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AGENTS

Dementia Caregiving Network

The Dementia Caregiving Network (DCN) achieved improvements in services, supports, and care for persons with dementia and their family caregivers. Initiated in January 2014, the DCN was composed of nationally recognized leaders with expertise in practice, policy, and research related to caregiving for persons with dementia.

Taking Action

Highlights of their activities and information about work, which continues to advance, includes:

- ***Profiling evidence-based interventions that address the needs of family caregivers:*** Using interprofessional teams, the DCN developed and tested a carefully defined methodology for conducting comprehensive reviews of evidence-based programs for persons with dementia and their family caregivers. This work will help provider and payer organizations and other potential users understand the available evidence-based programs and care practices and make decisions about which ones to provide, pay for, and use. Separate grant funding is being sought for creation of a “community-friendly” online decision support tool to make comprehensive information about programs’ research and implementation characteristics more broadly accessible, with program-comparison features, as well as feedback from current implementation sites.
- ***Developing a practical approach to identify family members who are providing care to older adults:*** The DCN is working to embed reliable and culturally sensitive tools in the electronic health record to assist in the identification of those providing care to family members. The goals of this work have been built around the following tenets:
 - Family caregiver information should be clearly visible to clinicians during all healthcare encounters.
 - Schedulers and providers should be able to enter/edit information about the family caregiver.
 - Information should be put into a structured field that is reportable.
- ***Improving dementia care and identification, engagement and support of family caregivers within integrated health and long-term care delivery to dually eligible beneficiaries of Medicare and Medicaid.*** The DCN contributed to documenting, evaluating and disseminating the promising practices of the State of California’s Dementia Cal MediConnect program that strengthened the training and capacity of health plans to better coordinate dementia care with community agencies providing supportive services to family caregivers. With funding from the Administration on Community Living, Dementia Cal MediConnect has produced a toolkit with essential resources for health plans, community organizations, care managers and family caregivers. The DCN mobilized necessary actors in other states and communities to adopt these promising practices in dementia care and family caregiver support. Texas and Rhode Island are including these practices in their duals demonstration projects.
- ***Contributing to ongoing work on the development of performance/ quality measures: for dementia care that is person and family-centered.*** DCN members submitted comments on national quality measures which resulted in substantive changes in work produced by the [National Quality Forum](#). Commentary was also provided to the American Academy of Neurology/American Psychiatric Association for their proposed quality measures for dementia management, *Dementia: Quality Measurement Set Update*. DCN members have completed a publication, *Improving Measurement of Dementia Care Quality to Advance Person-Centered Care* for peer-reviewed publication (Gary Epstein-Lubow et al., 2016).
- ***Fostering collaboration across national, state and local organizations*** to enhance the network of support services for dementia caregivers and influence practice change in all domains. One or more DCN members provided leadership or participated in the following activities:

- AARP Public Policy Institute Collaborative on Managed Long-Term Services and Supports which produced a report, [Family Caregivers & Managed Long-Term Services and Supports](#), featuring the Dementia Cal MediConnect project.
- In 2015 and 2016 DCN members contributed to the development and delivery of this series. Geriatric-Competent Care Webinar Series Caring for Individuals with Alzheimer’s Disease, which were developed by the American Geriatrics Society in collaboration with Community Catalyst and The Lewin Group and hosted by the Centers for Medicare & Medicaid Services Medicare-Medicaid Coordination Office Integrated Care Resource Center –These webinars were delivered twice and reached an average attendance of 500 health professionals in all settings and disciplines with an emphasis on expanding their knowledge and skills in the unique aspects of caring for older adults with Alzheimer’s disease and in working with their caregivers. Webinars and associated resources are available [here](#).
- Supporting the [National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers](#) as part of the National Alzheimer’s Project Act.

Members

The DCN was co-chaired by **Alan Stevens**, PhD, Baylor Scott & White Health, and **Nancy Wilson**, MSW, Baylor College of Medicine, Michael E. DeBakey Veterans Affairs Medical Center.

Members included a multi-sector interdisciplinary team of experts in the field of dementia caregiving:

- **David Bass**, PhD, Benjamin Rose Institute on Aging
- **Chris Callahan**, MD, Indiana University
- **Debra Cherry**, PhD, Alzheimer’s Greater Los Angeles
- **Amy Cotton**, MSN, Eastern Maine Health Services
- **Gary Epstein-Lubow**, MD, Brown University
- **Joseph Gaugler**, PhD, University of Minnesota
- **Laura Gitlin**, PhD, Johns Hopkins University
- **Lisa Gwyther**, MSW, Duke University School of Medicine
- **Katie Maslow**, MSW, The Gerontological Society of America

Contributions to the John A. Hartford Foundation Change AGents Initiative

The DCN was an active part of the larger Change AGents Initiative, collaborating closely with the initiative’s Patient Centered Medical Home (PCMH) Network, as well as with the initiative’s leadership team and the broader Change AGents community. Together, the DCN and the PCMH Network identified practice change opportunities on a range of subjects and built the Change AGents community’s knowledge and willingness to take action toward improving the health and well-being of older adults and their families.

For more information

To learn more about the Dementia Caregiving Network, please visit: <http://www.changeagents365.org/change-agents-networks/dementia-caregiving>

About the John A. Hartford Foundation Change AGents Initiative

The John A. Hartford Foundation’s Change AGents Initiative was a three-year effort dedicated to improving the health of older Americans, their families, and their communities through practice change. The initiative harnessed the collective strengths, resources, and expertise of the foundation’s interprofessional community of scholars, clinicians, and health system leaders.