



EOHHS

Key Evidence-Based Caregiver Stress and Burden Assessment Tools & Resources

April 2024

Contents

Introduction	4
All Caregivers	5
Zarit Caregiver Burden Interview Tool	5
Caregiver Intensity Index (2018)	5
Caregivers of Older Adults	6
Modified Caregiver Strain Index	6
Montgomery Borgatta Caregiver Burden Scale	6
Kingston Caregiver Stress Scale	6
Quality of Life in Alzheimer’s Disease (QoL-AD) (1996)	7
Diversity	7
Cultural Justification for Caregiving Scale	7
Inter Tribal Council of Arizona Caregiver Assessment	8
Cultural Diversity and Caregiving	8
Caregivers of Children	9
Parental Stress Scale	9
Caregiver Reaction Scale	9
Impact on Family Scale	10
Other Assessments and Key Respite Resources	10
State Caregiver Assessments (ACL)	10
Emerging Respite Care Strategies in Medicaid Home and Community-Based Services Waivers for Older Adults, Adults with Physical Disabilities, and their Family Caregivers	11
ARCH National Lifespan Respite Technical Assistance and Resource Center	11
Charting the Life Course: Respite Guide (2023)	11
2022 National Strategy to Support Family Caregivers	12
The Lifespan Respite Care Act (LRCA) Program	12
National Center on Caregiving (Family Caregiving Alliance)	12
National Alliance for Caregiving	13
Caregiver Action Network	13
Generations United	13
Relatives as Parents Program (RAPP)- The Brookdale Foundation Group	14

References	15
------------------	----

Introduction

The RAISE Family Caregiver Act of 2018 defines “family caregiver” as an adult family member or other unpaid individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation.¹ The Lifespan Respite Care Act of 2006 defines “respite care” as planned or emergency care provided to a child or adult with a special need in order to provide temporary relief [respite] to the family caregiver of that child or adult. Respite services may be provided in a variety of settings, including in the home, adult day care centers, or residential care facilities.²

As a Massachusetts Respite Innovation grantee, your organization is working to test innovative respite models to support families and natural support caregivers. Many grantees will be evaluating the effectiveness of their respite models by measuring caregiver stress levels throughout the grant period. Numerous assessment tools exist, and your organization may already have something that works well. However, **if you are looking for or are interested in learning more about other evidence-based caregiver stress and burden assessment tools for use by non-clinicians in community-based settings, or seeing what tools other states are using, we offer the information and resources below.**

Assessment tools include those for adult caregivers of people of any age, some that are focused on caregivers of older adults, and one for caregivers of children. **Please contact PCG Technical Assistance with questions or for more information.** We hope you find this information helpful!

All Caregivers

In 2019, at least 53 million people were providing informal, usually unpaid, care and support to aging family members and people of all ages with disabilities (including mental health conditions). At the same time, at least 2.7 million grandparents—and an unknown number of other relative caregivers—carried the primary responsibility for caring for grandchildren whose parents were unable to do so. These numbers are increasing rapidly for a variety of reasons.³ While many tools to measure caregiver stress and burden are primarily designed for and tested on caregivers of older adults, the most widely used tool, the Zarit Caregiver Burden Interview Tool, is for adult caregivers of people of any age.

Zarit Caregiver Burden Interview Tool (2015)

The Zarit Burden Interview (ZBI) is a caregiver self-report measure used to assess personal and role strain for adult caregivers. It's generally considered to be the most widely used tool to assess caregiver stress and burden. The current version has 22 items, each scored from 0 to 4; however, the ZBI is also available in different versions ranging from 1 to 22 items, with the 6-item version providing similar diagnostic utility to the original 22-item version with the fewest items. The Zarit Burden Interview has been translated into several languages, including Chinese, French, Japanese, German, Hebrew, Spanish, Korean, Hindi, and Portuguese (Bachner & O'Rourke, 2007).⁴

Link: Review and [download the 22 and 12 item Zarit Burden Interview tools and a 4-item correlated caregiver screen](#).

Caregiver Intensity Index (2018)

The Caregiver Intensity Index, updated in 2020, is a 25-question web-based 2-minute “quiz” that helps caregivers quantify the intensity of their caregiving experience and identify the top two things driving that intensity and the top two things alleviating it. The score relates to a color (red, yellow, and green) that helps caregivers validate the intensity of their experience, offers a framework for communicating about it, and provides information that helps caregivers believe that the stress they are feeling is real. Providers can then use the info to connect caregivers with existing resources that can help them manage those intensity-driving challenges. The tool is available online and requires a valid email address to access the assessment.

