



PROGRESS UPDATE

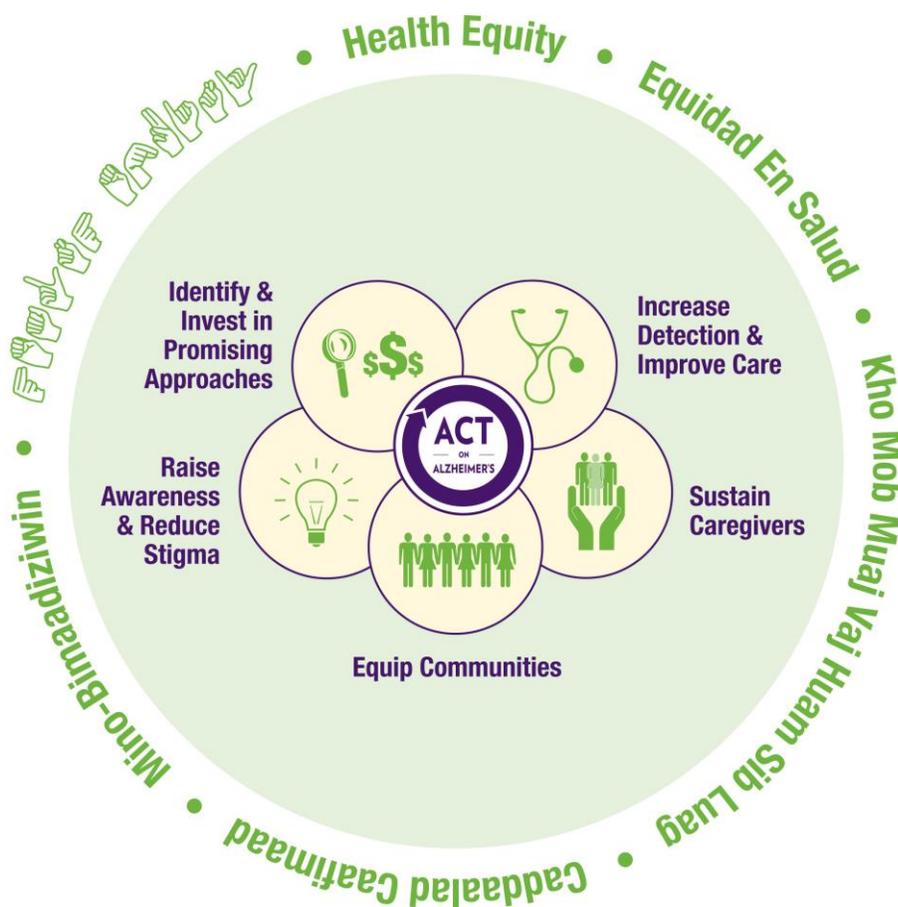
SEPTEMBER, 2014

ACT on Alzheimer's is a transformative, multi-dimensional initiative seeking to prepare and build capacity in Minnesota communities to address the spiraling care and support needs associated with the increasing prevalence of Alzheimer's disease and other dementias. ACT on Alzheimer's uniquely addresses the impacts of Alzheimer's disease, seeks to change systems at multiple levels, and uses evidence-based, emerging practices and innovative tools to effect change locally and statewide. ACT on Alzheimer's is a volunteer-driven collaborative involving over 60 public and private organizations and some 400 individuals focused on five interconnected goals.¹

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¹ The genesis for ACT on Alzheimer's began in 2009, when the Minnesota Legislature called on the Minnesota Board on Aging to establish the Alzheimer's Disease Working Group (ADWG) to study and make recommendations to the Legislature for needed policy changes related to Alzheimer's disease. The ADWG delivered recommendations to the Minnesota Legislature in January 2011. After the recommendations were filed, a subgroup of the ADWG participants committed to ensuring that the recommendations were implemented. To that end, ACT on Alzheimer's was established in June 2011.



GOAL 1: IDENTIFY AND INVEST IN PROMISING APPROACHES THAT REDUCE COSTS AND IMPROVE CARE.

