



*Act on Alzheimer's®*  
**Evaluation Report (2013-2015)**  
*Executive Summary*

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## **Executive Summary**

*ACT on Alzheimer's*® is a voluntary, state-wide collaboration in Minnesota. It was launched in June 2011, building off of the work of the Alzheimer's Disease Working Group (ADWG) and their recommendations to the Minnesota State Legislature.

Five goals were set forth in 2011 for the *ACT on Alzheimer's*® initiative (formerly Prepare Minnesota for Alzheimer's 2020) to advance the dementia capability of the state. A Leadership Council and five Leadership Groups of voluntary members were organized to perform the work:

1. Increase detection of Alzheimer's disease and improve ongoing care and support.
2. Equip communities to be "dementia capable" to support residents who are touched by Alzheimer's disease.
3. Sustain caregivers by offering them information, resources and in-person support.
4. Raise awareness and reduce stigma by engaging communities.
5. Identify and invest in promising approaches that reduce costs and improve care.

The five Leadership Groups were: (1) Detection and Quality Health Care, (2) Preparing Communities, (3) Caregivers, (4) Awareness, and (5) Investing in Promising Approaches. Each Leadership Group had a defined purpose and focus, corresponding to the five stated goals. Implementation plans for the first 18 months of work (mid 2011-2013) set targets and activities. Thereafter, each group set additional plans based on progress they had made and the evolving interests of group members. A sixth group was added in 2014 (Health Equity).

Most of the groups worked through 2014. The group that is still active is the Detection and Quality Health Care Leadership Group (as of October, 2015). The Leadership Council will hold its' final meeting November, 2015. Plans for sustaining or transforming the initiative to its next stage are underway.

A modest formative evaluation provided opportunity to document progress and fold key learning back into the work. Four focus areas were chosen: (1) development and use of health care practice tools, (2) community engagement, (3) impact on caregivers, and (4) influence on policy.

By fall of 2015, progress had been made on the five stated goals. Given the organic and evolving nature of the initiative, working group activities responded to opportunities based on member interests and available funding throughout the 3+ years reviewed.

- *Detection & Quality Health Care* – Through the work of many experts and organizations, this working group created many tools and resources for use in the field (Minnesota and beyond) such as health care provider practice and decision-support tools, and educational curricula. Implementation of the health care tools and dementia curricula is growing in Minnesota and is a current area of focus for members who are interested in sustaining the effort around dissemination and implementation. Information from the early adopters of these practice tools offer insight into key factors that enable use in health care settings.

- *Communities* – These working group members fostered community engagement by organizations and individuals in more than 30 communities throughout Minnesota—far exceeding expectations. Through the work of individuals and organizations and with the assistance of a technical consultant, a *Dementia-Capable Community Toolkit* was created and piloted. Four steps for community engagement guide communities using this Toolkit: (1) Convene, (2) Assess, (3) Analyze, and (4) Act. From the four pilot communities who first tested the Toolkit, lessons and modifications were wrapped into the next stage effort. Grant funding and structured technical assistance allowed an additional 30 communities from areas throughout Minnesota to be supported.

All “ACTion” communities have been utilizing the Dementia Capability Toolkit and community engagement process. Hundreds of people and organizations working together across sectors (e.g., social service agencies, government, health care, housing, education, faith communities, employers/businesses) have been involved. Key catalysts have included: grant funding, one-on-one and group technical assistance and education, access to additional resources through the ACT website (e.g., videos, templates), and peer-to-peer learning. These key supports facilitated the work of the ACTion community coordinator and team members (largely volunteers) and guided each community to work through the required steps and make progress.

Some changes to the Toolkit are needed, based on consistent input from coordinators and others in the field. Recommendations about refinements to the Toolkit, particularly changes to the surveys, have been synthesized and are offered in this report. Further work is needed on how to maintain community engagement and evaluate/measure impact. Communities are looking for technical assistance, funding support, and guidance in these areas. Communities also want to make best use of their collective experience and are looking for ways to maintain or increase shared learning.

