Supporting Family Caregivers of Older Adults through Adult Day Services

INITIATIVE REPORT
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From 2018 to 2021, Archstone Foundation’s Supporting Family Caregivers of Older Adults through Adult Day Services Initiative funded five organizations providing Adult Day Services in Los Angeles and Orange counties to enhance or add programs and services to support the needs of family caregivers. The Initiative also included technical assistance and peer learning activities that promoted organizational sustainability and collaboration.

This evaluation report is organized as follows: First, there is a description of the context of the Initiative and the need for a focus on family caregivers at Adult Day Services, followed by a detailed review of the Initiative’s desired outputs and outcomes. Next, there is a brief description of the evaluation methodology. The largest section of the report is the findings section, which is divided into categories of outputs and outcomes. This section compares the intended goals of the Initiative with actual results of the caregiver-focused offerings at Adult Day Services. The next section presents unexpected outcomes of the Initiative, including a shift in culture to a focus on family caregivers at Adult Day Services and an expansion of family caregiver services through teams and technology. The report concludes with a set of recommendations for Adult Day Services, philanthropy, and other stakeholders of services for older adults and their caregivers.

1 Funded organizations included: Alzheimer’s Family Center, Alzheimer’s Orange County, Meals on Wheels Orange County, ONEgeneration, and OPICA.
Findings indicate that the focus on family caregivers was not only hugely beneficial to the caregivers, but also to the family members in their care. Despite the strain and struggles that manifested from the COVID-19 pandemic, Adult Day Services (ADS) innovated and pivoted to support family caregivers virtually, and caregivers were grateful for and benefitted from the continued support.

- ADS programs increased numbers of family caregivers over the course of the Initiative (with limited decrease at the start of the pandemic in transition to virtual services).
- A vast majority of family caregivers served by all ADS programs reported satisfaction with the services they received.
- When utilized by family caregivers, extended hours for respite has a positive impact on caregivers, giving them time to tend to other responsibilities or rest, which reduced their stress and strain.
- Counseling and support groups for family caregivers improved mental health, wellness, and in some cases, self-care.
- ADS offerings of Evidence-Based Programs (EBPs) for family caregivers improved caregivers’ knowledge and confidence.

The following recommendations for ADS emerge from these findings:

1. Provide accessible counseling and support groups specifically for family caregivers
2. Provide accessible Evidence-Based Programs (EBPs) – trainings and classes – to support the development of family caregivers’ skills and knowledge
3. Provide extended hours for respite opportunities when and where caregivers indicate they are likely to use the services
4. Assess caregiver needs as well as the impact of caregiver programs and services
5. Provide culturally informed and linguistically accessible services, either directly through in-house staff, and/or through partnerships with other organizations
6. Advocate for local, state, and federal funding to facilitate continued access to ADS
Family caregivers of adults age 65 and older with chronic illnesses and functional, cognitive, and sensory impairments are critical to the well-being of their family members facing these conditions. ADS provide safe, stimulating, and therapeutic environments for those needing care while their caregivers work or tend to other responsibilities. Their services lead to better outcomes for those requiring care, for their family caregivers and their households, and cost savings for the health system. It is no surprise that Bold Goal number 4 of the California Master Plan for Aging (2020) for 2030 is “Caregiving That Works,” given the vital importance of high quality and accessible caregiving to these older adults.

In 2018, Archstone Foundation launched the Supporting Family Caregivers of Older Adults through Adult Day Services Initiative (the Initiative), a three-year initiative funding ADS to pursue a variety of counseling and support groups, Evidence-Based Programs (EBPs), and program enhancements, including extended hours, extended hours for respite, and increased cultural and linguistic competency for racially and ethnically diverse caregivers. Caregivers often experience severe burden, stress, and depression from the variety of responsibilities and challenges they encounter in caring for older adults with functional, cognitive, and sensory impairments. These program enhancements aim to reduce burden, increase training and supports, and improve caregiver well-being. The Initiative also sought to promote improved organizational sustainability, systems change on a regional level to support collaboration, coordination, and shared learning, and to contribute to the national conversation about the importance of adult day services and supporting caregivers among organizations in the Initiative.

This evaluation reviews the successes and challenges experienced by grantees in achieving the desired outputs and outcomes of this Initiative. In 2020, the COVID-19 pandemic created unprecedented challenges for the older adults requiring care (“participants”) and their family caregivers – as well as for the organizations that support them. Within days, caregivers whose family members spent their days in ADS programs lost access to that lifeline as those Centers needed to close their doors to comply with the public safety order and prevent transmission of COVID-19. Participants lost access to precious services that provide opportunities for skilled nursing, socialization, and therapies. Even so, Archstone Foundation grantees responded with flexibility, resilience, and innovation and found ways to connect with their participants as well as to serve their caregivers. Recognizing this major change outside of the control of ADS programs, this evaluation recognizes that outcomes in years two and three of the Initiative (March 2020 through April 2021) did not always look the same as in year one (pre-COVID).
The Initiative funded five organizations in Los Angeles and Orange counties:

- ONEgeneration, Los Angeles (ONEgen)
- OPICA Adult Day Services, Los Angeles (OPICA)
- Alzheimer's Family Center, Orange County (AFC)*
- Alzheimer's Orange County, Orange County (AlzOC)
- Meals on Wheels Orange County, Orange County (MoW OC)*

Enhance or add programs and services to support the needs of family caregivers. A general and overarching goal of the Initiative was to improve the well-being of family caregivers, particularly from communities of color and non-English speaking communities for whom services are scarcer and thus, both their vulnerability and needs are heightened. The detailed desired outputs and outcomes of the Initiative can be found in the Logic Model (Appendix I). Those outputs and outcomes that organizations addressed are summarized as follows:

**Desired Outputs**

Through a variety of services and programs, including Evidence-Based Programs, counseling and support groups, extended hours, and more, the Initiative sought to increase:

- The number of caregivers served through extended hours for respite;
- The number of caregivers to benefitting from counseling and support groups;
- Increased number of caregivers participating in Evidence-Based Programs; and
- The availability of services and materials in threshold languages.

The Initiative also supported organizational development by way of Organizational Sustainability Assessments, a formalized assessment of key business areas, and tailored technical assistance.

