

Caregiver Action Network Offers Practical Resources for Caregivers of People with Dementia

In 2013, RRF awarded a \$20,000 grant to the Caregiver Action Network (CAN, formerly known as the National Family Caregivers Association) to create a website with easily accessible and practical resources for caregivers of people with dementia.

CAN created 21 short and practical videos. Each video, professionally produced and well-edited, is only about two minutes long, in recognition of the limited time generally available to family caregivers. The compelling videos cover four subject categories. Each category is introduced by a professional, followed by several brief videos of roundtable discussions featuring family caregivers' practical stories and insights. The first, *Discovering Alzheimer's Disease*, features peer caregivers sharing their journeys of discovering their loved one's disease, the symptoms, and progression. The second, *Life as a Caregiver*, includes personal stories of best practices in day-to-day caregiving. The third, *Caregiver Tactics*, covers tips for staying connected to their loved ones. The last, *Finding Support*, emphasizes the importance of recognizing the caregiver's needs as well as those of the loved one.

CAN created a section on its website that links family caregivers to the videos and other useful resources. The new section, called the Alzheimer's Caregiver Video Resource Center, can be found at <http://www.caregiveraction.org/resources/alzheimer-videos/>. CAN used several outreach strategies to promote the website, including the organization's e-newsletter, posts on Facebook and Twitter, and presentations to the LEAD Coalition (Leaders Engaged in Alzheimer's Disease). CAN's efforts were successful in driving traffic to the website. In 2014, there were more than 35,500 page views within the resource center section of the website. Almost everyone who clicked from the home page of the website to the resource center viewed a video, resulting in more than 2,600 video views. Eighty percent of viewers also explored family caregiver tips and educational materials on other sections of CAN's website.

Family Caregivers Learn Delirium Prevention Strategies for Patients with Hip or Knee Arthroplasty

Delirium is a life-threatening, frequently reversible condition, characterized by sudden onset and fluctuations in orientation, memory, disorganized thinking, perceptual disturbances, and compromised ability to communicate. Delirium is a common problem following hip and knee arthroplasty (replacement) with older adults, especially those with co-morbidities, uncontrolled pain, dehydration, and taking multiple prescription medications. Family caregivers are potential partners in early recognition of delirium

symptoms in their loved ones and can play an important role in minimizing negative consequences. However, they often lack knowledge about delirium symptoms and its potential causes.

In 2013, RRF awarded a one-year, \$104,480 grant to Marquette University for a feasibility study to test the efficacy of a telephone-based educational intervention that prepares family caregivers to recognize delirium symptoms in older adults during and following hospitalization for elective knee or hip arthroplasty. The telephone-based intervention was developed to improve upon an earlier in-person training program that a feasibility study found not viable.

The telephone-based intervention included four classes and follow-up assessments at one and two months following completion. Content included pain management and possible adverse reactions to medication; activities to prevent delirium (current events, puzzles, card games, etc.); and emphasis on the use of eyeglasses and hearing aids. Forty-one families were recruited from the Veterans Administration (VA) and Wheaton Franciscan Health Care. Seven dropped from the study before enrollment due to death of a patient, illness of caregivers, and changes in surgery schedule. All 34 families that enrolled completed the study.

The study found that caregivers were able to recognize the presence and absence of delirium symptoms in case vignettes and in their older adult family member. They learned how to use the family version of the Confusion Assessment Measure and were able to communicate their observations to health care providers. The caregivers consistently expressed satisfaction with the intervention.

Only three patients developed delirium, one while hospitalized and two after returning home. In all three cases, the patients or caregivers called the physician, who revised pain medications, and the delirium cleared up. The relatively low rate of delirium development may have been a positive result of the intervention, which taught caregivers strategies for delirium prevention as well as how to recognize symptoms.

The study also investigated family caregivers' experience in coping as they care for their family member following hospitalization. The study surprisingly found that both family caregivers and older adults reported relatively low levels of difficulty in coping with post-hospitalization. While ratings were low, caregiver problems included lack of knowledge of potential medication side effects and lack of information on instructions the physician had given the older adult.

In conclusion, the telephone-based intervention was found to be acceptable and effective in increasing family caregiver knowledge of delirium symptoms and actions to take. These findings provide a basis for pursuing a study that employs a control group and sharing the intervention more broadly.

