Act on Alzheimer’s®
Evaluation Report
(2013-2015)

Written by:
Deborah Paone, DrPH, MHSA
Paone & Associates, LLC
Minneapolis, MN

October 31, 2015
Acknowledgements

Thanks to the great team of ACT directors and project leads: Olivia Mastry, Michelle Barclay, Emily Farah-Miller, and Mary Ek, and to the many who stepped forward to create, foster, disseminate, and guide the work: the Leadership Group/Council chairs and members, ACTion Community Coordinators and team members, Area Agency on Aging staff contacts, Alzheimer’s Association educators, State of Minnesota Department of Human Services and Department of Health staff, all the organizational representatives and individuals from community sectors, and finally, the caregivers and persons with Alzheimer’s disease. Thanks to the funders who contributed over $2 million to the ACT initiative, and especially to the GHR Foundation that funded this evaluation.

About the Author

Deborah Paone, DrPH, MHSA, is principal and owner of Paone & Associates, LLC, a company she founded in 2002. Dr. Paone has worked and consulted in the health care field and in aging services for over 20 years—with clinics, hospitals, community-based settings, housing providers, health plans, research institutions and government agencies. She was the principal consultant for a five-year implementation study and cost analysis of an evidence-based Alzheimer’s caregiver intervention for the State of Minnesota. She conducted a study of factors associated with successful implementation and sustainability of an evidence-based program as part of her doctoral dissertation. She served as Executive Director of a community-based aging and caregiver services organization where she guided implementation of several evidence-based programs and worked with community coalitions and partnerships. In that capacity, she co-led one of the ACT on Alzheimer’s ACTion communities (Edina).

Deborah holds a Doctor of Public Health from the Gillings School of Global Public Health, University of North Carolina-Chapel Hill, a Master of Health Services Administration from the University of Michigan, and a Bachelor of Arts in Gerontological Issues in Community Health from the University of Rochester, NY.

She can be reached through www.paoneandassociates.com.
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) 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) 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 boarders—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.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page #</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Acknowledgements, About the Author</td>
<td>1</td>
</tr>
<tr>
<td>II. Executive Summary</td>
<td>2</td>
</tr>
<tr>
<td>III. Background on <em>ACT on Alzheimer’s®</em></td>
<td>10</td>
</tr>
<tr>
<td>a. Introduction</td>
<td>10</td>
</tr>
<tr>
<td>b. Goals</td>
<td>10</td>
</tr>
<tr>
<td>c. Structure</td>
<td>11</td>
</tr>
<tr>
<td>d. Success Measures</td>
<td>12</td>
</tr>
<tr>
<td>IV. Evaluation</td>
<td>15</td>
</tr>
<tr>
<td>a. Introduction</td>
<td>15</td>
</tr>
<tr>
<td>b. Key Focus Areas</td>
<td>15</td>
</tr>
<tr>
<td>c. Methods &amp; Data Sources</td>
<td>16</td>
</tr>
<tr>
<td>d. Literature Review, Framework &amp; Logic Models</td>
<td>17</td>
</tr>
<tr>
<td>V. Evaluation Focus Area: Health Care Tools</td>
<td>20</td>
</tr>
<tr>
<td>a. Literature Review &amp; Logic Model</td>
<td>20</td>
</tr>
<tr>
<td>b. Detection &amp; Quality Health Care Tools Development</td>
<td>22</td>
</tr>
<tr>
<td>c. Dissemination &amp; Implementation</td>
<td>23</td>
</tr>
<tr>
<td>d. Case Example</td>
<td>25</td>
</tr>
<tr>
<td>VI. Evaluation Focus Area: ACTion Communities &amp; Building Awareness</td>
<td>28</td>
</tr>
<tr>
<td>a. Literature Review &amp; Logic Model</td>
<td>28</td>
</tr>
<tr>
<td>b. Communities Leadership Group Work</td>
<td>31</td>
</tr>
<tr>
<td>c. Toolkit</td>
<td>33</td>
</tr>
<tr>
<td>i. Design</td>
<td>33</td>
</tr>
<tr>
<td>ii. Assessment/Surveys</td>
<td>34</td>
</tr>
<tr>
<td>iii. Testing</td>
<td>35</td>
</tr>
<tr>
<td>iv. Lessons Learned</td>
<td>36</td>
</tr>
<tr>
<td>d. Dissemination &amp; Implementation</td>
<td>38</td>
</tr>
<tr>
<td>e. Highlights from Selected Communities</td>
<td>40</td>
</tr>
<tr>
<td>f. Support &amp; Technical Assistance</td>
<td>50</td>
</tr>
<tr>
<td>a. Regional, “Hands-on”</td>
<td>50</td>
</tr>
<tr>
<td>b. Learning Collaborative Peer Group Meetings</td>
<td>53</td>
</tr>
<tr>
<td>c. ACT Project Director Support</td>
<td>55</td>
</tr>
<tr>
<td>g. Measuring Components &amp; Results</td>
<td>56</td>
</tr>
<tr>
<td>a. Evaluating the Community Team Itself</td>
<td>56</td>
</tr>
<tr>
<td>b. Examining Community Assessments, Priorities &amp; Action Steps</td>
<td>58</td>
</tr>
<tr>
<td>c. Coordinators’ Perspectives</td>
<td>59</td>
</tr>
<tr>
<td>d. Examining Referrals to Alzheimer’s Association</td>
<td>61</td>
</tr>
<tr>
<td>h. Successes, Challenges &amp; Areas for Further Development</td>
<td>62</td>
</tr>
<tr>
<td>i. Key Success Factors</td>
<td>64</td>
</tr>
</tbody>
</table>
# Section Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page #</th>
</tr>
</thead>
<tbody>
<tr>
<td>VII. Evaluation Focus Area: Impact on Caregivers/Care Partners</td>
<td>66</td>
</tr>
<tr>
<td>a. Caregiver Leadership Group Work</td>
<td>66</td>
</tr>
<tr>
<td>b. ACTion Communities’ Efforts</td>
<td>67</td>
</tr>
<tr>
<td>c. Successes, Challenges &amp; Leadership Insights</td>
<td>67</td>
</tr>
<tr>
<td>d. Caregiver Focus Group Findings</td>
<td>68</td>
</tr>
<tr>
<td>e. Measuring Impact</td>
<td>70</td>
</tr>
<tr>
<td>VIII. Evaluation Focus Area: Advancing the Field</td>
<td>72</td>
</tr>
<tr>
<td>a. Models &amp; Policy Development</td>
<td>72</td>
</tr>
<tr>
<td>b. Dissemination/Communication</td>
<td>72</td>
</tr>
<tr>
<td>c. Leadership Insight</td>
<td>72</td>
</tr>
<tr>
<td>d. Influences – State</td>
<td>73</td>
</tr>
<tr>
<td>a. Minnesota Department of Health</td>
<td>73</td>
</tr>
<tr>
<td>b. Minnesota Department of Human Services</td>
<td>75</td>
</tr>
<tr>
<td>IX. Additional Accomplishments</td>
<td>80</td>
</tr>
<tr>
<td>a. Collective Action</td>
<td>80</td>
</tr>
<tr>
<td>b. Funding</td>
<td>81</td>
</tr>
<tr>
<td>c. Health Equity</td>
<td>82</td>
</tr>
<tr>
<td>d. Communication, Outreach, &amp; National Visibility/Influence</td>
<td>82</td>
</tr>
<tr>
<td>e. Outcome Indicators Revisited</td>
<td>86</td>
</tr>
<tr>
<td>f. Leadership Insights</td>
<td>88</td>
</tr>
<tr>
<td>X. Discussion</td>
<td>90</td>
</tr>
<tr>
<td>a. Collective Action Structure</td>
<td>90</td>
</tr>
<tr>
<td>b. Funding/Visibility</td>
<td>90</td>
</tr>
<tr>
<td>c. Action Communities</td>
<td>90</td>
</tr>
<tr>
<td>d. Health Care</td>
<td>91</td>
</tr>
<tr>
<td>e. Policy Influence</td>
<td>92</td>
</tr>
<tr>
<td>f. Top Accomplishments</td>
<td>92</td>
</tr>
<tr>
<td>g. Next Stage Efforts</td>
<td>93</td>
</tr>
<tr>
<td>h. Closing Thoughts</td>
<td>94</td>
</tr>
<tr>
<td>XI. Conclusion</td>
<td>96</td>
</tr>
<tr>
<td>XII. References</td>
<td>97</td>
</tr>
<tr>
<td>XIII. List of Evaluation Reports Produced</td>
<td>101</td>
</tr>
</tbody>
</table>
Figures

Figure 1. Goals of ACT on Alzheimer’s 11
Figure 2. Framework for ACT Evaluation 18
Figure 3. Logic Model for Adoption of ACT Practice Tools & Curricula 20
Figure 4. Logic Model on ACTion Communities 31
Figure 5. Key Elements of a Dementia-Capable Community 33
Figure 6. Priority Action Matrix 35
Figure 7. Map Depicting the ACTion Communities, 2014 39
Figure 8. Potential DFC Evaluation Framework, 2015 71
Figure 9. Potential Dementia Friendly America sites 83

Tables

Table 1. Suggested Outcome Indicators (2013) by Focus Area 14
Table 2. Toolkit Question Structure and Scale Response 34
Table 3. Dementia Champions training evaluations and suggestions 42
Table 4. Types of AAA Support 51
Table 5. Additional Resources Needed in Role 52
Table 6. Top Accomplishments – Coordinators & Team Leads of ACTion Communities 53
Table 7. Technical Assistance Resources 54
Table 8. What Would Do Differently 54
Table 9. What to Accomplish Next 54
Table 10. MN Health Care Home Learning Collaborative Sessions – Attendance 74
Table 11. Evaluation Data from MN Health Care Home Learning Collaboratives 74
Table 12 – Progress at a Glance – ACT on Alzheimer’s Output – 2012-2015 84
Table 13. Outcome Indicators, by Focus Area – Revisited 86
Background on ACT on Alzheimer’s®

Introduction

ACT on Alzheimer’s® is a voluntary, state-wide collaboration 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.¹ These seven recommendations were:

1. Identify Alzheimer’s Early
2. Use the Health Care Home Model for Alzheimer’s Care
3. Achieve Quality and Competence in Dementia Care
4. Prepare Minnesota Communities and the Public
5. Train Medical Providers in Dementia Care
6. Pursue Cost-Saving Policies
7. Intensify Research and Surveillance

Many members of this ADWG voluntarily agreed to assist in this new initiative—first called “Prepare Minnesota for Alzheimer’s, 2020” (PMA2020). Additional experts and leaders from service sectors, industry groups, advocates, government and others were also invited to participate (June-December, 2011). The PMA 2020 (now ACT on Alzheimer’s) collaboration launched in June 2011 “seeking to transform the State’s medical and long term care systems and communities, to better support individuals with Alzheimer’s disease and their families.” The initiative is described as a collaboration of medical, academic, community, government, business and nonprofit stakeholders across Minnesota . . . organized under a unique collaborative structure that is intended to foster collective ownership and accountability for furthering the ACT on Alzheimer’s vision. No single organization owns, funds, or controls the initiative. Instead, the vision and goals are furthered through collective contributions of over 400 participants, including over 60 nonprofit, governmental and private sector organizations (See: www.actonalz.org).

Goals

ACT on Alzheimer’s set forth five goals in 2011 to address over five+ years. In 2014 it added the commitment to fostering a health equity perspective as the work continued. These goals were (see: http://www.actonalz.org/about-the-collaborative; Accessed September 1, 2015):

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


Paone & Associates, LLC
Structure

The governance structure of the initiative included a Management Steering Committee and a Leadership Council to provide overall direction, and help secure human and financial resources. The Leadership Council was to also provide guidance to 6 Leadership Groups, and to the team of “staff,” hired to shepherd the work. This included an executive lead, co-lead, project director, and project manager.

The initiative depended heavily on volunteer efforts of leaders and advocates from all types of organizations and groups, such as: senior housing organizations, community social service organizations, medical care and therapy services providers (e.g., health systems, hospitals, clinics, rehabilitation service providers, home care agencies), health plans, consumer advocacy and associations, trade industry groups, municipal, county, and state agencies and departments, health care quality measurement and quality improvement organizations, academic and other educational institutions, and others. It also depended upon the involvement of individuals affected by the disease and their caregivers/care partners. Individuals from all of these sectors made up the composition of the Leadership Groups.

Each Leadership Group had a defined purpose and focus, corresponding to the five stated goals for the initiative. Implementation plans for the first 18 months of work (mid 2011-2013) set
targets for work. Thereafter, each group set additional plans based on progress they had made and the evolving interests of group members.

The 6 Leadership Groups were:
- Detection and Quality Health Care
- Preparing Communities
- Caregivers
- Awareness
- Investing in Promising Approaches
- Cultural & Linguistic Communities Committee (added in 2012) – renamed the Health Equity Leadership Group (in 2014)

Each Group had a Chair or Co-chair and a defined membership, although others were invited to participate by current group members or through request to the Chair. The roster and contact information for each Leadership Group was maintained by the project manager for ACT on Alzheimer’s. She also prepared and disseminated the meeting agenda, minutes, and working documents as directed by the Chairs. When the Leadership Group completed a component of its work, information was included on the ACT on Alzheimer’s website (www.actonalz.org).

Success Measures

The five-year goals set in 2011 included “reach” measures for success. Each Leadership Group considered these measures as it planned and executed its’ work.

Goals and selected measures as they were outlined in 2011 are shown below (for more information on the long-range goals, see the companion document Evaluation Appendix & Instruments Repository):

1) **GOAL - Increase early identification of Alzheimer’s disease and improve ongoing treatment based on recommended care practices**

   Measures focused on influencing Minnesota certified health care homes to incorporate/address disease detection and elements of care coordination, and also measures for institutions and instructors to adopt learning modules and educational curriculum that addresses Alzheimer’s disease detection—used for training students in health care professions. Examples of these success measures included:
   a. By November, 2012, Minnesota Health Care Home learning collaborative curriculum incorporates dementia specific practices
   b. By June, 2013, health care homes that received messages regarding dementia and practice algorithm:
      i. 50% report increased awareness of need for screening and early diagnosis/intervention
      ii. 40% report that they are developing or have participated in training related to early screening and diagnosis

---

1. Source: *ACT on Alzheimer’s Cumulative Success Measures, 2011. See:*

*Paone & Associates, LLC*
iii. 30% have implemented the early screening and practice algorithm into their practices

   c. By December 2013, at least 2 Minnesota medical education programs, 10 continuing education programs in allied health professions, 2 Minnesota nursing school programs, and 10 caregiver education programs will have incorporated dementia-specific training into applicable curricula

2) GOAL - Equip and engage communities in supporting individuals with the disease and their caregivers

Measures focused on developing a community toolkit for creating “dementia capable communities,” then piloting the toolkit in 3 communities—with expansion to new communities throughout Minnesota. Examples of success measures include:

   a. By September, 2012, a prototype community tool kit offering a menu of community engagement focus areas will be developed and by October 2012 piloting in three communities will begin

   b. By December, 2013 the three pilot communities will have established community implementation plans related to dementia-specific community goals

3) GOAL - Sustain caregivers through access to and navigation of organized information about supportive services and resources

Measures focused on improving/enhancing the state-sponsored information and service provider repository (minnesotahelp.info) to include dementia resources, and provide more support to caregivers through dementia-capable navigators and care coaches. Examples of these success measures included:

   a. By September, 2013, the State-sponsored resource (minnesotahelp.info) will provide and maintain organized information and tools for individuals with dementia and their caregivers; a State-sponsored dementia capable navigator will support caregivers and those with dementia in locating appropriate resources

   b. By September, 2013, caregivers will have access to enhanced care coaching resources and by June, 2014, such access with be statewide.

4) GOAL - Raise awareness about and reduce stigma regarding Alzheimer’s disease and related dementias

Measures focused on developing statewide web-based resource that would include ready-to-use communication tools, messages, press kits, and other materials to assist communities, organizations and individuals as they held public forums, educational sessions, and conducted community engagement efforts. Examples of success measures included:

   a. By November, 2013, a public facing website will be available for a diversity of audiences and will incorporate and showcase the pilot and other new Action communities

   b. New Action Communities will be engaged as follows: 6 by September, 2013, an additional 6 by January 2014, and an additional 10 by January 2015

5) GOAL - Establish and garner stakeholder investment in promising interventions that are projected to bend the cost curve for Alzheimer’s and related dementias –
Measures focused on building an economic model that would project the direct and indirect cost of Alzheimer’s disease in Minnesota and would demonstrate the empirical cost savings or economic impact within Minnesota of implementing promising interventions. Examples of success measures included:

a. By June, 2013, an econometric model for Alzheimer’s disease and related dementias will project the total annual direct and indirect costs of the disease to Minnesota from present day to the year 2025

b. Model promising interventions and reflect their potential economic impact and communicate the results to various external stakeholder groups.

In addition, several “reach” longer-term outcome indicators were offered by the ACT leads/staff in 2013 as potentially able to be met by the end of 2015 for purposes of the evaluation:

### Table 1. Suggested Outcome Indicators (2013), by Focus Area, for ACT on Alzheimer’s

<table>
<thead>
<tr>
<th>Focus Area:</th>
<th>“Reach” Indicators for 2015:</th>
</tr>
</thead>
</table>
| **Health Care Practice Tools & Curriculum** | - 60% of organizations/individuals involved in the ACT initiative have used ACT tools  
- 20% of relevant organizations (e.g., health care providers, community based organizations) involved in ACT are adopting/embedding the tools and/or training  
- At least 25 certified health care home clinics have adopted the ACT provider practice tools  
- Of the clinics that adopted the tools, there is a demonstrable increase in the number and rate of persons identified with AD  
- At least one major institution has adopted the dementia curriculum |
| **Communities** | - New communities begin using the ACT Toolkit and experience a streamlined process/experience as compared to pilot communities  
- ACTion communities undertake at least one priority action step following community assessment  
- ACTion communities report increased knowledge/awareness of AD  
- Communities report an increase in the resources and services available to persons with AD or AD caregivers |
| **Caregivers** | - There is statewide dementia training for caregiver consultants  
- At least 50% of Senior Linkage Line call center staff have received basic dementia training  
- At least 25 community based organizations (with Caregiver Consultants) have been trained  
- Caregivers report that the statewide database is supportive of AD caregivers |
| **Investment in Promising Practice** | - At least one health plan is paying for the evidence-based practice that was modeled as having cost savings through the ACT economic model |

---

3 Source: GHR Foundation proposal, 2013.
Evaluation

Introduction

A private foundation\(^4\) funded a modest process/formative evaluation of this initiative to document progress toward the *ACT on Alzheimer’s* goals. A process/formative evaluation progresses along with the initiative. Typical uses area to: understand the nature of implementation within the context of its environment, document progress toward goals, detect unanticipated events, assist with interpretation of results, and recommend strategies for adaptation for the next phase of work.

The evaluation timeframe was from October 2013 – October 2015. This evaluation was designed around the ACT goals and was intended to assist ACT project leads to take stock of progress, capture lessons learned, and adjust their course of action, if needed. The evaluator was a participant in one of the five Leadership Groups (2011-2013) and maintained participation in the ACT Leadership Council. She also served as co-lead for one of the 34 ACTion communities. She was therefore familiar with the initiative’s structure, goals, and components and could serve as an embedded evaluator. This provided significant advantage in conducting the examination and interpreting the results. A summary table of all of the reports produced as part of this evaluation is at the end of this report. The full reports can be found on the *ACT on Alzheimer’s* website at [http://www.actonalz.org/evaluation%20reports](http://www.actonalz.org/evaluation%20reports).

Key Focus Areas

Four key focus areas for the evaluation were chosen by the ACT leads as follows:

- Detection and health care provider practice tools – development, dissemination, adoption
- Communities –community engagement toolkit and process development dissemination, implement priority actions
- Caregivers –work to reduce stigma and enhance caregiver resources, assistance
- Influence/Promising Practice – influence of ACT on investing in promising practices and on state policy

Goals and suggested indicators for progress in these four focus areas had been set for this evaluation as described. However, upon researching the availability of data for assessing progress toward these indicator goals, the evaluator determined that several of these indicators (e.g., health care home and clinic adoption and use of tools, rate of AD detection, caregiver satisfaction with statewide database) required baseline as well as ongoing data collection that is either not being done or is not publicly available.