Link: With a valid email address, caregivers can [take the quiz online at the Archangels website](#).

Caregivers of Older Adults

While there are many different caregiver assessment tools, some have been developed and tested specifically with caregivers of older adults. Below is information about a few of the more commonly used tools.

[Modified Caregiver Strain Index](#) (2018)

The Modified Caregiver Strain Index (MCSI) is a tool that can quickly screen for caregiver strain in long-term caregivers. The tool has 13 questions that measure strain related to care provision. There is at least one item for each of the following major domains: Financial, Physical, Psychological, Social, and Personal. This instrument can be used to assess individuals of any age who have assumed the caregiving role for an older adult living in a community-based setting. The Modified Caregiver Strain Index (MCSI) is a more recent version (2003) of the Caregiver Strain Index (CSI) developed in 1983. Scoring is 2 points for each 'yes', 1 point for each 'sometimes', and 0 for each 'no' response. Scoring ranges from 0 to 26, with higher scores indicating a higher level of caregiver strain (Travis et al., 2003; Thornton & Travis, 2003).^{5,6}

Link: Review and [download background and a PDF copy of the 13-item Modified Caregiver Strain Index](#).

[Montgomery Borgatta Caregiver Burden Scale](#) (2006)

The Montgomery Borgatta Caregiver Burden Scale (MBCBS) scale is used to measure the caregiver's perceived impact of care tasks on the caregiver's life. The MBCBS is a refinement of 1989 work on burden and distinguishes between emotional impacts and impacts on resources such as time, physical health, physical space and for finances. The updated MBCBS scale has three conceptualizations of burden: 1. Objective Burden, defined as perceived infringement or disruption of tangible aspects of a caregiver's life, 2. Subjective Demand Burden, defined as the extent to which the caregiver perceives care responsibilities to be overly demanding, and 3. Subjective Stress Burden, defined as the emotional impact of caregiving responsibilities on the caregiver. Each question is scored from 1 to 5, with each burden section ranging from 4 to 30, and higher total scores related to more caregiver stress. (Montgomery, Rhonda J.V., 2006)⁷

Link: [Read full-text and download PDF instructions and assessment questions](#) (in Appendix A).

[Kingston Caregiver Stress Scale](#) (2016)

The Kingston Caregiver Stress Scale (KCSS), created in 2016 in Canada, is primarily a scale to allow family caregivers to express the level of stress that they are experiencing. The scale is designed for community-living lay caregivers. The scale can be used to monitor change in an individual caregiver's stress over time. The KCSS consists of a set of ten (10) questions grouped into three categories: care giving, family, and financial issues. Rather than assigning stress values to caregiving activities, the KCSS directly asks how much stress the caregiver feels. This approach recognizes that individual caregivers experience stress differently, and their sources of stress may vary (Kilik LA, & Hopkins RW., 2019)⁸.

Link: [Download a PDF of the Kingston Caregiver Stress Scale Instruction Manual](#).

Link: [Download a PDF of the Kingston Caregiver Stress Scale.](#)

Quality of Life in Alzheimer's Disease (QoL-AD) (1996)

The Quality of Life in Alzheimer's Disease is a 13-item questionnaire that provides both the patient living with Alzheimer's Disease and their caregiver. It covers domains such as physical health, mood, and social relationships. Individual satisfaction items score between 1 (poor) and 4 (excellent), with higher total scores indicating a higher level of satisfaction with the quality of one's life⁹.

Link: [Download PDF instructions and both the participant and caregiver QoL-AD assessments.](#)

Diversity

Acknowledging the importance and impact of culture on caregiving expectations, perceptions, and stress is essential when working with diverse populations. While there may be no better way to understand a culture than to immerse oneself in it, that is often not possible for respite providers. The [Zarit scale](#) (described above), has been translated into numerous languages and may be useful to those working with diverse populations. The additional information and resources below may also be helpful in measuring stress and understanding the impact that culture has on how diverse caregivers consider, accept, and use respite care.

