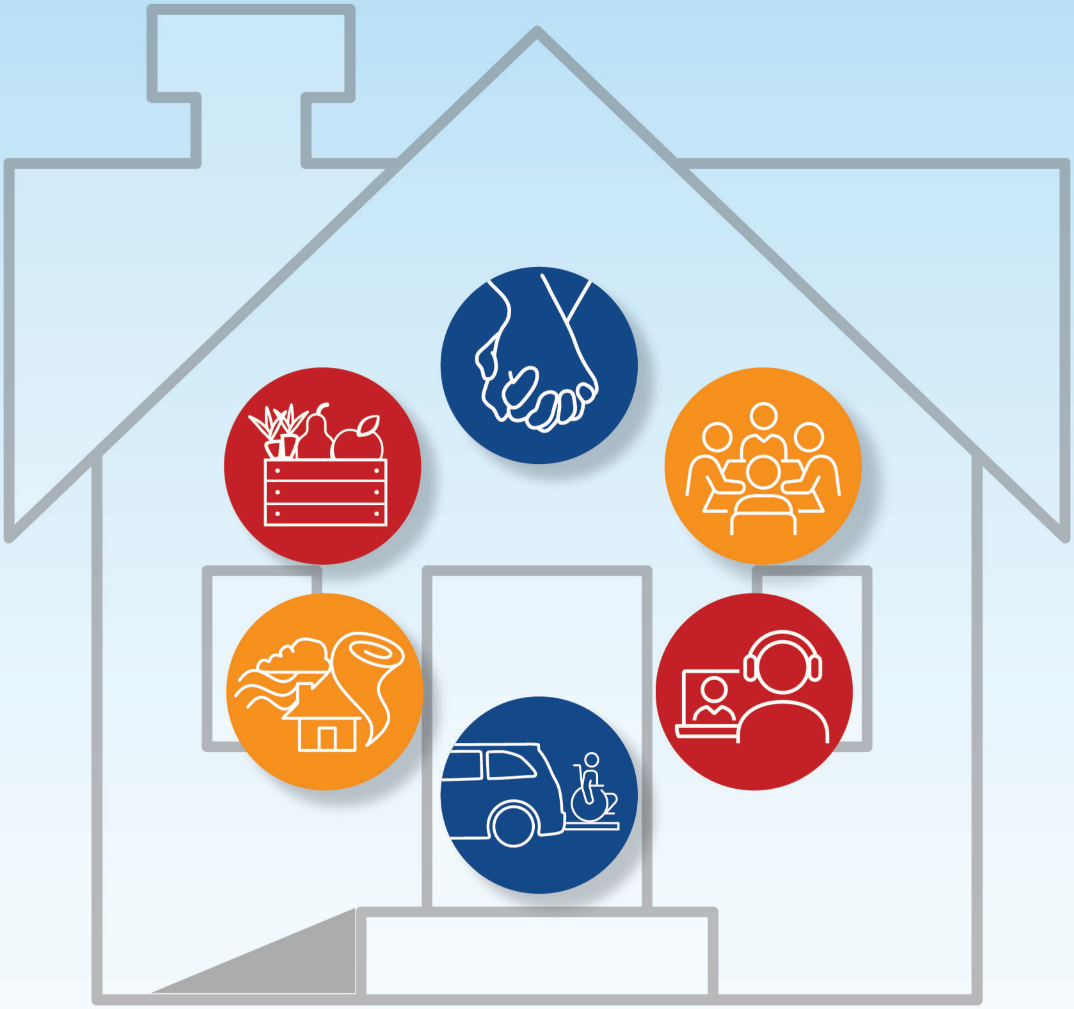
ACL Rapid Cycle Research and Evaluation

Administration for Community Living



Review of Respite Models for Family Caregivers of Alzheimer's Disease and Related Dementias

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ACRONYMS

ACL	Administration for Community Living
ADRD	Alzheimer’s disease and related dementias
ADS	Adult Day services
FDC	Farm-based daycare
HCBS	Home and Community-Based Services
HHS	U.S. Department of Health and Human Services
PWD	People living with dementia

EXECUTIVE SUMMARY

Background

An estimated 6.5 million Americans aged 65 and older are living with Alzheimer's disease and related dementias (ADRD), equating to nearly 11% of the overall older adult population (Alzheimer's Association, 2022). In the United States, an estimated 70% to 80% of people living with dementia (PWD) reside at home, the majority receiving care from unpaid family members and friends. Family caregivers report a lack of time for self and other non-caregiving related activities as one of the main barriers in caregiving. A possible short-term solution to ameliorate the time constraints family caregivers experience is respite care.

Broadly defined, respite care provides a temporary break in caregiving duties. Respite care can be provided at the home of the PWD, in a community-based setting (e.g., adult day centers), or in residential settings; the duration of respite care can also vary anywhere between a few hours to a weekend or more.

Despite the positive outcomes associated with respite care utilization (e.g., decreased feelings of loneliness, increased quality of sleep, reduced impact on caregivers' emotional health), respite care remains underutilized by family caregivers (Lee, Choi, & Park, 2022; Leocadie, Roy, & Rothan-Tondeur, 2018). Concerns related to quality of care, finances, and cultural awareness are cited as common barriers to respite care utilization; however, the level of satisfaction of these services remains high among family caregivers who do use them (Lee, Choi, & Park, 2022).

The Administration for Community Living (ACL) is interested in respite care for PWD and their family caregivers. This task supports ACL's interim learning agenda, which is focused on family caregivers. It will also support the National Family Caregiver Strategy, a product of the RAISE Family Caregivers Act, enacted in 2018 (ACL, 2018). To better understand the current landscape of respite care targeting family caregivers of PWD, ACL contracted with RTI International to conduct a two-pronged approach, consisting of a literature and programmatic document review, to address the following research questions:

1. *What are the common methods and models of respite care for family caregivers of PWD?*
2. *Under what circumstances or conditions are these methods and models most beneficial to family caregivers and PWD?*
3. *What are common barriers to accessing respite care for family caregivers and PWD?*

Methods

We conducted a systematic review of the peer-reviewed literature and programmatic documents. Nineteen peer-reviewed publications met our inclusion criteria: relevance to the research questions and published in English between 2012 and 2022.