While some of these indicators could not be measured with quantitative data, this evaluation presents qualitative evidence to determine progress toward goals.

It is important to note that some activities, (such as dementia screening, dementia training for staff, community-level caregiver support services development) are conducted using other (non-

\(^4\) GHR Foundation

*Paone & Associates, LLC*
ACT) materials and resources. Therefore, the issue of attribution to the ACT on Alzheimer’s effort is relevant—and cannot be ascertained with the information available. Given the data/information issues, this evaluation focused on capturing progress and learning from specific ACT on Alzheimer’s activities that could be tracked and documented. Detail is provided throughout this report—with information about what was searched, data that was available, and what was observed. The results described are associated with ACT and rest on the foundational work of the ADWG that launched the ACT initiative. This includes:

- **Practice tools** - what practice tools were created; how they were disseminated, and the early adoption or implementation by organizations or individuals (convenience sample)
- **Community engagement** – creation of a toolkit and guided process for community engagement, growth in # of communities engaged and their experience with the scripted process (convene, assess, analyze, and act); what these ACTion communities chose to do and what results were observed, lessons learned, and recommendations
- **Caregivers** - how caregivers were involved, what these caregivers did within the initiative, how a sample of caregivers perceived short-term results and longer-term desired impact, and what state activities occurred around building caregiver information supports/training
- **ACT Influence** - on state and national efforts around Alzheimer’s disease and building “dementia capability”
- **Collective action** – how the effort was organized, volunteer stakeholder engagement, leadership perspectives of those involved in the ACT collective action work, accomplishments and key outputs, and observed results

**Methods & Data Sources**

Researchers have set forth methods for evaluating community coalitions based on their work in various fields, particularly health care and public health (Butterfoss and Francisco, 2004). Process measures they offer include:

- Number of members and volunteers recruited
- Quality of planning and products
- Financial resources generated
- Ratings of the importance of the coalition’s objectives by members of the coalition

Output or interim outcome measures include:

- Community actions taken
- Services provided
- Ratings of satisfaction with the coalition process

Methods for evaluating coalitions include:

- Observational methods; participating in the work
- Event logs and data tracking of specific outputs
- Member surveys and key informant interviews
- Meeting materials, reports, survey data of the coalition

This evaluation has utilized these kinds of measures and methods to document activities and determine progress. We tapped into several data sources to measure progress around the four
key focus areas. Methods were largely qualitative, although some quantitative data were available. Data collection and sources are enumerated:

- **Primary data collection through:**
  - Structured key informant interviews - with key participants, organizational leads, community coordinators – usually via telephone interview using scripted protocol and occasionally in-person/on-site
  - Electronic surveys – designed by evaluator based on purpose and focus of inquiry, for specific informants/participants (e.g., Area Agency on Aging key contacts providing technical assistance; specific ACTion community regarding group cohesion)
  - Focus Group – with caregivers to capture in-depth insights
  - Structured conversations with project leads and managers
  - In-person observation – e.g., through onsite participation in ACTion community meetings and through attendance in meetings (e.g., Leadership Council, Leadership Group Meetings, Learning Collaborative Meetings, Health Summit Meeting)

- **Secondary data review and analysis of:**
  - Evaluation/survey results, e.g., around Dementia Friends/Champions training
  - Meeting minutes and materials – particularly from Leadership Groups and Council, and from ACTion communities (selected)
  - Selected ACTion communities’ survey data results and narrative comments
    - Information participant organizations, e.g., from MDH on attendance at Health Care Home Learning Collaboratives where ACT information was presented
  - ACT website

**Literature Review, Framework & Logic Models**

The evaluation approach began with a brief review of the literature on community coalition-building and on dissemination and implementation (D&I) of innovations. This provided guidance on development of a framework and clarified evaluator assumptions around what helps coalitions to make progress in collective action, and on what advances implementation of innovations or best practices—particularly in the field of public health, health care, social services, and education. A brief overview of this literature is offered here.

Community coalitions are described as “alliances among different sectors, organizations or constituencies for a common purpose” (Francisco, Paine, and Fawcett, 1993, p. 403). Researchers with extensive experience studying coalitions in community and public health, health promotion, and health care, have demonstrated that there are key characteristics related to effectiveness of community coalitions. These can be measured by member satisfaction, commitment to the coalition, and the quality of planning efforts. For example, a study of community coalitions showed that: *community leadership, shared decision-making, linkages with other organizations, and a positive organizational climate*, were key determinants of member satisfaction and participation (Butterfoss, Goodman and Wandersman, 1996).
Many studies have identified both internal and external factors that support adoption and implementation of community or organizationally-focused innovations. External factors (for example, reimbursement and payment parameters, federal or state policies, community characteristics) influence the scope of what organizations can do (Durlak & DuPre, 2008; Klein & Knight, 2005; Meyers, Durlak, & Wandersman, 2012; Miller & Shinn, 2005). At the same time, internal factors (for example organizational culture, staff capability, administrative supports) heavily influence successful implementation of programs (Fixsen, Blase, Naoom, and Wallace, 2009; Fixsen et al, 2005; Brownson, Colditz & Proctor, 2012; Goodman, 2000; Aarons et al, 2012). In studies of implementation success of evidence-based programs, factors such as program-to-organization fit, mission alignment, presence of a strong organizational champion or leader, strong technical support, and continuity of stable funding, have been shown to be important (Paone, 2015; Kaczorowski et al., 2011; Ory et al., 2010; Aarons et al., 2009; Greenhalgh et al., 2004).

One early task in this evaluation for ACT on Alzheimer’s was to develop a framework for evaluating the four specific focus areas within the initiative. To do this, the evaluator considered this literature review and her involvement as an active participant in the leadership group work from 2011-2013 and as a member of the Leadership Council (2011-2015). An important starting point assumption made was that the work of ACT on Alzheimer’s would be grass-roots, evolving, and organic. ACT on Alzheimer’s work group efforts would be happening as other efforts occurred within the state that were also focused on improving support to people with Alzheimer’s disease and caregivers. In addition, there would be environmental factors and community characteristics that could enhance readiness or impede progress. Finally, the provision of technical and other support would be important to the progress, adoption and implementation. The evaluator adapted a theoretical framework offered by Durlak and DuPre to offer a depiction of this concept (Figure 2).

---

**Figure 2. Framework for ACT Evaluation**
Adapted from Durlak, J.A. and DuPre, E.P. (2008)
The graphic places the *ACT on Alzheimer’s* initiative within a context/larger environment. The larger environment and community as well as organizational characteristics were expected to influence the communities’, organizations’, and providers’ level and rate of adoption and progress around the 5 stated goals. Within each organization or community that would be participating, readiness factors, delivery system capacity, technical support/training, and the “fit” of the work/tools with the community/organization would impact adoption and implementation.

These same assumptions were also weaved into two logic models. A logic model helps to portray initial assumptions and expectations. The first logic model pertained to the *ACT Practice Tool & Curriculum Adoption* and the second logic model focused on the *ACTion Communities*. These logic models are discussed and presented in the next two sections of this report.
Evaluation Focus Area: Health Care Tools

Initial long-term goals and anticipated impact of ACT on Alzheimer’s and specifically the work of the Detection and Quality Health Care Leadership Group were set forth in 2011:

- increase the rate of cognitive screening,
- recognize cognitive impairment as an organizing principle of care,
- ensure patients with AD receive coordinated care through Health Care Homes,
- enhance palliative and end-of-life care for persons with AD,
- build dementia training so that dementia care management competencies are taught, and
- include best practice standards of care are included in medical training for physicians

(Source: PMA 2020 Charter)

Literature Review & Logic Model

The evaluation examined the development of the ACT health care practice tools and curriculum and the adoption and implementation of these tools and resources. Adoption would be considered an indicator of progress toward the goal of improved detection and quality health care. The evaluator created a logic model for this component in late 2013. This particular logic model depicts expected contextual factors, inputs, implementation activities, and short/long-term outputs or outcomes for adoption and implementation of the ACT health care practice tools and the dementia curriculum (Figure 3).

![Logic Model](image-url)

Figure 3. Logic Model for Adoption of ACT Practice Tools and Curricula – Revised January, 2014
Pertaining to context and the environment in which the practice tool would be implemented, the evaluator hypothesized the following key factors:

- Issue importance (the issue of detection and care for persons with dementia—perceived importance within the organization or setting)
- Identified need for the tool, new practice, training
- Evidence-based foundation for the tool and/or state-of-the-art nature of the tool
- Right climate and timing for adoption/implementation
- Organizational and clinical leadership support
- Internal champion(s) to drive adoption and promote the value

Regarding the activities around implementation, the evaluator assumed that there would be a specific work plan and “launch” process developed for promoting effective adoption, teaching others how to use the tool(s), tracking progress, getting feedback, analyzing the pilot test, and re-adjusting the approach.

Forecasting the early outputs of the implementation, the evaluator identified a few possible markers, such as:

- The tool/curriculum/resource is successfully integrated into the processes of the organization (e.g., is written into the electronic record, added to the protocol, part of the required training, incorporated into the educational modules, etc.);
- A set of individuals, such as physicians, students, staff, etc. experience use of the tool or curriculum and early response is positive;
- Post-use data analysis shows a benefit to using the tool or resource, as compared to a baseline before use.

Looking further out, the logic model identified short-term outcomes, such as: greater staff awareness of the issue of dementia and need for detection and follow-up; increase in the number of individuals being diagnosed; evidence that students are better prepared (e.g., through testing). Finally, the long-term impacts that are the key goals of ACT on Alzheimer’s included: reducing stigma of the disease, raising awareness, improving care, increasing the ability of clinical and professional staff to respond to needs of patients, and the increase in the coordination of help to the individual with dementia and his/her care partner.

The logic model was based on the research and practice literature from health care, public health, and other fields, where the adoption or implementation of a proven innovation or practice improvement has been studied. There is a growing body of research on the art and science of implementation and dissemination—and much of it points to challenges, including the amount of time and effort required to successful implement and embed innovations—even when value is clearly demonstrated.

However, there is also research around what enables successful implementation. For example, four key support components have been shown to aid in the implementation of innovations: tools, training, technical assistance, and quality improvement support. Evidence suggests that these four key components need to be integrated to maximize value (Wandersman, Chien, and Katz, 2012). As part of their examination around innovations and implementation effectiveness,
Wandersman and colleagues specifically focused on the development of tools. They describe common pitfalls in such development which can adversely affect adoption/implementation. Wandersman and colleagues argue for a tool development process that is both evidence-based and user-centered. Even when fully implemented, keeping a tool useful may require routine updates that are based on evidence of utility and feedback from users (Wandersman, Chien, and Katz, 2012).

Studies specifically focusing on physician practice change in primary care can offer additional insight into what influences adoption and implementation of practice improvements. For example, a recent study of the implementation of a systematized “Screening, Brief Intervention, Referral to Treatment” (SBIRT) process in six primary care clinics found that key facilitators of implementation were buy-in from physician and clinic leadership, and seamless integration of the process in the electronic medical record (Muench, et al., 2015).

Utilizing electronic decision support systems has been shown to be an effective approach within the primary care setting to foster integrated dementia care. A study in Germany of a computerized Intervention-Management-System (IMS) to facilitate dementia care management showed additional identification of unmet needs of the person with dementia (PWD) and family caregiver, as well as an increase in specific recommendations for patient management by the general practitioner. The users in this pilot evaluated the system as “very helpful” and wanted to utilize a revised version of the IMS in their practices in the future (Eichler, et al, 2014).

There is also evidence underscoring the difficulty in transforming the approach from diagnosis to end-of-life care in health care and social support systems, as in the United Kingdom. For example, a mixed methods study in the U.K. examined the results of a large-scale effort to educate health care professionals and enhance interdisciplinary collaboration in dementia care from diagnosis to end-of-life. The study found that the intervention/efforts did not greatly alter general practice care management, even when incentives, policy pressure, and consumer demand favored the changes (Iliffe et al., 2015).

Detection & Quality Health Care Tools Development

A key message and principle of ACT on Alzheimer’s is that early detection and diagnosis of Alzheimer’s disease is critical for improving the physical and emotional impact of the disease and reducing the financial impacts. The ACT on Alzheimer’s website notes that “unfortunately, medical providers do not routinely assess the cognitive health of their patients, leading to delayed Alzheimer’s diagnosis and post diagnostic care. Currently, less than 35 percent of people with Alzheimer’s disease and related dementias have the diagnosis documented in their medical record” (See http://www.actonalz.org/importance-of-early-detection).

Through the largely voluntary work of more than 40 individuals involved in the ACT on Alzheimer’s “Detection and Quality Health Care Leadership Group,” a set of best practice tools and resources, as well as curriculum for educators, were developed and revised in an iterative fashion, utilizing the expertise of clinicians, researchers, and other dementia experts—between September 2011 and June, 2015. This tool development built upon work of previous efforts, such...
as through Minnesota Board on Aging and the Alzheimer’s Disease Working Group. The iterative process allowed for valuable input and feedback from potential users, as well as initial trial in a few sites through periodic use or on a case-by-case basis.

A review of meeting agendas, minutes and materials from 2011 to 2015 showed the diversity of group membership as well as clinical and researcher expertise that was consistently utilized throughout the development of these tools. Key supports in addition to the volunteer efforts of group members included funding to cover costs of editing, printing, and production of the tools and some expert consultation funding. This funding was provided through federal or state grants⁵ (see: [http://www.actonalz.org/provider-practice-tools](http://www.actonalz.org/provider-practice-tools), [http://collectiveactionlab.com/content/meeting-agendas-andsummaries-o](http://collectiveactionlab.com/content/meeting-agendas-andsummaries-o), [http://www.actonalz.org/sites/default/files/documents/ACT-PracticeToolsResources.pdf](http://www.actonalz.org/sites/default/files/documents/ACT-PracticeToolsResources.pdf), [http://www.actonalz.org/dementia-education](http://www.actonalz.org/dementia-education)).

These ACT-created tools included:
- After a Diagnosis (Rev. 12/01/14)
- Clinical Provider Practice Tool (Rev. 02/18/15) and training videos and webinars
- Care Coordination Practice Tool (Rev. 02/18/15) and training videos
- Community Based Service Provider Practice Tool (Rev. 02/18/15)
- Dementia Curriculum (10 Modules – text and slides)
- Dementia Trainings for Direct Staff (Rev. 06/08/15)
- Electronic Medical Record (EMR) Decision Support Tool, including the EMR Decision Support Tools Template (Rev. 02/16/15) and a Guide to Implementation 01/2014)
- Managing Dementia Across the Continuum Practice Tool (Rev. 06/10/14)

Dissemination & Implementation

To support providers and their organizations to implement suggested methods consistently and with ease, the ACT on Alzheimer’s practice tools and resources have been available without charge, downloadable from the ACT website. There are training videos that show how to conduct screening, deliver a dementia diagnosis, and conduct follow-up care coordination to assist persons with dementia and their caregivers. These videos and webinars are easily accessible. In addition, clinician experts are available to provide in-person training for other clinicians and healthcare professionals, at a modest cost (see: [http://www.actonalz.org/sites/default/files/documents/ACT-DementiaTraining.pdf](http://www.actonalz.org/sites/default/files/documents/ACT-DementiaTraining.pdf)).

In addition, ACT provided training through the Health Care Home Learning Collaborative sessions sponsored by the Minnesota Department of Health, in 2013-2014. ACT also secured funding to support the development and provision of peer-to-peer training sessions in 2014-2015.

⁵ For example, the development of the ACT Dementia Curriculum was supported by funds from the Bureau of Health Professions (BHP), Health Services Research Administration (HRSA), Department of Human Services (DHHS) under a grant to the Minnesota Area Geriatric Education Center (MAGEC), Grant #UB4HP19196, Director Robert L. Kane.
There were 27 presentations and on-site trainings conducted from October 2014 – October 2015 in Minnesota health care, social services, long-term care, and housing providers—held at organizational settings or at state or regional conferences. This included 9 peer-to-peer trainings, reaching 195 individuals practicing in clinics designated as health care homes. In all the ACT staff were able to track a total of 1,367 participants that were exposed to presentations or trainings conducted by ACT on Alzheimer’s. For some of these sessions, a follow-up evaluation survey was distributed to participants.

Examining this evaluation data, a total of 254 responses from 418 participants were received (61%). These responses showed that 34% of participants worked in primary care settings. Other characteristics tracked showed that 31% worked in medically underserved communities and 44% worked in rural areas. Forty-three percent of participants were physicians/nurse practitioners, 19% were registered nurses, and 25% were social workers. Ninety-eight percent of respondents indicated that they had learned something new (strongly agree or agree), and most were more confident about their skills. The most frequently mentioned action that individuals planned to incorporate into their practice in the next 3 to 6 months were: to utilize the screening tools, and make referrals (source: session evaluation data provided by ACT staff).

Between February and May, 2014, the evaluator conducted a survey of all individuals who were actively involved in the work of ACT on Alzheimer’s (N=92). The survey asked participants—assumed to be “early adopters” given their involvement in the development of the tools—to report on how they were utilizing the tools and resources generated by ACT. The most frequently used resources at that time were the Dementia Capable Communities Toolkit, the “After a Diagnosis” brochure, and the Care Coordination Tool (Paone, Survey of Participants as Early Adopters, 2014).

Telephone interviews of the ACT Leadership Group chairs were conducted (October-December 2014) – each key informant (Chair) had been involved in the work for 3 or more years. Responses from these leaders about the ACT tools and resources indicated strong support and sense of accomplishment around the development and pilot testing of these tools. It was considered a very important output of the effort. One leader’s offered the following:

*We had a very busy productive group. The 7 provider and other practice tools that were created and vetted included the provider practice tool, EMR decision support tool, implementation guide for health systems, mid-to late stage tool, Tool for caregivers, Community organizations, Tool for patients and families. We developed training to more widely disseminate to physicians and social workers; also 3 minute videos on 3 different screening instruments – all with real patients (Mini-Cog; SLUMS, MoCA)—and videos on how to deliver a dementia diagnosis, how to do care consultation from a social worker point of view. Those can stand alone. Providers, like anyone, like to see something being done it makes it more real.*

Leaders noted that during the next phase of the ACT on Alzheimer’s initiative efforts would need to focus on adoption of these tools—learning effective methods for adopting, implementing, and sustaining dementia practice tools in health care settings, as well as sustaining the work of the ACTion communities (Paone, Leadership Groups Chairs’ Perspectives, 2015).
We learned that it is a lot easier/faster to create a best practice tool then to implement it. Also there is a challenge with depth of implementation. There are 85 quality measures that doctors are rated on...e.g., Diabetes – on patient management – that come into play. Dementia wasn’t on this list – clinicians didn’t want to add one more measure. So we talked about dementia as a hidden barrier to patient compliance to any ongoing treatment. Showed base rates – on how common this is as a secondary condition. That was the message that resonated. This is because it directly impacted their practice. The other thing they said: This is great, but if we detect this condition, then what? Need tools for follow-up and help.

I would say on the practice tools, to have the number of health systems that are using them would be a good measure of progress. It would be good to have each health system or provider have a base rate of # of people diagnosed—and compare before the implementation of the practice tools to after the use--to see if the # of people diagnosed increases. So measures would be the # of clinicians and # of clinics using the tools. Regarding the Health Care Homes (HCH), the state can’t mandate the use of these tools, but they could have mandatory reporting on some metrics—getting dementia indicators on that list, such as the # diagnosed with memory loss, the # of cognitive screens done or the percentage of patients with cognitive screens. There is one related to caregivers, and that is a start.

A survey of the members of the Detection and Quality Health Care Leadership Group was conducted in 2015 to determine (1) what providers need to identify, diagnose, and manage patients with dementia, and (2) what barriers they face. Eleven members (41%) submitted responses. Consistent with the literature, they indicated that they face numerous barriers, with top barriers being time and insufficient system support for patients across care settings. Barriers included:

- Insufficient time to screen, diagnose, or manage care of these patients
- Lack of knowledge or insufficient interest in this issue
- Discomfort with delivering this diagnosis
- Lack of health care system supports
- The belief that nothing can be done
- Patient/family barriers (e.g., denial, resistance, lack of knowledge, lack of resources/support to deal with this issue

The key informant instruments used in these inquiries are found in the Evaluation Appendix & Instruments Repository which is a companion document to this report.