ACT on Alzheimer’s actions to advance the knowledge of care approaches that can slow the growth of dementia care costs include economic modeling on the impact of using evidence-based dementia care interventions. Phase one modeling concluded in December, 2013; phase two in May, 2014. The economic model was initially used to project the healthcare cost savings in Minnesota associated with implementing and participating in the New York University Caregiver Intervention (NYUCI), an enhanced caregiver support program. The model results, which were published in *Health Affairs*, showed a potential savings to Minnesota taxpayers and families of nearly \$1 billion over a 15-year period. The initial modeling assumed that all eligible Minnesotans would use the caregiver support program and did not deduct program costs from the savings. The second phase of modeling shows the net savings after deducting program costs and with very conservative rates of use of the caregiver support program (5%, 10% and 30% of eligible people). The model suggests that net direct healthcare savings are achievable within a few years of program implementation and, by 15 years, range from \$62 million for the most conservative participation rate (5%) to \$250 million at a 30% participation rate. These net direct healthcare cost savings do not include costs to increase awareness of the program and encourage participation, but are significant enough that such efforts could be funded. Find the *Health Affairs* article and the model at <http://www.actonalz.org/economic-impact>.

Future Impact: *This work aims to influence care delivery and payment policy to ensure persons with Alzheimer’s and their caregivers receive optimal care and support in a manner that may reduce the State’s and other payers’ burden. The economic model will remain available to model other care interventions that have been shown in research to produce cost savings in connection with the care of people with dementia.*

Funding: *This work was funded through grants from UCare, BCBS MN and Care Providers Foundation.*

GOAL 2: INCREASE DETECTION OF ALZHEIMER'S DISEASE AND IMPROVE ONGOING CARE AND SUPPORT.

ACT on Alzheimer's has developed a full array of provider practice tools for audiences ranging from primary care physicians, community-based providers, and care coordinators to persons with dementia and their caregivers. The tools include a protocol practice tool for cognitive impairment, an electronic medical record decision support tool for dementia care, a protocol practice tool for mid- to late-stage dementia, care coordination practice tools, and tips and action steps to share with a person diagnosed with Alzheimer's. The tools are incorporated into the ACT on Alzheimer's interdisciplinary curriculum. The curriculum will be the basis for a national dementia curriculum being developed by the Health Research and Services Administration (HRSA), as required by the National Alzheimer's Project Act Plan. This will ensure national dissemination of the tools and curriculum. The curriculum will be maintained and updated at a national level, which accomplishes a critical goal of embedding ACT on Alzheimer's work for continuance in other, more enduring organizations. Access the tools and curriculum at: <http://www.actonalz.org/improve-care>.

"It has been tremendously satisfying professionally to be transforming health care delivery here at Essentia [with the decision support tools] in such a crucial area for the population we serve."

Dr. Stephen Waring, (Co-chair, Detection and Quality Health Care Leadership Group)

To foster ongoing implementation of the tools in Minnesota, ACT is reaching out to and working with health organizations to hold a health system leadership summit in 2015 to share the tools and curriculum and explore potential for, and barriers to, adoption in Minnesota health systems.

Future Impact: *This work aims to foster adoption of optimal dementia care and support by: 1) embedding standardized provider tools into primary care, community based and care coordination processes; and 2) embedding dementia curriculum into professional education programs to ensure providers are prepared to detect, treat, and manage dementia.*

Funding: *This work was funded through HRSA grants directed to ACT on Alzheimer's from the University of Minnesota Geriatric Education Center (MAGEC).*

GOAL 3: SUSTAIN CAREGIVERS BY OFFERING INFORMATION, RESOURCES AND IN-PERSON SUPPORT.

ACT on Alzheimer's is advancing information and supports for caregivers of persons with dementia by:

- Providing the Minnesota Board on Aging with expert input into dementia-capability trainings for Area Agency on Aging staff in the Senior LinkAge Line® call centers
- Advising the Board on Aging on key elements for the website MinnesotaHelp.info®, with a focus on care navigation and in-person support for caregivers
- Developing an "After a Diagnosis" resource that coaches a caregiver, or a person in the early stages of Alzheimer's, through the care journey
- Developing provider practice tools that emphasize caregiver assessment and support as part of optimal dementia care
- Educating the business community about the relevance of Alzheimer's; namely, caregiver employees, customers with dementia, and employees experiencing cognitive impairment
- Building an economic case for offering in-person caregiver support to all dementia caregivers

Future Impact: *This work aims to ensure that caregiver support statewide includes dementia-specific components and that caregivers can access resources to navigate the care journey.*

Funding: *This work was funded by leveraging funds made available to the State of Minnesota through a federal System Integration grant.*

GOALS 4-5: RAISE AWARENESS AND REDUCE STIGMA BY EQUIPPING COMMUNITIES TO BE DEMENTIA FRIENDLY TO SUPPORT RESIDENTS TOUCHED BY ALZHEIMER'S DISEASE.