The programmatic document review analyzed six ADRD-specific respite programs that were deemed innovative or exemplary in the 2019, 2020, and 2021 editions of *Innovative & Exemplary Respite Service Reports*, published by the Access to Respite Care and Help (ARCH) National Research Network (ARCH, n.d.). As in the literature review, a qualitative thematic analysis was conducted on the extracted content.

Results

The literature review found that respite services can be delivered by a variety of providers, with different levels of training, in myriad settings. Providers can be distinguished between two types: individual providers (e.g., volunteers, social workers, home healthcare agency representatives) and provider organizations (e.g., home healthcare agencies, clinics, HCBS organizations). The most commonly studied setting of respite care delivery is in community-based centers, often referred to as adult day services (ADS). Family caregivers who have a PWD participating in ADS-based respite care report positive outcomes, such as having time away from the PWD to engage in other activities (e.g., socialization, housework, errands) and self-care. Respite care is most beneficial to both the family caregiver and PWD when the respite provider has specialized training that emphasizes preserving the dignity of the participant, building rapport with the family caregiver, and understanding the general pathology of common dementias.

Barriers to respite service utilization can be divided into three categories: individual, provider, and societal level. Results from the literature review found that both family caregivers and primary care providers may lack education and awareness of the benefits of ADRD-specific respite services. Financial strain is another commonly cited barrier to respite service utilization.

The respite programs examined in the programmatic document review are currently being implemented across the United States and employ a variety of methods, including community outings, interactive activities, and music therapy. These programs occur in a variety of settings including in the home, in the community, and in facilities. Self-reported outcomes and anecdotal recounts from PWD, their family caregivers, and the individual respite providers have been generally positive.

Conclusions

Findings suggest that ADS-based respite care services are beneficial to both the PWD and the family caregiver when providers are well versed in ADRD and necessary communication skills. In ADS-based respite care, the PWD is provided with opportunities for meaningful engagement, and the respite affords the family caregiver the opportunity to participate in and focus on non-caregiving related activities, allowing them to return to their caregiving role refreshed. Despite ADRD respite services coming in a variety of forms, with positive benefits, it remains underutilized across delivery methods. Based on the results of this report, RTI has included recommendations for ACL's consideration as part of its efforts to expand ADRD respite.

- HCBS provider organizations should encourage respite care for caregivers of PWD, including, but not limited to, ADS.
- ADRD respite provider organizations should be encouraged to think creatively about which methods of respite will best serve their communities.
- ADRD respite provider organizations should consider creating opportunities to introduce undergraduate and graduate students to gerontology to positively impact the future aging network workforce.
- In addition to primarily providing respite care, ADRD respite provider organizations should be encouraged to emphasize respite-related education for both family caregivers and primary care providers as a secondary objective.

INTRODUCTION

Approximately 6.5 million Americans aged 65 and older live with Alzheimer's disease and related dementias (ADRD), equating to nearly 11% of the overall older adult population (Alzheimer's Association, 2022). This number is expected to more than double in the next 30 years, with researchers estimating between 12.7 and 14.0 million total cases by 2050 (Alzheimer's Association, 2022; Parker & Fabius, 2020). In the United States, an estimated 70% to 80% of people living with dementia (PWD) reside at home. The majority of PWD receive care from unpaid family members and relatives. Research conducted in the last several years estimates that between 11 and 16 million Americans provide unpaid care to PWD (Lee, Choi, & Park, 2022; Roberts & Struckmeyer, 2018). Typical duties of a caregiver range from transportation and medication management to facilitating activities of daily living, including dressing, bathing, and eating (Feldman et al., 2021). In 2021, family caregivers provided upwards of 16 billion hours of unpaid caregiving, equating to around $271 billion in cost (Alzheimer's Association, 2022). Although family caregivers report positive aspects of caring for PWD, such as a sense of fulfillment, love, and confidence in their loved one's care, the ensuing impacts on their mental and physical health cannot be ignored (Feldman et al., 2021; Lloyd, Patterson, & Muers, 2016; Roberts & Struckmeyer, 2018). For this report, we refer to caregivers as "family caregivers" but acknowledge that caregivers can include friends and other unpaid aides.

In addition to the stress brought on by the diagnosis' trajectory, family caregivers are experience impacts on their social, emotional, physical, and financial health (Leocadie, Roy, & Rothan-Tondeur, 2018). Nearly half (45%) of family caregivers interviewed in a study experienced unmet needs in mental health, and 85% of family caregivers had unmet needs in community resources and education (Black et al., 2013). Family caregivers often do not have enough time to address needs outside of caregiving, such as errands, housework, and job obligations (Roberts & Struckmeyer, 2018), resulting in reports of time constraints as one of their main barriers. A possible short-term solution to ameliorate the time constraints family caregivers experience is respite care.

Broadly defined, respite care provides a temporary break in caregiving duties. Respite care can be provided at the home of the PWD, in a community-based setting (e.g., adult day centers), or in residential settings; the duration of respite care can also vary anywhere between a few hours to overnight, to a weekend or more (Maayan, Soares-Weiser, & Lee, 2014; Parker & Fabius, 2020). There is evidence that short-term relief from caregiving responsibilities results in reduced feelings of loneliness, depression, and anxiety, and alleviated time pressures on the family caregiver, which can lead to long-term health benefits like improved sleep quality (Leocadie, Roy, & Rothan-Tondeur, 2018; Vandepitte et al., 2016). Considering the number of family caregivers in the United States and the projected exponential increase in the number of PWD, the need for respite services is high. Despite evidence of the positive impact of respite services on caregivers, utilization remains consistently low with approximately 15% of family caregivers in the United States benefiting from the resources (Feldman et al., 2021; Washington & Tachman, 2017; Wolff et al., 2016).

