Dementia Action Alliance -

Vision

We envision a society where dementia symptoms are better understood and accommodated as a disability, and individuals and families living with dementia are fully included and supported.

Strategic Goals

The Dementia Action Alliance -

♦ Champions fully including individuals living with dementia and their care partners in all matters that affect them including clinical practices, research, public policy-making, and as speakers at professional events and forums.

♦ Provides a platform to amplify the voices of individuals living with dementia and care partners.

♦ Increases understanding about living with dementia and educates about the negative impact stigma and misperceptions have on individuals and families living with dementia.

♦ Recognizes dementia as a disability needing support and accommodations for changing abilities.

♦ Advocates for person- and relationship-centered practices that optimize holistic well-being and focus on the whole person rather than just on his/her dementia symptoms.

♦ Identifies beneficial technologies that enhance the lives of individuals and families living with dementia.
Outcomes Report

2018 IMPACT - Goal 1, Inclusion

- Individuals living with dementia were included for the first time at prestigious events such as The Milken Institute and the American Academy of Neurology’s Brain Health Fair.
- In 2018, the DAA launched a new service, ON THE MARK, for companies and organizations to be able to access individuals and care partners living with dementia to better inform and shape their dementia-related services and products. Three ON THE MARK sessions were successfully provided.
- For the first time in its history, AARP committed to supporting a specific disease condition – dementia. Working with the DAA, AARP filmed three Advisory Board members to announce its Disrupt Dementia campaign.

2018 IMPACT –

Goal 2, Amplify voices

- Individuals living with dementia from the DAA’s Speakers Bureau spoke at 28 events reaching over 5,000 aging leaders, policymakers, service providers, healthcare practitioners, and researchers. Events included The Milken Institute’s Future of Health Summit; American Academy of Neurology Annual Meeting, Health and Aging Policy Fellowship Spring Symposium; LeadingAge Annual Meeting; Brain Health Fair at the Los Angeles Convention Center; and the Southern Gerontological Society among others.
- The DAA’s Advisory Board of individuals living with dementia launched two monthly podcasts this year, This Dementia Life and Professional Insights as well as a weekly online discussion, Dementia Discussions. As of December 1, 2018 there have been 20,468 podcast views.
- Presented Caring Community Conversations to five communities reaching over 1,500 people. Conversations were held at Mercy Medical Center/Cedar Rapids, IA; Arbor Senior Living/Atlanta, GA; Oaknoll Retirement Residence/Iowa City, IA; and Kendall Crosslands and Longwood/Kennett Square, PA.
2018 IMPACT - Goal 3, Increase understanding & reduce stigma

- The DAA’s Advisory Board members developed *Living Beyond Dementia*, a 5-minute video about the issues surrounding the manner in which diagnoses of dementia are delivered. The video was submitted to the American Academy of Neurology’s 2018 Neuro Film Fest which was available for viewing by over 13,000 member neurologists.
- The DAA convened three community educational sessions with over 500 attendees in Newton, MA; Alexandria, VA; and Bloomington, IN.
- The DAA’s Advisory Board members developed two bookmarks - *Things People and Doctor’s Need to Know*. Over 5,000 bookmarks were strategically distributed during the year.
- The DAA’s website attracted 68,490 visits as of the first eleven months of 2018. The average viewing time to the website per visitor was over 4 minutes. According to the Nielson Norman Group, leaders in research-based user experience, the average visit time is less than one minute [https://www.nngroup.com/articles/how-long-do-users-stay-on-web-pages/].
- Launched in the spring, thirteen companies and organizations joined the DAA’s Corporate Leadership Council.

"Being on the Corporate Leadership Council is some of the most rewarding and useful time that I spend...The DAA’s ability to connect people living with dementia to care providers, care partners, and business and community leaders to solve challenges TOGETHER is so valuable for creating better understanding of the experience of dementia."

~ Erin Washington – Co-Founder, Embodied Labs

2018 IMPACT - Goal 4, Disability needing support & accommodations

- The DAA served on numerous councils and committees, such as Dementia Friendly America, LiveWell’s Leader Shift Academy, Camden, NJ’s Dementia Journey Navigator Program, Rutgers University Advisory Council, and LeadingAge’s Educational Committee.
2018 IMPACT - Goal 5, Person- and relationship-centered practices

- The DAA partnered with Community Ideas Stations, a PBS affiliate in Virginia, to produce Revolutionizing Dementia Care, an hour-long documentary about how using person- and relationship-centered practices best empowers and enables people living with dementia. The documentary will reach countless thousands of people across the country.

Through DAA’s connection with Dr. Fei Sun, the documentary will be subtitled in Mandarin and distributed in China.

- Partnering with The Eden Alternative, the DAA convened an Advisory Group of nationally recognized person- and relationship-centered champions and five setting specific (e.g., home, adult day services, home care, assisted living and skilled nursing care) Workgroups for its Raising the Bar initiative to work on developing unique setting specific operational practice guides.

2018 IMPACT - Goal 6, Beneficial technologies

- The DAA’s Technology Workgroup members heard from five technology innovators who spoke about how their technologies are providing benefits for individuals living with dementia.

“A huge thank you to the Dementia Action Alliance for their partnership and support in helping us create the documentary. Everyone there is extremely passionate in making a difference for those living with dementia.”

~ Mason Mills, Community Ideas Station PBS Documentary Producer/Director