/leap.1531>

2) Adult Day Service Use Among Minority Older Adults: Facilitators, Barriers, and Outcomes from an Updated Integrative Literature Review Between 2010 to 2021.

- Li, Y., Liu, J., Sun, F., & Xu, L. (2022). Adult Day Service Use Among Minority Older Adults: Facilitators, Barriers, and Outcomes From an Updated Integrative Literature Review Between 2010 to 2021. *Journal of Applied Gerontology*, 41(10), 2253–2263. <https://doi.org/10.1177/07334648221106772>

- 3) **Bridging the Gap – Enhancing Support for Immigrant Direct Care Workers**
 - PHI Quality Care through Quality Jobs
<https://www.phinational.org/resource/bridging-the-gap-enhancing-support-for-immigrant-direct-care-workers/>

- 4) **Caregiving Burden Among Caregivers of People With Dementia Through the Lens of Intersectionality**
 - Ruotong Liu, MPP, Iris Chi, DSW, Shinyi Wu, PhD (2022). Caregiving Burden Among Caregivers of People With Dementia Through the Lens of Intersectionality. *The Gerontologist*, Volume 62, Issue 5, Pages 650–661,
<https://doi.org/10.1093/geront/gnab146>

- 5) **Caregiving Status and Health of Heterosexual, Sexual Minority, and Transgender Adults: Results From Select U.S. Regions in the Behavioral Risk Factor Surveillance System**
 - Boehmer U, Clark MA, Lord EM, Fredman L. (2019). Caregiving Status and Health of Heterosexual, Sexual Minority, and Transgender Adults: Results From Select U.S. Regions in the Behavioral Risk Factor Surveillance System 2015 and 2016. *The Gerontologist*. Jul 16;59(4):760-769. <https://pubmed.ncbi.nlm.nih.gov/30215703/>

- 6) **Cultural Diversity Impacts Caregiving Experiences: A Comprehensive Exploration of Differences in Caregiver Burdens, Needs, and Outcomes.**
 - Tran J T, Theng B, Tzeng H, et al. (October 05, 2023) Cultural Diversity Impacts Caregiving Experiences: A Comprehensive Exploration of Differences in Caregiver Burdens, Needs, and Outcomes. *Cureus* 15(10): e46537.
 DOI 10.7759/cureus.46537

- 7) **Culturally Responsive Evaluation Theory, Practice, and Future Implications**
 - Hood, S., Hopson, R. K. & Kirkhart, K. E. (2015). In K. E. Newcomer, H. P. Hatry, & J. S. Wholey (Eds.), *Handbook of practical program evaluation*, 4th edition (pp. 281-317).

- 8) **Culturally Responsive Approaches to Evaluation**
 - Chouinard, J., & Cram, F. (2020). Thousand Oaks CA. Sage

- 9) **“Dismantling the Master’s House”: New Approaches to Studying Racial/Ethnic Diversity in Gerontological Research**
 - Brandy H Wallace, PhD, FGSA, Suzanne Meeks, PhD, FGSA (2022). “Dismantling the Master’s House”: New Approaches to Studying Racial/Ethnic Diversity in Gerontological Research. *The Gerontologist*, Volume 62, Issue 5, Pages 647–649, <https://doi.org/10.1093/geront/gnac045>