The goal of this review was to investigate the use of respite care among family caregivers of PWD. This report explores respite care in the United States through the following research questions:

1. *What are the common methods and models of respite care for family caregivers of PWD?*
2. *Under what circumstances or conditions are these methods and models most beneficial to family caregivers and PWD?*
3. *What are common barriers to accessing respite care for family caregivers and PWD?*

Contracted by the Administration for Community Living (ACL), RTI International conducted a two-pronged approach to addressing the above research questions, consisting of a literature and programmatic document review. Results of this study will provide ACL with a better understanding of the current landscape of respite care targeting PWD and their family caregivers.

METHODS

Literature Review

RTI conducted a literature review guided by a scoping approach, meaning that the research team considered a large range of study designs while conducting the review. Researchers suggest scoping studies be used to analyze both published and grey literature on program effectiveness (Levac, Colquhoun, & O'Brien, 2010). Because the team conducted a published literature review and a programmatic document review, the scoping approach best suited this report.

The purpose of the literature review was to investigate the current published research on ADRD respite care and reported effectiveness. RTI began the review by working with an experienced librarian to refine the approach to identifying relevant studies. ***Table 1*** presents the search terms, parameters, and sources used during the identification process.

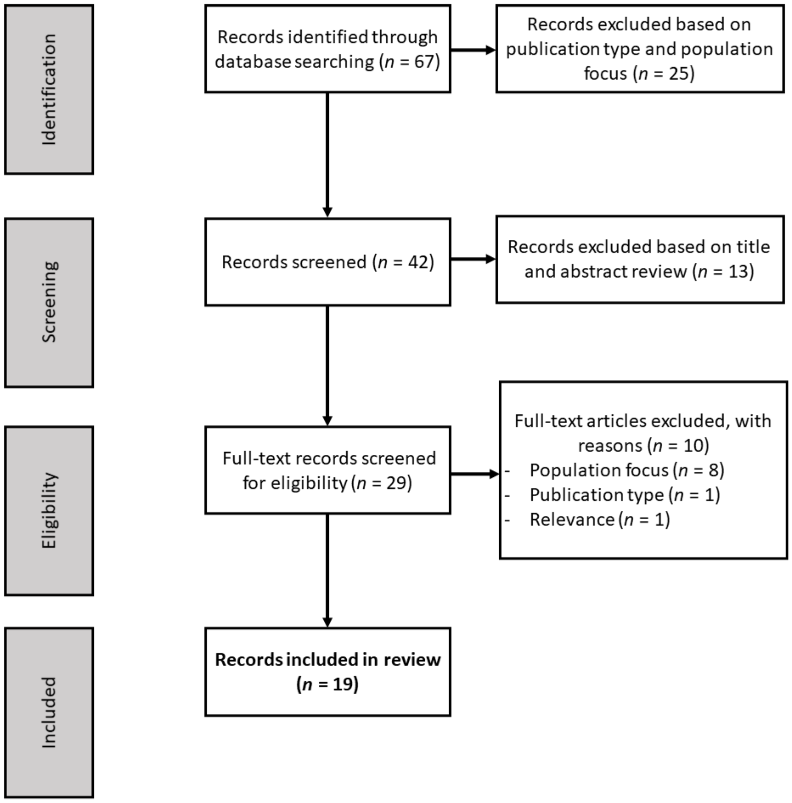
Table 1. Publication Identification Guidelines

Source	Search Terms	Parameters
PubMed	((caregiv*[ti] OR "care giv*"[ti] OR carer*[ti] OR ((caregiv*[ot] OR "care giv*"[ot] OR carer*[ot] OR "Caregivers"[Mesh]) AND (caregiv*[tiab] OR "care giv*"[tiab] OR carer*[tiab]))) AND ("respite"[ti] OR (("respite"[ot] OR "Respite Care"[Mesh]) AND "respite"[tiab])) AND (dementia*[ti] OR Alzheimer*[ti] OR "ADRD"[ti] OR ((dementia*[ot] OR Alzheimer*[ot] OR "ADRD"[ot] OR "Dementia"[Mesh] OR "Alzheimer Disease"[Mesh]) AND (dementia*[tiab] OR Alzheimer*[tiab] OR "ADRD"[tiab]))) AND ("2012/01/01"[Date - Publication] : "3000"[Date - Publication])) NOT ("Comment"[Publication Type] OR "Letter"[Publication Type] OR "Editorial"[Publication Type]) Filters: English	• Published within the last 10 years • Focus on ADRD-specific respite care programs • Based in the U.S., U.K., or Norway • English language
Web of Science	TI=((caregiv* OR "care giv*" OR carer*) AND ("respite") AND (dementia* OR Alzheimer* OR "ADRD")) and English (Languages) and Editorial Materials (Exclude – Document Types) Timespan: 2012-01-01 to 2022-12-31 (Publication Date)	
PsychINFO	(TI caregiv* OR TI "care giv*" OR TI carer* OR ((DE "Caregiver Burden" OR DE "Caregivers" OR DE "Caregiving") AND (AB caregiv* OR AB "care giv*" OR AB carer*))) AND (TI "respite" OR (AB "respite" AND DE "Respite Care")) AND (TI dementia* OR TI Alzheimer* OR TI "ADRD" OR ((AB dementia* OR AB Alzheimer* OR AB "ADRD") AND (DE "Dementia" OR DE "AIDS Dementia Complex" OR DE "Dementia with Lewy Bodies" OR DE "Presenile Dementia" OR DE "Pseudodementia" OR DE "Semantic Dementia" OR DE "Senile Dementia" OR DE "Vascular Dementia" OR DE "Alzheimer's Disease"))) Limiters - Publication Year: 2012-2022; English	

A total of 67 publications were identified from the search and subsequently screened for inclusion. Upon initial review, 25 publications were excluded based on population focus and publication type. The titles and abstracts of the remaining 42 publications were then screened, and 13 were excluded because of irrelevant population focus. The remaining 29 publications then underwent a full-text review by two RTI analysts. Ten publications were excluded based on population focus (8), publication type (1), and relevance (1). A qualitative thematic analysis was conducted on the final 19 publications selected for inclusion. The publication selection process is summarized in ***Figure 1.***

A team member imported the publications into a data charting tool, created to capture and organize information collected from the literature review. The tool allows information from the publications to be extracted and categorized based on applicability to the research question(s) and themes within each question. For example, information from a publication can be categorized to support RQ3, barriers to accessing respite care, and then further sorted to support provider-level barriers to accessing respite care.

