The Case for Expanding Caregiver Support Through Adult Day Services



Results from an Archstone Foundation Initiative yield next steps for providers, philanthropy and policymakers



Adult day services (ADS) are designed to serve frail older adults, providing social interaction, planned activities in a group setting, and sometimes even health care. What gets less attention are the many secondary, though critically important, benefits ADS can deliver for the family members, friends and others caring for older people.

Caregivers often suffer financial burden, physical stress, and depression from the variety of responsibilities and challenges they encounter in their caregiving role. Recognizing this, and in response to the 2016 "Families Caring for an Aging America" report from the National Academies of Sciences, Engineering and Medicine, Archstone Foundation funded a \$1.5 million, three-year initiative to enhance or create programs and services explicitly for family caregivers at five ADS providers in Los Angeles and Orange counties.

The results from our Family Caregiving Initiative report are unambiguous: There are significant benefits to making ADS providers a hub of logistical, emotional, and educational support for caregivers. This work has demonstrated that increasing caregiver engagement in the ADS setting—and relieving caregivers' mental and physical stress—is crucial not only for caregivers' health but also for improving the quality of care for those receiving ADS.

The report reveals clear next steps including:

- Conveying the importance of expanding caregiver programming to more ADS providers;
- Finding additional philanthropic support to bolster services for family caregivers who are disproportionately people of color; and
- Seeking additional state and federal funding for ADS programs (both health and social models) for frail adults and caregivers, in part by stressing the long-term Medicare and Medicaid savings that would be achieved.

Participants in the Initiative

- Alzheimer's Family Center
- Alzheimer's Orange County
- · Meals on Wheels Orange County
- ONEgeneration
- OPICA Adult Day Program and Counseling Center

The Challenge Facing Caregivers

ADS organizations have traditionally served those 65 and older with chronic illnesses and functional, cognitive, or sensory impairments. This work has contributed to better outcomes for those requiring care, improved lives for family caregivers and their households, and reduced expenses for the health system.¹

The challenge is that, despite increasing access to ADS, the nation's 44 million family caregivers still provide the most help with activities of daily living for older relatives suffering from complex mental and physical disabilities. They furnish

the bulk of their personal and physical support, and even play a central role in delivering medical care. As a result, far too many caregivers confront significant mental health, physical health, and financial challenges.

Recommended Action for ADS Providers

There are several concrete actions that organizations providing ADS can take:

- Offer counseling and support groups to family caregivers
- Provide training and classes to develop family caregivers' skills and knowledge or partner with organizations who can provide these services
- Assure new programming is culturally appropriate and available in families' native languages
- Extend hours of operation so caregivers have more respite time
- Regularly assess caregiver needs and the impact of caregiver programs and services

A New Approach

In 2018, Archstone Foundation began to test the theory that family caregivers' lives could be substantially improved through the work of ADS providers. It awarded three-year grants so that five not-for-profit organizations in Southern California could pursue a range of options including:

- Counseling and support groups for caregivers
- Training and classes to improve caregiving skills and health care knowledge
- Improved communication with caregivers most comfortable with a language other than English
- Culturally informed services for diverse groups of caregivers
- Cultural awareness training for ADS providers
- Extended operating hours to provide more respite time for caregivers

The five grants also sought to improve organizational sustainability and promote collaboration among ADS providers, so that they could spur a national conversation about the importance of ADS and supporting caregivers.

What We Learned

The Family Caregiving Initiative demonstrated that intentional, responsive services and programs for family caregivers benefit our most vulnerable older adults, allowing them to continue to live at home and in their communities. And the wellness of these caregivers is inextricably connected to the wellness of those they care for.

Support for Caregivers Works

Despite the significant obstacles introduced by the COVID-19 pandemic, the new programming increased the number of caregivers served by all five ADS providers. A vast majority of family members reported very high levels of satisfaction with the services they received. They described the individual counseling and support groups as improving their mental health and wellness, including sleeping better. They credited the education and training offerings with improving their knowledge and confidence and welcomed the classes offered in languages other than English. Those who used the extended weekday and weekend hours said they benefited from the time to rest or tend to their other responsibilities.

Caregivers also reported that enhanced transportation services would increase the use of expanded ADS hours for respite time since many lack transportation and many are older adults who can be uncomfortable transporting their loved ones after dark.

As the Family Caregiving Initiative took place during the pandemic, we were heartened that providers proved adept at switching their education, support groups, and counseling from in-person to online. Caregivers welcomed the new programs with comparable enthusiasm, and the virtual offerings enabled family members far from southern California, as well as some of those most vulnerable and affected by inequitable systems of care, to benefit.

