USAging

CASE STUDIES: Caregiver Supports in Partnership with Health Care

AAAs' Partnership With School of Medicine Expands Dementia Caregiving Services

CICOA Aging & In-Home Solutions
Indianapolis, IN
www.cicoa.org

LifeSpan Resources
Albany, IN
www.lsr14.org

USAging highlights successful programs and health care partnerships that support caregivers to provide inspiration for Area Agencies on Aging (AAAs) and other community-based organizations to advance their work in this area. Find more case studies at ***www.usaging.org/research****.*

Dementia-related challenges and time demands can often lead to caregiver stress and burnout. To address the needs of unpaid dementia caregivers, 10 of Indiana's 15 AAAs have implemented the Caregiver Stress Prevention Bundle of the evidence-based program known as the Aging Brain Community (ABC program). The care coaching program, delivered in partnership with the Indiana University School of Medicine (IU) and the Indiana Family Social Services Administration (FSSA) Division of Aging, helps caregivers identify their stressors and use tools to reduce those stressors, encourages use of respite and support groups and ensures caregivers have an updated crisis plan.

LifeSpan Resources and CICOA Aging & In-Home Solutions shared their agencies' experiences with implementing the caregiver stress prevention portion of the ABC program. LifeSpan serves four largely rural counties in southern Indiana, and CICOA, located in Indianapolis, serves eight central counties. Caregiver support is fundamental to both AAAs' missions because unpaid caregivers are integral to older adults' health, well-being and ability to remain in their homes and communities.

The ABC Program

The ABC program is designed to help caregivers use evidence-based coping strategies to manage their loved one's cognitive, functional, behavioral and psychological disabilities without becoming burned out. A care coach first assesses caregivers and their situation using the Healthy Aging Brain Coach monitoring tool (HABC Monitor), which measures the care recipient's burden of dementia-related caregiving tasks and assists in tailoring the caregiving coaching.

Next, the coach and the caregiver examine together the assessment results and prioritize areas of greatest stress for focus. Evidence-based protocols provide caregivers with stressor-specific trainings that improve caregiver stress scores in those areas. Regular reassessments examine caregiver progress toward stress reduction as well as new areas for focus.

Caregivers meet with coaches at least monthly during the first three months, then move to quarterly meetings if caregiver stress scores remain in the "green zone" of low stress. Participants may continue in the ABC program while residing in the AAA's service area and their care recipient remains at home.

The programs are relatively small, with 13 active caregiver participants at LifeSpan and 24 at CICOA. Caregivers are eligible for the ABC program if the care recipient has a dementia diagnosis and is currently care managed. The AAAs select participants from referrals from community service agencies, their current service recipients and individuals on waiting lists.

IU and FSSA recruited CICOA for the first cohort of AAAs implementing the care coaching portion of the ABC program due to its leadership in dementia education. Specifically, CICOA helped start and lead Dementia Friends Indiana and was providing community education on the issue, which caught FSSA's attention. IU also featured CICOA team members in some training videos for ABC program coaches. LifeSpan was part of IU's second cohort as the initiative expanded.

The Indiana University Department of Geriatrics supports the AAAs and other organizations implementing the ABC program. Implementation support includes program training and technical assistance, provision of ABC materials (such as the HABC Monitor) and protocols and program evaluation.

A U.S. Administration for Community Living grant initially funded the ABC program, and now FSSA provides ongoing funding for the program using state funds.

Data Sharing Challenges and Solutions

AAAs' care coaches collect data on program participants from their initial assessments and ongoing reassessments and then enter this data into an IU platform. AAAs receive the HABC Monitor results on stress levels so they can monitor caregivers' progress in terms of stress and other indicators and know which specific protocols to offer, depending on the sources and extent of caregivers' stress. Thus, AAAs can monitor stress levels; existence of a crisis plan; and caregiver participation in services, support groups, trainings and other activities.

IU provides a dashboard for AAAs to benchmark their results with statewide data and IU's preset goals for caregiver participation. Both LifeSpan and CICOA used their program data to monitor progress and identify areas for improvements. For example, if the dashboard indicated that only half of ABC participants were in support groups, the AAAs identified and reduced barriers to participation.

The AAAs have had to overcome challenges with data sharing and tracking. Coaches must enter data into both the IU system and the AAA's case management system. IU analyzes the HABC Monitor data entered by and reported back to care coaches. To track and analyze caregiver participation in AAA activities, coaches must also document caregivers as individual clients in the agency's case management platform. It took a while, but IU and the AAAs now have a data reporting system that works well for both. Each group understands how the other uses and talks about data, so they can both use the information better.

Outcomes

Both LifeSpan and CICOA enthusiastically endorsed the ABC program, citing factors such as the rigorous program development, consistent positive outcomes and availability of implementation support.

In the initial months of adoption, both AAAs had to help care coaches adjust to the evidence-based program's rigid requirements for assessment protocol, prescribed sets of activities, and structured outcomes and performance measures. Some coaches perceived that the program's standardized approaches to care did not align well with their person-centered philosophy. Over time, the reductions in caregiver stress along with caregivers' positive feedback and continued program participation demonstrated the value of the program's standardized approach.

Another outcome is that caregivers also learned about the AAAs' other programs and services, and some began using adult day, personal care or other assistance. LifeSpan and CICOA also report that ABC program promotions have enabled their AAAs to reach additional caregivers at other health systems and organizations.

Finally, ABC allows the AAAs to expand their ability to take a holistic approach to serving family units, rather than only older adults with dementia. Care recipients receive support from caregivers, and now caregivers receive support from care coaches.

Advice for AAAs

As this program is delivered in partnership with IU and FSSA Division of Aging, it is important to maintain strong communication and clear expectations. Both organizations have supported the AAAs in transitioning the service from a grant-funded program to a nonwaiver-funded program by providing ongoing training and support following implementation. The AAAs recommend monthly case conference meetings as a valuable resource. The team members share issues and obstacles, then brainstorm solutions, communication techniques and community resource tools that might benefit the family.

> ***There was an individual that was an elopement risk. The caregiver was struggling to keep vigilance at all hours of the day. This challenge was discussed during a case conference, where team members suggested door alarms as a potential aid, and that these can be obtained through the Medicaid waiver in Indiana. This wraparound approach benefits families and helps them stay together in the community longer.***
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> —AAA Case Manager

When AAAs become established in providing direct service to caregivers through new funding streams, they can look to increase program reach and revenue by connecting with caregivers of their clients about the program.

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