Figure 1. Publication Selection Process



Programmatic Document Review

The programmatic document review analyzed six ADRD-specific respite programs that were deemed innovative or exemplary in the 2019, 2020, and 2021 editions of *Innovative & Exemplary Respite Service Reports*, published by the Access to Respite Care and Help (ARCH) National Research Network (ARCH, n.d.).

The six programs included in this review are as follows:

- **Caregiver Volunteers of Central Jersey/Alzheimer's Respite Care Program** *(Toms River, New Jersey)*
- **Lifespan of Greater Rochester, Caregiver Respite Program** *(Rochester, New York)*
- **Alzheimer's Disease Caregiver Support Initiative** *(Plattsburg, New York)*
- **Family to Family Adult Care Service** *(Memphis, Tennessee)*
- **Music Therapy Respite Program at the Cleveland Clinic Lou Ruvo Center for Brain Health** *(Las Vegas, Nevada)*
- **The Home Away from Home Respite Center at SUNY Geneseo** *(Geneseo, New York)*

The purpose of the programmatic document review was to analyze the methods and settings each of these six programs utilize for delivering respite care. This review also looked for documentation of family caregiver and PWD outcomes. As possible, RTI sought out information additional to what was provided in the *Innovative & Exemplary Respite Service Reports* regarding these programs (e.g., program websites). As in the literature review, a qualitative thematic analysis was conducted on the extracted content. Due to the varying amount and level of details available, the information obtained through the programmatic document review was limited in scope compared to the information obtained through the literature review.

Throughout both the literature and programmatic document reviews, providers were distinguished between two types: individual providers (e.g., volunteers, social workers, home healthcare agency representatives) and provider organizations (e.g., home healthcare agencies, clinics, HCBS organizations).

RESULTS

Summary results of the literature and programmatic document review are presented below, organized by research question (RQ).

RQ 1: What are the common methods and models of respite care for family caregivers of PWD?

Settings of Respite Care

Respite care can be provided in various settings, including the homes of the family caregiver or PWD, community-based centers, residential care facilities, and universities (Guerrero, Jimenez, & Tan, 2017; Parker & Fabius, 2020). Adult day services (ADS) provide PWD with opportunities for meaningful interactions and activities; at the same time, ADS allows family caregivers time away from exposure to distressing behavioral and psychological symptoms of dementia, like aggression and irritability (Bangerter et al., 2021; Lee, Choi, & Park, 2022). Caregivers who utilized ADS as a break from chronic stress related to caregiving reported decreased impacts related to mental and physical health.

Home-based respite care is understudied, despite the fact that the majority of PWD reside at home (Hogan, 2021 Roberts & Struckmeyer, 2018). Outcomes of both family caregivers and PWD who receive home-based respite care are mixed, with some studies concluding that home-based interventions reduced impact to physical and mental health on the family caregivers and others finding insignificant results regarding these impacts on the family caregiver or PWD (Hogan, 2021).

Farm-based daycare (FDC) is a novel setting being explored internationally. In FDC, caregivers are able to engage in other activities while PWD participate in activities such as gardening, animal care, and farm maintenance (Taranrød et al., 2021). PWD who participated in FDC exhibited positive outcomes, including better sleep after a day of FDC participation, improved mood, and forming new friendships with other participants. Family caregivers also reported unanimous positive attitudes toward the program, citing properly trained staff and close communication as facilitating factors (Taranrød et al., 2021).

Because of the broad range of respite care settings, conclusions on their general effectiveness are inconclusive; however, there are indicators that some settings may be more effective than others. For example, studies of ADS and an initial study of FDC indicate beneficial outcomes for caregivers (e.g., increased time for other activities) and PWD (e.g., increased socialization, positive mood).

Providers of Respite Care

As with the settings of respite care, individual providers and provider organizations of respite care also vary. Examples of individual providers of respite care may include trained professionals (e.g., certified nursing assistants, occupational therapists, social workers), volunteers, and college students (Guerrero, Jimenez, & Tan, 2017; Hogan, 2021; Washington & Tachman, 2017).

Cleveland Clinic Nevada's 90 minute **Music Therapy Respite Program** sessions are delivered by a board-certified music therapist, with support from trained volunteers. The Clinic reports that music therapy positively impacts motor skills, communication, memory, and emotional expression in PWD (Cleveland Clinic Nevada, 2022). The family caregiver is not engaged in the music therapy, so the program offers them the opportunity to attend support groups while their person receives therapy. The pandemic resulted in the Music Therapy Respite Program moving to a virtual model; removing the dual benefit of the in-person therapy and the access to a support group.

The Alzheimer's Respite Care Program, a part of the **Caregiver Volunteers of Central Jersey**, trains its volunteers on topics including stages of dementia, typical behaviors and management, and best practices to support the family caregiver. Volunteers in this program spend 2 to 3 hours each week providing companionship and emotional support to PWD and family caregivers. The **Alzheimer's Disease Caregiver Support Initiative** at SUNY Plattsburgh is facilitated by trained volunteers who provide respite care tailored to the cultural needs of and level of care for the PWD and family caregiver. Services provided by the Alzheimer's Disease Caregiver Support Initiative are consumer-directed, which means the family caregiver can choose the volunteers and location of services, which can vary from the PWD home, a community center, or a facility.