Case Example

One case example of adoption/implementation of these health care practice tools is offered by HealthPartners. HealthPartners is a large, consumer-governed nonprofit health care organization. It is an integrated health care system that provides health care services as well as health insurance. HealthPartners serves more than 1.5 million medical and dental health plan

Paone & Associates, LLC
members. It includes a multispecialty group practice of more than 1,700 employed physicians and a regional network of more than 148,000 doctors and other care providers in Minnesota, western Wisconsin, South and North Dakota. The network of organizations within the HealthPartners family includes: 50+ primary care clinics, 7 hospitals, 22 urgent care centers, 26 pharmacies, an orthopedic center, transitional care center, and other clinics and centers in specialty areas, such as neck & back, eating disorders, memory and aging, and others. The organization also has an Institute for Education and Research (See: www.healthpartners.com/public/about).

The HealthPartners Center for Memory & Aging provides diagnostic services, treatment, counseling, and supportive care to individuals with memory and cognitive disorders. The most common dementia that the Center sees in patients is from Alzheimer’s disease, although practitioners specialize in atypical and less common forms of dementia as well (e.g., Lewy Body dementia, frontotemporal dementia, etc.). The Center uses an approach that combines care providers and research professionals, to allow patients the opportunity to participate in breakthrough clinical trials (https://www.healthpartners.com/public/care/providers/cdac/). The team includes specialists from neurology, neuropsychology, geriatric psychiatry, pharmacy, nursing, and other specialty areas. The Center describes their process for a first and second visit so that the patient, and a family member or friend who accompanies the patient, is prepared (https://www.healthpartners.com/public/care/providers/cdac/visit).

Two clinicians from the HealthPartners Center for Memory & Aging were deeply involved in the ACT on Alzheimer’s health provider practice tools development (2011 to 2015). One member, Dr. Terry Barclay was co-chair of the Detection and Quality Health Care Leadership Group for ACT on Alzheimer’s.

In January, 2014, a brief description of the implementation efforts within HealthPartners to encourage use of the ACT Electronic Medical Record (EMR) Decision Support Tool noted the following characteristics and methods that contributed to success to date in adoption of the tools within HealthPartners:

- Implementation of the EMR tool was driven by a “bottom-up” approach, starting with a small group of champions from neurology with expertise in dementia;
- A pilot within the neurology department allowed for early feedback from physicians and leaders, to tailor the tool to the HealthPartners system;
- The EMR tool then was vetted with physician leadership within primary care and others within the larger healthcare organization to identify additional clinics that could pilot the tool;
- Internal buy-in required personal conversation and contact by the clinical champions
- A key component was having a research approach with outcome measures built into the implementation plan;
- Utilization data from the organization was used to show that patients with unrecognized cognitive impairment were much higher utilizers of cost emergency room and inpatient services.

The process of internal buy-in to launch additional clinic adoption had taken about 18 months.
Regarding challenges at this stage (January, 2014), the following were noted:

- Difficulty identifying who could help drive implementation;
- Incomplete buy-in from leadership regarding the proposed benefits of cognitive screening and related EMR guidelines for dementia care;
- Competing priorities in the organization – there were previously identified quality care initiatives for other conditions in primary care and elsewhere that had been vetted and approved;
- Diffusion of responsibility related to carrying out intended goals.

To update this case example, the evaluator conducted an in-person interview with Dr. Terry Barclay (Clinical Director, HealthPartners Neuropsychology/Neurosciences Division, Center for Memory and Aging, and Adjunct Associate Professor in the Department of Neurology at the University of Minnesota) in August, 2015. The interview questions were provided prior (the instrument used is found in the Evaluation Appendix & Instruments Repository which is a companion document to this report). Dr. Barclay briefly demonstrated the decision support tool within the electronic medical record after the interview was completed.

The key elements of progress at this point (18 months later) were:

- Tools embedded in the EMR - The implementation of nearly the entire set of ACT on Alzheimer’s provider practice tools within HealthPartners; incorporating these tools within HealthPartner’s electronic medical record as a set of clinical decision support tools available systemwide.
- Data analysis - The results from a retrospective review of HealthPartner member data for those recently screened and diagnosed with Alzheimer’s disease showed significantly higher utilization of the ER and other medical care services resulting in higher total costs of care compared to HP members matched based on specific criteria but who did not have the disease.
- Prospective pilot study - Launch of a prospective (real-time) pilot study collecting and analyzing HealthPartner member data related to the cost of care and care outcomes for individuals just diagnosed.
- Clinic engagement by more than 7 primary care clinics within HealthPartners to implement early detection and follow-up methods consistently within their practices.

A key success factor noted was getting the attention of senior leadership within HealthPartners, which was done through presenting the results from the retrospective data review and through engaging senior leaders to attend a 1-day Health Care Summit, organized by ACT on Alzheimer’s held in February, 2015 (see: [http://www.actonalz.org/sites/default/files/documents/ACT%20Health%20Leadership%20Summit.pdf](http://www.actonalz.org/sites/default/files/documents/ACT%20Health%20Leadership%20Summit.pdf)).

For the full report see: Paone, 2015 – Adoption/Implementation of ACT Tools Case Example: Health Partners, MN.
Evaluation Focus Area: ACTion Communities & Building Awareness

Literature Review & Logic Model

A literature review again informed the development of assumptions and a logic model by the evaluator to assess the ACT on Alzheimer’s “ACTion” communities.

The literature offers theories and frameworks for conceptualizing coalition development and community engagement that is relevant to this ACT on Alzheimer’s collective action approach. A key concept in the literature is to consider the phases or stages of coalition development that would promote active community involvement and engagement. “Conceptualizing coalition functioning in terms of stages of development may be particularly useful for evaluation in that a coalition’s functioning and factors important to its functioning may evolve through stages of development or readiness” (Granner and Sharpe, 2004, p.514).

Butterfoss and Francisco describe three levels of coalition development:

- Level 1 - Early stage of coalition development where the group creates an infrastructure, recruits members, conducts a needs assessment, sets up its processes and develops a plan
- Level 2 – Implementation stage where the coalition engages in tasks and action steps for which it was created
- Level 3 – Evaluation phase – where the coalition considers what has been accomplished and how action is yielding positive changes, e.g., in health, community benefit

A systematic literature review on the measures for coalition characteristics and functioning found 146 measures—the largest number of which pertained to individual and group characteristics, and the smallest number of measures which focused on coalition impact and outcomes. The review looked for evidence of tested, valid, and reliable measures (Granner & Sharpe, 2004).

Researchers warn that “coalition evaluation is fraught with barriers . . . is often not built into the planning process or [is] inadequately funded . . . does not always have the commitment of lead agency, staff, or members . . . or may not be based on a solid logic model” (Butterfoss & Francisco, 2004, p.111). Furthermore the issue of attribution (distinguishing between cause and effect and what outcome can be attributed to what coalition activity) is a real challenge.

Some ways to address these issues include (Katz et al., 2013):

- Using feedback loops from the field to modify and update logic models as experience grows related to contextual factors that impede or advance progress
- Incorporating proximal outcomes to data collection and modeling activities to recognize “small wins” and document meaningful progress
- Using formative evaluation methods that embeds the evaluation within the work and promotes ongoing feedback from the coalition members in a structured way
- Engaging key stakeholders in the evaluation to ensure commitment to the evaluation work
With this foundation, the evaluator anticipated three discernible phases that ACTion Communities would move through (hypothesized). These assumptions were shared with ACT staff leads. In addition, the evaluator developed a set of questions for communities to consider as they shaped their own evaluation approaches (see the Evaluation Appendix & Instruments Repository). Assumed phases for ACTion communities that could guide evaluation of and by the communities as they progressed were offered by the evaluator as follows:

1. **Initial Process Focus** – This roughly corresponds to the “convene, assess, and analyze” steps put forth in the ACT Toolkit. It includes the group process for prioritizing among potential activities and creating a written plan of action. An evaluation of communities at this phase would focus on documenting what was done, how the community used the ACT Toolkit, what technical assistance they needed, how their community team came together, what they found out was the community’s strengths or gaps, and the overall experience of the community team members as they moved through these steps.

2. **Implementation Focus** – From the action planning step, the community must move to implementation. The steps that the community coalition took in moving from planning to action would be the focus in this evaluation work. Possible indicators for progress in this phase would be that there was a specific written work plan with lead accountabilities that had been prepared and was being followed by the ACTion community. The community might be undergoing transitions in team membership and lead coordinator, as the priority action step might involve need for different expertise or stakeholder input. This could be a time where the group would perform a coalition self-assessment to identify group cohesion, areas of strength, and areas where more support or changes were needed. Another marker would be that the implementation plan had interim outcomes and measures articulated with data collection and reporting resources defined. The group would need to re-affirm its infrastructure, process, communication and evaluation methods.

3. **Proximal outcomes, Community changes/impact** - This final phase would move toward outcome evaluation. What did the coalition accomplish in the timeframe—what is observable and identified as community impact related to preparing the community to be dementia friendly? How can the team or the community tell they have been successful? At this stage, the coalition may have identified how certain community capacity had grown and how tools or competencies have been embedded. Institutionalizing dementia capability components, such as training, services, policy, environmental changes, public education, ongoing core funding, would be markers of progress and results. The community might also recognize where new relationships and shared work efforts across organizations were occurring. Sustaining the work or transitioning it to a new phase would be another focus area. It would be up to the community to come up with a community status measure or set of impact measures that were meaningful to them.
The evaluator hypothesized that a critical phase in the life of these ACTion communities would be as they transitioned from assessing, analyzing and prioritizing action steps—to actually taking action and implementing the plan. It seemed logical that, depending on the action steps and priority focus, there could be a need to re-form the team. For example, priority action around improving quality health care might call for a leader from the medical community. Priority action around preparing first responders might require fire/police or government leadership in the team. Thus, the ACTion team leadership and composition could be different from the composition of the group that first came together and that facilitated the assessment and analysis. Therefore, community-level technical support and guidance might need to focus on how to move the community coalition from planning to action, and how to re-form the composition and leadership of the community team with minimal disruption. Hopefully such a move or transition would serve to bring new energy and vitality to the community effort, as roles and individuals changed to accommodate the needs of the community effort. One component of a community-level evaluation could be focused on this phase—how the team/coalition moved successfully to the next phase of action and what enabled that to happen.

In creating a logic model for ACT on Alzheimer’s ACTion communities, the evaluator assumed that new ACTion communities would be invited to participate (from the original four pilot communities), and that these new communities would use the Dementia Capability Toolkit that had been developed in 2012, piloted, and revised in 2013. Each ACTion community would be comprised of individuals and organizations with interest in improving dementia capability in their geographic area or affinity community. The work by these grass-roots community coalitions or teams would help disseminate the tools and resources that had been developed or collected by ACT. The ACTion communities work would also build awareness statewide of the issue of Alzheimer’s disease/dementia and of caregivers. The logic model (Figure 4) portrays expected factors important in the implementation and progress of ACTion Communities.
Figure 4. Logic Model on ACTion Communities

This logic model depicts elements that were anticipated by the evaluator to be important in the environment in which the ACT on Alzheimer’s community engagement would be implemented. These include leadership and peer support, individual involvement, and availability of other resources. It also depicts expected activities that would be part of the implementation process, key outputs of the community ACTion team work, and short-term and long-term expected outcomes.

Communities Leadership Group Work

The ACT on Alzheimer’s “Preparing Communities” Leadership Group met from September, 2011 through December, 2013. Representation of this Leadership Group included individuals from several Area Agencies on Aging, aging and caregiver services providers, advocates, educational and academic institutional representatives, housing providers, caregivers, and trade or industry group representatives. In 2012, funding from Greater Twin Cities United Way provided seed money to contract with Stratis Health as the technical consultant (working with members of this Leadership Group) to create a Dementia Capable Communities Toolkit (first called “Toolkit for Developing Prepared Communities”). The purpose of the Toolkit would be to:

1) Increase awareness and engagement of Alzheimer’s disease and cognitive impairment among community influencers and all community residents;
2) Support communities in identifying and prioritizing community goals regarding Alzheimer’s disease and related dementias; and
3) Trigger community action in responding to needs arising from Alzheimer’s disease and related dementias.

Meeting summaries from this Leadership Group indicate that the group envisioned community “champions” who would be inspired by the vision and focus on preparing communities for Alzheimer’s disease, and would be invested in starting a conversation to bring key stakeholders together (See for example February 16, 2013 Meeting Summary found at: http://www.collectiveactionlab.com/content/meeting-agendas-and-summaries-1)

To begin, members examined the community engagement literature. Expertise was provided by the University of Minnesota’s Extension Center for Community Vitality (Dr. Scott Chazdon). The Community Readiness Model developed by the Tri-Ethnic Center for Prevention Research of Colorado State University particularly informed the approach (Edwards et al., 2000).

Theories and models of community engagement present stages of readiness and development. Specifically, the Tri-Ethnic Center Model outlines 6 key dimensions: (1) existing efforts, (2) community knowledge of efforts, (3) leadership, (4) community climate, (5) community knowledge of the issue, and (6) resources related to the issue (Edwards et al, 2000; Kelly et al., 2003). Chazdon presented to the Leadership Group in 2012 and discussed characteristics of communities that were ready for engagement (Chazdon, S. 2012; Chazdon and Lott, 2010). He also shared information about cross-sector collaboration—as an effective method for building support and linkages that strengthen the work and the community as a whole. For example, he offered this definition of “cross-sector collaboration” from the literature: “Linking and sharing of information, resources, activities, and capabilities of organizations in two or more sectors to achieve jointly an outcome that could not be achieved by organizations in one sector separately.” This was a key concept that the Preparing Communities Leadership Group absorbed and used in creating the Dementia Capable Community Toolkit and community engagement process.

Key elements of dementia capability were defined within the Toolkit, beginning with Awareness (see flowchart Figure 5).
Figure 5. Key elements of a dementia-capable community (Source: ACT on Alzheimer’s website: www.actonalz.org, Accessed April 15, 2015).

**Toolkit**

*Design* – The Toolkit was designed around a structured process for a community to assess its own dementia awareness and resources and determine priority areas for action. The format and resources would guide communities through these four steps:6

1. **Convene** key community leaders and members to understand Alzheimer’s disease and its implications for your community. Then, form an Action Team.
2. **Assess** current strengths and gaps in meeting the needs that result from the disease and related dementias, using a comprehensive community assessment tool.
3. **Analyze** your community needs and determine the issues stakeholders are motivated to act on; then set community goals.

---

4. **ACT Together** to establish implementation plans for your goals and identify ways to measure progress.

**Assessment/Surveys** - In the surveying or assessing phase, the ACTion community team members are to identify individuals and organizations within their community to conduct telephone or in-person interviews. The Toolkit has 13 different sector surveys (e.g., health care, social service agency, community member, employer/business, day care, transportation, etc.). In each survey, questions ask about the current level of activity on a specific issue or function or resource, and then ask the interviewee about his/her opinion whether than issue/function/resource should be a priority for action (Table 2.)

<table>
<thead>
<tr>
<th>Level of Current Activity</th>
<th>Priority for Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Strongly disagree</td>
<td>1. Strongly disagree</td>
</tr>
<tr>
<td>2. Disagree</td>
<td>2. Disagree</td>
</tr>
<tr>
<td>3. Neither agree or disagree</td>
<td>3. Neither agree or disagree</td>
</tr>
<tr>
<td>4. Agree</td>
<td>4. Agree</td>
</tr>
<tr>
<td>5. Strongly agree</td>
<td>5. Strongly agree</td>
</tr>
<tr>
<td>0. Do not know</td>
<td>0. Do not know</td>
</tr>
</tbody>
</table>

In the analysis phase, survey data are entered into a spreadsheet that then plots each response onto a matrix (Figure 6). The upper right quadrant becomes the focal point for team discussion and prioritization around action steps—the areas of low activity, but high priority.
Testing - In the beginning of the Toolkit development process (2011), the Preparing Communities Leadership Group members envisioned a Toolkit and process that was entirely self-directed. As they learned more about community engagement and piloted a beta version of the Toolkit, they realized that additional resources and technical assistance would be needed.

The executive lead had this to say about the Toolkit content, design, and materials:

When we started this we wanted to create a process that was completely self-directed, self-explanatory and didn't need technical assistance. We then wanted to pick communities that had some connections in Alzheimer’s disease and had a champion or a number of champions. We are learning that some guidance and technical assistance is needed to support communities along their journey.

The process and Toolkit were piloted by four communities in Minnesota in 2012 and 2013.\(^7\) Three of these communities were geographically defined, and one was an affinity community.

\(^7\) A description of the experience of those four pilot communities is found at:
They were: Jewish Community (Twin Cities metropolitan area), St. Louis Park (west metro), Walker (greater Minnesota), and Willmar (greater Minnesota).

Each of the pilot communities provided input into content for the Toolkit and subsequently provided feedback in iterative cycles as the Toolkit was refined. Each community was then asked to test it within their geographic area or affinity community.

While each community had distinct differences, they had the following in common:

- **Group Focus & Composition** - Pilot-testing community coalitions were formed out of an existing task force or working group within their community. That foundational or original group had previously been created with an identified interest in addressing Alzheimer’s disease or dementia in some way. While this group composition and cohesion helped jump-start the pilot work around using the ACT Dementia Capable Communities Toolkit, the previous group focus and composition may not have fully aligned with this new effort. Notably, the communities’ need for education around dementia had been a primary driving force for creation of the existing task force or group. Respondents said that their task force or group had already had several years of experience with offering educational and awareness-building sessions/events to their respective communities.

- **Coordinator and Group Strengths** - Each community had a coordinator as well as several active lead members who facilitated the work of the whole group or taking a lead in one part of the process (with additional group members and other volunteers participating). The work was conducted as a voluntary effort—while there were individuals employed by various organizations, almost all of the effort occurred outside their normal job duties.

- **Time Commitment** - The Toolkit development represented a large component of the total work effort by these four pilot community coalitions during the timeframe examined (2012–early 2013). The time commitment was significant.

- **Statewide Momentum** – Being part of a statewide initiative helped bring energy and momentum to the effort of helping to design and pilot the Toolkit. Community team members felt that they were creating something unique and innovative to enhance the goal of dementia capability not only for their given community but for the whole state.

- **Pilot Design Challenges** – Overlapping the development of the Toolkit, while simultaneously using it in the community was difficult to manage. There were changes to survey language and assessment process while these assessments were going on.

*Lessons Learned* – One significant result of the pilot testing was the lessons learned by the communities. These lessons were gathered through key informant interviews conducted by the evaluator with each community team coordinator and several core team members that had been involved in the pilot testing and community engagement process. These lessons were shared
with ACT leads and with the Area Agencies on Aging to assist other communities as they would launch this process.

Those lessons included:

- Have a very strong leader/Coordinator or co-Coordinators
- Team-building and group cohesion is critical
- Ensure you have enough people involved; build a bigger team from the start, to allow for some shrinkage of the group over time
- Bring diversity onto the group; ensure community representation
- Select volunteers with specific skills
- Walk through all of the Toolkit and plan for the various phases of work, perhaps bringing in different talent/expertise among group members that is tailored to the task at hand
- Set realistic goals as a group, including timeframes
- Practice with the tools; role play and provide each other feedback
- Communities should pick the assessment areas and scope of their assessment process
- Offer educational and other leave-behind material following the assessment
- Communities differ in the amount of technical assistance they will need
- Do data entry as soon as the assessment is completed, don’t wait
- Involve the group in conducting the analysis and interpreting the results
- The process of conducting the interviews and completing the assessments raises awareness; it builds momentum for “what’s next”

As a result of these pilots, changes were made to the Toolkit and additional resources were added. In addition, Area Agencies on Aging managers and Alzheimer’s Association staff were engaged as education and technical assistance supports to the new ACTion communities that would be starting the process. (See Pilot Communities Composite Report published June, 2013, found at: [http://www.actonalz.org/sites/default/files/documents/FINAL%20Pilot_Communities%20Composite%20Report-%20Paone%20June_2013%281%29.pdf](http://www.actonalz.org/sites/default/files/documents/FINAL%20Pilot_Communities%20Composite%20Report-%20Paone%20June_2013%281%29.pdf) and the AAA webinar, presented January, 2014, found at: [http://www.actonalz.org/sites/default/files/documents/Evaluation-LearningsToDate.pdf](http://www.actonalz.org/sites/default/files/documents/Evaluation-LearningsToDate.pdf)
Dissemination & Implementation

While these four communities continued, five additional communities formed and began their work in 2013 (Brainerd/Baxter, Cambridge, Forest Lake, Roseville, and St. Paul Neighborhoods). They were provided information and resources through the website and with assistance from the ACT project director.