- *Caregivers* – Progress by this working group focused on assisting the State of Minnesota in its development of training and state data resources, as well as providing input into the other working groups. Progress toward ACT goals was made at the state level, including enhancements to the state web-based resources & information database ([www.minnesotahelp.info](http://www.minnesotahelp.info)) and caregiver consultant dementia training through the Minnesota Board on Aging and Area Agencies on Aging. The Caregiver Leadership Group provided extensive time, expertise, focused input, and information to support these state-led efforts. There is still work to be done to reach the capacity/access goals for all caregivers statewide to have access to care navigators, trained caregiver consultants, and dementia-specific resources. Caregivers who have been deeply involved in the ACT on Alzheimer's efforts within their respective communities have offered measures for evaluating impact that would be meaningful from their unique perspectives.
- *Awareness* – Working group members created a professional website ([www.actonalz.org](http://www.actonalz.org)) that now has hundreds of resources and tools to support work within Minnesota and across the nation. The website has been funded through philanthropic contributions and is a comprehensive repository capturing and presenting the work of the initiative as well as

organizing resources from other national and international sources—all in the framework of the five stated goals. The website is robust. It will need ongoing financial support to be maintained and updated. Suggestions for refinement with search functions and formatting to help with locating information have been recommended to the ACT staff.

- *State Policy Influence (Toward Goal of Investment in Promising Practices)* – Working group members created an economic model and utilized the model to conduct an analysis of one intervention showing potential cost savings to Minnesota to be achieved within 15 years. Authors published the findings in a credible industry journal (*Health Affairs*). The State has included this intervention as a covered service under the Title III-E Caregiver Services definitions. The State continues to sponsor training sessions for caregiver consultants to be certified to provide this evidence-based intervention. However, none of the Minnesota health plans have chosen to cover this intervention within their product lines of businesses. The State's own forecast determined that cost savings did not accrue in the timeframe necessary for being included in defined services covered under Medicaid.

In addition to this economic modeling, individuals from two state departments—the Minnesota Department of Health and the Minnesota Department of Human Services—participated in the work of ACT on Alzheimer's, offering expert advice and input in all of the ACT Leadership Groups. In addition, several MBA/DHS grants required use of the ACT on Alzheimer's tools, such as the CSSD/LiveWell at Home grant for Alzheimer's disease health care home demonstrations. Another noteworthy outcome is the 2015 legislative action by the Minnesota State Legislature authorizing \$750,000 in grant funding to select/fund Minnesota community collaborative proposals in order to support next-stage efforts. This builds off of the work of the ACT on Alzheimer's communities throughout the state. The focus is on health care detection, dementia care follow-up, linking caregivers to community support, increasing caregiver supports, and building awareness through educational and community engagement efforts.

Additional noteworthy activities and results, which *ACT on Alzheimer's* fostered and which furthered and extended progress toward ACT's stated goals, included:

- *Collective Action* - Extensive engagement of industry leaders and advocates throughout Minnesota far exceeded expectations. Engagement in all facets of the work included more than 600 individuals and 50 organizations—many devoting significant volunteer time and personal or organizational resources to working within this collective action structure where no one organization “owned the work.” The main involvement of these individuals through working groups has now been completed. The groups completed their product/tools development and disseminated these through the website, trainings, presentations, and the ACTion communities. There are plans to move this work from the original collaborative infrastructure to existing organizations, such as the AAAs and the Alzheimer's Association, as well as the state government agencies and provider-associated organizations.

At the writing of this report, the *ACT on Alzheimer's* initiative is evolving. Many individuals, including Leadership Group Chairs, have expressed interest in continuing this collective

action effort—to absorb what has been learned, launch structured efforts around implementation of tools statewide, and set up an implementation evaluation approach that moves toward measuring outcomes and impact.