TimeOut@UCLA, the **Houseguest** program, and the **Home Away from Home Respite Center** are three examples of intergenerational respite programs that engage college students (Guerrero, Jimenez, & Tan, 2017; Washington & Tachman, 2017; SUNY Geneseo, 2022). In TimeOut@UCLA, family caregivers drop-off their care recipients at the UCLA campus Dementia Care Program to meet with their student partner. Family caregivers benefit from eight-week TimeOut@UCLA program by receiving up to 6 hours of respite care each week and the PWD benefit from being paired with students with whom they engage in conversation and activities. Family caregivers reported positive attitudes toward the program, citing mental stimulation, attention, and social engagement as primary benefits for the PWD (Guerrero, Jimenez, & Tan, 2017). In Houseguest, Master of Social Work students received training on dementia caregiving and were paired with a family caregiver and PWD. Houseguest participants received six 90-

minute home visits with students in the program. During post-interviews, family caregivers reported that their care recipients benefited from socialization with the students, and they benefited from the additional time to attend to chores and self-care (Washington & Tachman, 2017). Founded by the Center for Community at SUNY Geneseo, the Home Away from Home Respite Center trains student volunteers on communication techniques, navigating challenging situations with PWD, and an overview of memory-related diseases. Students in this program are also trained to facilitate meaningful activities such as chair yoga, cooking projects, and interactive activities (e.g., arts and crafts, games). PWD can spend approximately 8 hours a week at the Center, located on the campus, when the program is active during the academic year (SUNY Geneseo, 2022).

The reviewed literature and programs reveal that a range of providers (e.g., professionals, students, non-student volunteers, music therapists) are supporting caregiver respite programs. In each example, training of the provider is emphasized (e.g., dementia caregiving, communication techniques) and positive outcomes for PWD (e.g., emotional expression, socialization) and caregivers (e.g., additional time to complete chores and self-care) are noted.

Methods of Respite Care

Among the programs included in our programmatic and literature reviews, methods for the delivery of respite for the PWD included social activities (Alzheimer's Disease Caregiver Support Initiative; Home Away from Home Respite Center), worship services (Alzheimer's Disease Caregiver Support Initiative), arts and crafts (Home Away from Home Respite Center),and interactive games (TimeOut@UCLA; Home Away from Home Respite Center). Respite providers also recognize the benefit of providing transportation to facilities or worship services, as provided as part of the **Lifespan of Greater Rochester**, which is a key factor in a PWD's ability to participate in meaningful activities. For family caregivers, respite providers also supplement traditional services to include development of self-care plans (Houseguest) and educational and emotional support opportunities (Caregiver Volunteers of Central Jersey).

Some respite programs sponsor trips to art museums, galleries, and other cultural resources for both the family caregiver and PWD. Family caregivers who participated in cultural activities with the PWD reported that the program was a break from the stressors encountered in everyday caregiving (Pienaar & Reynolds, 2015).

Respite care models identified in the literature review are presented in ***Table 2***. ***Appendix A*** describes the programmatic document review results in further detail. It should be noted that the information obtained in the programmatic document review was limited in scope.

Table 2. Respite Programs Included in Literature Review

Program Name	Setting(s)	Provider Type	Method(s) Used	Training Received	Intended Outcomes
TimeOut@UCLA (Guerrero, Jimenez, & Tan, 2017)	UCLA campus	Undergraduate students	Social activities, structured activities (e.g., card games, crossword puzzles, bingo)	Students are selected through an application process, and nearly half (46%) have had prior experience working with PWD	To encourage undergraduates to pursue careers in gerontology; To allow family caregivers time away from the PWD to attend to errands or relax
Houseguest (Washington & Tachman, 2017)	PWD's home	Master's of Social Work students	Interactive activities tailored for the PWD, self-care activities tailored for and designed by the family caregiver	Students received training via a credit-bearing elective course called Dementia Caregiving	To introduce students to the field of gerontology and promote community engagement; To allow family caregivers to engage in a desired self-care activity while the PWD is receiving personalized care
Adult Day Services (Wylie et al., 2021)	Community setting	Volunteers	Interactive activities, general supervision and care	Communication skills, building rapport with family caregiver and PWD	To provide family caregivers a break from responsibilities related to caregiving and time to attend other activities
Farm-Based Daycare (Taranrød et al., 2021)	Farms local to the PWD	Farmers, health, and social services representatives	Farm building, gardening, animal care, physical and social activities	Farmers are educated on preserving the dignity of the PWD, how to adapt to the PWD's level of function, and building rapport with the family caregiver	To provide family caregivers time to attend to other activities and reduce feelings of burden, worry, and depression
Art Therapy (Pienaar & Reynolds, 2015)	Art galleries local to the PWD	Tutors from participating art galleries	Joint art gallery visit with both the family caregiver and the PWD, four 90-minute art and craft-making sessions for the family caregiver while the PWD was receiving respite care in the gallery	Communication skills, cultural awareness, managing group dynamics	To provide family caregivers a break from responsibilities related to caregiving while creating art to express their emotions; To provide both family caregiver and PWD an opportunity to engage in a leisure-based experience like touring an art gallery

RQ 2: Under what circumstances or conditions are these methods and models most beneficial to family caregivers and PWD?

When used consistently, respite services have been shown to have major positive effects for caregivers. Utilization of respite services can be protective against the profound impact that the demands of caregiving can have on the family caregiver's emotional, psychological, and physical health (Bangerton et al., 2021; Feldman et al., 2021). Utilization of respite lowers caregiver exposure to care stressors (i.e., the behavioral and psychological symptoms of dementia), which are the major sources of psychological distress for family caregivers (Bangerton et al., 2021).

Individual-level Benefits

Numerous benefits are associated with utilization of respite services, particularly for caregivers. Dementia caregivers, in multiple studies, expressed that they feel they do not have a balance between time spent providing care and time spent focusing on their other activities (Lee et al., 2022; Leocadie, Roy, & Rothan-Tondeur, 2018; Roberts & Struckmeyer, 2018; Wylie et al., 2020). Providing respite care allows for caregivers to receive a "break" from caregiving by providing mental and physical relief to caregivers, reducing the caregiving burden, and protecting against the chronic stress related to caregiving (Lee et al., 2022). Flexibility is an important factor in a caregiver's decision to utilize respite care. Programs like the **Alzheimer's Disease Care Support Initiative**, recognize the need for flexibility and offer services provided in the home or away from home in an adult day center, in an effort to make things easier for the caregiver and the PWD. Some service providers also provide other complimentary supports, such as counseling and support services for the caregivers themselves and household chore services (Roberts & Struckmeyer, 2018).