In 2014, ACT on Alzheimer’s staff and working group members secured substantial funding to support and engage additional Minnesota communities to conduct this community assessment and engagement process. Funders included: Blue Plus (affiliate of Cross Blue Shield of Minnesota), Medica Foundation, and the Greater Twin Cities United Way. Many of these communities began their work in April 2014, with additional communities coming together in November 2014. By then, there were 34 ACTion communities within Minnesota that had responded to the request for grant proposals and were awarded funding (see map of communities, Figure 7). 8

By May, 2015 most of these ACTion communities had worked through the first three phases (Convene, Assess, Analyze) and many were into phase 4 (Act). Communities were putting together work plans and initiating these plans to address one or two priority items as had been determined through the assessment and analysis process.

Phase 4 grants in the amount of $5,500 to $16,000 were awarded to 26 communities to implement action priorities as follows: Becker, Bemidji, Brainerd/Baxter, Cloquet, Detroit Lakes, East Iron Range (Aurora, Biwabik, and Hoyt Lakes), Edina, Forest Lake, Harmony, International Falls, Mankato/North Mankato, Marshall, Mille Lacs (Onamia and Isle School Districts), North Branch, Northfield, Paynesville area, Redwood Falls, Roseville, Sauk Rapids, St. Paul Northeast Neighborhoods, Stillwater area, Willmar, Centro (reaching Twin Cities Latino populations), Dr. Solomon Carter Fuller/NorthPoint Health and Wellness Center (reaching North Minneapolis populations), Minnesota Council of Churches, and St. Paul African-American Faith Community. These communities represent small and large rural, suburban, and urban communities as well as communities with ethnic and cultural diversity and communities of affinity, such as the faith communities.

The ACTion communities are continuing their work, most with funding that extends through 2015. Thereafter, there is not a clear next step for these communities.

8 Source: www.ACTonAlz.org/realities accessed on December 20, 2013
Comments from leaders in this working group about the key accomplishments included:
(Source: Paone, 2015- ACT on Alzheimer’s Leadership Group Chairs: Perspectives)

[A key accomplishment was] deciding that a Communities Toolkit would be the way we could help Minnesota communities work together to become dementia-friendly, then developing that Toolkit. We were very intentional about this—having a Toolkit and process. We looked at the literature, and drew on the experience of the Lifetime Communities work. The Toolkit was structured, but not too bureaucratic or burdensome. The second part of that was the funding—recognizing that having a little money to support the community engagement work would be key. Then having so many communities actually engage. We weren’t sure that many would step forward. The willingness of leaders to volunteer and help facilitate the work in their communities and the sector involvement—all of those things have been important.

We’ve learned that having the Toolkit tested and then revised based on the experience of real communities was important. Having grants that could fund communities was critical for dissemination and then engagement. The role of the AAAs was also important to bring this possibility to the communities in Minnesota. We are just beginning to learn what works on implementation and dissemination – there is still a huge learning curve on what the dementia friendly community is and what the Toolkit is all about. The first round of applicants – they knew what they wanted to do – evolved more into a community engagement process. However, in the next round, the focus was on having the assessment tell the community what it wanted to do. The idea was to build off of the surveys and assessments. So it was not as clear for them at the beginning.
Some communities are now moving into Phase 4 and just starting to implement an ACTion item. We see that many times the goals come back to building more awareness as to what is there in their own community. They are finding out there are a lot of resources available but people don't know about them. So this is one important finding. This work is evolving as the communities have best practices—they can learn from each other and share successes.

**Highlights from Selected Communities**

The evaluation included detailed examination of a few selected communities in addition to the original four pilot communities. These Minnesota communities were selected by the ACT project lead and director as follows: St. Paul Neighborhoods, Cambridge, Latino Collaborative, Dr. Solomon Carter Fuller, and Minnesota Council of Churches. These five communities represent metro, rural, diverse, and affinity communities. There are separate reports on each of these five communities found on the ACT website. Highlights are offered below.

**St. Paul Neighborhoods**

The St. Paul Neighborhoods Action Community Team (SPN ACT) was the fifth community to begin this community engagement and coalition-building process, and the first to use the completed *ACT on Alzheimer’s* Dementia Capable Community Toolkit. SPN ACT is made up of six neighborhoods: Highland Park, Macalester-Groveland, West 7th, Summit Hill, Summit University and Union Park. This St. Paul Neighborhoods effort began with a community kick-off presentation and “call to action” meeting in February, 2013.

SPN ACT moved through the first three phases of the Toolkit and process in 2013. The Coordinator was funded part-time through an additional grant and was employed by a senior housing and health care services organization. The Coordinator worked with others to put together a robust team of local organizations and community members from all sectors—more than 68 people were involved. The team completed 127 surveys by August 2013.

Moving from assessment and analysis to Phase 4 action occurred in late 2013. In October and November of 2013 the full SPN ACT group participated in a facilitated group process to narrow scope and come to a consensus decision on one or two priority areas, with specific objectives and activities for the SPN ACT effort. The analysis process that the SPN ACT team conducted resulted in two top priority areas: (1) Awareness, and (2) Information/Education. Objectives for each priority area were developed, with specific action steps tied to the objectives. SPN ACT completed their ACTion Plan development in early 2014, which included identifying members of the ACTion team who would help with each of the activities as well as ongoing outreach to the community.

---

9 As of January, 2015 there were 33 ACTion communities utilizing the Toolkit & community engagement process through grants provided through the ACT on Alzheimer’s initiative (See: [http://www.actonalz.org/minnesota-communities](http://www.actonalz.org/minnesota-communities))
As the group came together for action, the focus was on (1) creating an easy-to-use directory that provided information on local resources for persons with dementia and their caregivers and on (2) embarking on a community education effort to offer basic training to lay people living or working in the SPN ACT neighborhoods about Alzheimer's disease and to build community awareness of the disease and of caregiver issues. The group identified the following activities for focused action in the St. Paul Neighborhoods geographic area in 2014:

- Create and distribute a SPN ACT brochure that describes the effort
- Create and distribute a bookmark that includes the 10 warning signs on one side and a few key community resource/service organizations on the other
- Create and maintain a community specific resource directory
- Utilizing the “Dementia Friends” training from the United Kingdom as a foundation (See example from Scotland at: [http://www.dementiafriendscotland.org/](http://www.dementiafriendscotland.org/)) modify the training to offer sessions throughout the community. This would include supporting organizations and individuals willing to host and conduct the Dementia Friends training to maximize distribution/dissemination.

The Dementia Friends and Dementia Champions training that was piloted by SPN ACT in 2014, was imported from the United Kingdom. The SPN ACT team had heard about the training and team members decided that this training could be adapted for use in the St. Paul neighborhoods to address the priority area of improving education about the disease within the neighborhoods. The SPN ACT core team, together with the project staff members from the Alzheimer’s Association and ACT on Alzheimer’s, reviewed this U.K. Dementia Champions training session content to see how it could be streamlined from a full day workshop to a few hours.

The resulting curriculum included:
- Basic facts and figures about Alzheimer’s Disease
- Comparison and contrast between normal aging and dementia (10 warning signs)
- Description of dementia as a disease of the brain, with illustrations
- Discussion about what it feels like to lose part of one’s memory, using the “puzzle pieces” and “bookcase” metaphors
- Communication tips and strategies
- Individual and group exercises such as:
  - matching phrases/facts in “broken sentences”
  - writing out each step in a series to complete a daily task (e.g., brush teeth)

From September through December (2014) “Dementia Champions” trainings were held in the St. Paul Neighborhoods geographic area to build a corps of trainers. Champions, in turn, held Dementia Friends sessions which were open to the public and also held for specific groups (e.g., employees of a bank, parish members of a church, friend social clubs, etc.).

---

10 There is a two-step train-the-trainer approach. Modifications were to shorten the workshop “Dementia Champion” curriculum to 2.5 hours (later reduced again based on feedback from participants and expert facilitators) and also modify the “Dementia Friends” 1-hour session curriculum to foster more discussion and engagement among participants.
The evaluator conducted an electronic survey of those trained in Dementia Champions (December, 2014) to capture their responses to this modified training and collect any suggestions they might have to further refine the training. The responses to this Dementia Champions survey were largely positive, however suggestions were made to shorten or adjust the content, format, and some of the exercises (See Table 3).

### Table 3. Dementia Champions training evaluations and suggestions (Sept-Dec, 2014)

<table>
<thead>
<tr>
<th>N=27</th>
<th>Fine as is</th>
<th>Minor adjustments needed</th>
<th>Significant adjustments needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content</td>
<td>11 (41%)</td>
<td>15 (55%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Length</td>
<td>20 (74%)</td>
<td>6 (22%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Language</td>
<td>21 (78%)</td>
<td>6 (22%)</td>
<td>0</td>
</tr>
<tr>
<td>Format</td>
<td>14 (52%)</td>
<td>9 (33%)</td>
<td>4 (15%)</td>
</tr>
</tbody>
</table>

The Champions training was therefore revised in December and early January, 2015 by *ACT on Alzheimer’s* and Alzheimer’s Association staff, taking into account the feedback from evaluations and the experience of SPN ACT Champions and the SPN ACT Coordinator. This revised training was then disseminated widely to all others who were interested from any other ACTion community. A training session for new Dementia Champions to be trained was offered in late January and early February, 2015 by an educator from the Alzheimer’s Association, using the revised curriculum (content and format modifications had been made).

Subsequently, this training was incorporated as an online, self-directed training module. It is now offered online (available free) through the *ACT on Alzheimer’s* website. The Champions Guide and Dementia Friends Workbook have been added to the *ACT on Alzheimer’s* website, making all of these materials accessible and easy to download and review (see: [http://www.actonalz.org/Dementia-Friends-Champion-Webinar](http://www.actonalz.org/Dementia-Friends-Champion-Webinar)). This has allowed any person, at any time, to train him/herself. This was a significant contribution of the SPN ACT community to the entire state and beyond.

The leads from SPN ACT were interviewed in 2015 to capture lessons learned, advice, and sustainability. Sample comments are offered:

*We’ve had over 650 individuals trained as Dementia Friends and 87 as Dementia Champions. Also the variety of organizations interested. We’ve also been responding to many calls and people interested outside our 5 neighborhood area. The interest is exciting, but it has stretched our capacity.*

*The promise of widespread community impact from SPN ACT and Dementia Friends continues to flourish which is a blessing, but a challenge all at the same time as SPN ACT has limited personnel and financial capacity to field all of the interest from our community and beyond.*
We also feel that impact is demonstrated by the engagement of people and organizations that are from service sectors that we don’t traditionally associate with “caring for Alzheimer’s disease.” Also these people and organizations creating new opportunities and programs, for example: a regional bank system training all of their employees, a faith community conducting trainings within the church for congregational members and others, individual residents living in a senior housing campus conducting “living room” Dementia Friends sessions through personal invitation and networking, the Minnesota Historical Society offering sensory-based tours for individuals with memory loss on certain days/times, and a Memory Café created and held monthly at a local senior housing residence, open to all.

We continue to make sure that the scope of our work is manageable and sustainable. The momentum behind our efforts illustrates we are achieving our initial goals to: increase awareness, offer education, and reduce stigma about dementia. We will continue to work on transitioning to where this is not so resource-intensive and also move some of this to the Alzheimer’s Association or AAAs going forward.

It is exciting that our ACTion team has done such a fine job of promoting this initiative to make St. Paul (and beyond!) dementia friendly.

While we are able measure attendees and evaluate their feedback on the Dementia Friends program, how to measure the impact that our Dementia Friends are having out in the community will be part of our next phase of action. This plan has not yet been devised.

With regard to our SPN ACT 5 neighborhood area, active conversations with organizational leaders are occurring to determine sustainability and how this transforms to the next phase. Ongoing collaboration with other ACTion communities to share learnings and sustainability strategies will be important. Also- having key team members and organizations who are truly passionate about the work is an important ingredient. Finally, having support from key organizational decision makers is essential to carrying the work forward.

Cambridge, MN

Cambridge is a city of just over 8,200 residents located in Isanti County, in the central region of the state of Minnesota. Approximately 17.5% of the population is over age 65.

The Cambridge ACTion team launched its work in May 2013 with involvement of individuals representing many sectors of the community. The Coordinator was from a senior housing and health related services organization. The Cambridge community ACTion team included involvement and input from many sectors of the community and by more than 23 individuals. Sectors represented included: law enforcement and safety, social service agencies, home care providers, respite care providers, hospice providers, faith communities and parish nurse programs, additional senior housing providers, Isanti county and city offices, and secondary education and community education representatives.
The ACTion team meetings not only worked through the process of conducting a community assessment, but also provided education about Alzheimer’s disease, facilitated discussion about the meaning of “dementia-capable,” and highlighted resources for individuals with the disease or for their caregivers that are available in or near Cambridge. The Cambridge community ACTion team structured their work using sub-groups, including a sub-group of members who served as their Survey Team. A total of 67 surveys were completed, covering all of the sectors except adult day care (that service is not available in the city of Cambridge). This team also helped interpret and analyze the results and present findings to the full ACTion team.

The synthesis of the survey results was conducted from February through May 2014. By far, the predominant theme identified throughout many of the surveys (either as an opportunity or a barrier) was lack of knowledge in the community about Alzheimer’s disease and about resources to help. In the community interviews, respondents also shared their concern about the decrease in available funding for dementia services in the community—which some believed had already negatively impacted the city of Cambridge. Some described how, because of the lack of available services, dementia care and support services are perceived as more “risky” to offer. In addition, caregivers may have difficulty paying for services that are fee-based.

Employers were also identified by the Cambridge community as a possible entry point for changing the landscape of awareness and support for people living with dementia, primarily caregivers caring for someone diagnosed with Alzheimer’s.

Discussion focused on increasing public awareness of Alzheimer’s disease within the community. Additional action items were to: support first responders, and provide information and resources to health care providers so that they can offer information and support in a timely way immediately after diagnosis.

Benefits realized from engaging in this community assessment and engagement effort have included the strong identity as a “connected city,” with new connections being built between people and sectors within the community. This grassroots ACT on Alzheimer’s community effort has reinforced the positive relationship-based energy and capacity for action within the City of Cambridge.

Several successful strategies were offered by the Cambridge ACTion team members. First, the Toolkit can seem overwhelming, and the entire process can be daunting. Managing this process by dividing the activities into reasonable tasks with small measurable goals has been effective. Having short-term small goals helped the group make and mark progress. Second, group members said that it is important not to be too rigid in how to do the community assessments/surveys. Flexibility is important, as this part of the process can be overwhelming.

Like other ACTion communities, Cambridge team members discovered that having wider representation from the community helped enhance community engagement and advance their goals of increasing awareness and fostering dialogue across community sectors. One respondent commented that having community leaders from the city and county, along with newspaper reporters, helped add credibility. This also increased visibility of the effort. For example, the
local/county newspaper Isanti County News included a dementia awareness update in their monthly guest column.

Having stakeholders who understand the local resources and current services was also important, as it gave members access to up-to-date, accurate information. Involving city and key civic stakeholders provided benefit to the Cambridge team as well. The county commissioners and sheriff have helped the ACT team access new members and contacts in the community that the group may not have considered.

[It’s a] matter of the whole community coming together in a unified idea of what is Alzheimer’s disease and how does it affect - individuals, families and the entire community. This is where we touch people and make a difference - helping to pick someone up. Knowledge is power. Once you understand [it], great things can happen.

**Latino Collaborative**

The Latino Collaborative is an affinity community of Latino and Chicano families who live in greater numbers in sections of Minneapolis and St. Paul. The lead agency for the Latino ACTion community is Centro Tyrone Guzman. Groundwork to create the Latino Collaborative ACTion community began through efforts of a few individuals. A Spanish-speaking member of the ACT on Alzheimer’s Health Equity Leadership Group contacted the Executive Director of Centro Tyrone Guzman and invited her participation and leadership. They reached out to others in their community and this core group of individuals began working together as an ACTion community in July 2014.

The ACTion team (8 individuals) met in July, August and September to develop their approach. The ACTion Team discussed the importance of this disease in their community and of getting the word out. The Latino Collaborative had two community-wide kick-off events, one in English (October 23, 2014, with 44 participants) and one in Spanish (November 15, 2014, with 74 participants). At both events, the ACTion Team members introduced themselves and explained the ACT on Alzheimer’s initiative in brief, and the Latino Collaborative as a local effort to reach Hispanic/Latino residents in the area. Two physicians were invited and presented information about the disease. The content included:

- What is Alzheimer’s disease
- The difference between Alzheimer’s disease and normal aging
- Other types of dementia
- What treatment is available to slow the process (for some patients)
- Actions that Alzheimer’s patients and families/caregivers can take after receiving a diagnosis
- The importance of maintaining a healthy diet and exercise, socialization and brain health
- Testimonials from clients with Alzheimer’s disease and their caregivers.
Following the formal presentations, the ACTion Team facilitated a Question & Answer session. Team members noted that many participants had heard about dementia and Alzheimer’s disease but did not know much about this. As a result of the Kick-off events, more individuals came forward to join the Latino Collaborative ACTion Team.

The AAA key contact from the metropolitan area participated in the monthly meetings and served as a resource to this community. The team set about learning about how to facilitate the community engagement process that is outlined in the Toolkit, including how to reach out to community members and those working in the various sectors, and how to conduct face-to-face interviews.

While the guided community engagement process that is laid out in the Toolkit was very helpful to the team members, the language and length of the surveys/assessments within the Toolkit proved difficult for this community to work with. The experience of this ACTion team was that the survey questions were too detailed, there were too many of them, and they assumed that the interviewee had knowledge they did not have. Several of these key informants described the challenges with the surveys as they were written. A team member noted that the survey questions assumed some knowledge about the disease, aging, caregiving—and these assumptions did not match the community.

The administrative support staff member entered all of the survey data. In March and April of 2015 the ACTion team came together to review the results from the surveys, and to analyze these results and brainstorm possible action steps. The ACTion team set forth two priority goals as follows:

#1) Awareness- Prepare the Minneapolis Latino community to actively engage in creating a safe and respectful environment for individuals with dementia and Alzheimer’s and their caregivers by coordinating activities designed to: raise awareness, garner support, and encourage open and non-judgmental dialogue about community members’ experiences with dementia and Alzheimer’s disease.

#2) Information and Education for People with Dementia and their Families- Foster a safe and respectful environment for Latino Minneapolis residents with dementia and their caregivers, by engaging the broader Latino community in activities aimed to: educate about Alzheimer’s disease and dementia, reduce stigma, and increase access to information and resources.

The ACTion team put together a three-year written Action Plan. They then presented it to other members of their professional network, asking for feedback and opinions on the best way to reach out and to implement the plan. Activity began in August and the community has achieved some impressive progress and tried unique methods for raising awareness—such as through an original play conducted in the community in Spanish. They also participated in a public television documentary that has featured the Latino Collaborative effort, and they are continuing with community forums and other events.

Team members envisioned how the dementia-capable community will look and feel once it is a reality.
A measure of success will be when the Latino community can talk about “I see some signs of my relative that may have dementia” – and a friend or a neighbor brings the 10 Warning Signs flier.

When the doctor responds. When the referrals to community resources on Alzheimer’s are given and there are Spanish-speaking caregiver support groups, respite care, Alzheimer’s Association and other Spanish-speaking caregiver consultants. When people have enough knowledge, not feel ashamed, and can advocate for attention and address this issue.

**Dr. Solomon Carter Fuller**

The Dr. Solomon Carter Fuller ACTion community involves several North Minneapolis neighborhoods. This North Minneapolis area has many strengths as well as challenges. It is one of the most economically and ethnically diverse areas in Minnesota. The lead agency is a federally qualified health center located in the heart of this area and has a long history of service and community health/engagement. Two community advocates and activists served as lead Coordinators for this ACTion community.