**Desired Outcomes**

The goals from expanding the services described above to more family caregivers and underserved communities included the following:

In the short term (1-2 years), the goals were to maintain and/or increase caregiver satisfaction and to reduce caregiver stress. Short-term goals also included the improvement of participating organizations’ effectiveness and sustainability, as well as improved coordination and cooperation between participants in the longer term.

Long term outcomes (see pg. 15 under Achieving Desired Outcomes) included:

- Improved caregiver mental well-being (reduced stress and/or depression)
- Improved caregiver health
- Decreased financial stress for caregivers
- Increased caregiver empowerment and feelings of confidence
- Fulfillment of familial obligation/accomplishment

Finally, the Initiative intended to lay the groundwork for the following collective future outcomes:

- Increased regional and national recognition of the importance of ADS and the support of caregivers
- Increased funding for caregivers and ADS

*Formerly Alzheimer’s Family Services Center
*Formerly SeniorServ
Charitable Ventures, a regional nonprofit that provides capacity building and fiscal sponsor services, provided technical assistance and evaluation services for the Initiative. The technical assistance aspect of this Initiative included administration of the Organizational Sustainability Assessment (OSA) to each of the grantee organizations’ staffs, volunteers, and boards of directors. The OSA is an evaluation instrument that assesses nine critical areas of organizational development to identify aspects of an organization’s internal operations that can be strengthened or supported for the purpose of organizational sustainability. The OSA was then used to create individualized technical assistance plans in areas revealed as organizational “vulnerabilities,” which were augmented by program evaluation training and peer convenings on a number of grantee-selected topics. One-to-one capacity building included work on Board development and program evaluation. Topics covered in peer convenings included Board development, site reopening post-COVID, fund development (in times of crisis/COVID), advocacy, and program evaluation.

As an evaluator, Charitable Ventures worked with Archstone Foundation to develop the logic model pertaining to this Initiative, and used quantitative and qualitative data provided in grantee reports, raw data sets, and final interviews to evaluate the successes and challenges of the Initiative.
This section of the evaluation will review the cohort’s achievements in the areas of the Initiative’s intended outputs, which included:

- Increased number of caregivers served through extended hours for respite
- Increased number of caregivers to benefitting from counseling and support groups
- Increased number of caregivers participating in evidence-based programs
- Increased availability of services and materials in threshold languages, and
- Grantee participation in Organizational Sustainability Assessments and technical assistance

Years two and three of the Initiative were 2020 and 2021 – the first and second years of the COVID-19 pandemic. In 2020, ADS were faced with closing their doors to protect their participants and staff, and pivot service delivery modality to almost completely virtual. Although the opportunity for COVID-19 vaccination had been made available by late 2020 into early 2021, the way that ADS were able to provide services continued to be impacted throughout year three by the surge of the Delta variant and ongoing concerns for maintaining safe environments for participants and their caregivers. It was not until fall of 2021 that the Orange County Office on Aging released their COVID-19 Resource Toolkit as senior centers and other older adult-serving programs throughout Orange County began to slowly re-open and return to limited pre-pandemic offerings.

*It is important to note that the numbers-served by AlzOC are dramatic because of the nature and delivery of service. By offering caregivers through “lighter-touch” educational services through a variety of partner organizations, the organization was able to reach many more individuals.*
Over the three-year Initiative, all organizations increased the unduplicated number of family caregivers served. Although many served caregivers in some capacity prior to the Initiative, they all became more intentional and more focused on addressing the needs of caregivers. Furthermore, these organizations were also able to pivot from in-person to completely virtual services with the onset of the pandemic without an overwhelming dip in service.

The chart on page 8 captures data reported by each organization yearly and/or cumulatively (depending on the format that grantees provided data). The majority of ADS maintained or increased their service numbers over time, but all that provided in-person services were severely impacted as they had to transition to virtual and hybrid service provision in years two and three due to the COVID-19 pandemic. All organizations continued serving ADS participants and caregivers through zoom-based classes and support groups, activity packets, counseling calls, nursing check-in calls, outdoor services, resource referral, swing-by visits or caravans.

### Extended Hours for Respite

All organizations offered extended hours for respite to caregivers in years one and part of year two of the Initiative; and the use and impact of this service varied across ADS.

- **Alzheimer’s Family Center (AFC)** piloted the Adult Evening Health Services, which consisted of an evening program one night per week (4 to 9 pm). However, this program was not used by caregivers due to the difficulty of leaving home in the evening for themselves and/or the participants made it undesirable.

- For Alzheimer’s Orange County (AlzOC), the uptake of extended hours for respite was also limited. Although AlzOC staff assessed caregiver interest in extended hours prior to launching the offerings, they were not utilized as much as expected. In year one, there was limited Saturday extended hours for respite utilization at the organization’s South County Adult Day Services (SCADS) location. In year two, limited extended hours were offered and utilized as needed as SCADS pivoted and piloted an adjusted offering of one weekend day and two weeknights per month.

- At Meals on Wheels OC (MoW OC), 156 evenings for extended hours for respite were provided to caregivers during years one and two. MoW OC found that caregivers were most likely to utilize extended hours when they could participate in EBPs for themselves at the same time on site. This was a unique popular service-pairing for MoW OC.

- For ONEgeneration, extended hours for respite programming was offered on Saturday mornings in years one and two until the pandemic required an interruption of in-person services.

- OPICA also offered extended hours for respite services to, on average, eight families during years one and two on Tuesday and Thursday evenings and Saturdays. There was value in these extended hours, and thus, both ONEgeneration and OPICA plan to reassess need and capacity to offer such programming in 2022.