Respite programs can also be beneficial for the PWD, but the effect on PWD is less clear and may be more dependent on the person's stage of dementia (Roberts & Struckmeyer, 2018). This could be attributed to the fact that the majority of existing literature on respite services is from the caregivers' perspectives (O'Shea, Timmons, O'Shea, & Irving, 2019b). Some programs, such as **Lifespan of Greater Rochester**, provide activities that may be beneficial for those in early stages of memory loss. Respite care also benefits PWD through its impact on caregivers. Taking breaks from caregiving allows the caregiver to "recharge," and participants in a study done by Roberts & Struckmeyer (2018, p. 9) reported being able to take on their caregiving responsibilities with "renewed emotional and physical vigor."

Provider-level Benefits

Providers and caregivers are an integral part of the care team for PWD, and respite can be used as an opportunity to strengthen this relationship. A caregiver who is feeling overwhelmed may not be able to provide the highest level of care or may feel ill-trained to manage the complex care needs of a PWD (Leocadie, Roy, & Rothan-Tondeur, 2018). Many caregivers reported feeling that they do not know where to find resources for respite care or for caregiver training. Respite and the supplementary services and supports that come with it provide an opportunity for providers to equip caregivers with educational materials and resources to prepare them for their caregiver roles (Leocadie, Roy, & Rothan-Tondeur, 2018; Roberts & Struckmeyer, 2018). Respite care centers and programs, such as the **Caregiver Volunteers of Central Jersey**, make formally trained providers available for educational meetings and webinars in support of caregivers. Proper training and resources afford both providers and caregivers the opportunity to collaborate on the caregiving options available to them

Societal-level Benefits

Public and policy support for respite care has grown over the years, as it has been recognized that earlier use of services is more likely to produce long-term benefits for both the caregiver and the PWD (Feldman et al., 2021). Building a robust support network for caregivers and PWD will better support caregiver resilience through the course of their family member's dementia (Roberts & Struckmeyer, 2018). Family caregivers who utilize respite care report a significant decrease in desire to institutionalize the PWD (Hogan, 2021). In 2022, the total national cost for caring with PWD, excluding unpaid caregiving provided by family or friends, is expected to reach $321 billion; approximately, 64% of that total cost is expected to fall on Medicare and Medicaid to cover (Alzheimer's Association, 2022). Utilizing respite care may somewhat alleviate the future need for more costly public services, such as those funded by Medicare and Medicaid, the Older Americans Act, and state-funded services.

RQ 3: What are common barriers to accessing respite care for family caregivers and PWD?

Numerous barriers can limit access to ADRD respite services. Common barriers to accessing ADRD respite services include inadequate family caregiver knowledge on service availability and ability to navigate the social service system; inadequate primary care professional knowledge of benefit of respite service and its availability; financial strain of services; family caregiver guilt; care quality concerns; and use of respite time and perceived effectiveness (Leocadie, Roy, & Rothan-Tondeur, 2018; O'Shea et al., 2019; Parker & Fabius, 2020; Vandepitte et al., 2016). The following sections categorize and analyze these barriers at the individual, provider, and societal level.

Individual-level Barriers

Despite the suggested effectiveness of respite care, family caregivers are often hesitant to utilize such services. Feelings of guilt for seeking respite from caregiving duties are often reported among family caregivers (Leocadie, Roy, & Rothan-Tondeur, 2018; O'Shea et al., 2019b; Roberts & Struckmeyer, 2018). These feelings are further exacerbated if the PWD is either resistant to participating in respite programs or reluctant to accepting help from others (Lee, Choi, & Park, 2022). O'Shea and colleagues (2019b) conducted qualitative interviews with various stakeholders (e.g., PWD, caregivers, frontline staff) to understand different perspectives on accessing respite services. PWD responses revealed that some PWD found overnight residential respite environment "cold" and "clinical." Therefore, some family caregivers interviewed in this study were reluctant to further pursue respite services to avoid conflict and guilt. Additionally, respite care may be framed as a break from the “burden” of caring for the PWD; this “burden-based conceptualization” of respite care can be challenging to family caregivers seeking these services, as it becomes framed as a “carer-centered venture” rather than one that benefits both the family caregiver and PWD (O’Shea, Timmons, O’Shea, Irving, 2019b, p. 496).

Inadequate and inaccurate knowledge of ADRD respite services and the ways in which it can be delivered hinders utilization among family caregivers. Family caregivers reported believing that respite services are only for PWD entering the final stages of their disease and that respite services are associated with a decline in health in the PWD (Leocadie, Roy, & Rothan-Tondeur, 2018). Meanwhile, other family caregivers expressed concern over the quality of care the PWD would receive through respite and legitimacy of respite service providers (Leocadie, Roy, & Rothan-Tondeur, 2018).

Limited studies on the effects of race on ADRD respite care attitudes and utilization have been conducted. Regarding utilization, Caucasian family caregivers were more likely to utilize respite services compared to Hispanic or Latinx family caregivers (Feldman et al., 2021). Caucasian and Black family caregivers are more likely to experience feelings of guilt surrounding respite services than Hispanic or Latinx family caregivers (Leocadie, Roy, & Rothan-Tondeur, 2018). As a result, Black family caregivers are more likely to rely on other family or friends for assistance (Parker & Fabius, 2020). Further research is needed to understand individual-level race-related barriers to respite service, including attitudes and utilization rates. Race-related barriers at the societal-level are discussed further in this report.

Some family caregivers are not aware of respite services, which may, in part, be the result of primary care providers’ lack of knowledge in ADRD respite (O’Shea et al., 2019a). Primary care provider knowledge and the ability to articulate the value of respite has a sizeable impact on service utilization.