A starting point for this community was the foundational work done by the Health Equity Leadership Group of ACT on Alzheimer’s. The Health Equity Leadership Group members set forth a goal to “embed a set of principles and values” including embracing the richness of cultural diversity and reducing health disparities into the “operational lens of all ACT on Alzheimer’s work” (See ACT on Alzheimer’s website at: [www.actonalz.org/sites/default/files/.../HEidentity-purpose-082714.docx](http://www.actonalz.org/sites/default/files/.../HEidentity-purpose-082714.docx))

As the Health Equity Leadership discussions continued, the group determined that there should be more focus on African-American and Latino communities that were designated “ACTion communities.” Groundwork began in March of 2014 to create one for North Minneapolis. A core group of individuals met and wrote a proposal which was then funded through ACT.

This ACTion team had between 9 and 15 regular members who met monthly to develop their approach and work through the components of the Toolkit.

The team working on this initiative re-named their group the *Dr. Solomon Carter Fuller* ACT team. The ACTion community is named after the African American psychiatrist who worked alongside Dr. Alois Alzheimer to identify the disease. Dr. Fuller was the first known black psychiatrist in America and a pioneer of research on the physical changes in the brain (See Alzheimer’s Association website at: [http://www.alz.org/africanamerican/bios.asp](http://www.alz.org/africanamerican/bios.asp)).

A kick-off event with the entire community invited was held in September, 2014 with attendance of approximately 70 people. The ACTion team described *ACT on Alzheimer’s* and invited ongoing engagement. Several new community members and organizations stepped forward.

The team reviewed the Toolkit and process, but had difficulty with some of the terminology. They revised the language they used—avoiding the term “survey” as it has negative connotations in the community—and instead talking about having conversations and about community engagement. Forty-one individuals participated in these conversations from October-December, 2014. Tabulating the results occurred in January/February 2015.

*Paone & Associates, LLC*
A second community-wide meeting in February showcased the results and resulted in a Call to Action and individual “pledges” for personal action steps that would be taken. The most frequent pledges were to: become a trained Dementia Champion, offer Dementia Friends sessions, and/or host an educational/awareness session at a local church.

The Co-Coordinators described the advantages of being part of a coordinated effort—part of the larger ACT on Alzheimer’s initiative. The Health Equity Leadership Group had led to the establishment of this ACTion community within the Northside community. Having the scripted community engagement process and the technical assistance and seed money through ACT was critical to initiating and then working through the Dementia Capable Community Toolkit—it provided some resources to do the work. In addition, the information and sharing from other ACTion community leads was also important for helping to address some of the challenges and short-cut or avoid bumps in the process.

Challenges have included the language and terminology used in the Toolkit, the lack of culturally relevant resources, the complexity of the assessment and analysis process, and the time commitment this process took. The Co-Coordinators note that there is a heavy demand on many African American community based non-profit organizations and churches—coming from many agencies and from government. These larger organizations want to partner/collaborate, but there is an inequality of resources between the organizations. They also are hoping for some kind of shared learning across communities of color around this issue.

Nationwide it is important for the African American community to know about this disease. We are interested in connecting with other African American groups, coalitions, organizations, or grassroots efforts that are focusing on this disease in the African American population. Finding what is going on across the country and learning from their work is a higher priority now as compared to when we started.

**Minnesota Council of Churches**

The Minnesota Council of Churches (MCC) has 24 member denominations that “represent the regional governing and administrative bodies of Mainline Protestant, Historic Black, and Orthodox judicatories.” According to interviews with key members involved in this Action team work, the MCC’s Graceful Journey training and presentations to many member churches and the development of the Congregations of Care model were both instrumental in setting the groundwork for this ACT on Alzheimer’s project. Those team members who had participated in this Congregations of Care training felt that it helped them understand more fully the challenges that caregivers of persons with various types of terminal illness face—including Alzheimer’s disease. Thus, they believed that additional training about Alzheimer’s disease would be “a natural follow-up.”

An MCC staff member convened seven member churches in September of 2014 to introduce the ACT on Alzheimer’s® initiative and to engage representatives in a discussion about Alzheimer’s disease and caregivers. The meeting began with a presentation of factual information about Alzheimer’s disease and dementia, including the 10 Warning Signs. The MCC Coordinator walked through the Dementia Capable Community Toolkit. The ACT on Alzheimer’s initiative was described as a community engagement process.
Though participants had different expectations about the purpose and focus of the initial meeting, good discussion ensued at that first meeting. Individuals shared stories and spoke about the impact of the disease and generated many ideas that could be part of the community action efforts. Representatives from the different churches agreed that they would take a look at the surveys and the Toolkit to see how or whether they would be able to conduct this assessment and follow this process in their congregations.

During and following the meeting, members expressed some consternation about the surveys and their focus. The fact that none of the surveys were written for a faith community was of concern. As members reviewed the survey questions, they discussed the need for a different set of questions if they were to conduct assessments within their communities. The MCC staff created a revised set of questions and these were used to have conversations within the four churches that agreed to move forward and participate. Phone and in-person interviews were conducted by members from each church. In total, group members completed 34 surveys.

Following this (during the analysis phase) the members discussed their experiences in conducting assessments using the modified question set. They described a number of challenges, including finding people willing to be interviewed, scheduling a call or meeting, finding enough time as volunteers to conduct the survey, and the difficulty with the survey questions themselves. The group from these participating churches agreed that if ACT on Alzheimer’s wanted to have faith communities involved in the work, then there should be a survey that is created specifically for communities of faith—with perhaps a set of questions for the pastor or lay leaders, and a set for lay congregational members. They pointed to the set of surveys that had been developed for the healthcare sector. A similar attention to faith community structure, service, and orientation should be attempted.

One thing that didn’t work was surveying church leaders only about what support is provided—[this] is only half of the picture. It didn’t give us any information about what the needs of the congregation are—how many members have dementia? How many are caregivers in the home? How many are caregiving from afar? What would they find most helpful? Do they need rides to church? Respite care? Calls from a pastor? A Befriender? Education? A night out?

In discussing the results from their interviews, the team members said they saw and heard stories of fear, denial, and lack of knowledge about Alzheimer’s disease and dementia. They also heard about the stigma associated with the disease and of the difficulties faced by family caregivers.

This Action team shared ideas and discussed what would be helpful to them to raise awareness of this issue. For example, the group talked about having prepared sermon notes around dementia and caregiving. Members from each church needed to go back to their church and consider what they could lead, get others to be involved in, or delegate to others. They also had to consider current and ongoing programming. They determined that this effort needed to fit into existing structures and programming—such as a Sunday educational hour or existing support group format.
The fact that we were attending the sessions with other churches helped us see that each congregation would have different needs and would have to go about supporting folks in different ways. It made our conversations a lot richer.

Results indicated that the churches’ congregations needed more information and awareness-building around dementia and caregiving. Members of the team also decided that a list of resources would be helpful—particularly for those churches that have parish nurses and assist people one-on-one. Each church was asked to determine their next steps and possible action items to pursue within their congregation, with pastoral leadership blessing. Action steps emanated thereafter from each church on its own, based on the interests of the team members and pastoral leadership, time availability, and how the proposed activity fit into the larger programming of the church (i.e. calendar).

We talked about how many resources we already had in place that could be brought to bear if we thought about them differently. This last point was really important, because our congregation is really active and engaged—and the idea of creating a whole new structure to address an issue in the congregation was overwhelming and exhausting to most of the leaders we interviewed.

Examples of action steps included: having individual members trained as Dementia Champions, including information about Alzheimer’s disease and caregiving in the church newsletter, and setting up plans to do a survey of the congregation’s needs.

So education, awareness-building, and reaching out to caregivers—those were the priorities we selected.

Support & Technical Assistance

Regional, “Hands-on” Technical Assistance - As funding was secured to launch up to 30 new ACTion communities, some of these resources were devoted to the Area Agencies on Aging to serve as technical assistance regional centers to the new communities in their areas--on the ACT Toolkit and community engagement process. The Alzheimer's Association (MN-ND Chapter) was also contracted to provide education and resource information to these ACTion communities. The Alzheimer’s Association’s support focused on providing education to the communities and sharing the resources and materials of the Alzheimer’s Association, as communities needed or requested these.

The Area Agency on Aging technical support was designed to be “hands-on.” Each AAA designated a key contact person to serve as the organizational subject matter expert and liaison to the ACTion community team and Coordinator. This AAA staff member attended at least one, and often many, of the ACTion community meetings. The AAA contacts provided guidance, information, education, and other support from 2014 – 2015 (continuing to the present). Each AAA was provided $4,500 per community to provide technical support/assistance. The “launch” of this technical support occurred in late 2014.
The evaluator conducted an electronic survey of these AAA key contacts in 2015 (N=12, 100% response rate). By that time, the AAA staff members serving in this capacity had about one full year of providing technical assistance to their respective communities. Results indicated that about one-third (5) of the technical assistance staff members were assisting only one ACTion community, however more than half (7 individuals) were assisting three or more communities. Hours spent by the AAA staff members varied from about 3-5 hours a month to more than 20 hours a month. The midpoint and most frequent response was that they spent from 6-9 hours a month on providing the ACTion communities technical assistance and support. Some of the support was in-person and other was providing over the phone or via Skype meetings.

Additional comments offered indicated that many AAA key contacts were participating regularly as a member of the ACTion community team. A few communities did not need the help offered. A few other communities needed extensive support.

In addition to their time, other resources needed by the communities included:

- Data analysis and technical skills, e.g., in analyzing survey data
- Assistance with navigating and finding resources on the ACT website
- Access to the ACT project lead staff member(s)

The types of support that these individuals were providing particularly focused on helping the community to understand the ACT initiative and orienting them to the Toolkit. Many also helped: convene the community team, facilitate meetings, conduct surveys, work on the analysis of the community assessments/surveys, and put together an action plan. See detail in Table 4.

<table>
<thead>
<tr>
<th>Table 4. Types of AAA Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q For each ACTion community you are supporting, indicate what types of support you’ve provided to them—in their community engagement process for ACT. Check all that apply. (Number of AAA checked responses are shown in parenthesis)</strong></td>
</tr>
<tr>
<td>▪ Understanding the ACT Initiative (22)</td>
</tr>
<tr>
<td>▪ Orientation to the Toolkit (18)</td>
</tr>
<tr>
<td>▪ Putting together an ACTion plan (22)</td>
</tr>
<tr>
<td>▪ Help with analysis (of surveys (15)</td>
</tr>
<tr>
<td>▪ Info on community resources (14)</td>
</tr>
</tbody>
</table>

The AAA staff members said that additional information and resources could be helpful to them in their role of providing technical support to the ACTion communities. See their responses as provided in Table 5.
Table 5. Additional resources needed in role (AAAs)

<table>
<thead>
<tr>
<th>What more would be helpful to you in your role of providing technical support to the ACTion communities? Check any that apply or write your own.</th>
<th># Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repository of helpful tips, practices, advice for using and training others on the Toolkit and process</td>
<td>6</td>
<td>55%</td>
</tr>
<tr>
<td>Assistance with helping communities set up metrics/measures for evaluating their progress</td>
<td>5</td>
<td>45%</td>
</tr>
<tr>
<td>Time with other AAA mentors/key contacts to share learned experiences</td>
<td>4</td>
<td>36%</td>
</tr>
<tr>
<td>Better understanding of principles of community engagement</td>
<td>3</td>
<td>27%</td>
</tr>
<tr>
<td>Opportunity for me to provide support via video stream/other live media - to cut down on my travel time</td>
<td>2</td>
<td>18%</td>
</tr>
<tr>
<td>Coaching or ideas on how to best support the local ACTion team Coordinator</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Help with PR/Communications</td>
<td>1</td>
<td>9%</td>
</tr>
</tbody>
</table>

Additional write-in open, ended comments offered:

- The development of a tool for assisting with the analysis of the surveys. It is very labor intensive.
- A Communication Plan template would be helpful.
- Keeping up with ACT tools and resources on the website as it grows. Example: I have a difficult time accessing the ACT brochures and notecards easily and quickly.
- Would suggest investment in streamlined data collection/analysis tools - these were a challenge and time consuming for communities without time/skills.
- Helped to have funds to pay for someone - but they are still clunky to use. Also, more explanation of how to transfer matrix data into priority worksheet, would be helpful.
- All of the Act materials have been very helpful, and needed to "seed" information and ideas for action teams.
- Have appreciated the great support from ACT staff and the trainings organized.
- Information about the ACT collaborative, training or clarification on the toolkit, helping the community understand "community engagement"
- Access to ACT staff, travel and copies.
- Just staying on top of the contents of the Toolkit.
- Connected multiple times with Emily to locate documents on the website, discuss approaches to communities who had struggles, and clarify expectations for Phase IV
- TA on data analysis and use of matrix. Use website resources regularly.
- The best and most effective method of support has come through the ACT learning collaborative workshops.
- Team leads have felt it very beneficial to discuss and share experiences with other community leaders
- I have had the resources I needed but the website is overwhelming because of the scope of information. Could we evaluate its efficacy? Could it be more user-friendly?

In their unique positions—both engaging with the community and providing support to the community—these AAA staff members were able to reflect and share on the results that they had seen to date. Summarizing their comments, the consensus was that significant energy and commitment had been shown by the communities, and that raising awareness of the disease and of caregiver issues were the most common priority action areas revealed.

They also noted that successful communities had coordinators and team members that stepped forward with great leadership and project management skills. The ACT on Alzheimer’s project staff provided significant support to both them and to the communities when called upon. The
key informant instrument is found in the *Evaluation Appendix & Instruments Repository* which is a companion document to this report.

*Learning Collaborative Peer Group Meetings* – In addition to the Area Agency on Aging and Alzheimer’s Association assistance, the ACT project director organized 1 day peer-to-peer learning collaborative meetings and webinars for ACTion communities to exchange information and learn more about strategies and successes. Four in-person learning collaborative meetings were held (October, 2013, June, 2014, October 2014, and June 2015). Most of the coordinators and many core team members attended these meetings—in fact the number of individuals per community had to be kept to three people, as the meetings were becoming very large. Individual comments to the project director and post-session evaluations indicated that the participating ACTion community members found this very valuable. This was especially helpful in learning from each other and discussing strategies, challenges, action items, and results. This shared learning across communities was one of the highlights reported. Through this forum coordinators were more aware and informed of the community engagement statewide.

A post-session evaluation of participants from the June 2015 Learning Collaborative (N=20) provides useful information from these ACTion community coordinators and team leads about what they thought were the top accomplishments of the ACTion communities, what technical assistance they had needed, what they would do differently, and what more they wanted to do. This information was collected electronically by the Minnesota Board on Aging and shared with the ACT project director. The evaluator analyzed the responses to identify common themes. Note that the questions were posed as open-ended/write-in, so that more than one response could be given by the participants. In many cases, the participants offered several comments for each question. The next four tables provide detail from four of the questions posed.

Community engagement was clearly the top accomplishment as seen by these coordinators, with the community awareness/education being a common goal and activity as well (Table 6.)

<table>
<thead>
<tr>
<th>Themes that emerged:</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community engagement; involvement of people, organizations, sectors</td>
<td>17</td>
</tr>
<tr>
<td>Education and community awareness-building actions</td>
<td>7</td>
</tr>
<tr>
<td>Action plan development and follow-through</td>
<td>6</td>
</tr>
<tr>
<td>Identifying the community’s top needs</td>
<td>4</td>
</tr>
<tr>
<td>Dementia Friends training</td>
<td>3</td>
</tr>
</tbody>
</table>

The technical assistance of the Area Agencies on Aging was noted as essential to the community’s progress and was recommended for new communities as well (Table 7).
Table 7. *Technical Assistance Resources (N=20)* [note that individuals could list more than one thing]

<table>
<thead>
<tr>
<th>Similar comments were grouped as follows:</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAA support and guidance as they have done</td>
<td>7</td>
</tr>
<tr>
<td>Help with marketing, communications</td>
<td>4</td>
</tr>
<tr>
<td>Admin support, including with survey data</td>
<td>3</td>
</tr>
<tr>
<td>Specialized knowledge, e.g., health care, policy/advocacy, Alzheimer’s info</td>
<td>3</td>
</tr>
<tr>
<td>Evaluation</td>
<td>2</td>
</tr>
<tr>
<td>Community organizing strategies</td>
<td>2</td>
</tr>
</tbody>
</table>

These leaders would have gotten more people engaged early on and also spent less time on the survey process (Table 8).

Table 8. *What Would Do Differently (N=20)* [note that individuals could list more than one thing]

<table>
<thead>
<tr>
<th>Similar comments:</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orient more volunteers, get more involved at the beginning, more partners</td>
<td>7</td>
</tr>
<tr>
<td>Less time on surveys and/or different surveys</td>
<td>7</td>
</tr>
<tr>
<td>Better foundation/understanding of ACT and more peer learning before launch</td>
<td>3</td>
</tr>
<tr>
<td>Grant writing, funding</td>
<td>2</td>
</tr>
<tr>
<td>Too many priorities chosen – so would choose fewer</td>
<td>1</td>
</tr>
<tr>
<td>Would research what options we could consider more before deciding</td>
<td>1</td>
</tr>
<tr>
<td>No changes</td>
<td>3</td>
</tr>
</tbody>
</table>

Regarding what to accomplish next, these ACTion team coordinators and team members indicated that the next priority would be to create more services and supports for people with Alzheimer’s disease and their caregivers. Several types of services and supports needed in their communities were listed (Table 9).

Table 9. *What to Accomplish Next (N=20)* [note that individuals could list more than one thing]

<table>
<thead>
<tr>
<th>Similar comments:</th>
<th># reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create more services and supports for persons with AD and their caregivers, e.g., meaningful engagement, caregiver outreach, adult day, etc.</td>
<td>13</td>
</tr>
<tr>
<td>Community educational and awareness efforts, e.g., films, conferences, etc.</td>
<td>4</td>
</tr>
<tr>
<td>Additional partners, sectors</td>
<td>3</td>
</tr>
<tr>
<td>Funding, sustainability</td>
<td>3</td>
</tr>
<tr>
<td>Marketing, visibility, PR</td>
<td>2</td>
</tr>
<tr>
<td>Culturally relevant resources and information</td>
<td>1</td>
</tr>
<tr>
<td>A paid community resource person</td>
<td>1</td>
</tr>
</tbody>
</table>

ACT Project Director Support – The ACT project director served as the lead staff person fostering all 34 ACTion communities and serving as the liaison to the AAA key contacts. She reviewed all of the grants, provided ongoing information and support to communities as requested, and was the “go to” person throughout the state. She facilitated training and supported the AAA technical assistance key contacts, including providing webinars, resources, and one-on-one help.

The evaluator conducted a key informant interview of this project director in August, 2015 to capture her perspectives on what has been learned from the work of the ACTion communities, and through her own experience as the key “infrastructure/management” support component undergirding the effort. Excerpts from that interview point to the importance of volunteer community engagement, the utility of the Toolkit (some refinement needed), successes, and infrastructure requirements going forward. Selected comments are offered:

Q: You have had the role of fostering the process across all of the communities. From your perspective, what are key take-away lessons or insights about what it takes for communities to engage in collective action around this goal—creating dementia-friendly communities?
A: A shared understanding of what Alzheimer’s disease is and how it can impact their communities—residents, families, and the various organizations and service sectors within those communities. We’ve also learned it takes at least a small core team of passionate, committed individuals who are able to work together effectively. It did come down to one person (usually) who needed to be a good facilitator, organizer, messenger—who was good at volunteer recruitment, communication, and project management.

Q: Talk to me about the Dementia Capable Community Toolkit and guided community engagement process overall—what worked, what didn’t?
A: The tools in Phase 1 (Convene) worked well. They helped with education, increasing awareness, engaging team members. We provided visuals, marketing pieces too—communities used those a lot. We had templates that were easily adaptable, and communities did adapt them to suit their needs. The tools in Phase 2 (Assess) were not so adaptable—we got feedback that the surveys were too complicated and lengthy. The surveys used terminology that was often confusing or unfamiliar to the interviewer and the person being interviewed. The surveys were also weighted to probe on general awareness of AD. I heard from communities and I agree additions and refinements are needed. For example, we need different surveys for retail/business, faith community, family caregiver, and one for the person with the disease. In Phase 3 (Analysis)—there was consistent feedback that this was burdensome and too time-consuming. On the other hand, once the data were entered and plotted, the information was easier to understand and use.