Research highlights the benefits of extended hours for respite for family caregivers, possibly now more than ever given the additional stressors imposed by the COVID-19 pandemic. However, a lesson learned from the Initiative______

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5 Due to the closure of centers in years 2 and 3 because of the COVID-19 pandemic, all center-based extended hours for respite offerings were put on pause during the last year of the initiative.

is that simply providing extended hours for respite is not straightforward. Scheduling extended hours for respite is uniquely challenging for family caregivers. Some of the challenges include:

- Each family's uniquely complex schedule (some include children in addition to older adults requiring care)
- Many family caregivers are also older adults, and they are often not comfortable transporting their loved one during evening hours
- Adding extended hours into the older adult requiring care's schedule can be disruptive and lead to behavioral difficulties and discomfort
- Some older adults requiring care also require specialized medical support, while extended hours for respite is often offered as a social model only
- Lack of additional transportation outside of the usual schedule
- Sense of guilt or irresponsibility to take advantage of extended hours for respite

These challenges do not mean that extended hours for respite for caregivers is impossible. However, the way it is provided is likely to be more costly and labor-intensive for providers/agencies than initially expected. It is important to assess the needs and demand of the caregivers before launching a extended hours for respite program. Factors to assess include ideal schedule, cost, and services available for participants during extended hours. If caregivers do not express interest in utilizing extended hours for respite, it is important to determine why. There might be nuanced barriers that could be overcome with subtle changes to program offerings. Although flexibility can be difficult for organizations, it is important to consider the caregiver and participant benefits of striking the balance in respite offerings.
Counseling and Support Groups

All ADS organizations also offered individual counseling and/or support groups for caregivers, and were able to sustain these services even through center closures in years two and three by offering virtual and telehealth services. In March 2020, when ADS participants suddenly lost access to the many services provided by ADS, including physical therapy, nutritional support, care coordination, skilled care during the workday, life for caregivers became even more stressful than usual overnight. Counseling and support groups were among the most impactful types of support to caregivers, which will be explored further in the outcomes section later in this report.

- Alzheimer’s Family Center offered individual counseling services, which it increased from four sessions in year one, to eight sessions in both years two and three. During year three, organizations sustained, and in some cases even increased counseling provided to caregivers who were facing additional stressors from the pandemic and reduced services for their family members.

- Alzheimer’s OC served an increasing number of individuals each year through support groups and counseling, from 111 monthly in year one, to 160 monthly in year two, and to 1,801 monthly in year three. Evidence-Based Programs and other educational content were provided online/virtually, through partnerships and for the general population.

- Meals on Wheels OC served family caregivers through 33 bilingual support groups in both years one and two which coordinated with extended hours.

- ONEgeneration also offered counseling and support group alternatives to caregivers. Six Spanish language support group sessions were offered in year one and year two, and in year three, 5 additional support group sessions were offered. In year one, 18 individuals benefited from counseling, 21 in year two, and 22 in year three. In years two and three, the organization also launched a men’s group since they found that male caregivers more comfortable in an all-male setting and more likely to utilize the service.

- At OPICA, in year three, five support groups were offered with 36 attendees. One-to-one counseling was offered, but not utilized very much. Feedback included that family members “do not have the time for the sessions and/or are not sure one session would be helpful.” OPICA continued to offer services in hopes that the caregivers would find time to utilize them.

Evidence-Based Programs and Tools

Initiative organizations both added new Evidence-Based Programs (EBPs) and expanded existing offerings for family caregivers that they served.

<table>
<thead>
<tr>
<th>Organization</th>
<th>Evidence Based Programs (EBPs) Offered or Tools Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Family Center</td>
<td>Pre/Post Modified Caregiver Strain Index (MCSI)</td>
</tr>
<tr>
<td>Alzheimer’s OC</td>
<td>Savvy Caregiver (English, Spanish, Vietnamese, Korean)</td>
</tr>
<tr>
<td>Meals on Wheels OC</td>
<td>Powerful Tools, Chronic Disease Self-Management, Stressbusters, Fall Prevention Program (English and Spanish)</td>
</tr>
<tr>
<td>ONEgeneration</td>
<td>MCSI, Powerful Tools, Savvy Caregivers (English and Spanish)</td>
</tr>
<tr>
<td>OPICA</td>
<td>Savvy Caregivers, Savvy Caregivers Express, and Powerful Tools, Memory Training, Matter of Balance, Walk with Ease, Alzheimer’s Disease and Dementia Care, Healthier Living, Mindful Art Therapy and Yoga</td>
</tr>
</tbody>
</table>
The Modified Caregiver Strain Index (MCSI) used by AFC and ONEgeneration is a helpful tool for practitioners to use in their program evaluation since it is validated, relatively simple, and standardized for comparisons.

During the course of the Initiative, AlzOC offered Savvy Caregiver in English and in Spanish to more than 120 caregivers in year one, 58 in year two, and 86 in year three (delivered online). In year one, the organization took the evidence-informed, online caregiver training program and adapted it to the needs of the population – providing it in Vietnamese and Korean in year two and beyond Orange County in year three. As education is a key strategy at AlzOC, the organization directed ample energy to providing online education, including relevant guest speakers, physicians, and more, to caregivers and the public via YouTube in year three.

MoW OC offered nine sessions of Evidence-Based Programs in years one and two, which included Powerful Tools, Chronic Disease Self-Management, Stressbusters, and the Fall Prevention Program in both English and Spanish. In year three, the organization provided nine sessions via one-to-one online format due to the COVID-19 Stay at Home Order.

ONEgeneration expanded the offerings of 2 EBPs - Powerful Tools and Savvy Caregivers (and Savvy Caregivers Express). The majority of participants stated that education was beneficial to their ability to provide care (79% in year one and 90% in year two with the remaining percent of people responding that they didn’t know).

Finally, OPICA offered a wide variety of evidence-based and evidence-informed programs including Savvy Caregivers, Savvy Caregivers Express, and Powerful Tools. OPICA also offered Memory Training, Matter of Balance, Alzheimer’s Disease and Dementia Care, Healthier Living, Mindful Art Therapy, and Yoga. Family members felt that the education programs gave them tools for self-care and a community of other caregivers with similar challenges.

Threshold Language Offerings and Cultural Awareness

ADS organizations expanded threshold language offerings in different ways in accordance with their program offerings, local populations, and partnerships. With many Spanish-speaking participants and caregivers in their community, AFC provided a limited amount of counseling in Spanish. MoW OC also provided support groups and EBPs in Spanish. According to MoW OC, “the day-to-day program staff members clearly understand the importance of being responsive to each caregiver’s beliefs and values, religion, primary language, and other cultural factors to ensure culturally sensitive decisions are considered.” As previously mentioned, AlzOC offered evidence-based

7 Threshold Language means a language that has been identified as the primary language, as indicated on the Medi-Cal Eligibility System (MEDS), of 3,000 beneficiaries or five percent of the beneficiary population, whichever is lower, in an identified geographic area.
and evidence-informed programming and Family Care consultations in multiple languages, including Spanish, Korean, Vietnamese, Chinese, Farsi, and Arabic. They were able to provide these services by partnering with trusted community partners such as Somang Society to provide Korean caregiver education and others. At ONEgeneration, support groups in Spanish were offered, and staff went through cultural awareness trainings. At OPICA, staff went through a diversity training in year two of the Initiative.