Provider-level Barriers

Clinical training in geriatrics is not mandated in the United States medical education system (Hyer et al., 2019). As a result, primary care providers often do not pursue advanced gerontological training as part of their education despite their patient base being predominantly older adults (Morgan et al., 2020). Consequently, the provider’s ability to detect and diagnose dementia in a patient can be suboptimal or delayed (Mansfield et al., 2019). This can impact providers’ knowledge of the availability of respite services and ability to effectively guide/refer family caregivers to these support opportunities (O’Shea et al., 2019a). In a similar vein, family caregivers reported that respite provider availability was limited even in emergency circumstances. This could be telling of a discrepancy between what the family caregiver and primary care provider consider to be urgent situations (O’Shea et al., 2017).

Respite care for PWD is most effective when the respite provider has specialized training that emphasizes preserving the dignity of the PWD, building rapport with the family caregiver, and understanding the general pathology of common dementias (Guerrero, Jimenez, & Tan, 2017;

Leocadie, Roy, & Rothan-Tondeur, 2018). However, some service providers have reported inconsistent training requirements for staff that impacts care delivery (O'Shea et al., 2017). The needs of caregivers can be met through adequate training and structure regarding care for the PWD (Leocadie, Roy, & Rothan-Tondeur, 2018). Without a level of trust in the providers caring for the PWD, family caregivers can be dissuaded from seeking future respite services (Leocadie, Roy, & Rothan-Tondeur, 2018).

Societal-level Barriers

One of the most commonly reported barriers to respite service use is financial strain, especially for services provided in an ADS or residential setting (Hogan, 2021; O'Shea et al., 2017; Parker & Fabius, 2020). In particular, families who are in the middle-income range may find themselves in a predicament in which they cannot afford private-pay respite services but do not qualify for Medicaid-funded home and community-based services (Hogan, 2021). For example, families reporting an income of less than $30,000 are more likely to utilize respite service use compared to families reporting an income of less than $60,000 (Feldman et al., 2021). Family caregivers who do utilize respite services incur an average of approximately $5,500 in out-of-pocket expenses annually.

For Black family caregivers in the United States, trust in the health and social care systems may be impacted because of historical marginalization from such systems (Alexander et al., 2022; Parker & Fabius, 2020). A proportion of Black family caregivers report being subjected to culturally insensitive medical professionals; half of Black Americans have reported experiencing ADRD care discrimination, and over a third of Black Americans believe discrimination would be a barrier to receiving ADRD care. Likewise, 42% of Native Americans, 34% of Asian Americans, and 33% of Hispanic Americans have reported facing racial discrimination when seeking ADRD care (Alzheimer's Association, 2021).

Family caregivers have reported that navigating the health and social care systems is significantly difficult when searching for respite services (Alexander et al., 2022; O'Shea et al., 2017). This includes identifying respite organization personnel who are able to connect family caregivers and PWD with resources and identify level of support need for the PWD (O'Shea et al., 2017). Difficulty accessing accurate and current information regarding respite services, such as conditions for admission, physical preparations, and caregiver involvement, continues to negatively impact respite utilization (Leocadie, Roy, & Rothan-Tondeur, 2018).

CONCLUSION

Findings from our review of the literature and programmatic document indicate that respite care is provided in homes of the family caregiver or PWD, community-based centers, residential care facilities, and universities. They also suggest that respite care provided outside the home of the family caregiver or PWD is most beneficial to the family caregiver. The break from the PWD allowed the family caregiver to attend to other responsibilities or relax, allowing them to become better caregivers because they returned to their duties "recharge[d]" (Roberts & Struckmeyer, 2018). However, there is a lack of literature on the circumstances and conditions under which respite care is most beneficial to the PWD. Providers benefit from respite care through being exposed to the field of gerontology (such as with student volunteers) and by receiving formal training in respite care. Furthermore, society benefits from respite care use, as family caregivers who utilize respite care tend to report a significantly lower desire to institutionalize the PWD (Hogan, 2021). Medicare and Medicaid are expected to cover over $200 billion in 2022; reducing institutionalization of PWD can assist with lowering this cost burden (Alzheimer's Association, 2022).

Successful respite care programs that reported positive outcomes from the family caregiver, PWD, and respite provider were largely student volunteer-based (TimeOut@UCLA, Houseguest, Home Away from Home Respite Center). Not only do these programs provide respite care outside the home of the family caregiver or PWD, but they encourage students to pursue a career in gerontology through their experiences as the respite provider. Because the United States is facing a dementia specialist capacity shortage (Morgan et al., 2020), programs such as these may inspire future dementia specialists.

Barriers to accessing and utilizing respite care included those at the individual (e.g., feelings of guilt, misunderstanding of respite care, quality of care concerns), provider (e.g., lack of awareness of ADRD respite services in primary care providers, lack of training for respite providers), and societal level (e.g., financial strain, navigating social care system).

Our recommendations and justifications for them are presented in ***Table 3***.

Table 3. Recommendations and Justifications for ADRD Respite Care

Recommendation	Justification
HCBS provider organizations should encourage respite care for caregivers of PWD, including, but not limited to, adult day services.	There is research evidence on adult day services yielding positive outcomes on the family caregiver.
ADRD respite providers should be encouraged to think creatively about which methods of respite will best serve their communities.	There is growing evidence that a range of methods or activities can benefit caregivers and PWD (e.g., social activities, worship services, arts and crafts, interactive games, transportation services to alleviate the family caregiver of that responsibility, developing plans for self-care, educational and emotional support, art or music therapy).
ADRD respite programs should consider creating opportunities to introduce undergraduate and graduate students to gerontology to positively impact the future aging network workforce.	Promising programs have been successfully delivered with students or trainees who will be the future backbone of the aging network workforce.