Partnerships Are Essential

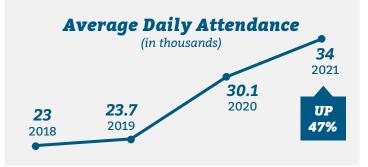
Archstone Foundation's Family Caregiving Initiative was in part designed to enhance the sustainability and collaboration of the five organizations funded. Through the Initiative, it was clear that ensuring ADS providers are on a solid organizational footing and able to operate collaboratively is central to the success of ADS caregiver programs.

This work suggests these ADS service expansions—all of them readily replicable—have a strong probability, over the long term, of enhancing caregivers' mental and physical health, reducing their financial stress, bolstering their confidence, and improving their sense of fulfillment of a family obligation.



A Growing Presence in California

Four of the five grantees in the Initiative are providers of health-based (as opposed to social-based) adult day services, which have been growing steadily in the nation's most-populous state. In the past four years:







Source: California Department of Agina

Resources to guide organizations in expanding their programming to meet the needs of family caregivers include:

- Best Practice Caregiving offers a searchable database of effective programs for family caregivers.
- <u>California Area Agencies on Aging</u> have resources for organizations looking to provide services to family caregivers, in addition to information for older adults and their caregivers.
- <u>Family Caregiver Alliance</u> has a wealth of resources for caregivers, in multiple languages, from which ADS providers can learn.
- <u>California Caregiver Resource Centers</u> provide information and support for caregivers across the state.
- The <u>California Department of Aging</u> houses the <u>California Master Plan for Aging</u>, links to caregiver resources, data and reports related to caregiving and ADS, and more.

What's Next for the ADS Community: Expanding Services, Building Partnerships, Inspiring Change

The Family Caregiving Initiative revealed that ADS providers, in California and across the nation, can be confident in knowing they are not only vitally important to their older adult participants but that they are also a critically needed family caregiver support provider.

Even for ADS providers on a tight budget, modest investments in additional staffing and licensing to address the needs of family caregivers — like those already provided by the program — can have a significant effect on caregivers' mental and physical health, as well as on the quality of care for the older adults already reliant on adult day services. Importantly, caregiver support and training can generally be incorporated into existing programs.

In addition to developing partnerships with community-based organizations to share expertise and programming, a critical component of creating successful programs for caregivers is for ADS providers to support and learn from others' advocacy efforts. While not all ADS organizations see advocacy as part of their work, others are committed to being systems change agents. Whether on their own or in collaboration with others, providers have an opportunity to influence the decisions facing both state and federal policymakers.

What's Next for Philanthropy: Investing and Community Building

While there has been significant investment in family caregiving approaches, supporting family caregivers through adult day services has not been a focus of philanthropy. With this Initiative, Archstone Foundation sought to demonstrate the benefits of even relatively modest contributions from private funders and to encourage similar investments by others in the philanthropic community who are interested in caregiving, health care, and older adults. Grantmakers In Aging members can join the Family Caregiving Funders Community, a group of grantmakers funding or exploring family caregiving programs who meet regularly to learn about new models of care and potential ways to collaborate on and co-fund projects.

There is also a tremendous opportunity for philanthropies to help other states develop master plans for aging similar to <u>California's</u>, build family caregiving coalitions, and convene stakeholders to advance this work.

And, as organizations elevate the importance of diversity, equity, and inclusion in their work, helping extend ADS programs for caregivers offers a new avenue for identifying and meeting the needs of diverse populations.

What's Next for Policymakers: Protecting and Increasing Funding

California's 2020 Master Plan for Aging put appropriate new emphasis on the needs of both older adults and their caregivers. COVID-19 has also prompted Capitol Hill to focus new attention on both groups, because they were disproportionately vulnerable to the difficulties and dangers of the pandemic. Now policymakers, in Sacramento and Washington, need to spend what's necessary to sustain adult day services as an essential part of the government safety net preserving the health care of both the participants and those caring for them.

Direct funding for adult day services was significantly cut from the California budget a decade ago. With the state newly awash in surplus, the time is ripe to more than reverse those reductions. If Congress considers any additional legislation aimed at pandemic recovery, then funding to benefit ADS should have a part. Meanwhile, it is essential to protect the level of federal support to Medicaid for the adult day services the program currently covers.

Despite the many physical and mental health benefits of ADS—and the attendant health system cost savings—most private insurance plans provide only limited coverage for adult day services. There is almost no Medicare benefit. This is a main contributor to the financial stress endured by caregivers, especially in low-income families, who struggle with the cost of ADS. This can and should change as health care and social service systems seek to create an equitable aging experience for all older adults.