Efforts to build partnerships with community organizations led-by and serving communities of color and provide access to caregiver support programs in languages other than English were evident. However, data is not available to provide specific evidence of whether these groups benefitted from such expansion. This data should be intentionally collected as caregiver supports to and through these groups are continued beyond the Initiative.

**Organizational Sustainability Assessment and Technical Assistance**

Leadership on all levels, from boards to key volunteers, in each organization participated in the Organizational Sustainability Assessment (OSA). The OSA is a proprietary organizational development and sustainability tool developed by Archstone Foundation’s evaluation and technical assistance partner for this Initiative, Charitable Ventures, and includes an exploration of nine critical business areas. Those are mission/vision/planning, infrastructure, human resources – staff support and communication, leadership – board of directors, leadership – executive director, resource development, financial management, program evaluation, and collaboration.

Charitable Ventures carried out analysis, follow-up reviews of the findings with organizational leadership, and focused on technical assistance topics related to those findings. While findings indicated fairly strong levels of development in many areas across the Initiative Organizations in general, areas of strength and potential areas of vulnerability or growth in other areas did appear for each organization. Those areas were topics of conversation and in some cases, technical assistance, and are summarized below. Asterisks indicate areas that were represented as strengths for some organizations and areas of potential growth or challenge for others.

**Organization Strengths**
- Mission/vision commitment and planning
- Executive leadership: knowledge, dedication, qualifications
- Board leadership: knowledge, dedication, qualifications*
- Financial management
- Collaboration*

**Organization Areas of Vulnerability/Growth**
- Resource development
- Human resources: Salary and technology
- Board leadership*
- Program evaluation
- Collaboration*
- External factors: policy, economy, and high cost of living that impact programs and staffing
Organizational leadership was receptive and not surprised by the results of these assessments. One-on-one technical assistance largely focused on building capacity around program evaluation. Staff members demonstrated learning on data collection methods and the utility of data. All Initiative organizations could benefit from further capacity building around analysis and use of data.

Capacity building meetings with ADS staff on data and program evaluation topics included how it ties into assessing the impact of caregiver serving (and other) programs, as well as to make the case for donors and foundations. More specific capacity building exercises such as the development of logic models for caregiver programs at each organization and the review and improvement of survey and data collection instruments were also carried out. Although organizations could benefit from more practice on how to collect and utilize outcomes data, the barrier to this seemed to be time and/or a lack of incentive. In future Initiatives, it would be beneficial to create reporting instruments with the evaluation partner, integrated with the progress report, in order to ensure that organizations are incentivized to learn those skills in a meaningful and applied fashion.

Program evaluation did seem to be a “safe” and/or accessible area of organizational development for one-on-one technical assistance, whereas it did not seem that organizations were very interested in receiving one-on-one capacity building around human resources or board leadership. This could possibly be because they had not reached a comfort level to working on more-sensitive topics with consultant support before the pandemic hit and demanded organizational attention to pivot to “crisis mode,” in which staff needed all of their time to develop new methods to engage families at home.

During the end of year two and the duration of year three, the Initiative organizations shifted from in-person one-to-one technical assistance to one in-person followed by virtual facilitated peer-learning meetings covering key areas of potential growth. Those areas included board development, fund development in times of elevated uncertainty, reopening planning, continued program evaluation, and advocacy.

Participation and open exchange in these groups was substantial. One or more representatives from each organization attended every peer learning gathering. The majority shared ideas and practices from their own experience and readily asked questions of the group. Closing interviews with organizational leads at the end of the Initiative revealed that these were helpful opportunities to learn and share. The organizations that found them beneficial would have wanted to “go deeper” and work more closely together, in a more structured fashion. This is not surprising as collaborative work is time-consuming, difficult, and requires that collaborators be vulnerable and open to shared goals.
Achieving Desired Outcomes

This section of the evaluation will review the cohort’s achievements in the area of the Supporting Family Caregivers of Older Adults through ADS Initiative’s intended outcomes, which included in the short term:

- Caregiver satisfaction
- Reduced caregiver stress
- Improved organizational effectiveness and sustainability
- Improved coordination and cooperation between participants

In the long term, desired outcomes include:

- Improved caregiver mental well-being (reduced stress and/or depression)
- Improved caregiver health
- Decreased caregiver financial stress
- Increased caregiver empowerment and confidence
- Fulfillment of familial obligation/accomplishment

Finally, aspirational collective future outcomes include:

- Increased regional and national recognition of family caregiving issues
- Increased funding to support family caregivers

Caregiver Satisfaction

Family caregivers across all Adult Day Services organizations expressed satisfaction with the services they were offered. Whether through qualitative data such as testimonials or survey results from assessment of particular programs, data shows very high levels of satisfaction across the board. Satisfaction is unpacked in detail in the sections to follow.

Caregiver Mental Health, Knowledge and Empowerment

Different program offerings funded by the Initiative, in particular counseling, peer support group, extended hours for respite, and EBPs, had a measurable positive impact on caregiver mental health. In some cases, this was measured as decreased stress, burden, or depression, and in other cases, it was described as increased knowledge that empowered them or made them feel more in control.

Each organization also used different surveys and methods for collecting outcomes data. For a majority of organizations there are gaps in outcomes data reported, which is likely a result of limited organizational capacity – both technical (as staff skills were developing around how to collect, analyze and report outcomes data) and time, resources, and access once the pandemic hit and closed service doors in early 2020.

Mental health and wellness outcomes as a result of caregiver counseling, support groups, and EBPs are explored by Initiative organization.
Alzheimer’s Family Center

Data reflects a positive impact of caregiver counseling on a number of well-being indicators, as well as knowledge and empowerment. Caregiver counseling proved to be a valuable and effective service for caregivers served by Alzheimer’s Family Center. A few highlights are below:

- In year one, 100% of caregivers responded to a survey stating that counseling made a “positive change” in their lives.
- In year one, 75% noted an improvement of symptoms of poor health and 84% noted a reduction in stress.
- In year two, a year marked by COVID, those reporting improvements of symptoms decreased to 30% of caregivers, however 93% reported that sessions reduced stress, with 73% indicating a reduction in depression and 94% a reduction in anxiety.
- The organization only measured the improvement of self-care in year one, with 67% of caregivers indicating that counseling led to improvement in self-care.
- In years one and two, 50% and 100% of caregivers respectively, noted that counseling led to increased empowerment and confidence in providing care.