Cultural Justification for Caregiving Scale (2005)

The Cultural Justification for Caregiving Scale (CJCS; Dilworth-Anderson et al., 2005)¹⁰ is a 10-item measure designed to assess caregivers' cultural reasons and expectations for providing care. Cultural reasons and expectations are important to understand because we all bring our own experiences, point of view, and cultural norms to both the idea of using respite and assessing a caregiver's need for it. Understanding, for instance, that research among some caregivers of people with dementia found there were significant culture-based differences between Whites, Blacks, and S. California Latinos (because not all Latin populations are the same) in how long it took to accept the use of respite care and the length of time they used the service overall.¹¹ Knowledge about what and why those difference occurred led the providers to be more effective in helping caregivers successfully incorporate respite services into their care routine. The CJCS helps to identify some cultural aspects of caregiving, with responses coded as follows: 4 = Strongly Agree, 3 = Somewhat Agree, 2 = Somewhat Disagree, and 1 = Strongly Disagree. Items are summed, and scores may range from 10 to 40, with higher scores indicating stronger cultural reasons for giving care.^{12,13}

Link: [Download the 10-item CJCS.](#)

Link: [Download background and scoring information for the CJCS.](#)

[Inter Tribal Council of Arizona Caregiver Assessment](#) (2023)

The Inter Tribal Council of Arizona (ITCA) was established in 1952 to provide a united voice for tribal governments located in the State of Arizona to address common issues of concerns. Twenty-one (21) of the 22 AZ tribes are ITCA members (the Navajo Nation is not). The ITCA serves as the Area Agency on Aging for its members and administers the federal National Family Caregiver Program for 18 tribes.¹⁴ The 6-page fillable PDF tool is a full caregiver assessment, not just a measure of stress and burden, but may be valuable to those working with American Indian caregivers. Likewise, entities administering Title VI Older Americans Act funds in Massachusetts may have similar assessment tools.

Link: [Download a fillable PDF of the ITCA caregiver assessment.](#)

[Cultural Diversity and Caregiving](#) (2011)

Rates of caregiving vary somewhat by ethnicity and culture. Studies show that ethnic minority caregivers provide more care than their White counterparts and report worse physical health than White caregivers (McCann et al, 2000). Several studies have found that African American caregivers experience less stress and depression and garner greater rewards from caregiving than White caregivers (Cuellar, 2002; Haley et al, 2004). Hispanic and Asian American caregivers, however, exhibit more depression than White caregivers (Haley et al, 2004). LGBT older adult caregivers are more likely to face poverty or economic difficulty, and for many rural caregivers, poverty combines with lack of health services to create additional caregiver stress.¹⁵ While not a caregiver stress measurement tool, this quick read from the American Psychological Association provides some basic insights about diverse caregivers.

Link: [Visit the Cultural Diversity and Caregiving webpage.](#)

Caregivers of Children

Parents, families, and caregivers ensure children are healthy and safe, and equip them with skills and resources to succeed.¹⁶ However, the usual challenges of parenting are compounded for parents and primary caregivers of children with special needs, resulting in a greater stress burden. Finances are often a source of stress, as frequently one parent sacrifices their career to attend to the child's needs with a resulting loss of income for the family. The emotional impact is also enormous and may include fear and worry, guilt, feelings of isolation, and grief.¹⁷ While most assessment tools for caregivers of children are lengthy and typically used in clinical environments; however, some tools that may be useful to respite grantees seeking to measure stress and burden of caregivers of children with complex needs are listed below.

Parental Stress Scale (1995)

The Parental Stress Scale was developed by Berry and Jones (1995) as an alternative to the 101-item Parenting Stress Index. The scale attempts to measure the levels of stress experienced by parents, considering both positive and negative aspects of parenting. The 18-item self-report scale includes emotional benefits, personal development, demands on resources, and restrictions as themes of parenthood. Respondents agree or disagree in terms of their typical relationship with their child or children. The instrument uses a 5-point response scale ranging from strongly disagree to strongly agree as possible responses, with the cumulative score reflective of the level of caregiver stress (lower scores indicate less stress, higher scores indicate more).¹⁸

Link: [Download a fillable PDF version of the Parental Stress Scale.](#)

Caregiver Reaction Scale (2007)

The Caregiver Reaction Scale is an instrument adapted from Pearlin, et al. (1990). The scale assesses emotional reactions and coping strategies related to caregiving. The 55 questions are designed to help understand the types of difficulties family caregivers face, so that appropriate supports can be identified. Each item is rated on a scale from 1 to 4 points, with higher cumulative scores indicating higher levels of caregiver stress and need. Typically used in a clinical setting, but effective in community settings as well.