ACT on Alzheimer's continues to engage dementia-friendly communities, which are informed, safe and respectful of persons with Alzheimer's and related dementias and their families and provide supportive options that foster quality of life. As of July, 2014, 32 Action Communities are working in all regions of the state to become dementia friendly, including geographic-based, faith, and those with shared ethnic and cultural interests. Communities named in April (12) and July (13) can be found in announcements on the ACT website's [News page](#). Visit <http://www.actonalz.org/minnesota-communities> to learn more.

"Stillwater is a compassionate community with a history of coming together to help one another. Many community members have had personal experience with dementia, which underscores their commitment and brings a sense of urgency. Putting the two together – a community that cares and an issue that deeply touches so many – is electric."

Beth Wiggins, Team Lead
Stillwater Action Community

Shared goals that some Action Communities are undertaking include:

- Creating dementia-friendly businesses
- Training Dementia Friends and Champions
- Training health care providers on ACT tools
- Developing Rabbi training
- Training local emergency responders
- Creating memory cafés
- Increasing awareness through a community-wide read of *Still Alice*
- Training teens within the Jewish community
- Using trained, volunteer, community educators
- Planning to host a caregiver conference (May 2015)

ACT on Alzheimer's, in partnership with Minnesota's Area Agencies on Aging and the Alzheimer's Association Minnesota North Dakota, provides process support, sector-specific technical assistance and shared learning opportunities for communities. In partnering, growing and learning with the communities, ACT will explore whether the community toolkit could be configured as a national portal for communities to become dementia friendly (similar to the national dissemination of ACT curriculum).

"The Paynesville area has a talented group of people with a passion to make a difference for those with dementia and their caregivers."

Linda Musel, Team Lead
Paynesville Action Community

Future Impact: *This work aims to impact communities across Minnesota in setting and implementing goals that foster supportive environments for persons with Alzheimer's disease and their caregivers.*

Funding: *This work was funded through grants from Blue Plus (an HMO affiliate of Blue Cross and Blue Shield of Minnesota), the Medica Foundation and the Greater Twin Cities United Way.*

OVERARCHING GOAL: ADOPT HEALTH EQUITY FOCUS IN ACT ON ALZHEIMER'S.

To ensure that ACT on Alzheimer's is broad and inclusive in its reach, the work across all goals and participant groups is evolving to include a health disparity/health equity focus related to dementia care and beyond. The Health Equity Leadership Group has identified two principal work initiatives it will focus on through 2015. The first is to establish a health equity call to action for the overall collaborative and for ACT organizational participants that will help accelerate health equity in dementia care. The call to action will outline principles and values as well as steps organizations can take to foster health equity in dementia care. The second focus of work will be to embed a health equity lens into the provider practice tools, the website and the community toolkit.

EVALUATION, FUNDING, REACH, FUTURE

ACT on Alzheimer's is evaluating its work under a formative evaluation plan, which has been funded by the GHR Foundation and is being implemented by an independent evaluator.

In addition to four individual donors, ACT on Alzheimer's has received funding from the following organizations:

- Alzheimer's Association
- Aging Services of MN Foundation
- Bigelow Foundation
- Blue Cross Blue Shield of Minnesota
- Care Providers of Minnesota Foundation
- GHR Foundation
- Greater Twin Cities United Way
- Medica Foundation
- Pohlad Foundation
- St. Paul Foundation
- UCare
- University of Minnesota Geriatric Education Center (HRSA funds)

ACT on Alzheimer's work has reached other regions of the U.S. and Europe, including:

- Providing counsel to the other states, national coalitions and other countries to support their Alzheimer's plan efforts or initiatives
- Sharing ACT's work at the National Alzheimer's Project Act and showcasing ACT tools at other national and international forums

Post-2015 planning – With the conclusion of the formal ACT collaborative at year-end 2015, discussions for sustaining work beyond 2015 are underway. The goal is to embed the work of ACT on Alzheimer's in such a way that health and community providers have access to and support in using the provider practice tools; communities have self-sustaining support in developing dementia-friendly communities; and caregivers have access to effective and proven supports and resources throughout the state.

The ACT on Alzheimer's Steering Team will seek feedback and guidance on sustainability options they bring forth to the [Leadership Council](#) at a September 4, 2014 meeting.