In the words of one caregiver: “My particular counselor has been a remarkable asset to my own learning about Alzheimer’s in general and my understanding and dealing with my husband’s specific current condition. Having a solid, knowledgeable listener made a tremendous difference in my outlook on the disease and on my own coping and how to move forward as a more effective and aware care partner and wife.”

“My particular counselor has been a remarkable asset to my own learning about Alzheimer’s in general and my understanding and dealing with my husband’s specific current condition. Having a solid, knowledgeable listener made a tremendous difference in my outlook on the disease and on my own coping and how to move forward as a more effective and aware care partner and wife.”
Alzheimer’s Orange County

In 2020, at the Alzheimer’s Orange County (AlzOC) sites Acacia ADS and South County ADS, caregivers reported that their levels of stress reduced by 47% and 81% respectively as a result of services they received. One caregiver said, “Acacia provides a safe place for my father to be for five hours a day, giving my brother and I time to recoup and recharge. I maintain a full-time job and my brother cares for my father as his full-time job. Sometimes, our sanity is challenged, but knowing that my father has a place to go on weekdays is a relief.”

"Acacia provides a safe place for my father to be for five hours a day, giving my brother and I time to recoup and recharge. I maintain a full-time job and my brother cares for my father as his full-time job. Sometimes, our sanity is challenged, but knowing that my father has a place to go on weekdays is a relief."
Meals on Wheels Orange County

In years one and two, 94% of respondents to a Meals on Wheels Orange County (MoW OC) Caregiver Survey reported an improvement in their well-being and felt more knowledgeable about their health and the health of those they care for. More specifically, 94% of respondents reported they felt more able to manage the day-to-day challenges and remain calm and positive, as well as feeling more in control of their situation. MoW OC unexpectedly needed to expand their caregiver support groups given the high demand for and satisfaction with them.

Caregiver testimonials from MoW OC also indicated that extended hours allowed them to do things that they were otherwise unable to do, such as to participate in valuable EBPs, as well as to go grocery shopping, go to the movies, and the like. This can be of significant value to someone who would otherwise be unable to do so.

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8 There is a contradiction between data in year 1 and 2 reports and final report (year 3), which has a higher %. All are unclear about which outcomes specifically are improved.
ONEgeneration provided aggregated caregiver survey data that points toward the impact of their programs. In year one, 100% of caregivers responding to the ADS annual survey agreed or strongly agreed that ONEgen was providing them with extended hours for respite. In year two, the results dipped slightly, given that this was the first year of COVID. In year three, the organization shifted to assess the impact of specific COVID-time offerings. In year one, 100% of respondents also stated that ONEgen had significantly reduced [the caregiver's] level of stress in both years one and two. When asked what they gain from their loved ones participating in ONEgen programs, the most frequent answer was “peace of mind” and “time.”

Caregivers participating in ONEgen’s counseling sessions stated that counseling was good (11%), very good (33%), or excellent (56%), and in year 2, 100% of those responding to the survey stated they felt less sadness because of counseling.
OPICA supported caregivers primarily through Evidence-Based Programs. Qualitative caregiver evaluations of these programs were positive. Feedback from caregivers about Savvy Caregivers and Powerful Tools include:

- “[The instructor] was great in explaining the different stages and explaining the different ways to help people with dementia”
- “This class was very informative and helpful. Questions were addressed thoroughly”
- “Allows me to be more constructive, positive, and supportive by listening, planning, and acting toward goals”
- “Allows me to know my emotions are “normal”

Qualitative caregiver evaluations of these programs were positive. During final interviews, the Executive Director of OPICA shared:

“Caregivers enjoy Savvy [Caregivers] and Powerful Tools quite a bit, and the memory program can also help them de-stress as well. Through these programs, they learn and feel that they’re not alone, they bond with other caregivers, and they gain knowledge. [Our instructor] is really good at making things tangible.”
Although programs do not directly address caregiver health, the connection between socio-emotional wellness and health is known and the positive impacts on health was an indirect positive outcome of the Initiative in many cases. Most ADS did not measure, or did not report, the impact of their programs on caregiver health. For Alzheimer’s Family Center, who did attempt to measure this outcome, in year two, 75% of participants reported improvement of symptoms of poor health, most notably sleep. However, in year three, the year of the pandemic, only 30% reported these improvements.

Caregiver Financial Stress

Financial stress is a relevant component of overall stress for many caregivers. Caregivers are not only tasked with managing their own finances, but the often separate finances of the individual for whom they are caring. Another related issue is that caregivers are often dependent upon ADS to provide care for family members so they can continue to work. Most make every effort to ensure that caregivers and participants from all income brackets are able to access their services, whether through reduced costs, insurance coverage, or other adjustments. However, inquiring about the connection between ADS and financial stress is complicated and sensitive.

A progress report from AFC captures the stress well. According to their report, “approximately 25% of caregivers (9 of 35) served in the first year expressed significant financial hardship due to limited financial resources. Some of these clients were on Medi-Cal but most gave the impression they were marginally above the allowable income to qualify for Medi-Cal. Several found themselves unemployed for periods of time largely due to their caregiver role and a majority provide most or all caregiving duties because of an actual or perceived inability to afford assistance. Even caregivers who had solid financial resources were emotionally strained by the excessive costs of both caregiving and medical conditions. Eligibility through insurance continues to be a challenge faced by this program with the marginal number of caregivers whose insurance companies AFC is contracted with for the outpatient program. Additionally, even a copay amount is too great a financial burden for some caregivers.”

Qualitative data provide evidence that the stress would be less with more insurance coverage for both medical as well as social model adult day services. This intersects with the opportunity for organizations to work collaboratively and participate in advocacy. However, not all organizations see themselves as systems change participants. Instead, some see themselves as crucial service providers, and advocacy does require specific resources such as skilled staff and time.