Q: Any particular successes stand out with regard to an approach or result?
A: Where we’re at right now is very interesting. All the ACTion communities have work plans and they are giving these things a try—moving through their activities. Given the focus on awareness in the surveys, it is not surprising that most of the communities are focusing their actions on this issue—on information and education.

A huge success and surprise was the number of communities that picked up the Dementia Friends training—as piloted in St. Paul. These communities are conducting the D.F. training sessions as a core part of their awareness building. It is successful. They say that it is very easy to hold sessions, the sessions engage more people, there are positive messages, and good tips. People see and feel the outcomes in terms of one-on-one comments and more engaged individuals.

Another thing that is slowly growing is an increase in engagement by law enforcement and first responders, and also by businesses, and by faith communities.

Finally, the shared peer-to-peer learning across communities is a success story. It either happens through me as a conduit, or they find each other. The Learning Collaborative meetings turned out to be very important as a component in facilitating progress and keeping the coordinators motivated and informed.

Q: For those communities who have reached Phase 4 – Action plan – what is the next step following that work – where are communities going from there? What are they asking for to help them continue or sustain this work—or move to the next phase around building a dementia-friendly community?
A: Most of the communities had some kind of dementia-focused effort or group that they tapped into and will likely continue to utilize to continue to address dementia issues in their community. Some efforts will be adopted by a host organization. Others may morph into part of another local working group. Some will seek additional grants to continue the team work and create their updated action plan. There is a need I have been hearing from the communities for guidance on “Phase 5” which they frame as evaluation and sustainability. That is another component that could be developed in the Toolkit that doesn’t exist right now.

Q: What kind of overall infrastructure is needed—the behind the scenes work and resources—to guide this kind of collective action process? What are key components to that infrastructure?
A: Well, there is a need some kind of centralized support system, at least for data gathering and shared learning. It seems this would be at the state level, although perhaps this could happen at a regional level, through the AAAs. The AAAs would capture information and then share and network with other AAAs so that all the communities’ learning and progress could be captured and shared. There is a need to collect the same information consistently, and feed this back so that the information is analyzed, interpreted, and utilized by all.

There is also a strong need for communication support, graphics, printed materials, outreach and “marketing” and how to communicate within the team and especially outside of the community team to external audiences. There is the need for a core person to respond to communication and related information needs consistently across the state; maybe a centralized coordinator.

Measuring Components & Results

Evaluating the Community Team Itself

To assist communities in determining group/coalition cohesion and group strength, the evaluator developed a self-assessment tool for ACTion communities to assess their own characteristics and strengths, and help them determine if adjustments were needed. One
community, the St. Paul Neighborhood Community Action Team (SPN-ACT) utilized this self-assessment at a mid-point, following their community assessment, analysis and prioritization steps.

The content of the survey is based on work of researchers11 studying how coalitions function and what factors help drive success. For example, in a review of community coalitions, factors predicting satisfaction, participation, and planning included: community leadership, shared decision-making, linkages with other organizations, and a positive organizational climate (Butterfoss, Goodman, and Wandersman, 1996).

Researchers who have extensive experience in the field (working with community engagement coalitions around health or other key social issues) recommend that the coalition evaluate its results at three levels (Butterfoss and Francisco, 2004):

1. Level 1: Coalition Infrastructure, Function, and Processes
2. Level 2: Coalition Programs and Interventions
3. Level 3: Health and Community Change Outcomes

This survey was focused on the “Level 1” elements of the SPN ACT group—their infrastructure and processes, leadership, and how members worked together. The questions probe the following areas:

- Understanding about purpose
- Organizational structure
- Resources available
- Group participation, Engagement
- Communication
- Outreach & representation of the community
- Effectiveness
- Group strength
- Commitment
- Confidence

The survey was designed to be used at key points in the life of the team/coalition. In each natural phase of evolution of the coalition’s lifecycle, the players/participants may change—thus those who are completing the instrument would also change. Natural phases in the life of the ACT on Alzheimer’s Community ACTion Teams were assumed to include:

- After the convening, assessing, synthesizing steps have been completed (Phase 1, 2, 3)
- After the action planning around the top priority area(s) is done, with a workplan generated that includes action steps and leads, timeframe, and measures or markers for gauging progress (Phase 4)
- After the community has initiated one or more action steps, involving collective action by individuals and organizations in a coordinated way, and have finished/completed those

---

11 Researchers include: Francisco, Schlutz, Fawcett, Becker, Wandersman, Goodman, Butterfoss, Miller, , Katz, and others. See list of references provided.
steps and are working toward elements of sustainability or embedding the efforts in one or more organizations (Phase 5)
- During a collective review or final evaluation process

The survey had 12 questions and was designed to be very simple to complete. Scaled adjectival response options were given for each question. The scale is shown below:

<table>
<thead>
<tr>
<th>Yes, Always or Yes, Definitely</th>
<th>Most of the Time</th>
<th>Sometimes</th>
<th>Not Usually</th>
<th>No, Never</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

Each survey participant chose a response option closest to his/her experience, and was invited to provide more detail in an additional comment narrative text box. The survey was anonymous. The survey was administered and distributed electronically via a dedicated URL link address. It was mailed to everyone that the St. Paul Neighborhoods ACTion team coordinator had on a mailing list. Of these 67 individuals, about half of them were active in the effort (indicated by regular meeting attendance). The response rate of 32 individuals equates to a 100% response rate. Most respondents completed the survey in 2 to 3 minutes.

The results from this self-assessment showed strong positive feedback on team members’ understanding of the purpose for the initiative, the way that the effort had been organized, the opportunity for involvement, and their own commitment to the effort. Two areas for additional work were to: increase representation of sector representatives who had not been too involved (e.g., business, faith communities), and to ensure adequate resources to do the work.

**Examining Community Assessments, Priorities, & Action Steps**

Following Phase 3 (Assess), many of the ACTion communities determined that the top needs and priority action items were: raising awareness, providing education about Alzheimer’s disease and caregiver issues, and increasing support to caregivers.

The evaluator reviewed the work plans of ACTion communities, looking at the action items listed in the communities’ Phase 4 grant applications. Not surprisingly, the types of actions chosen by these communities focused on awareness and education about Alzheimer’s disease and about caregivers. The way that each community approached that goal was unique, although several communities chose to follow in the footsteps of the St. Paul Neighborhoods community and offered the revised Dementia Friends training/education sessions. The list of the actions planned (as of early 2015) provide more detail on community focus and actions:

- Conduct a community awareness campaign or other community-wide program (e.g., community theatre production, television, newspaper, bookmark, or other print material
- Distribute books and resources about Alzheimer’s disease

- Create and distribute a list or brochure about local community resources – with specific services for persons with memory loss and their caregivers
- Create or enhance a community volunteer program
- Conduct “Dementia Friends” training (adapted from curriculum developed in the United Kingdom) and offered as community education or in small group settings
- Create additional Caregiver or Dementia Support Groups
- Show films that depict individuals and caregivers dealing with dementia
- Create and host workshops, conferences, and other community/caregiver educational meetings
- Conduct special training sessions for first responders, e.g., fire, police
- Organize drop-in “Memory Cafés”
- Reach out to businesses/employers and conduct training or education sessions for their employees to raise awareness and sensitivity on how to interact with persons appearing confused or with memory impairment
- Reach out to leaders in the faith community – offer to provide education and training for Pastors, Priests, Imans, Rabbis, and other faith community leaders, offer Dementia Friends sessions in their congregations, and provide sermon notes or other resources
- Conduct physician and care coordinator training
- Conduct the Powerful Tools for Caregivers evidence-based workshop and build capacity to sustain this
- Increase wellness and meaningful engagement programs and offerings for persons with memory impairment and their caregivers
- Increase youth engagement by providing books for kids and other school resources

Coordinators’ Perspectives - Community coordinators and core team members offered insight and advice through key informant interviews conducted by the evaluator (2014-2015) about their experiences. For all comments, review the community evaluation reports provided on the ACT website. Selected representative comments are offered:

I think you have to have a partially-funded team Coordinator, or a highly committed volunteer, and that person must be skilled at facilitation, communication, and fostering collaboration. Capacity is expanded when we build on the relationships between
organizations and individuals. Having a clearly defined action plan with objectives, actions, outcomes and specified timelines was essential in moving to implementation. This helped focus the group and define purpose and tangible next steps.

Finding time is difficult. I had to make this a priority, but I did that because I know it’s important. My leadership understands the value of ACT, but I wouldn’t do it if I didn’t love it.

Communities such as ours don’t have the resources—staff time—available to donate to an effort such as this. Organizations leading this may or may not be able to do that. So a community such as ours starting this up would need to think through how they can have an all-volunteer force.

It is very important to receive this information in your language, and in a culturally appropriate environment, where you feel you are welcome—where you can ask different questions about it—where you can feel like you are at home and you have a family to support you without judging you.

Supporting those who are highly engaged and interested—and helping them to become role models and mentors to others is what works.

In addition, we have continued the format we started from the beginning—monthly meetings, followed by updates and meeting summaries. This keeps individuals aware and engaged and they can tell others.

We’ve had great support from numerous local organizations. What really drove their involvement was dedication from individuals representing these organizations.

I would say that getting people engaged is an important point. More visibility is the first step. That is the primary focus of our plan going forward. Raise awareness, start the conversation.

- Choose a lead organization with capacity and deep ties/services in the community
- Build a strong ACTion team
- Be prepared for the time commitment—especially the assessment process
- Maintain good communication with the community and try to involve as many people and organizations as you can
- Read the whole Toolkit and go on the ACT on Alzheimer’s website and view the videos, resources, etc.
- Keep everything organized

I have learned that people will gather together to help each other when they understand that there is a need. That is very encouraging. Even if we don’t have all of the answers and resources—they will help.

Keep in mind, any action is better than no action—passion can help move your group in any direction you want. . . . You can be as big or as little as you want it to be, but meet your
own expectations, and tailor to your group to the needs that you all have identified. Invite people out, and you will be surprised and who attends the group.

There are a lot of issues that are systemic. They are not particular to the Latino community. Such as awareness of this as a brain disease, what are the signs, how to get a diagnosis, what your physician should do to arrive at a diagnosis, what kind of follow-up should happened, what kind of help should be provided to caregivers, etc. These issues are not unique to the Latino community—I mean we can't take on the whole health care system. We can do what we can do to build awareness and educate in our community.

Meanwhile, there has to be a bigger effort at the systems level. There has to be a big push into policy. Setting some requirements for health care. We can't do it all from the grassroots.

Additional information about each of the funded ACTion communities is found on the website (http://www.actonalz.org/minnesota-communities).

Examining Referrals to Alzheimer’s Association

The evaluator requested and received data from the Alzheimer’s Association-Minnesota-North Dakota Chapter—showing the number of referrals to the association through physicians and the “Direct Connect” referral system from the ACTion communities. The purpose of this data analysis was to trace the potential influence of the ACTion community work on calls and referrals into the Alzheimer’s Association—since the name and telephone number of the Alzheimer’s Association was on every resource and guide created by ACT—as the first place to go for information and follow-up.

The data had been collected by the Alzheimer’s Association through their normal tracking system. The evaluator grouped a set of zip codes corresponding to the geographically-defined ACTion communities and provided a table for the Alzheimer’s Association to use. Data requested were for physician referrals and referrals through Direct Connect, as well as helpline calls from 2011, 2012, 2013, and 2014. Only physician referrals and helpline call data were available. Together with the zip-code specific data, the Association provided statewide data indicating all of the calls received.

Statewide, total calls rose from 1,695 in 2011 to 2,064 in 2012, and thereafter dropped to 2,035 in 2013 and to 2,014 calls in 2014. Physician referrals rose from 123 in 2011 to 229 in 2012 and again to 256 in 2013—more than doubling in three years. However, in 2014, physician referrals dropped to 171.

Examining the community-specific data shows that many communities—especially those in greater Minnesota (e.g., Walker, Willmar, Bemidji, Cambridge, Harmony, International Falls, Marshall, Becker, Onamia, Sauk Rapids) —had no referrals that were captured in this data set/tracking system over these four years. Some metropolitan communities (such as North Minneapolis, St. Paul Northeast, St. Paul Neighborhood, Roseville, St. Louis Park) saw a rise from
2011 to 2012, and then a drop in referrals in 2013 and 2014. Referrals were generally in the single digits, with only one community, Edina, having more than 4 referrals in 2014 (they had 10).

The results do not indicate sustained change. These data seem to show a fairly consistent rise in referrals from 2011 to 2012—which could be related to the ACT initiative as it gained visibility. However most of the ACTion communities did not begin their work until early 2014. In 2013 there was a gradual drop in referrals, and the 2014 patterns return closer to baseline. However, these numbers are very small, which yields uncertainty in interpretation. It appears that, either this measure/data source is not capturing the full extent of calls and referrals, or that the work of the communities is not yet resulting in referrals to the Alzheimer’s Association. Currently the measure/data is not adequate to draw conclusions.

Successes, Challenges & Areas for Further Development

The ACTion community engagement statewide had clear success, as well as a few challenges or areas for further development.

Successes – Successes included:

- Community receptivity across regions of Minnesota – Communities of all sizes and geographic locations, as well as affinity communities, such as the Latino community, Jewish community, Dr. Solomon Carter Fuller (in North Minneapolis area), expressed interest, wrote grant applications, and initiated the community engagement process using the Dementia Capable Communities Toolkit. This growth, from 4 pilot communities to 34 communities, occurred in about 2 years.

- ACTion Community Coordinator grassroots leadership – Each community was led by a Coordinator lead or co-lead. In general, these individuals maintained their commitment throughout the multi-year process, dedicating untold unpaid hours and showing great project management and group facilitation skills.

- Toolkit and related components – The Toolkit, and the many additional resources developed to complement the Toolkit (developed in 2013, 2014, and 2015), was well-received by communities and team members. The Toolkit performed as intended, to walk the community through the four phases of community engagement around creating a more dementia-capable community: Convene, Assess, Analyze, Act. One exception, noted by many community team leads, was the survey instruments (noted under Challenges).

Challenges – The most frequently cited challenges related to the time commitment and balancing the ACT work with full time employment or other demands. The amount of information and detail was somewhat overwhelming for many of the ACTion community teams. Advice from community coordinators was that: “While the Toolkit may now be better refined, future groups should be aware that it still takes time. Furthermore, groups considering this work should understand that they don’t have to do every category/sector.” Challenges included:
Community capacity - The “position” of Coordinator to lead the community team and move through the engagement process required both significant time commitment and a set of quality and skills such as effective communication, project management, group facilitation, leadership, and boundary-spanning networking.

ACT project and technical assistance capacity constraints – The ACT staffing capacity was strained as the project director was the key contact person responding to information requests and project/grants management to an increasingly larger group of communities that began the work in 2013, 2014, and 2015. The AAA key informant data also notes the significant time commitment made to serve the ACTion communities as their technical assistant.

Understanding or interpreting key concepts (“dementia-capable” and “community assessment”) – A challenge mentioned during the interviews with ACTion community coordinators concerned two of the integral concepts in the ACT on Alzheimer’s initiative—describing these as “complex.” These concepts include: the meaning of “dementia-capable,” and what it means to implement a “community assessment.” On their own, the terms seem clear, but coordinators expressed initial confusion on their part and by their team members, particularly in conceptualizing what a dementia-capable community was. They also questioned why conducting a convenience sample of interviews with individuals from their community would provide enough information for prioritizing action and developing strategies for improving the community so that it would become more dementia-capable. Given that this was not a rigorous community assessment, some individuals felt that the information gathered could be skewed, providing a fuzzy or incomplete picture about the current level of capability, awareness, or priorities. This concern continued as the team moved to analysis of the results.

Surveys/Assessment Process – While the Toolkit was mentioned as a valuable resource, challenges with the surveys and assessment process were encountered and reported. These challenges were consistent across the communities studied. Many individuals requested that the surveys and process be streamlined and revised. Recommendations, particularly changes to the surveys, have been offered. Terminology, language, and formatting changes have been suggested. The wording was particularly difficult for the diverse communities, but other community core team members voiced the need for changes to the survey and to the data entry/analysis process. This user input from the field could help direct refinements. Components of that did not work for some communities:

- The language and terminology used, particularly the survey wording, length, question content and response scale
- The lack of culturally-relevant resources, terms
- The complexity of the assessment process, need for flexibility, streamlining
- The time commitment this process took
- The data entry and analysis

- The lack of specific survey instruments for at least two key participants and community informants: (1) caregivers of persons with Alzheimer’s disease, and (2) faith community representatives

Suggestions for improvement focused on simplifying the survey items and questions so that they had a similar focus on three things: (1) the gaps in the community, (2) the strengths and resources of the community, and (3) how the interviewee/informant experienced interaction with persons with Alzheimer’s disease in their job or in that sector, and (4) what more was needed.

Sustainability & Evaluation - Most of the ACTion communities have moved through the four steps—convene, assess, analyze, and act. Most are working through their action plan. Many have asked: “what happens after Phase 4?” They are at the point of discussing how to sustain the work after the grant funding ends in 2015. Some are moving into an evaluation phase to assess progress and community impact to date. The communities are calling for additional technical support to guide them as they seek to sustain efforts and measure results. A comment from one of the group leaders is offered below:

*We should look at the level of engagement of the people and organizations. Look at the breadth of the community sectors that are engaged. Regarding impact, we should look at whether the communities were able to identify priorities and move to project implementation work . . . Then we have to get local resources—additional services in the community—social workers, caregiver supports. It has to be accessible, local for caregivers.*

Key Success Factors

Success factors that enabled progress by the ACTion communities are summarized:

- A voluntary community engagement effort, supported by organizational structure and community-embedded leadership, can be successful.

- Alzheimer’s disease, and the needs and issues that people with this disease and their family caregiver face—are compelling issues that resonate with individuals and with organizations. Many people felt a personal as well as a professional “connection” to these issues—which fostered voluntary action and engagement.

- The Toolkit helped enable a process that structured activity to reach out across sectors (business, health, faith, housing, social services, etc.) and connect individuals from these sectors and across neighborhoods—people who might otherwise not have met. However, the survey process needs work.

- To make this work, the effort needs a strong Coordinator who is supported by a leading organization that is willing to provide resources for the good of the whole.
Specific skills and competencies, including group facilitation, communication (written, verbal, social network media, etc.), ability to be inclusive and encouraging involvement while also not getting derailed, and strong organizational skills are needed. Constantly responding to new individuals who had just heard about the effort and wanted to become involved, is exciting but also challenging for these Coordinators.

Keeping the group focused on specific action items, while also connecting those actions to the larger vision, helps to avoid dissolution of effort on tangential activities or confusion.

Key supports to the communities 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.
**Evaluation Focus Area: Impact on Caregivers/Care Partners**

**Caregiver Leadership Group Work**

Caregivers of persons with Alzheimer’s disease and related dementias—usually a family member or significant other—live the journey of disease and address daily living challenges with their partners. Caregivers are extremely important—vital. Thus, their perspectives were very important in the work of *ACT on Alzheimer’s*.

The Caregivers Leadership Group was comprised of five caregivers, as well as individuals from social services organizations, AAAs, clinic and health care systems, and the Alzheimer’s Association, as well as the Minnesota Board on Aging.

This working group met 17 times from September, 2011 to May, 2014. At the initial meeting of the group, members decided to focus on two long-term outcomes that they would hope to see as a result of their work:

1) Caregivers have a variety and robust supply of culturally competent information AND informal and formal support services that includes, among other things, clinical, legal and financial information and services, professional care management, and access to a flexible education curriculum based on best practices, AND

2) Caregivers experience culturally competent, proactive information and services relating to self-care.

Much of their work over the next 3 years focused on providing input as informed and engaged caregivers into existing state training and information resources to help improve its content or be easier to use. This included input into the basic and advanced dementia training for caregiver consultants and into planned programming updates to the Minnesotahelp.info state database and consumer-focused information repository. The Caregiver Leadership Group also served as a resource to the other ACT Leadership Groups to comment on their tools, products, website development, etc.

One key output that can be observed are the changes to the MinnesotaHelp.Info state database. This resource was enhanced and redesigned, with a roll-out in July, 2015. Recommendations and caregiver perspectives were provided through extensive input of this *ACT on Alzheimer’s* Caregivers Leadership Group, serving as a de facto focus group and a set of advisors or technical assistance supports to state managers charged with modifying the resource.