CJE SeniorLife Adjusts Systems for Shift to Managed Care

In 2014, RRF awarded a one-year, \$50,000 organizational capacity building grant to CJE SeniorLife to prepare for significant changes that would occur as its clients

transitioned into managed care under the Illinois Medicare Medicaid Alignment Initiative. For several years, CJES care managers and clients were responsible for determining the use and frequency of long-term care services and supports covered under direct contract with the state of Illinois. In the new system, CJE would become a service vendor, receiving fees for service under contract with six different private insurers, which would take over responsibility for managing care. CJE expected 500 clients to be transitioned to managed care organizations (MCOs), including seniors receiving CJES home- and community-based services and residents at Lieberman, a skilled care facility operated by CJE. New clients that were deemed "dual eligible" (i.e., low-income older adults who qualified for both Medicare and Medicaid services) would also come in under the new managed care system.

CJES goal was to transition CJE clients seamlessly to the MCOs (as well as accept new MCO clients) by structuring the service delivery system to fit with MCO requirements and revising billing procedures to ensure fees would be collected from MCOs for each contracted service.

CJE established a multi-departmental team from Finance, Information Technology, and Direct Service Programs to integrate managed care contracting into the CJE system. The team was divided into two groups: one for community-based services and the other for nursing home services. Each subgroup developed mechanisms for reviewing new service requests and receipt of needed service authorization; an information flow chart for each impacted department; and processes to facilitate reimbursement for contracted services. All new mechanisms were successfully integrated into current CJE systems. CJE trained staff and educated clients about the transition to managed care.

Initially, CJE hired temporary staff to call the MCOs regularly about client eligibility, care plans, and authorizations. In the middle of the grant period, CJE realized it needed a more consistent, dedicated position for these tasks and hired a new staff member to track services and monitor reimbursements. Securing appropriate reimbursements became more efficient.

By the end of the grant period, CJE had enabled 56 clients in the Medicare Medicaid Alignment Initiative (MMAI) to transition to MCOs. The lower than expected number was due to changes the state made in MMAI. The state delayed the enrollment process and changed the requirements from auto-enrollment to an opt-in process. Most clients ended up not making the switch or opting out soon after initial enrollment. However, many more clients will be transitioning over the next year, and CJES new systems will be put to the test as volume increases.

From inception, MMAI has been fraught with problems in its design and communication practices. Older adults and service providers continue to be confused about the transition to managed care due to inconsistent and often contradictory information from the state and the MCOs. In some cases, the lack of coordinated, consistent care management by MCOs has prevented CJES clients from getting services they need. CJE has been assisting clients on an individual level to advocate for better service and documenting and submitting concerns to the state. The

Governor's Office has begun working with the Illinois Department of Healthcare and Family Services (the MMAI program administrator) to improve the program's operations.

CJE has submitted testimony, commented at public forums, and educated state legislators about these problems. Recently, CJE joined with 15 service providers in a state-wide meeting to discuss the issues with representatives from the Illinois Department of Healthcare and Family Services and the MCOs.

UIC Promotes Adoption of Fit and Strong! Exercise Program

From 2011 to 2013, RRF made two grants, totaling \$193,929, to the University of Illinois at Chicago (UIC) to promote adoption of Fit and Strong!, an evidence-based exercise program targeting individuals with arthritis. The pain of arthritis frequently contributes to a sedentary lifestyle. Inactivity raises the risk of falls, exacerbates other chronic ailments, and can lead to isolation, which affects cognition and mood.

Fit and Strong! is an eight-week program in which small groups of arthritis patients gather in three, 2-hour sessions. Participants learn gentle stretching and strengthening exercises under the direction of certified fitness instructors. Sessions enable participants to experience the benefit of activity, discuss their progress, solve motivational challenges, and share successes. UIC's Roybal Center developed Fit and Strong! and tested it in two randomized clinical trials. Results showed that participants improved exercise frequency, reduced lower extremity stiffness, and had enhanced energy.

Objectives of the two RRF-funded projects included: 1) develop a readiness assessment instrument to evaluate the willingness and capacity of different types of organizations to adopt Fit and Strong!; 2) develop and test the ability to bundle Fit and Strong! with other evidence-based programs for disease prevention; 3) identify regional or national organizations to adopt and maintain Fit and Strong!; 4) create and disseminate a Spanish version of the program; 5) embed the program in Illinois managed care plans; and 6) ensure participation of Fit and Strong! in the national demonstration of evidence-based programs conducted by the Centers for Medicare & Medicaid Services.