Initiative organizations often connected caregivers to resources and information to navigate financial stressors. For example, ONEgeneration provided a training in year two on legal and financial concerns, which was well evaluated by participants.
Leadership staff from ADS organizations in the Initiative were asked in closing interviews to respond with regard to multiple outcomes, including impact of the Initiative on organizational effectiveness and sustainability. Although organizational sustainability goes beyond financial sustainability, many of the responses received did have to do with funding and resources. Based on feedback from these leaders, the Initiative’s focus on supporting caregivers and providing technical assistance had a positive impact on organizational sustainability. A few examples follow:

- AFC has been able to demonstrate the impact of caregiver counseling since implementing pre and post surveys, and are now able to attract more funding for this valuable programming
- Three ADS organizations indicated that the findings of the OSA motivated them to pursue new, diverse funding streams (new foundations, new contracts such as telehealth counseling, and large gift donor development)
- All ADS organizations showed marked growth in their understanding of program evaluation

While the negative effects of COVID-19 on older adults with dementia and other cognitive decline are not to be minimized, one unexpected positive outcome of the intersection of the Initiative and COVID-19 was that caregiver education, support groups, and counseling were extremely valuable programs that were already well underway and could easily pivot to virtual modality and reach beyond the local and participating caregivers. Collaboration and reach increased in many cases as a result of COVID-19 programming changes, which is discussed in further detail in the following section on collaboration between Initiative organizations and the section on Expanding Services.

Collaboration Between Initiative Organizations

One of the goals of the Supporting Family Caregivers of Older Adults through ADS Initiative was to increase collaboration between Initiative organizations. Although, as mentioned in the section on Organizational Effectiveness and Sustainability, participation and exchange was great in convenings and facilitated peer learning opportunities, when asked about the impact of the Initiative on the level of collaboration among Initiative organizations, the responses were mixed.

Absent the Initiative, it is not likely that these organizations would have had or taken the opportunity to connect on topics as varied and substantive as board development, advocacy, reopening, fund development, and program evaluation. One leader mentioned that the opportunities to connect with other ADS organizations, “to be there around the table talking to others was helpful. Sometimes you stay in your fishbowl.” The opportunity to speak to leaders from other organizations helped to spark ideas and think differently. Another mentioned the valuable opportunity to connect with organizations from a neighboring county (Los Angeles and Orange).

By contrast, several leaders noted that the Initiative organizations could have “done a better job” with collaboration. Collaboration is not without its challenges. The feedback they provided could be helpful in crafting future Initiatives seeking to motivate collaboration. One leader stated that the Initiative “provided an opportunity to share implementation processes and experiences. Overall, it provided an opportunity where we have room to maximize it.” The same leader mentioned the barrier or challenge that COVID-19 imposed to achieving collaboration and also stressed the importance of communication and Initiative organization-driven goals to improve it in the future.

Initiative organizations also noted the impact of the Initiative on the creation of partnerships with other organizations, in particular when related to the extension of linguistically and culturally responsive services and materials or in the provision of other services that were outside the wheelhouse of the organization. One Adult Day Services organization referenced the creation of relationships with 12 new community partners as a result of the Initiative. “Through collaboration with other agencies, expanded “wrap-around” services were provided to caregivers, including services that otherwise may not be available to these families.
Groundwork for Collective Future Outcomes

The Initiative also aimed to work toward the following outcomes: increasing the regional and national recognition of the importance of adult day services, elevating the importance of supporting all caregivers, and increasing regional funding for caregivers and adult day services. Steps toward achieving these outcomes were certainly achieved.

In terms of the first outcome, the Initiative achieved programmatic and cultural alignment with the California Master Plan on Aging in focusing not only on the health and well-being of older adults with care needs, but also on their caregivers. This focus on caregivers is an enormous transformation, and despite the negative impact of COVID-19, a potential silver lining is that the importance of family caregivers of older adults and older adults themselves has been brought into the focus more than before due to the fact that caregivers and older adults were disproportionately vulnerable to the difficulties and dangers of COVID. Additionally, leaders of the organizations indicated that the Initiative and the pandemic led to an increased focus on caregiver needs and understanding of their importance.

With regard to the second goal of increasing the regional funding for caregivers and adult day care, there has been some progress, but state and federal funding is complex, and were also subject to massive cuts in 2020.9 There is a unique opportunity to obtain funding now – with the state of California awash in surplus, millions of federal dollars coming in through the American Rescue Plan, and the possibility of additional federal spending coming soon. It is up to cross-sector stakeholders to advocate for those funds to be allocated to both caregivers and those who they care for.

Progress in part has come from increased philanthropic funding. With the increased understanding of the vulnerability of older adults and the importance of caregivers as a result of the California Master Plan for Aging and the pandemic, Archstone Foundation was prompted to provide four additional sources of funding to support ADS organizations:

1. A COVID-19 emergency grant in May 2020 for the Alliance for Leadership and Education (ALE) in partnership with the California Association for Adult Day Services (CAADS). The grant was for ALE to provide education and information to ADS organizations through bi-weekly webinars during COVID-19 to continue providing services in support of the caregivers and participants they serve

2. A continuation grant for ALE in February 2021 to continue the webinars and supports provided for ADS providers, especially as they transition back to some form of in-person congregate services

3. A capacity building grant to OPICA for the acquisition of technology to enable the organization to expand the reach of their virtual programs and services for caregivers

4. A grant to AlzOC for caregiver education classes provided in conjunction with partner organizations, and built in evaluation expectations so that the sector can learn more about the benefits of in-language services

In order to acquire more public dollars, some form of advocacy is needed. While some Initiative organizations are involved in regional and state advocacy, and indirectly involved in federal advocacy, others do not see this as part of their core mission. Regional advocacy and collaboration in Orange County appears to be clearer and more identifiable than in Los Angeles. Some Initiative organizations have the desire to ramp the advocacy efforts up to protect funding for ADS and to increase health care funding for medical as well as social models in order to make services more accessible to participants and their caregivers.

During final interviews, ADS organization leaders vocalized a few unexpected outcomes of the Initiative, including a shift in culture to focus more on caregiver needs in all programming and an expansion of services. Notably, these unexpected outcomes are complementary with the 5 Bold Goals of the California Master Plan for Aging.

### A Shift in Culture

Initiative organizations reported a culture shift focused on caregiver needs, especially related to mental health, as a result of the Initiative. One describes the change as a “shift in the culture of the agency. Prior to Archstone Foundation’s grant, caregiver counseling was not heavily emphasized due to lack of funding and dedicated staff. Once agency members understood the service and grant, referrals came in from every department of the agency, resulting in a year two goal of 133 caregivers served, and year three, nearly triple that of year one with 90 caregivers served.” Another organization reported that with the Initiative, “The needs of family caregivers have been brought to the forefront more than they had been for many program staff members. Consequently, these needs are discussed more…” Another organization mentioned that the “grant served as the catalyst for caregivers to address their own mental health concerns. The grant, in essence, made therapy safe to talk about, share about, and refer others to.” This focus on caregiver needs is a real transformation of the status quo where the caregivers’ needs are not considered despite how critical they are to the well-being of older adult ADS participants.