Part of the site upgrade included the addition of a “finders” function. This function allows consumers/users to answer a set of targeted questions—which will then direct them to the appropriate provider service tied to the location where they are searching for services. Another specific feature added identifies settings or services with “dementia-trained staff.” The definition of “dementia-trained staff” is now tied to the state certification for professionals and paraprofessionals who are specially trained and certified to provide care for individuals with dementia, as per the Minnesota Dementia Care law. Providers that enter their data into the site are able to select this feature indicating they have “dementia-trained staff” onsite. This will provide additional information to consumers searching dementia expertise in staff.

**ACTion Communities’ Efforts**

One of the 5-year goals of the ACT on Alzheimer’s initiative was to: “sustain caregivers through access to and navigation of organized information about supportive services and resources.” Based on information from the ACT project director, all of the 34 ACTion communities had at least one caregiver involved either as a member of the team or as an interviewee in the community assessments. As a result of their analysis (described in the previous section of this report), many of these communities identified needs and priorities for action as: (1) build awareness about the disease and of caregivers in their communities, and (2) develop more support for caregivers.

**Successes, Challenges & Leadership Insights**

One big challenge for this working group was that it was set up as an advisory group more than a product development group. Members report that they did not have either the in-kind organizational resources or outside funding to help create resources for caregivers or build new caregiver services/supports statewide. The group provided valuable insight to all of the other working groups, but did not feel that they were able to make significant progress toward goals. Comments were offered by leads through key informant interviews:

*Unlike the other Leadership Groups, we are a collection of individuals more than organizations. We relied on the Department of Human Services and where they wanted to or could go. Our presence and advice was important, but we ourselves cannot implement. Some things have a significant cost – who is going to pay for what caregivers really need? Going forward we need policy and advocacy support--some coalition or group that will advocate for the needs of caregivers and help direct resources toward their needs. Research is showing that the person-to-person coach, a person who could help, listen, guide, is needed. We need to simplify all of our systems and make it easier for the caregiver to get human to human help that is consistent and ongoing. Most caregivers don’t reach out until crisis.*

*I think that originally our group wanted to focus on caregivers as a large and invisible community. We needed to give voice to their needs. We came up with a list of many of problems they deal with. A big part of what we wanted to do is increase the awareness; increase understanding of the caregiver.*

*We had some very important suggestions. Our Leadership Group has discussed many of the common issues that arise during the course of disease. Early on we were hoping to have a caregiver coach for each caregiver. We have supporting information on how important that is. It helps avoid isolation, crisis. It provides timely supportive resources for caregivers. So our group was focused on 2 things: (1) competent, consistent care management from beginning to end for each caregiver, and (2) access to easy, navigable*

---

information that is not overwhelming, but adequate to the specific task or need. We are definitely not there yet. Obviously, this has policy and payment implications.

The original Alzheimer’s Disease Working Group didn’t have a caregiver component. That made it difficult to incorporate the caregiver voice in this group, as ACT was building off of the recommendations of that Working Group. It was not clear how the caregiver would be incorporated; perhaps it should have been woven into all of the groups, rather than a stand-alone. The other groups had specific deliverables and an organized framework with funding to move those things forward.

An example may be seen in the Community Toolkit—it is great to focus on the service sectors, but there is really no survey instrument designed to capture the gaps/resource availability/dementia capability perspective of the AD caregivers living in that community. Those caregivers may be the most knowledgeable about navigating in that community, therefore a survey that is designed to capture their insights might be a good addition to the Toolkit.

Because we are individuals, without the backing of big organizations or funding behind us, we turned into a reviewer group for other efforts. We ended up doing a lot through the DHS and helped with teaching on training for the Tiers for caregiver consultant and phone line staff. We spent a lot of time reviewing Minnesotahelp.info database. We reviewed it extensively and made many recommendations. We looked at the Navigator. We reviewed the brochures going out (the After the Diagnosis brochure, for example). So we were a resource to other Leadership Groups.

As we all know, change happens at a glacial pace when you are talking about big systems—such as health care or government. I believe we did influence thinking and hopefully future policy.

Caregiver Focus Groups Findings

As part of this evaluation a focus group of caregivers was facilitated by the evaluator. A focus group is one research or evaluation method for obtaining information from a defined group of people with special characteristics or knowledge. The people participating in the focus group should be alike in specific ways. The focus group method provides the opportunity to obtain more detailed information through fostering in-depth thinking and discussion. The group is designed to be small to allow for issues and information to be probed in a deeper, more substantive way. This is a qualitative research method that is widely used.

This group was focused on obtaining in-depth perspectives from engaged/informed caregivers about their perceptions of progress and results to date in their respective ACTion communities (they represented four different communities) and on how they would advise others to measure impact.

---

The evaluator held the caregiver focus group in May 2015 with four caregivers who had been active in one of four ACTion communities for a year or more. Caregivers were personally invited by the evaluator based on the individual’s personal commitment and engagement in the work of the ACTion community and willingness to share his/her viewpoints in order to weave this perspective into the work. ACTion team coordinators were a key source of information to select these engaged caregivers. Criteria used to select the caregiver participants were:

- Person has been or continues to be a caregiver of a person with Alzheimer’s disease
- Person has been active in one of the furthest along ACTion communities (i.e., the community completed Phases 1, 2, and 3 and started Phase 4 by January, 2015)
- Person lives in the metro area (for convenience in transportation)
- Person had been recommended by the ACTion community Coordinator
- Person was willing to participate in the 1.5 hour group discussion

Four individuals were invited via email with a follow-up email, phone call or mailed confirmation. All agreed to participate. Each caregiver received a set of potential questions/focus areas that would be discussed in an informal setting. No one had to complete the questions or submit anything in writing. The questions were designed to focus on what they, as caregivers and informed community members, saw as different in their respective communities now as compared to when the ACTion community work began, about their perspectives on access or availability to meaningful dementia-specific resources in their communities, and about measures or measurement domains that are meaningful to caregivers for evaluating impact over time. The four caregivers participated in this 1.5-hour interactive discussion that was facilitated by the evaluator. The key informant instrument is found in the Evaluation Appendix & Instruments Repository which is a companion document to this report.

The caregivers in this focus group shared the opinion that one of the greatest results of their ACTion communities’ efforts had been to raise the issue and visibility of Alzheimer’s disease and dementia and of caregivers. They felt that there was more awareness, conversation, and discussion about these issues in their respective communities. They mentioned Dementia Friends training sessions, film series, conferences, lectures, and other tangible evidence of the increasing number of opportunities within their communities to learn about the disease.

They also remarked that it was very encouraging to see professionals working across sectors and organizations, as a result of the ACT on Alzheimer’s community engagement process.

Selected comments are offered below:

> I am amazed at the number of people involved. The professionals, the community members, and from so many sectors of our community—City Council, police, church, residential senior housing, health care, social service agency, etc.—it is truly impressive.

> We found out how important it is to have something concrete, like the Dementia Friends training sessions that can be held really anywhere. The scripts and materials are already to go. I’ve seen the great need in these senior residential buildings to have this—these awareness building and educational sessions. There are so many people living with this disease in these buildings. Whether silently, without diagnosis, or with—still it is there and
everywhere. You see it—even when sometimes the younger adult family members who come for occasional visits don’t see it, or don’t want to see it.

With regard to caregiver support, I do think it is also important to take into consideration how the patient is accepting the diagnosis. Some individuals are not accepting the diagnosis. Then the caregiver has a much harder time. Of course the person with the disease does not want to talk about it. She/he may not want the caregiver telling anyone anything. That inhibits help all around.

That is a good point. There is also the issue of when the care partner or significant other will not accept the diagnosis. The denial goes both ways. Sometimes a care partner wants it to be anything else—my loved one received an initial diagnosis of Parkinson’s disease. His care partner hung on to that—rather than Alzheimer’s.

Sometimes it is this issue around mental health and the stigma associated with having behavior that is different. What people have to understand is that there are physical changes in the brain. This is a brain disease. It is not a mental illness. But still, the stigma related to behavior changes gets attached to this.

I see slow progress in some parts of the community—changing the mindset and talking about this openly is one of the best ways to support the caregiver at this point.

Caregivers spoke about the great need for meaningful social engagement for both the caregiver and the person with the disease—and mentioned a number of programs that currently provide essential support. They each said that more is needed in this area.

The most meaningful dementia-specific resources are those that provide something meaningful and relevant for both the caregiver and the person with the disease.

Measuring Impact

When asked about measuring impact—toward an increase in “dementia-capability”—these caregivers discussed a set of domains and essential supports that will be important for the dementia-capable community of the future. These were:

- **Mental and social well-being as a focus**—caregiver and person with the disease
- **Counseling** for caregiver and for person with the disease
- **Family communication and help with family dynamics**
- **Accessibility and availability of caregiver communities and networks**
- **Education and awareness opportunities throughout the community**
- **Transitions in care and “safety net” services**—proactive

- **Navigators** – caregivers will have one “go-to person” who is there for the journey to help navigate, even as the individual goes through the stages of the disease

- The **medical care “gold standard”** is followed

- **Polypharmacy is addressed proactively**

While these caregivers noted that this ideal community does not yet exist, measures of success over time would be that these things are *growing in number and sophistication*. For example, that the number of caregiver support groups grows; that they are held around town at all times of day/days of week to make it easier for caregivers to access them. Also, that the caliber of medical and social services care is consistently high in organizations throughout their communities (e.g., well-trained staff, consistent, effective response).

They expressed hope that the *ACT on Alzheimer’s* ACTion communities will measure progress in these important areas.

As an affirmation, a short-term ACT working group that was focused on evaluation met for four months April – July 2015 and specifically identified the impact on caregivers as central to measuring success of any dementia-capable community. Their initial framework is shown below:

---

**Figure 8. Potential DFC Evaluation Framework (2015)**

### Community Capability--Possible Outcomes/Measures:

Adoption of dementia friendly practices, programming, and services as outlined in the community capability toolkit, with focus on the following elements:

- Community awareness raising activities
- Adoption of sector-specific dementia friendly practices in at least 70% of community sectors
- At least 50% of providers/vendors within each sector adopt dementia friendly practices

### Person w/ Dementia and Care Partner--Possible QOL Outcomes/Measures

**Health-related quality of life (measured using validated tool)**

- Domains include: mobility, self-care, usual activities, pain/discomfort, anxiety depression
- Collected through partnering health system via validated tool

**Care Partner Burden (measured using validated tool)**

- Collected through partnering community-based service organization via validated tool

**Care Partner Depression (measured using validated tool)**

- Collected through partnering community-based service organization via validated tool

### System Capability--Possible Outcomes/Measures:

Adoption of optimal dementia care as outlined in the ACT provider tools, with focus on the following elements of the tools:

- Disease identification
- Assessment and responsive care plan
- Identification/inclusion of a care partner
- Disease management
- Linkage/Integration with Community Supports

---

*Paone & Associates, LLC*
Evaluation Focus Area: Advancing the Field

Models & Policy Development

The Investing in Promising Practices (formerly Economics) Leadership Group met from October, 2011 through January 2014 to create a modeling method in order to calculate potential cost savings to the state through investing in promising practices. The group included representation from industry trade groups, research, provider systems, health plans, government, business, and advocacy groups. An independent economist consultant was hired to develop the model and conduct the analysis. The work was funded through grants from local health plans and trade groups including: UCare, Care Providers of Minnesota Foundation, and Blue Cross and Blue Shield of Minnesota.

The model was developed that simulated disease progression, place of residence, and direct costs of care for individuals with Alzheimer’s disease. The model estimated potential savings to Minnesota from offering the New York University Caregiver Intervention, a program of enhanced support services to spouse and adult child caregivers of persons with dementia living in the community. The cost savings were derived from estimating direct costs for people with dementia using data from the Medicare Current Beneficiary Survey. The model did not take into account implementation factors such as program or marketing costs or less-than-complete participation rates. It also did not estimate either cost savings from reduced use of health care services or cost additions from greater use of community support services. Findings from the simulation model suggested that broader access to this evidence-based intervention/support program could produce a positive return for the state from delayed nursing home placement that resulted in Medicaid expenditures. The model projected $996 million in cumulative savings from nursing home costs avoided over fifteen years.

Dissemination/Communication

The findings from the economic model analysis were disseminated through the ACT website and through an article in the publication Health Affairs (see: http://content.healthaffairs.org/content/33/4/596.abstract?ijkey=81Sa5vdZNrEvc&keytype=ref&sitedid=healthaff). This work was selected by Neurology Today’s editorial advisory board as an influential study in Alzheimer’s disease and dementia in 2014. A White Paper was also developed and distributed.

Leadership Insight

The Economic Group did the bulk of our work in 2012 and 2013. It has been very exciting, interesting, lots of new “ah-hahs.” Important questions for research – e.g., how do you determine numbers, what does the evidence say, how do you define costs? What prevalence figures to use? What models and methods and examples are there around making economic determinations and analyses? We had a good turnout in every LGp meeting. An intangible is how folks took this home and used it. However, it is expensive to do this work. Research costs money. At the end of the day we have a unique model. We have
publications. We have citations. We identified, studied, published. But that didn’t move the dial to the investment part. I'm political, so it is not a surprise. The investment is long term and that is rarely done in policy – mostly short term focus, by necessity; so there is more work to be done.

Influences – State

In Minnesota the ACT on Alzheimer’s initiative has been supported by, and has influenced, the work of several state departments as part of the ongoing effort to improve the state’s dementia care. These state departments include the Department of Health and the Department of Human Services. Both have extensive responsibility around the health and wellbeing of Minnesota residents. Information in this section of the report was provided by or supplemented by staff managers from these respective departments.

Minnesota Department of Health (MDH) - The Minnesota Department of Health has a vision to: Keep all Minnesotans Healthy and a mission to: protect, maintain and improve the health of all Minnesotans. The MDH goal framework (adopted October 25, 2010) includes promoting health throughout the lifespan, helping all people to get quality health care services, and assuring strong systems for health (see: http://www.health.state.mn.us/about/goals.pdf).

One important role that the MDH plays is to survey and certify the state’s health care homes. A health care home (also called medical home), is: an approach to primary care in which primary care providers, families and patients work in partnership to improve health outcomes and quality of life for individuals with chronic health conditions and disabilities (see: http://www.health.state.mn.us/healthreform/homes). Health care home providers must meet a set of standards and criteria in order to be certified as a health care home in Minnesota. As of early 2015, there were more than 330 certified health care homes in the state.

Minnesota Department of Health managers were involved in the work of ACT on Alzheimer’s as participants or invited guests in the Detection and Quality Health Care Leadership Group. Concurrently, this leadership group provided expert opinion to MDH. In 2013, this leadership group reviewed the current health care home certification requirements, particularly focusing on care coordination elements, to determine what could be added or modified to address the issues of detection and care coordination or follow-up for patients with Alzheimer’s disease. The input of this leadership group provided valuable information to MDH staff. However, the decision by MDH was not to include additional specific requirements about AD detection—over and above the standards set. In 2013, the Minnesota Department of Health, together with the Minnesota Department of Human Services, issued a Health Care Home Care Coordination Toolkit that included information about the ACT on Alzheimer’s provider practice tools (see: http://www.health.state.mn.us/healthreform/homes/collaborative/carecoordtoolkit.html). The toolkit was developed through the workgroup “Multi-Payer Advanced Primary Care Practice (MAPCP)” with funding from the Centers for Medicare and Medicaid Services as one product of the MAPCP Demonstration Project (ended December, 2014; information is available at
http://www.health.state.mn.us/healthreform/homes/medicare/index.html). Many members of the MAPCP were also involved in the ACT on Alzheimer's leadership groups.

The ACT on Alzheimer’s provider practice tools were also featured in four Health Care Home Learning Collaborative educational meetings (2012-2014), sponsored by the Minnesota Department of Health (for example, presentations made to the HCH Learning Collaborative include “The A-Z Guide to Simplify and Organize Dementia Care” See: http://www.health.state.mn.us/healthreform/homes/collaborative/learningday2014/alzslide.pdf). Table 10 provides data on the attendance of the HCH Learning Collaborative sessions where the ACT on Alzheimer’s provider practices tools and project information were presented.

<table>
<thead>
<tr>
<th>Table 10. MN Health Care Home Learning Collaborative Sessions – Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># of Learning Collaborative Sessions</strong></td>
</tr>
<tr>
<td># of Learning Collaborative Sessions</td>
</tr>
<tr>
<td>Attendance</td>
</tr>
<tr>
<td><strong># Sessions featuring ACT Provider Practice Tools or Guidelines</strong></td>
</tr>
<tr>
<td># Sessions featuring ACT Provider Practice Tools or Guidelines</td>
</tr>
</tbody>
</table>

Evaluations from participants at these Learning Collaborative Sessions provide information on how the participants rated these sessions related to specific learning indicators (Table X).

<table>
<thead>
<tr>
<th>Table 11. Evaluation Data from MN Health Care Home Learning Collaborative Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Learning indicator 1</strong></td>
</tr>
<tr>
<td>How well did the session meet the outlined objectives?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Learning indicator 2</strong></td>
</tr>
<tr>
<td>Please rate the speaker – 94% Excellent to Well</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Learning indicator 3</strong></td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
The work of ACT on Alzheimer’s was also presented to a number of MDH Task Forces, Work Groups and Committees. For example, Kari Bentley presented the ACT on Alzheimer’s initiative, particularly its work to develop dementia friendly communities, at the December 3, 2013 meeting of the Metro Refugee Health Task Force (see: http://www.health.state.mn.us/divs/idepc/refugee/metrotf/min13dec.pdf).

Pam Van Zyl York presented the work to the Rural Health Advisory Committee of Minnesota Department of Health in May, 2013 (see: http://www.health.state.mn.us/divs/orhpc/rhac/attachments/azleg.pdf)

**Minnesota Department of Human Services** - The Minnesota Department of Human Services (DHS) oversees the Aging and Disability Services Division and supports the Minnesota Board on Aging. The DHS mission is to: *help people meet their basic needs so they can live in dignity and achieve their highest potential.* The DHS Framework for the Future (2015) focuses on healthy people, stable families, and strong communities (See: https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6464D-ENG).

Minnesota DHS administers and funds specific home and community-based services through five Medical Assistance (MA) waivers and the state funded Alternative Care program for older persons. These programs serve older persons and persons with disabilities who are eligible for MA and at risk of institutional placement but who prefer to live in their home or another community setting. Services are also provided to caregivers of those persons eligible for these programs.

DHS Aging and Disability Services Division also:

- Administers and provides oversight of both the Vulnerable Adults Act (VAA) and county adult protective services to follow-up on VAA reports of potential adult abuse, exploitation or neglect;

- Administers the *Live Well at Home Grants* (formerly known as Community Services/Service Development grants) program, which provides seed money to a broad range of providers and organizations, to support new or expanded service models.

The Live Well at Home grants relate to the goals of ACT on Alzheimer’s, as they are intended to: *improve their community’s capacity to develop, strengthen, integrate and maintain home and community-based services for individual’s age 65 and older, at-risk of long-term nursing home use and/or spending down into Medical Assistance. Proposals may include strengthening services for the caregiver support and respite care network. Grants are intended to stimulate innovation by providing one-time, start-up funds to test new approaches in housing and home and community-based services development, and to develop and support core home and community-based service providers* (see: http://mn.gov/dhs/images/Live-Well-RFP.pdf)

The Minnesota Department of Human Services incorporated the *ACT on Alzheimer’s* provider practice tools into the 2013, 2014 and 2015 *Live Well at Home Requests for Proposals* (RFPs) to foster dementia capacity in the state. The RFPs issued in 2013, 2014 and 2015 had a specific...
category for responders on “Dementia Capable Health Care Home and Communities” that refers to the ACT provider practice tools and other resources created by ACT on Alzheimer’s. The RFP language notes that: “strategies implemented through ACT on Alzheimer’s align with the goals and recommendations outlined in National Plan to Address Alzheimer’s Disease.”

To date (2015), two certified health care homes have been awarded grants related to this component. The Essentia Health Systems grant piloted dementia capable health care homes at the Ely and West Duluth clinics (2013-2014). The ACT provider practice tools were embedded in the EPIC electronic medical record system utilized by Essentia. These tools were to be employed during the annual wellness visit with Medicare patients. The second health care home, Lakewood Health System, was in the early implementation phase as of July 2015. This system planned to adopt the Essentia Health electronic medical record system decision support tools that include the ACT provider practice tools.