UIC focused on promoting adoption of Fit and Strong! in four types of settings so that it could learn how to maximize replication. The settings included service providers connected to Area Agencies on Aging, schools of public health, large health systems, and senior housing sites. These settings were selected because they have staff trained in other evidence-based programs, which should make adoption of another such program easier. The goal was to reach 2,000 participants, which is one of the criteria for inclusion in CMS's national demonstration.

By the end of the grant period, UIC had made significant progress in meeting its objectives. Although UIC had not reached the target of 2,000 participants, it had enrolled 877, with an additional 225 expected to be enrolled by mid-December. Staff turnover within nonprofit organizations that were potential Fit and Strong! sites proved to be the greatest challenge to enrollment. UIC expects that other projects participating in

the CMS demonstration have faced the same problems and anticipates it will be able to meet CMS criteria. UIC noted that many more participants enrolled in Fit and Strong! during the grant period but did not agree to have their data shared for the CMS demonstration.

During the grant period, UIC recruited and trained 212 new Fit and Strong! instructors and 10 new trainers. A Spanish version of the program, *Fuerte y en Forma!*, was created and used by three Chicago nonprofit organizations and two others in the southwestern part of the U.S. An organizational readiness tool was created to help Fit and Strong! program staff evaluate whether a nonprofit organization has the resources needed to launch the program successfully. The tool is now on the National Council on Aging's website.

UIC promoted Fit and Strong! through a variety of dissemination activities. The program was presented at 12 national conferences, including the American Public Health Association, Gerontological Society of America, National Council on Aging, Society for Social Research, National Association of Area Agencies on Aging, and others. Fit and Strong! products were made available through the National Council on Aging and the Center for Disease Control.

Despite significant effort, UIC was not able to get the managed care organizations to adopt Fit and Strong!. Although the MCOs stood to benefit from enrolling members in Fit and Strong!, they were facing too many challenges in their new role of care coordinators under the Medicare Medicaid Alignment Initiative to focus their attention on this program.

UIC learned several lessons about replicating Fit and Strong!. Senior centers were found to be the easiest to work with because they often had staff dedicated to health promotion. University Centers on Aging were also effective in adopting the program. Instructors trained in other evidence-based physical exercise programs were receptive to training on Fit and Strong! as they felt it helped them teach their other programs as well. The uptake of Fit and Strong! required multiple, simultaneous dissemination strategies and ongoing support for adopter sites. Further replication will require adequate financing in the future.

Zion Evangelical Lutheran Church Installs Platform Lift

In 2013, RRF awarded a \$30,000 Accessible Faith Grant to Zion Evangelical Lutheran Church to make accessibility improvements to its facility. Located in Elgin, Zion Evangelical is a 265-member congregation. Thirty-five percent of its members are age 65 or older. Seniors are very involved in the programs that occur within the facility, including the weekly Soup Kitchen, adult education, and several AA and Al-Anon groups. The church also serves as a temporary shelter for homeless persons and a regular gathering place for a neighborhood association.

The grant enabled Zion Evangelical Lutheran Church to install a platform lift to provide access up to the sanctuary and down to the lower-level meeting rooms. The

project also involved modifying doors on both levels to accommodate wheelchairs and redesigning the sidewalk to eliminate steps at the building's entrance.

Heavy rains this past spring delayed the project by two months, but otherwise it was completed as planned and within budget. The congregation successfully raised \$75,000 toward the cost of the project. The pastor emphasized the importance of RRF's grant in giving the congregation the confidence to launch a major fundraising campaign.

Although it is too early to determine the impact of accessibility improvements, the pastor reported that the AA groups and soup kitchen have already had a slight increase in participation. The pastor is in discussion with the Elgin Parks and Recreation Department to hold additional community events at the church now that the facility is accessible. For the first time, the church will host the Coalition of Elgin Religious Leaders' annual Thanksgiving Worship, an interfaith service that attracts more than 200 worshippers. Elgin's mayor will be the guest speaker, which means there will be local press coverage and an opportunity to highlight the importance of accessibility and full inclusion.

Note: RRF staff takes much of the information for Grant Highlights directly from grantees' final reports. Staff often asks questions and holds discussions with grantees to get a more complete understanding of the results of grants and to understand challenges grantees faced.