

Question & Answer (Q&A): Innovations in Alzheimer’s Disease and Related Dementias (ADRD) Caregiver Support Programs: Building and Leveraging Support Systems

Webinar participants submitted questions during the September 2022 Innovations in Alzheimer’s Disease and Related Dementias (ADRD) Caregiver Support Programs: Building and Leveraging Support Systems webinar. We refined participants’ questions and edited speakers’ responses for clarity. The webinar recording, slides, and transcript can be found on the Resources for Integrated Care (RIC) website:

[Innovations in Alzheimer’s Disease and Related Dementias \(ADRD\) Caregiver Support Programs: Building and Leveraging Support Systems Webinar](#)

Featured Speakers:

- David B. Reuben, MD, Chief, Division of Geriatrics at the University of California, Los Angeles; Director, UCLA Alzheimer’s and Dementia Care (ADC) Program
- Debra Cherry, PhD, Clinical Psychologist and Executive Vice President, Alzheimer’s Los Angeles
- Linda Wade-Bickel, RN, BSN, MBA, Senior Director, Population Health & Clinical Operations, Health Net
- Anita Chacon Terry, RN, BSN, CCM, PHN, Manager, Care Management, Health Net
- Ed Mariscal, MS, Director, Public Programs and Long-Term Services & Supports, Health Net

Caregiver Support Program Strategies and Components

Q1: Can you describe how caregivers of individuals with ADRD can be engaged in care navigation or care coordination?

- **Dr. David Reuben:** Because of the clinical consequences of the disease, individuals with ADRD must rely on caregivers to be their spokespersons and advocates. This may be facilitated by having a professional within the health system or in a community-based organization (CBO) who has responsibility for assisting with care coordination or navigation. The Alzheimer’s and Dementia Care (ADC) Program at the University of California – Los Angeles is able to bridge these gaps in obtaining needed care by streamlining care within the health system (e.g., facilitating referrals or communicating with inpatient teams when hospitalized), monitoring care through regular check-ins with a nurse practitioner or physician assistant Dementia Care Specialist (DCS) and administrative staff, and connecting caregivers to resources in the community. The ADC

Program engages caregivers by regularly communicating with them to address the medical, behavioral, and social components of the patient's care.

- **Dr. Debra Cherry:** Starting from the point of detection and certainly by diagnosis, it is appropriate that caregivers be engaged in care navigation. The person living with ADRD, especially in the early stage of the disease trajectory, should have a say in who will be involved in their care, but as the disease progresses, all people living with these conditions will need a care partner. The provider can engage the caregiver in several ways:
 - Provide them with disease education
 - Include them in the care team to plan and monitor the care plan
 - Include the caregiver when making any referrals to medical care or social supports. It is usually the caregiver who will make appointments, monitor medications, arrange for transportation, etc. Therefore, these individuals are essential to implementation of any care plan. Furthermore, proactive care navigation services help direct caregivers to appropriate care and services in the community (e.g., financial planning, end of life planning, early-stage support groups, respite services, etc.).
- **Anita Chacon Terry:** Caregivers of individuals with ADRD can be engaged to attend doctor appointments, ask questions, and provide updates on what is happening at home. Most importantly, caregivers can let the care team know if they need help. Caregivers may also join support groups to learn more regarding how they can assist with care navigation.

Q2: How does your program track the use of CBO services for dually eligible individuals?

- **Dr. David Reuben:** The ADC Program tracks CBO services through annual assessments of patients and their caregivers as well as during additional visits in between annual assessments. In addition, the program has contracted with several CBOs, home care agencies, and community therapists to provide vouchers for an array of services that can benefit the person living with dementia and their caregiver. The voucher program is philanthropically funded and provides patients and caregivers the ability to access resources in the community, ranging from respite care through adult day programs and home care agencies to counseling services. Eligibility for vouchers is based on the DCS's determination of patient or caregiver needs and resources.
- **Dr. Debra Cherry:** Alzheimer's Los Angeles tracks referrals to the organization by health plans serving dually eligible individuals, and also tracks all services provided or for which a referral is provided regardless of the individual's Medicare or Medicaid eligibility status. However, some families contact Alzheimer's Los Angeles independently and are not referred by a provider.

- **Ed Mariscal:** Health Net is fortunate to have a large network of long-term services and supports (LTSS) and community-based providers, including over 150 Community-Based Adult Services (CBAS) centers and over 350 nursing facilities that specialize in serving individuals with ADRD in our service area. LTSS and CalAIM Community Supports are Medi-Cal services authorized by Health Net. Thus, we track utilization when we know our members are engaged in these services. When our dually eligible members are working with a Case Manager, and the Case Manager identifies a need for additional supports available through the member’s Medi-Cal plan, there is a warm hand-off from the Case Manager to the Public Programs team for additional care coordination. This includes working with waiver programs, such as In-Home Supportive Services (IHSS) programs and Multipurpose Senior Services Program (MSSP) sites, and LTSS providers such as CBAS centers. All information is documented in our electronic systems.

Q3: Can you tell us more about your caregiver support and education programs and resources? (e.g., Are they evidence-based? Are digital versions available?)