- *Funding Infrastructure, Tool Development & Communities' Support* – One very important element, in addition to the volunteer human resources, was the financial support that was received from philanthropic organizations, advocacy organizations, federal grants, academic institutions, and health care systems/health plans. Over \$2 million was secured in 3 years. These dollars covered the costs of the ACT management team as well as specific activities that received targeted funding—usually to pay for expert consultant time (e.g., economist, clinical consultants, marketing/communications consultant, evaluation consultant, etc.) as well as cover printing and meeting costs, website development, video training production, and other marketing and dissemination efforts. A significant portion of this outside funding provided seed money via small grants to the 30+ ACT on Alzheimer's communities. Dollars were awarded based on a competitive review granting process that was managed by the ACT project director. Receipt of this level of outside funding was beyond expectations and allowed ACT participant members to develop professional-looking tools with sound content, utilizing industry and subject experts.
- *Health Equity* – In the course of the work, particularly around engaging communities, several ACT participant members identified a gap in the representation of diverse communities and individuals from various affinity groups (e.g., ethnic, language, religious, cultural, etc.). As a result, these members created an additional working group to develop the principles and framework for incorporating these perspectives. This was named the Health Equity Leadership Group. The group developed a “Call to Action” and agreed to work with the other leadership groups to incorporate the “health equity lens” into the tools and products of ACT. This has led to enhanced resources such as culturally-responsive screening tools for health care providers.
- *National Visibility & Influence* – The ACT initiative worked extensively to push content out beyond the state borders—helping to gain visibility. These efforts worked very well, as ACT achieved unanticipated national and international attention around the products developed through the working groups. As of October, 2015, attention from Health Resources Services Administration, Administration for Community Living, National Institute on Aging, National Quality Forum, and other federal agencies and national working groups or committees, has provided the opportunity for *ACT on Alzheimer's* to influence national efforts around health professions training, community engagement in addressing Alzheimer's disease, and measuring dementia capability. This includes national curriculum scheduled for release in 2016 by HRSA, and the NAPA Advisory Council plan to foster up to 15 dementia friendly communities. Using ACT on Alzheimer's as a model, a national replication called Dementia Friendly America Initiative (DFAi) has recently been launched. This went beyond the initial goal of influencing State of Minnesota practice and policy, but has provided additional support for the work done through the hundreds of individuals in Minnesota acting collectively around a common goal.

Evidence supports the conclusion that this has been a very successful statewide community engagement effort which exceeded expectations in terms of volunteer participation, creation of tools/resources, and dissemination of information and tools throughout the state, nationally and even internationally. The examination across nearly four years of effort suggests that important factors in this success included:

- The collective action approach and structure with an effective core management team of staff members (shared ownership; sufficient infrastructure; strategy for engagement)
- Clear purpose & defined goals for the initiative that were tied to foundational work conducted by experts and industry leaders (ADWG) two years prior to ACT. ACT's goals derived directly from recommendations of this group (buy-in; credibility)
- Strategically invited individual experts, opinion leaders, and organizational representatives across sectors (credibility; buy-in; peer influence; systems thinking, leveraging for change)
- Significant additional funding for specific work efforts (sufficient resources; technical expertise; visibility)
- A professional and robust communication approach for raising visibility, disseminating products, and keeping individuals informed. This included effective use of the media (radio, television, print, electronic forums), professional website development as the primary vehicle for dissemination and diffusion of the tools, and purposeful outreach to local, state, and national media as well as presentations at national conferences (strategy; visibility; shared learning)

The initiative is moving into a new phase within Minnesota. Individuals and organizations are determining next steps toward the goal of "making Minnesota the first state in the nation prepared for Alzheimer's" as set forth in the Alzheimer's Disease Working Group Report to the Minnesota Legislature in 2011. Some funding has been allocated to the AAAs and the Alzheimer's Association to assist communities and keep the website. State agencies and provider organizations will also continue to promote the goals in their respective settings.

Suggested next steps based on the evaluation findings are to:

- Absorb what has been learned in the field to make any necessary refinements to the tools and products and community engagement approach.
- Set forth a structured plan for assisting communities in their next phase efforts, with technical assistance and peer-to-peer learning.
- Moving from development to implementation, create a targeted implementation evaluation plan that identifies and defines consensus measures, methods, and concrete data sources to provide information that the volunteer members of this initiative, funders, policy makers and others can use to assess results.
- Keep the best of collective action so that individuals can work outside of their silos.