- 10) **Disparities in Service Use and Expenditures for People with Intellectual and Developmental Disabilities in California in 2005 and 2013**
- Charlene Harrington and Taewoon Kang (2016). Disparities in Service Use and Expenditures for People with Intellectual and Developmental Disabilities in California in 2005 and 2013. *Intellectual and Developmental Disabilities*, 54(1), 1-18.
- 11) **Family Matters: Cross-Cultural Differences in Familism and Caregiving Outcomes**
- Francesca Falzarano, PhD, Jerad Moxley, PhD, Karl Pillemer, PhD, Sara J Czaja, PhD (2022). Family Matters: Cross-Cultural Differences in Familism and Caregiving Outcomes. *The Journals of Gerontology: Series B*, Volume 77, Issue 7, Pages 1269–1279, <https://doi.org/10.1093/geronb/gbab160>
- 12) **Greater Inclusion of Asian Americans in Aging Research on Family Caregiving for Better Understanding of Racial Health Inequities**
- Aggie J Yellow Horse, PhD, Sarah E Patterson, PhD (2022) Greater Inclusion of Asian Americans in Aging Research on Family Caregiving for Better Understanding of Racial Health Inequities. *The Gerontologist*, Volume 62, Issue 5, Pages 704–710, <https://doi.org/10.1093/geront/gnab156>
- 13) **Improving Hispanic Family Caregiver Projects: Identifying How Unique Barriers and Cultural Values Influence Service Utilization and Caregiver Roles**
- Adrian Rodriguez, BAPH, CHES®, Taylor Neher, DrPHH, MPH., Sarah E. Toevs, PhD, (2022). *Improving Hispanic Family Caregiver Projects: Identifying How Unique Barriers and Cultural Values Influence Service Utilization and Caregiver Roles*. Boise State University Public Health and Population Science. <https://drive.google.com/file/d/1rQuEC4fvUavLxxO-PLRRPCAoeMKCLVSz/view>
- 14) **It's More Than Language: Cultural Adaptation of a Proven Dementia Care Intervention for Hispanic/Latino Caregivers**
- Lauren J Parker, PhD, MPH, Katherine A Marx, PhD, MPH, Manka Nkimbeng, PhD, MPH, RN, Elma Johnson, MPH, Sokha Koeuth, MPH, Joseph E Gaugler, PhD, Laura N Gitlin, PhD, FGSA, FAAN (2022), It's More Than Language: Cultural Adaptation of a Proven Dementia Care Intervention for Hispanic/Latino Caregivers. *The Gerontologist*. <https://doi.org/10.1093/geront/gnac120>
- 15) **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>
- 16) **Paid Help and Caregiving Experiences of Black Caregivers of Community-Dwelling Older Adults**
- Chaneé D. Fabius & Lauren J. Parker (2022). Paid Help and Caregiving Experiences of Black Caregivers of Community-Dwelling Older Adults. *Clinical Gerontologist*, DOI: [10.1080/07317115.2022.2099776](https://doi.org/10.1080/07317115.2022.2099776)
- 17) **Participatory and Inclusive Approaches to Disability Program Evaluation**
- Sally Robinson, Karen R. Fisher & Robert Strike (2014): Participatory and Inclusive Approaches to Disability Program Evaluation, *Australian Social Work*, DOI: 10.1080/0312407X.2014.902979
<https://www.betterevaluation.org/sites/default/files/paia.pdf>
- 18) **Promoting Caregiver Mastery in Black American Dementia Caregivers**
- Kalisha Bonds Johnson, PhD, RN, PMHNP-BC, Glenna S Brewster, PhD, RN, FNP-BC, Ethan Cicero, PhD, RN, Kenneth Hepburn, PhD, Carolyn K Clevenger, RN, DNP, AGPCNP-BC, GNP-BC, Gaea Daniel, PhD, RN, Victoria Pak, MS, MTR, PhD, Sudeshna Paul, PhD, MS, Fayron Epps, PhD, RN (2022). Promoting Caregiver Mastery in Black American Dementia Caregivers. *The Gerontologist*, Volume 62, Issue 5, Pages 685–693, <https://doi.org/10.1093/geront/gnab147>
- 19) **Racial Differences in Respite Use Among Black and White Caregivers for People Living with Dementia**
- Parker, L. J., & Fabius, C. D. (2020). Racial Differences in Respite Use Among Black and White Caregivers for People Living with Dementia. *Journal of Aging and Health*, 32(10), 1667–1675. <https://doi.org/10.1177/0898264320951379>
- 20) **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>
- 21) **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>

22) Using a Multiple-Case Study Design to Explore the Worship Experiences of Black Families Affected by Dementia

- Gore JE, Brewster G, Sainz M, Ge Y, Xie J, James T, Epps F. Using a Multiple-Case Study Design to Explore the Worship Experiences of Black Families Affected by Dementia (2021). *Clin Gerontol.* 28:1-11. doi: 10.1080/07317115.2021.2017378. Epub ahead of print. PMID: 34962459; PMCID: PMC9237185.
<https://pubmed.ncbi.nlm.nih.gov/34962459/>

23) Who's Helping Whom? Examination of Care Arrangements for Racial and Ethnic Diverse People Living With Dementia in the Community.

- Parker, L. J., & Fabius, C. (2022). Who's Helping Whom? Examination of Care Arrangements for Racially and Ethnically Diverse People Living With Dementia in the Community. *Journal of Applied Gerontology*, 41(12), 2589–2593. <https://doi.org/10.1177/07334648221120247>

Webinars:

1) Public Health Center of Excellence in Dementia Caregiving

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>
- Cultural Adaptation in Dementia Caregiving, Part I
<https://www.youtube.com/watch?v=MF-AeN1Z1jA&t=8s>
- Cultural Adaptation in Dementia Caregiving, Part II
<https://www.youtube.com/watch?v=qaXoJJQg8k8>
- Cultural Adaptation in Dementia Caregiving, Part III
https://www.youtube.com/watch?v=zjM6_m95cks

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