Link: [Download a fillable PDF version of the Caregiver Reaction Scale.](#)

[Impact on Family Scale](#) (1980)

The Impact on Family Scale was developed to assess the overall impact on family life of having a child with a chronic condition. It was designed for use with parents or caregivers of children with medical conditions and has been widely used to assess the impact of a child's illness on families (e.g., Paynter et al., 2013). The original 27-item version was revised in 1980 and now has 15 items that include social and familial dimensions. The Scale uses a 4-point Likert-type scale (strongly agree – strongly disagree). The tool can be administered by phone.¹⁹

Link: The Impact on Family Scale is not readily available as a PDF, but it can you can find it in Table I on [this page of the National Library of Medicine's website](#).

Other Assessments and Key Respite Resources

Assessments to measure caregiver stress and burden to provide innovative respite services have been shared above. Often, however, service providers include stress and burden measurements in broader caregiver needs assessments and as part of caregiver support programs. The resources below provide information on caregiver assessments in other states and general resources for respite and caregiver services and programs.

[State Caregiver Assessments \(ACL\)](#) (2012)

In 2012 the U.S Administration on Community Living (ACL), an operating division of the US Department of Health and Human Services, began a comprehensive evaluation of its National Family Caregiver Support Program (NFCSP). This was the first comprehensive federal evaluation of the NFCSP, which serves over 800,000 family caregivers annually. As part of the evaluation survey, State Units on Aging across the country were asked to submit various documents including standardized caregiver assessments. Seventeen (17) states responded, and the assessments and instruments they provided are available for download on the ACL website.²⁰

Link: [Review and download any of 17 state caregiver assessments](#).

[Emerging Respite Care Strategies in Medicaid Home and Community-Based Services Waivers for Older Adults, Adults with Physical Disabilities, and their Family Caregivers](#) (2023)

In 2022, the National Academy on State Health Policy (NASHP) found that [47 states and DC](#) cover respite through Medicaid HCBS waivers serving older adults and adults with physical disabilities. After a [comprehensive 50-state review](#) of these respite services,, NASHP chose to do more in-depth interviews with seven states - Iowa, Kentucky, Louisiana, Missouri, Texas, Virginia, and Washington - due to their innovative approaches to administering respite care.²¹ This paper identifies emerging respite policy strategies and key themes from these interviews.

Link: [Review and download the NASHP report on Emerging Respite Strategies.](#)

[ARCH National Lifespan Respite Technical Assistance and Resource Center](#) (2023)

ARCH National Respite Network and Resource Center assists and promotes the development of quality respite and crisis care programs, helps families locate respite and crisis care services, and serves as a strong voice for respite in all forums. In 2009, the U.S Administration on Community Living began funding ARCH to house and operate the Lifespan Respite Technical Assistance and Resource Center (TARC). Through the TARC, ARCH provides training and technical assistance to the Lifespan Respite Network with a focus on performance measurement, sustainability, best practices, and research.²²

Link: [Visit the ARCH website for more information.](#)

[Charting the Life Course: Respite Guide](#) (2023)

The Respite Guide and accompanying toolkit are intended for anyone in a family or relationship that is providing the majority of care or support to a person who needs additional support and are also referred to as “caregivers” or “carers” throughout this guide. It is focused on the topic of respite, or short breaks for caregivers. The Respite Guide is meant to help caregivers and those who support them to understand the meaning and importance of respite/short breaks, see real life examples, understand the possibilities and options that exist for respite, within and outside the formal, paid service system, and create a successful plan that uses these short breaks to enhance the lives of all family members²³.

Link: [Download the Charting the Life Course: Respite Guide on the ARCH Respite website.](#)

[2022 National Strategy to Support Family Caregivers](#) (2022)

The 2022 National Strategy to Support Family Caregivers was created to support family caregivers of all ages, from youth to grandparents, and regardless of where they live or what caregiving looks like for them and their loved ones. The strategy was developed jointly by the advisory councils created by the [RAISE Family Caregiving Act](#) and the [Supporting Grandparents Raising Grandchildren Act](#), with extensive input from the public, including family caregivers and the people they support. The Strategy includes nearly 500 actions that can be adopted at every level of government and across the public and private sectors to ensure that family caregivers have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others.²⁴ The document may be useful to those working to improve services and systems of support for informal and family caregivers.