- **Dr. David Reuben:** In the ADC Program support for caregivers is provided through in-person and digital approaches. During the initial intake visit with the DCS, caregivers are provided a combination of text-based and web-based resources on dementia treatment and prognosis, effective communication, and the prevention and management of behavioral problems. Some educational materials provided are from the Alzheimer’s Association and the Institute for Healthcare Improvement. Caregivers are also provided resources and linkages to CBOs that provide additional support outside of the health system. In addition, through regular check-ins with the DCS and other staff, caregivers receive continuous education and guidance to better understand dementia, recognize and manage challenges, and prepare for future needs and crises. The ADC Program also partners with CBOs, community therapists, and local home care agencies to provide referrals and vouchers for services such as adult day care, assistance with applying for Medicaid, respite care, and counseling services.
- **Dr. Debra Cherry:** Alzheimer’s Los Angeles provides a range of services to people living with ADRD and their caregivers including:
 - Helpline for information and assistance
 - On-line and in-person early-stage support groups and mid-stage activity programs including the evidence-based [Memory Club™](#)
 - On-line and in-person caregiver support groups, disease education programs and materials, and evidence-based training programs such as [Savvy Caregiver™](#) and its derivatives – [Savvy Caregiver™ Express](#) and [Unidos en el cuidado](#)
 - Telephonic care counseling (e.g., assessment, care planning, support, crisis intervention, referrals etc.) including the evidence-derived [REACH Community program](#)

- Resources that can be accessed through our website (www.alzheimersla.org) and our social media accounts: [Facebook](#), [Instagram](#), [Twitter](#), [YouTube](#), and [LinkedIn](#)

All services are free and available in English and Spanish; some services are also available in other languages. Many services have been adapted for delivery in plain language or in a culturally acceptable format for diverse populations.

Q4: Are you leveraging any tools or technology to make care plans available to and actionable for caregivers (e.g., sharing data with providers)?

- **Dr. David Reuben:** Individual care plans are developed by the DCS and sent to the patient's partnering physician to review. After primary care physician approval, care plans are then shared with the caregivers and updated throughout the patient's time with the program. In addition, the electronic health record (EHR) can make care plans easily accessible via an online patient portal. When updates are made to the care plan, or when the care plan is considered complete by the primary care physician, the plan is automatically populated to the patient's portal for viewing. The team can also provide the care plan via secure email and mail for caregivers who cannot access the portal. The program continues to explore different ways to make the care plan and communication with caregivers as seamless as possible.
- **Anita Chacon Terry:** Our Health Net EHR system allows us to generate printed versions of our care plan which can then be mailed to the caregivers and providers. Caregivers may also be requested to attend or may request for themselves an interdisciplinary care team meeting to discuss the care plan.

Q5: What strategies do you use for population data trending and analysis? How do analysis and trends inform your program efforts?

- **Dr. David Reuben:** Since its inception in 2012, the ADC Program has used performance and clinical outcome measures for population data trending and analysis. Clinical outcomes for the patient and caregiver are measured by the following tools administered to caregivers: Modified Caregiver Strain Index (MCSI), Patient Health Questionnaire-9 (PHQ-9), and the Neuropsychiatric Inventory Questionnaire (NPI-Q). These measures are completed annually, and then DCSs gauge trends over time for individual patient-caregiver dyads to see if there have been increases or decreases in patient dementia-related behaviors and caregiver distress and burden. The program also looks at performance outcome measures for ADC patients to determine if the program has contributed to a reduction in the length of hospital stays, emergency department (ED) visits, unplanned hospital admissions, 30-day readmission rates, and days spent in the intensive care unit. These measures have led to feedback and changes to improve patient and caregiver outcomes.

- **Ed Mariscal:** Our member-centered strategy begins with a review of ED utilization and inpatient admissions. We receive daily ADT (admissions, discharges, transfers) data feeds from most hospitals in our network. Our population health team of social workers and clinical pharmacists engages in outreach to members identified as having utilized the ED or having been admitted to the hospital, and then has individual conversations with these members to prevent future avoidable trips to the hospital. Data gathered from ADT feeds and information from the conversations with members are captured in our internal risk stratification algorithms.

Supporting Diverse and Underserved Communities in Dually Eligible Populations

Q6: How does your program tailor or adapt services to individuals to ensure health equity?

- **Dr. David Reuben:** The ADC Program takes an individualistic approach to ensure that care and recommendations reflect all realms of the patient and caregiver's unique needs. The program aims to provide culturally competent and equitable care to reduce barriers for patients and caregivers. Before the initial visit, caregivers complete a pre-visit questionnaire, which provides insight into the patient and any potential medical, psychosocial, and socioeconomic barriers to dementia-related care. From there, the DCSs offer recommendations that encompass the needs of the patient and caregiver. Many of the materials and services, including support groups and caregiver training videos are offered in languages other than English. Through philanthropic funding, the program also provides vouchers for CBO services for patients and caregivers on an as-needed basis. The voucher system has provided significant access to patients and caregivers for utilizing respite care, applying for Medicaid and IHSS, and accessing counseling services.
- **Ed Mariscal:** Health Net stratifies our quality data based on race, ethnicity, and language and overlays social determinants of health (SDOH) data (e.g., housing and food insecurity data). We then geographically hone in on which members may need more support. We tailor programs and interventions to members' needs based on this information. We also survey our vast network of LTSS and community-based providers annually to confirm they continue to serve individuals with ADRD. The survey is an outreach to CBAS and long-term care (LTC) providers to capture the services they provide. Finally, internal teams are specifically trained on dementia care, including our Case Managers.

Lessons Learned from Program Implementation

Q7: From your perspective, what role may Medicare-Medicaid health plans have in supporting members living with ADRD and their family caregivers?

- **Anita Chacon Terry:** Medicare-Medicaid Plans (MMPs) can support members living with ADRD and their family caregivers by having clinical staff (e.g., registered nurses, licensed

clinical social workers) who are trained DCSs available to provide care management and coordination of care services. This includes assisting with education on management of ADRD and behaviors associated with ADRD and linking families to community resources.

- **Ed Mariscal:** MMPs with a large network of LTSS and CBOs, can provide education and training to providers who are serving our members with ADRD. At Health Net we leverage our data analytics to identify providers serving our members and proactively outreach to ensure adequate services for our members. This enables us to creatively collaborate on value-based programs and quality outcomes for providers serving members with ADRD.