### Expanding Services

Another unexpected outcome was the quick adaptation of organizations and families to the virtual and hybrid programs. Organizations learned that all parties, staff, caregivers, and participants benefit from flexible, hybrid models that can be utilized to suit individual needs. This utilization of technology to improve access is particularly useful for those most vulnerable and affected by inequitable systems of care.

One organization shared that “many caregivers recognized the benefits of meeting virtually (Zoom, camera on), saving time, transportation, and still receiving high quality services and feeling connected to the therapist. Year three, which was entirely virtual, had the highest completion rate, with nearly 60% of all patients completing all eight sessions, and 72% of patients completing four or more sessions.”

Another organization shared that the creative and often difficult pivot to online services led to higher staff and caregiver engagement. As this organization offered social work, as well as physical and occupational therapy on Zoom, staff expressed that they “learned more about caregivers and their individual needs, and thus had a fuller picture of the needs of each family.” They stated that these connections made their work more meaningful and that they have a greater sense of the previously unspoken needs of individual caregivers.

Furthermore, “the move to remote care has also opened up possibilities for the future, including hybrid services where participants at home can continue to be engaged in programs even while they are not at the center. Traditionally, when someone is recovering from a hospitalization, for example, they cannot attend the center. A hybrid model would allow for the center to continue to engage these participants while in recovery. Family caregivers at Alz OC have always been invited to the center for multi-disciplinary team meetings when their loved ones were due for six-month reassessments. Many of them could not come in due to work schedules. The new familiarity with Zoom will allow us to include more family members in these meetings, even when they cannot be there in person. For support groups, it also allows the center to reach a larger geographical area, providing support groups to caregivers who previously would not have been able to attend due to living a distance from the center.”
Technology is certainly not a perfect solution to expanding services and the tensions do need to be considered when funding and/or implementing programs. On one hand, technology allows services to be used outside of regular geographic areas (e.g., AlzOC reached “attendees beyond Orange County and Los Angeles County to Northern California, other states, and countries”), as well as communities, often communities of color, since online offerings “helped minimize the barriers of transportation, lack of extended hours for respite care, and stigma regarding attending in-person caregiver programs.” On the other hand, with a shift to remote, virtual support services, many family caregivers, particularly some older caregivers as well as Latinos, Vietnamese, other communities of color, or low-income individuals, struggled with having access to tech devices and Wi-Fi services. Programs need to take into account and address this technology divide. The County of Orange is currently focusing on this concern and set aside funds to help older adults gain digital literacy through GetSetUp, a peer-led video learning platform. Orange County’s Office on Aging is giving out free iPads with training for older adults 60+, with eligibility requirements targeted to make sure devices are given to those with incomes under $75k and at least one risk factor for isolation including living in a care facility, living alone, a health issue, limited mobility, functional disability, or limited English skills.

The Initiative showed how the increased engagement of family caregivers in the Adult Day Services setting increased the understanding of the needs of the ADS participants and their families, which led to better quality of care. One organization noted that the decline in program referrals of older adults from health care providers during the pandemic could also be indicative of an opportunity to provide additional outreach to healthcare providers about the organization’s dementia education and support available in multiple languages. When planning for care, whether in a social services or health care setting, placing the person and family at the center of that care is found to be most effective and ensures that their care preferences and goals are met. By creating stronger linkages and fuller integration of social services such as Adult Day Services to health care, this can create more effective and comprehensive care for older adults and their caregivers.
Learnings from the Initiative led to recommendations on how to strengthen the ecosystem available to family caregivers. Based on the utility and effects of programs and services in the Initiative organizations, it is recommended that ADS:

1. **Provide counseling and support groups specifically for family caregivers**

   The Initiative demonstrated the value of one-to-one counseling and support groups to reduce anxiety, burden, and depression in family caregivers. It is important for ADS to assess and implement the services that are right for their population. Support groups may be preferred to one-to-one counseling. Services are needed in languages other than English. Support groups for alternate kinds of caregivers such as for adults caring for their parents, while also caring for school-aged children, or groups for male caregivers (husbands, sons, etc.) are necessary. Being flexible and responsive to the needs of caregivers will lead to the positive mental health and wellness outcomes described above.

2. **Provide Evidence-Based Programs (EBPs) – trainings and classes – to support the development of family caregivers’ skills and knowledge**

   The Initiative also demonstrated the value of EBPs, in particular, Savvy Caregivers, Savvy Caregivers Express, and Powerful Tools, and others such as Memory Training, Matter of Balance, Walk with Ease, Alzheimer’s Disease and Dementia Care, Healthier Living, Mindful Art Therapy, and Yoga. The majority of participants in these sessions expressed gaining knowledge, empowerment, and additional skills that bolstered them to better care for their family member. During the pandemic, the Initiative showed that classes can successfully be offered in a virtual modality. They can also be paired with extended hours for respite services and offered in multiple languages to reach diverse caregiver groups.

3. **Provide respite opportunities through extended hours when and where caregivers indicate they are likely to use the services**

   Although the Initiative demonstrated that caregivers do not always take advantage of extended hours for respite offerings, it is true also that when they do utilize extended hours of ADS, it allows them time to do other things that they otherwise would not be able to – practice self-care, run necessary errands, or attend a class. Initiative findings show many participants feel that ADS itself is a valuable resource for respite. When caregivers are able to rely on skilled and trusted professionals for the care of their family member through extended respite hours, this offers them the invaluable asset of time and opportunity to fulfill unmet needs in other areas of their lives. It is important for providers to carefully consider the needs of caregivers and their families when planning extended hours for respite offerings.