Link: [Read and download the 2022 National Strategy report.](#)

[The Lifespan Respite Care Act \(LRCA\) Program](#) (2023)

Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Once implemented, Lifespan Respite Care programs improve the delivery and quality of respite services available to families across age and disability spectrums by establishing coordinated lifespan respite systems. Since 2009, Congress has appropriated approximately \$2 to \$4 million per year to implement Lifespan Respite Programs. To date, thirty-seven (37) states and the District of Columbia have received awards.²⁵

Link: [Learn more about the LRCA Program](#)

Link: [Download a PDF of the Lifespan Respite Care Act Program Factsheet.](#)

[National Center on Caregiving \(Family Caregiving Alliance\)](#) (2023)

Established in 2001 as a program of the Family Caregiver Alliance, the National Center on Caregiving (NCC) works to advance the development of high-quality, cost-effective policies and programs for caregivers in every U.S. state. Uniting research, public policy, and services, the NCC serves as a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders, and family caregivers throughout the country.²⁶ Many resources are available in Spanish, Chinese, Vietnamese, and Tagalog.

Link: [Visit the Family Caregiver Alliance website.](#)

National Alliance for Caregiving (2023)

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, government agencies, and corporations. The Alliance was created to conduct research, analyze policy, develop national programs, increase public awareness of family caregiving issues, strengthen state and local caregiving coalitions, and represent the U.S. caregiving community internationally. The Alliance's mission is to be an objective national resource aimed at improving the quality of life for families and care recipients.²⁷

Link: [Visit the National Alliance for Caregiving website.](#)

Caregiver Action Network (2023)

Caregiver Action Network (CAN) is a family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of older age. CAN serves a broad spectrum of caregivers ranging from the parents of children with special needs to the families and friends of wounded soldiers. CAN is a nonprofit organization providing education, peer support, and resources to family caregivers nationwide free of charge.²⁸

Link: [Visit the Caregiver Action Network website.](#)

Generations United (2023)

Generations United (GU) is the national membership organization dedicated to improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. GU represents more than 100 national, state, and local organizations representing more than 70 million Americans. With its emphasis on public policy, advocacy and programming, GU has served as a resource for policymakers and the public on the economic, social, and personal imperatives of intergenerational cooperation. Information for those working in kinship care and grandparents raising grandchildren may be of interest.²⁹

Link: [Visit the Generations United website.](#)

Relatives as Parents Program (RAPP)- The Brookdale Foundation Group (2023)

Established in 1996 in response to a growing need for enhanced services and supports for grandparents raising grandchildren, The Brookdale Foundation Group established RAPP to encourage and promote the creation or expansion of services for grandparents and other relatives who are surrogate parents due to the absence of the parents. Currently, RAPP provides supportive services, primarily to relative caregivers caring for children outside the foster care system, through an extensive network of support groups.³⁰

Link: [Learn more about the Brookdale Foundation Relatives as Parents Program.](#)