Recommendation	Justification
In addition to primarily providing respite care, ADRD respite provider organizations should be encouraged to emphasize respite-related education for both family caregivers and primary care providers as a secondary objective.	Lack of awareness and understanding of respite care is an access barrier. Supplying primary care providers with information related to ADRD-specific respite care programs in their area can facilitate respite care access among interested family caregivers. Likewise, delivering community-wide educational materials related to the ADRD trajectory, different modes of respite care, and how to navigate social services could greatly benefit family caregivers considering respite. Providing resources and education at the point of diagnosis will also encourage caregivers to use resources and lessen the barrier that is lack of education regarding what resources are available.

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APPENDIX A
PROGRAMMATIC DOCUMENT REVIEW HIGHLIGHTS

In addition to the peer-reviewed literature review, this report assessed six ADRD-specific respite programs that were deemed innovative or exemplary in the 2019, 2020, and 2021 editions of *Innovative and Exemplary Respite Service Reports,* published by ARCH (ARCH, n.d.):

1. **Caregiver Volunteers of Central Jersey/Alzheimer's Respite Care Program** *(Toms River, New Jersey)*
2. **Lifespan of Greater Rochester, Caregiver Respite Program** *(Rochester, New York)*
3. **Alzheimer's Disease Caregiver Support Initiative** *(Plattsburg, New York)*
4. **Family to Family Adult Care Service** *(Memphis, Tennessee)*
5. **Music Therapy Respite Program at the Cleveland Clinic Lou Ruvo Center for Brain Health** *(Las Vegas, Nevada)*
6. **The Home Away from Home Respite Center at SUNY Geneseo** *(Geneseo, New York)*

RTI did face a limitation during the programmatic document review. The programmatic document review was based on minimal available materials that provided varying levels of detail on services provided and outcomes for the family caregiver or PWD. In this section, programs are identified through their numbers above. The programs are listed in no particular order. ***Table A*** provides a breakdown of the respite programs included in the programmatic document review.

Respite services were provided at the PWD's home (1, 2, 3, 4), a facility (2, 3, 5), virtually (5), or at a university (6). Some programs offered flexibility in their settings, allowing the family caregiver to choose a setting most beneficial to their situation (2, 3), whether that be a facility or the PWD's home. The providers in these programs varied from trained volunteers (1, 2, 3, 4, 6), home health care agency representatives (2), a board-certified music therapist (5), and undergraduate students (6). Trainings received by providers included practical nursing skills (4), communicating with the PWD and their family caregiver (1, 6), and an overview of memory-related disease and their trajectories (1).

The method of respite varied depending on the program setting and provider type. Several programs offered interactive activities like arts and crafts and games (1, 2, 3, 6), while others provided transportation to faith-based services and other community outings (2, 3, 4). Other methods of respite care included basic financial planning (2), collecting oral histories (4), and music therapy (5).

Family to Family Adult Care Services (4) facilitates the *80 Plus Program* in which staff collect oral histories from PWD age 80 years and older. The goal of the program is to assemble these stories into a documentary to be shared with younger generations (ARCH, 2020).

Participating family caregivers and PWD self-reported their outcomes from a couple of the respite programs. In one program, a participating PWD provided anecdotal positive outcomes, citing improved memory because of the mental stimulation from the interactions with volunteers and other participants (6). A family caregiver participating in the same program reported experiencing “peace of mind” while their care recipient was away (SUNY Geneseo*,* 2022). Both family caregivers and PWD who participate in the Music Therapy Respite Program (5) reported positive outcomes as well, such as decreased feelings of depression. Music therapy has been correlated with increased cognitive activity, memory recall, and a sense of community among PWD (Cleveland Clinic Nevada, 2022). In addition to the positive outcomes of the Music Therapy Respite Program on PWD, family caregivers are able to utilize the 90-minute sessions to attend to errands, chores, or relax. However, it should be noted that these therapy sessions are currently held virtually due to the COVID-19 pandemic. Therefore, family caregivers may not be able to leave the PWD to attend to other responsibilities or activities.

Table A. Respite Programs Included in Programmatic Document Review

Program Name	Setting(s)	Provider Type	Method(s) Used	Training Received by Providers	Intended Outcomes
1. Caregiver Volunteers of Central Jersey[1]	PWD's home	Volunteers	Interactive activities	Communication skills, ADRD trajectory, building rapport with family caregiver and PWD. Monthly meetings with guest speakers.	To provide family caregivers time to attend to other activities; to provide community-wide resources on ADRD education
2. Lifespan of Greater Rochester[2]	Facility, community setting, PWD's home	Volunteers and home health care agency representatives	Transportation services, basic financial management, interactive activities	Dependent on the method but varies from regular in-services and workshops.	To provide family caregivers time to attend to other activities; to allow PWD to see whether they would like to reside in a facility permanently
3. Alzheimer's Disease Caregiver Support Initiative[3]	PWD's home or community setting	Volunteers or personal care assistants	Transportation services, interactive activities, transportation to faith-based services	Communication skills, cultural awareness.	To provide family caregivers time to attend to other activities
4. Family to Family Adult Care Service[4]	PWD's home	Volunteers	Community outings, transportation to faith-based services, collecting oral histories	Communication skills, building rapport with family caregiver and PWD, role playing simulations, practical nursing skills.	To assist the PWD with activities of daily living
5. Music Therapy Respite Program[5]	In-person at the clinic; Virtual (during COVID-19 PHE)	Board-certified music therapist	Music therapy	Requires board certification in music therapy.	To improve motor skills, communication, memory, and expressing emotions among PWD
6. Home Away from Home Respite Center[6]	University	Undergraduate student volunteers	Physical activities, interactive activities, therapy dog visits	Communication skills, problem solving, ADRD trajectory, building rapport with family caregiver and PWD.	To encourage students to pursue a career in gerontology; To provide engaging activities to PWD

[1] https://caregivervolunteers.org/get-help/alzheimers-respite-care/
[2] https://static1.squarespace.com/static/531f242de4b0467fe7ea5084/t/62339d519db10157ec60cadf/1647549778154/Respite-Short+Term+Stay.pdf
[3] https://www.wehelpcaregivers.com/respite-program/
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