4. **Assess caregiver needs as well as the impact of caregiver programs and services**

   In order for ADS to prove the impact of their programs as well as to make cases for systems leaders to fund ADS, it is important for outcomes data to be collected and disseminated. Although not all programs can be evaluated using the same assessment instruments, and some EBPs require the use of their own validated survey instrument, one very useful tool that assesses the level of “burden” that a caregiver is experiencing is the Modified Caregiver Strain Index (MCSI). When offered as a pre and post along with counseling, support groups, EBPs and other interventions, this can be a helpful tool to measure whether caregiver well-being is improving, declining, or remaining the same.
5. **Provide culturally and linguistically appropriate and accessible services, either directly through in-house staff, and/or through partnerships with other organizations**

Family caregivers are highly diverse. In order to adequately serve and reach them, counseling, support groups, EBPs, and other services must be culturally appropriate and in the language that they best understand and in which they feel most comfortable speaking. Initiative organizations made efforts to reach caregivers whose first language is Spanish, Korean, and Vietnamese. When it is possible to adequately provide services through in-house staff or resources, that is the best option. However, when it is not possible, an effective alternative is to utilize community partners that are well-connected to and representative of those communities to which caregivers are most strongly affiliated.

6. **Advocate for local, state, and federal funding to facilitate continued access to Adult Day Services**

Despite the many physical and mental health benefits, as well as health care cost savings that ADS yields for older adults participants and their caregivers, ADS are not fully covered or subsidized by public or private health benefits. It is not accessible and/or can entail a financial stress to some families, particularly low-income families. In order to advance a more equitable aging experience for all older adults, organizations that are able and willing should advocate for funding to support access to these services. At the federal level, one important priority is the protection of Medicaid (Medicare/Medicaid) funding for Adult Day Services.\(^{10}\) At the state level in California, direct funding to Adult Day Services were cut in 2012.\(^{11}\) It is important to stay abreast of the implementation of the Master Plan for Aging\(^{12}\) and to stay involved in the conversation to advocate for the needs of older adults and their caregivers. It is important to advocate locally with the local Area Agency on Aging (AAA) to support accessibility in every region.

As evidenced by the Initiative, intentional, responsive services and programs for family caregivers have an important positive impact on those individuals who keep our most vulnerable older adults safe and well, as they age at home and in their community. The COVID-19 pandemic only provided more support and clarity about the importance of supporting caregivers of older adults with chronic illnesses and functional, cognitive, and sensory impairments. The wellness of these caregivers is inextricably connected to the wellness of those they care for.

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\(^{10}\) [https://www.nadsa.org/public-policy-agenda-2/](https://www.nadsa.org/public-policy-agenda-2/)

\(^{11}\) [https://www.payingforseniorcare.com/adult-day-care](https://www.payingforseniorcare.com/adult-day-care)

\(^{12}\) [https://mpa.aging.ca.gov/NewsAndEvents/Index](https://mpa.aging.ca.gov/NewsAndEvents/Index)
### Archstone Foundation, Supporting Family Caregivers of Older Adults through Adult Day Services – LOGIC MODEL

<table>
<thead>
<tr>
<th>NEEDS/SITUATION</th>
<th>PRIORITIES/GOALS</th>
<th>RESOURCES</th>
<th>PROGRAM ACTIVITIES</th>
<th>PROCESS MEASURES</th>
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<tbody>
<tr>
<td>44 million Americans are family caregivers for adults age 65 and older with chronic illnesses and functional, cognitive, and sensory impairments. Family caregivers deliver extensive, ongoing help with activities of daily living, provide the bulk of personal and health care support, and play a vital role to healthcare delivery. Millions of caregivers may experience high levels of stress, depression, and negative physical and financial effects due to caregiving. Nearly 30% of family caregivers are of racial and ethnic minorities, and they are beset by cultural, socioeconomic, and other factors that affect care. The need for support for caregivers as the older adult population continues to grow. Family caregiving has not been addressed in many public and private sector initiatives to improve care and outcomes for this vulnerable population.</td>
<td>Strengthen the capacity of Adult Day Services programs as a support for family caregivers. Increase the implementation of Evidence-Based Programs and practices for family caregivers. Support strategic efforts that will contribute toward the long-term sustainability of Adult Day Services programs. Contribute to the national conversation about the importance of adult day service and supporting caregivers. Promote systems change on a regional level to support collaboration, coordination, and shared learning.</td>
<td>Dedicated Caregivers Committed and skilled program staff Existing and additional service hours to accommodate working family caregivers Programming to support emotional and/or functional caregiving needs Support for diverse family caregivers Culturally competent materials and staff Strategic support for long-term sustainability of the program Funding from philanthropic community, particularly the Archstone Foundation Collaboration of providers and funders Credible national and state level evidence reviews and recommendations for action from National Academies of Medicine (NAM) and California Task Force on Family Caregiving (CSTF)</td>
<td>Expanded ADS hours during week and/or weekend Individual counseling and/or support groups for caregivers Evidence-based educational programs for caregivers Culturally appropriate (i.e. multilingual) counseling, classes, and programs Family Days Transportation Completion and review of Organizational Sustainability Assessment surveys Technical Assistance for Evaluation and Sustainability Possible development of cohort model for shared learning and sustainability Creation of materials on program impact and needs, to be used for case-making Dissemination of results Peer learning sessions</td>
<td><em>Increased number of caregivers served through extended hours for respite hours</em> • Increased number of caregivers to benefitting from counseling and support groups* • Increased number of caregivers participating in evidence-based educational programs* • Increased availability of services and materials in threshold languages • Grantee participation in Organizational Sustainability Assessments and technical assistance</td>
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*All of these numbers are based on addition of unduplicated service recipients.*

### OUTCOMES MEASURES

<table>
<thead>
<tr>
<th>SHORT-TERM (First 1-2 years of initiative)</th>
<th>LONG-TERM (End of initiative)</th>
<th>Collective Future Outcomes (5 to 10 years with collective action)</th>
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<tbody>
<tr>
<td>Caregiver satisfaction</td>
<td>Improved caregiver mental Well-Being (reduced stress, depression)</td>
<td>Increased regional and national recognition of importance of adult day care and the support of caregivers</td>
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<tr>
<td>Reduced caregiver stress</td>
<td>Improved caregiver health</td>
<td>Change in funding for caregivers and adult day care</td>
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<tr>
<td>Improvement in participating organization’s effectiveness and sustainability</td>
<td>Decreased financial stress for caregivers</td>
<td>These outcomes are dependent on other activities organized and carried out by cohort, including:</td>
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<tr>
<td>Improved coordination and cooperation between participants</td>
<td>Fulfillment of familial obligation/achievement</td>
<td></td>
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- Understanding of state Medi-Cal program and budget process
- Public advocacy
- Coordinated consumer and provider activism