References

- ¹ RAISE Family Caregiver Act of 2018. 42 USC 3030s.
- ² Lifespan Respite Care Act of 2006. 42 U.S.C. 201et seq.
- ³ The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council; The Advisory Council to Support Grandparents Raising Grandchildren. (2022 September). 2022 National Strategy to Support Family Caregivers. ACL.org. URL: https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers-2.pdf
- ⁴ Bachner, Y. G., & O'Rourke, N. (2007). Reliability generalization of responses by care providers to the Zarit Burden Interview. *Aging & Mental Health*, 11(6), 678–685.
- ⁵ Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journals of Gerontology*, 58B(2), S127-S132.
- ⁶ Travis, S.S., Bernard, M.A., McAuley, W.J., Thornton, M., & Kole, T. (2003). Development of the Family Caregiver Medication Administration Hassles Scale. *The Gerontologist*, 43(3), 360-368.
- ⁷ Montgomery, Rhonda. (2006, accessed 2023 December). Using and Interpreting the Montgomery Borgatta Caregiving Burden Scale. Researchgate.net. URL: https://www.researchgate.net/publication/265679222_Using_and_Interpreting_the_Montgomery_Borgatta_Caregiving_Burden_Scale
- ⁸ Kilik LA, & Hopkins RW. (2019). "The Relationship between Caregiver Stress and Behavioural Changes in Dementia." *OBM Geriatrics*, 3(2):1-16.
- ⁹ Logsdon, R.G. (2024). Quality of Life in Alzheimer's Disease. CogsClub.org.uk. URL: <https://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf>.
- ¹⁰ Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). *Journal of Gerontology: Social Sciences*. 60B(5), A257-262.
- ¹¹ Starns MK, Karner TX, Montgomery RJ. Exemplars of successful Alzheimer's demonstration projects. *Home Health Care Serv Q*. 2002;21(3-4):141-75. doi: 10.1300/J027v21n03_08. PMID: 12669701.
- ¹² American Psychological Association. (2023 December). Cultural Justification for Caregiving Scale. APA.org. URL: <https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/cultural-justification>
- ¹³ Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). *Journal of Gerontology: Social Sciences*. 60B(5), A257-262.
- ¹⁴ Inter Tribal Council of Arizona. (2023). About ITCA. ITCAonline.com. URL: <https://itcaonline.com/about-itca/>
- ¹⁵ American Psychological Association. (2023 December). Cultural Diversity and Caregiving. APA.org. URL: <https://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity>
- ¹⁶ American Psychological Association. (2003). Parents and caregivers are essential to children's healthy development. APA.org. URL: <https://www.apa.org/topics/families/parents-caregivers-kids-healthy-development>
- ¹⁷ Boston University. (2023). Parenting Children with Special Needs. BU.edu. URL: <https://www.bu.edu/wellness/social-well-being/parenting/parenting-children-with-special-needs/>
- ¹⁸ Berry, JD, & Jones, W.H. (1995) The Parental Stress Scale: initial psychometric evidence. *Journal of Social and Personal Relationships*, 12, 463 – 472.

-
- ¹⁹ American Psychological Association. (2023). Impact on Family Scale Construct: Parental perceptions of the impact of a child's medical condition on the family. APA.org. URL: <https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/family-impact>
- ²⁰ U.S. Administration on Community Living. (2023). SUA Resource Library: State Caregiver Assessments. ACL.gov. URL: <https://acl.gov/sites/default/files/programs/2016-11/State-Caregiver-Assessment.pdf>
- ²¹ Hodges, K., Taggart, E., Kaye, N., Fox-Grage, W. (2023). Emerging Respite Care Strategies in Medicaid Home and Community-Based Services Waivers for Older Adults, Adults with Physical Disabilities, and their Family Caregivers. NASHP.org. URL: <https://nashp.org/emerging-respite-care-strategies-in-medicaid-home-and-community-based-services-waivers-for-older-adults-adults-with-physical-disabilities-and-their-family-caregivers/>
- ²² ARCH National Respite Network. (2023). Lifespan Respite Technical Assistance and Resource Center. ARCHRespite.org. URL: <https://archrespite.org/ta-center-for-respite/>
- ²³ ARCH National Respite Network. (2023). Charting the Life Course: Respite Guide. ARCHRespite.org. URL: <https://archrespite.org/caregiver-resources/planning-for-respite/#tools>
- ²⁴ U.S. Administration on Community Living. (2023). 2022 National Strategy to Support Family Caregivers. ACL.gov. URL: <https://acl.gov/CaregiverStrategy>
- ²⁵ U.S. Administration on Community Living. (2023). Lifespan Respite Care Program. ACL.gov. URL: <https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>
- ²⁶ U.S. Administration on Community Living. (2023). National Family Caregiver Support Program: Additional Resources for Caregivers, Useful Links. ACL.org. URL: <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>
- ²⁷ The National Alliance for Caregiving. (2023). Mission Statement. Caregiving.org. URL: <https://www.caregiving.org/mission/>
- ²⁸ Caregiver Action Network (CAN). (2023). About Caregiver Action Network (CAN). Caregiveraction.org. URL: <https://www.caregiveraction.org/about>
- ²⁹ Generations United. (2023). Who We Are: Generations United improves the lives of children, youth, and older adults. GU.org. URL: <https://www.gu.org/who-we-are/>
- ³⁰ The Brookdale Foundation Group. (2023). Relatives as Parents Program (RAPP). BrookdaleFoundation.net. URL: <http://www.brookdalefoundation.net/RAPP/rapp.html>