Minnesota DHS also supports the work of the Minnesota Board on Aging (MBA). The MBA is a governor-appointed 25-member board that serves as the federally designated “state unit on aging” to administer the federal Older Americans Act (OAA) funds. The MBA targets OAA in-home and supportive services to people age 60 and older who have low incomes, are members of diverse communities, live in rural areas, and need supportive services to remain independent.

MBA:

- Designates seven Area Agencies on Aging under the OAA to administer contracts for the provision of nutrition, chore, transportation, caregiver support and caregiver counseling. Area Agencies help local communities and providers develop new services to fill gaps. Area Agencies on Aging also administer contracts for health promotion, chronic care management and falls prevention.

- Operates, in partnership with the Area Agencies on Aging, the Senior LinkAge Line® to provide information and options counseling to older individuals and families as they look for options and services to meet their needs. The MBA also manages the website www.MinnesotaHelp.info™

- Operates Office of Ombudsman for Long-Term Care to act as a mediator for consumers and their families who are having problems with a facility or agency that is providing long-term care, and offer specific information about long-term care services and programs to consumers and their families.

- Administers federally funded projects on Alzheimer’s care, including piloting evidence-based models for persons with Alzheimer’s and their caregivers.

In 2009, the Minnesota State Legislature directed the MBA to establish the Alzheimer’s Disease Working Group (ADWG) to study and make recommendations for policy changes related to Alzheimer’s disease. This work has been the foundation for ACT on Alzheimer’s.

The ADWG delivered its recommendations to the Legislature in January 2011. ADWG participants led the charge to establish the ACT on Alzheimer’s (ACT) initiative (June 2011) to ensure the recommendations were implemented. The MBA and Area Agencies on Aging incorporated the ADWG recommendations into their policy and practice. They also provided significant staff involvement—working in all six of the ACT Leadership groups. The MBA remains one of ACT’s strongest participants. The working groups have served as incubators for continuous improvements to dementia health care practice guidelines or resources, dementia education resources, and other tools that are immediately shared and disseminated.

It is the goal of the Minnesota Board on Aging to build a dementia-capable state. The Minnesota Board on Aging has had a long history of advancing education and developing resources to promote this goal. This work has been woven into ACT on Alzheimer’s so that the initiative could take full advantage of what had already been developed, and so that efforts could be coordinated or linked. Additional detail on specific efforts is provided:

- **Practice Tools and Guidelines** - Beginning in 2003, the MBA, together with Minnesota Area Agencies on Aging piloted the development of clinic/physician and community based caregiver consultant partnerships. Both physician and caregiver consultant guidelines were implemented for early identification of possible dementia, diagnosis, joint care planning and family and caregiver education and support. Area Agencies on Aging facilitated the development of more than 20 clinic/community based organization relationships as part of this effort.

- **Dementia Training** - The Minnesota Board on Aging, along with the MN-ND Alzheimer’s Association Chapter and a local health system clinical expert (neuropsychologist, Terry Barclay), provided dementia education to physicians and clinic staff as well as aging service providers in the community. Between 2004 and 2014, more than 50 educational events were delivered. The MBA sponsored this training which was delivered by Dr. Barclay. This became the basis for the current ACT on Alzheimer’s provider dementia training.

The MBA also developed and implemented a multi-tiered dementia capability training program for caregiver consultants and front line telephone and access assistance professionals. Enhanced dementia training was provided in 2012, 2013, 2014, and is scheduled for November 2015. The training modules and webinars were offered by experts from the Alzheimer’s Association and neuropsychologist, Terry Barclay. Over 100 Senior LinkAge Line® staff received the basic dementia capability training, 103 caregiver consultants and care consultant professionals received advanced dementia capability training (14 hour in-person training), and 42 caregiver consultants have received Family Memory Care training.

State surveys continue to find that training and educational resources are very important. For example the MBA Caregiver Support Services Survey (August 2013) found that of the 364 agency representatives (providers of services to caregivers), respondents the two most requested training topics were ADLs/care (26%) and dementia
Investing in Promising Practices - Beginning in 2007 Minnesota initiated the first translation of the New York University Caregiver Intervention funded by the federal Alzheimer’s Disease Supportive Services Program. This evidence-based service was proven to delay nursing home placement by 18 months compared to a control group. A key component of the MBA - NYUCI translation (known in Minnesota as Family Memory Care/FMC) was an in-depth cost analysis by an outside evaluator (Paone and Associates, 2009) over four years. The results of this cost analysis were provided to help inform the work of the Economic Leadership Group. The group ultimately decided not to use the program cost data from Minnesota, as costs varied significantly from one program site to another.

The economic model created through ACT on Alzheimer’s did show considerable cost savings from delayed nursing home placement over fifteen years. Economists and data analysts within the State of Minnesota Department of Human Services then reviewed this work and also conducted forecasts of costs savings. However, using the state of Minnesota forecasting, cost savings did not accrue within the specified timeframe allowed by the State Legislature to count as attributable cost savings for the state.

Health Equity - In 2013 MBA staff offered the ACT on Alzheimer’s initiative an opportunity to consider issues of health disparities in diverse ethnic communities affected by Alzheimer’s disease, which led to the incorporation of health equity principles throughout ACT’s work. The MBA introduced the Minnesota Indian Affairs Council Declaration of Rights of Elders and 2014 Health Equity Report (Minnesota Health Department) which provided the base for participants to consider a restructuring of ACT’s principles for inclusion of health equity in all of its work. One of the most visible results of this change is the home page of the website that affirms the initiative’s focus on health equity.

As a result, the ACT’s Cultural and Linguistics Committee was reformulated as the ACT Health Equity Leadership Group (HELG). MBA staff participating in that group also agreed to participate in the Detection and Quality Health Care Leadership Group to enhance continuity and infuse the work of this group with the “health equity lens.”

MBA staff conducted literature and resource searches to bring forward alternative, culturally-responsive dementia screening and assessment tools for consideration for incorporation into the ACT Provider’s Toolkit. In addition, MBA staff made considerable efforts to recruit both national dementia experts and local community providers who reviewed the same information, offered suggestions and made other referrals.

As the ACT Initiative enters a mature state, MBA staff has focused the same health equity lens on the MBA Dementia Capability training series. Recent grant funding allows MBA to design, create and implement an online Dementia Capability training series that is
culturally responsive – taking into consideration the norms and values of the diverse ethnic, racial and cultural groups prominent in Minnesota. The goal is to increase cultural awareness among training participants that include the statewide aging network, Health Care Home Care coordinators, community health workers, county Medicaid staff and others. An additional goal is to build a core group of ethnically diverse providers who are trained to educate members of their cultural community on Alzheimer’s disease, as well as to increase the ability of family members and the community to successfully cope with the effects of the disease.

- **ACTion Communities & Awareness** - The Executive Director of the Metropolitan Area Agency on Aging served as Chair of the Communities Leadership Group. The Central Minnesota Council on Aging and the Arrowhead Area Agency on Aging directors were also engaged in the development and implementation of the ACT Dementia Capable Community toolkit. Minnesota Area Agencies on Aging provided technical support to the 34 ACTion Communities. Area Agencies on Aging continue to provide resource development, technical support, education, and coordination as one of their key roles.

- **Caregivers** - MBA continues its efforts to develop and implement evidence-based services for caregivers of people with Alzheimer’s disease in an effort to support independent community living as long as possible. In the 2015 legislative session, the Minnesota State Legislature appropriated funding to the MBA to administer a competitive grant program focusing on dementia and its impact on caregivers.

In summary, As ACT improvements were made in the guidelines, clinical tools, educational materials, and resources, they were incorporated back into the work of DHS, the MN Board on Aging and the Area Agencies on Aging. In this iterative fashion, learning and mutual efforts have enhanced both state agencies and *ACT on Alzheimer’s*. 
Additional Accomplishments

ACT of Alzheimer’s leaders expertly attracted and shepherded resources (human and financial) which furthered and extended progress toward ACT’s stated goals. In addition, the perspectives of diverse communities were given voice through the Health Equity Leadership Group. Another important ingredient in the success was the robust and proactive approach to communication, reaching out to gain national attention and urging other national groups to utilize the ACT resources and learning. These additional accomplishments are described below.

Collective Action

ACT on Alzheimer’s was designed as a collective action effort organized around five goals, each with a working group made of experts, industry leaders, and individuals. Individuals were invited for their expertise and leadership and asked to make a two-year commitment to the endeavor. From approximately 45 individuals engaged, ACT attracted investment and engagement far beyond expectations. Over 600 individuals and 50 organizations contributed to the work effort. Estimates of the value of these in-kind contributions were conservatively estimated at $250,000 every six months—or approximately $2 million as of June 2015. In addition to their direct contributions in the work products, many individuals also participated in the governance of the initiative and assisted in opening doors to funders.

The initiative was managed by four contracted “staff,” including an executive lead/co-lead, project director, and project manager. The initiative was governed by a Leadership Council. A Management Steering Committee provided guidance to the staff members. The Leadership Council met quarterly from June 8, 2011 through November 10, 2015. (See the Evaluation Appendix & Instruments Repository for more detail on the governance and management structure).

As part of this evaluation, key informant interviews were conducted between late October and December of 2014 with the 6 Leadership Group Chairs and Co-Chairs. Interview questions were mailed prior to the interview. The interviews generally took 1 hour and were conducted by telephone. The focus of the interview was on the key activities and the outputs/results that had been achieved by the particular Leadership Group and by the initiative overall.

Chairs were also asked to comment on lessons learned about implementation, what more needed to be done, and how to measure results. Key themes around major accomplishments emerged from these engaged leaders, as they discussed the ACT on Alzheimer’s initiative and the activities of their respective Leadership Groups. These included:

- **Structure/Process** - The structure/process of ACT itself (built on the foundation of voluntary, collective action which is not owned by any single organization), as well as the caliber and credibility of the people involved—were two factors instrumental in getting people to come to the table and stay involved.

- **ACTion Communities** - The 34 ACTion communities—each working through a community engagement and action planning process around dementia capability—were the most tangible and visible outcome of the work overall.

- **Tools/Resources** - The prolific development and then testing/piloting of tools and resources was notable—much was accomplished in 3+ years.

Collective Action Structure & Growth - One common response was the growth of the initiative in terms of number of people and organizations involved.

> From the beginning with just 20-25 leaders to the present—we much more than tripled the number of people and organizations—this is really significant. The coming together of collaborators; the networking and growth—this is an important outcome.

> I would say I think ACT has been particularly effective in bringing together organizations in the aging and health care communities around the issue of AD – at an unprecedented level. Really extraordinary in bringing organizations together and uniting them around a specific issue. This was a new form of collaboration.

> It is amazing what has been done in a short amount of time; people coming together voluntarily and working in a non-competitive way. This is really impressive.

> The ACT structure itself—right management, getting the right people involved. It’s worked really well. Cut down the noise and the process. The structure liberated folks in the cooperative. I think it’s been inspiring.

The key informant instrument is found in the Evaluation Appendix & Instruments Repository which is a companion document to this report.

**Funding**

A key element, in addition to the volunteer human resources, was the financial support 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 direct. 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.

*A number of those involved in the ACT initiative recognized that there was an opportunity and need to make a difference in communities of color and other groups, particularly those groups that have been traditionally underserved. This includes, for example those who have unique needs or perspectives, such as the deaf community, ethnic minorities, non-English-speaking communities. We identified and recruited people to participate from these and other diverse communities. We came together. We had to create some momentum, since we had not been part of the Leadership Council from the beginning.*

The work of these members also helped launch additional ACTion communities, such as the Dr. Solomon Carter Fuller and the Latino Collaborative communities.

*We are learning more about each community and its unique issues and challenges. For example, the Somali community, the Latino community—how they see and deal with or interpret memory loss and dementia. This led us to see how communities share information and how they discuss this issue. The Community Toolkit and the typical presentation and process may not work for all.*

**Communication, Outreach & National Visibility/Influence**

The ACT initiative worked extensively to push content out beyond the state boarders—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, the National Alzheimer’s Project Act Advisory Council, 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 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. This is an example of leveraging for systems change (Meadows, 1999).

In 2015 the National Institute on Aging (NIA) and the Health Resources and Services Administration (HRSA) included both the *ACT on Alzheimer’s* dementia curriculum and the provider practice tools on their websites, directing users through hyperlinks to the *ACT on Alzheimer’s* webpages to download these resources (see:
In July 2015 the “Dementia Friendly America Initiative” was announced at the White House Conference on Aging, with a charter and commitment as follows: “To foster livability and vitality, communities must be equipped to support people with dementia and their family and friend caregivers by becoming ‘dementia-friendly.’ A dementia friendly community is informed, safe, and respectful of individuals with dementia and their families, provides supportive options, and fosters quality of life.”

The Dementia Friendly America Initiative (DFAi) acknowledges the contributions of ACT on Alzheimer’s and its tools and resources as the foundational model for DFAi. The ACT on Alzheimer’s executive lead, Olivia Mastry, is serving as a strategy consultant for DFAi. All of the tools and resources developed by ACT are on the DFAi website as open source and available to the public. The initiative is building off of everything learned in Minnesota—including the collective action, communication, pilot communities, and funding strategies. The DFAi website includes a long list of supporting organizations. DFAi has begun selecting communities nationwide to serve as their pilot communities (see: http://www.dfamerica.org/). See Figure 9 for potential DFAi communities.

Figure 9. Potential Dementia Friendly America sites – as identified in June, 2015
<table>
<thead>
<tr>
<th>Group/Goal</th>
<th>Activities/Focus of Work</th>
<th>Outputs/Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Awareness – Raise awareness and reduce stigma</strong></td>
<td>Develop and orchestrate key messages about the initiative and create identity components and communication vehicles to ensure consistency and to disseminate information and tools. Provide input on the tools and products being developed by other Leadership Groups. Build awareness in Minnesota and beyond via media outlets/formats and through state and national/international groups working on issues of Alzheimer’s disease. Support ACTion communities visibility/outreach. Push content out into Minnesota and beyond – especially to national advisory groups.</td>
<td>Changed name from <em>Prepare Minnesota for Alzheimer’s 2020</em> to <em>ACT on Alzheimer’s</em>. Created logo &amp; key graphics. Created website as the primary information source and dissemination vehicle. Issued guidelines to maintain consistency in look, feel, and messages across ACT products and ensure appropriate use of the ACT logo. Created templates to support work of ACTion Communities, such as fliers, press releases, and other materials and supported communities to achieve extensive local, regional, state coverage, as well as national and international coverage. Created FaceBook page and Twitter. ACT on Alzheimer’s was awarded the 2013 Age Odyssey Policy Award by the Minnesota Board on Aging. ACT on Alzheimer’s was awarded the 2014 Rosalynn Carter Caregiving Award for Policy. Information and tools provided to: NAPA, HRSA, NQF, ACL, and other national bodies and groups.</td>
</tr>
<tr>
<td><strong>Detection/Health Care</strong></td>
<td>Create a “Compelling Case” for early detection. Develop a practice algorithm for providers on pathway from screening to diagnosis, to follow-up. Identify ways to incorporate the practice algorithm into electronic medical record systems. Develop a resource to guide Care Coordinators. Develop Community Based Organization resource on Mini-Cog screening. Develop “Dementia Curriculum” as educational modules for training students (medicine, nursing, social work, etc.) Work with MDH on Health Care Homes – to provide input into certification standards and Learning Collaborative conferences/sessions Developed training videos, webinars, slide decks, and launched an in-person training option, for a modest fee, with ability to customize training for a health care organization</td>
<td>A Full array of provider practice tools was developed. After a Diagnosis <em>(Rev. 12/01/14)</em>. Clinical Provider Practice Tool <em>(Rev. 02/18/15)</em> and training videos and webinars. Care Coordination Practice Tool <em>(Rev. 02/18/15)</em> and training videos. Community Based Service Provider Practice Tool <em>(Rev. 02/18/15)</em>. Dementia Curriculum. Dementia Trainings for Direct Staff <em>(Rev. 06/08/15)</em>. Electronic Medical Record (EMR) Decision Support Tool, including the EMR Decision Support Tools Template <em>(Rev. 02/16/15)</em> and a Guide to Implementation 01/2014). Managing Dementia Across the Continuum Practice Tool <em>(Rev. 06/10/14)</em>. Collaborated with MDH to conduct educational sessions for Health Care Home Learning Collaborative conferences (held in 2013, and 2014). DHS incorporates the ACT on Alzheimer’s provider practice tools into the2013, 2014 &amp; 2015 Community Services/Service Development (LiveWell). DHS/MBA issues RFP to further the ACTion communities, with $750,000 of new funding approved by the MN State Legislature in May, 2015. Collaborate with University of Minnesota and Mayo regarding their use of the Dementia Curriculum in teaching/training students. On the national level, working with the Health Research and Services Administration (HRSA) incorporating the ACT on Alzheimer’s dementia curriculum to create a national dementia curriculum, as required by the National Alzheimer’s Project Act Plan.</td>
</tr>
</tbody>
</table>
Progress at a Glance - *ACT on Alzheimer’s* Output 2012-2015 - continued

<table>
<thead>
<tr>
<th>Group</th>
<th>Activities/Focus of Work</th>
<th>Outputs/Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Investing/Economic</strong></td>
<td>▪ Develop economic model to test/demonstrate the impact of using evidence-based dementia care interventions on health care costs</td>
<td>▪ Economic Model developed using the New York University Caregiver Intervention which can be used in the future to study other evidence-based interventions ▪ Article published in <em>Health Affairs</em> showing a potential cost savings of $1 billion to Minnesota taxpayers and families. Article later receives recognition from the editors of <em>Neurology Today</em> as “truly revolutionary” work.</td>
</tr>
<tr>
<td><strong>Communities</strong></td>
<td>▪ Create a Toolkit and process to guide geographic or communities of interest to gauge their current strengths and gaps in being “dementia-capable” ▪ Pilot the Toolkit; make revisions ▪ Assist Minnesota communities who step forward to use the toolkit towards becoming “dementia-friendly”</td>
<td>▪ <em>Dementia Capable Communities Toolkit</em> developed &amp; tested (2012/2013) ▪ Toolkit revised (2013/2014) ▪ 34 ACTion Communities in process of using the Toolkit –Funding (small grants) for these provide support for admin and supplies costs ▪ Area Agencies on Aging and Alzheimer’s Assn provide technical assistance ▪ ACTion Communities Learning Collaborative ½ day sessions held (2 or 3 per year) to encourage cross-site exchange of ideas and lessons learned ▪ Working with NAPA Advisory Council to support 15 communities that would use the tools and community engagement process ▪ Launch Dementia Friends America Initiative for national use of the Toolkit and process</td>
</tr>
<tr>
<td><strong>Caregivers</strong></td>
<td>▪ Provide expert input to MN Board on Aging and Dept of Human Services regarding enhancements to training and MinnesotaHelp.info® resource ▪ Work with Detection/Health Care group to developed a tool to coach caregivers through the journey ▪ Advise other groups, as asked</td>
<td>▪ Enhanced training for Area Agency on Aging staff which is now incorporated (embedded) in training for all SLL call center staff ▪ On the provider portal of MinnesotaHelp.Info, added additional options for providers updating their information to indicate dementia programs, a “finder” function for users, and info on dementia-trained staff ▪ “After the Diagnosis” resource developed, edited, printed and available on the ACT website</td>
</tr>
<tr>
<td><strong>Cultural and Linguistic Communities Committee; renamed Health Equity</strong></td>
<td>▪ Focus attention on diversity; work to enhance the work of ACT that includes a “health equities” lens ▪ Review work of other ACT Leadership Groups and provide feedback ▪ Develop vision and “Call to Action” for health equity to add to the ACT goals and vision ▪ Provide guidance to ACT Leadership Council ▪ Support work to fund diverse ACTion communities through grant process</td>
<td>▪ Identified/recruited members from cultural communities to form a Health Equity Leadership Group ▪ Created document titled “Preamble” which outlined principles and values in fostering health equity in dementia-related care and activities – then a “Call to Action” ▪ Worked with ACT staff to redesign ACT logo to include vision of health equity ▪ Health Equity embedded as a fundamental value and goal in ACT initiative ▪ Met with chairs of other Leadership Groups about adding health equity information, principles, and questions for consideration in their tools and products ▪ Supported funding applications for culturally-specific dementia-friendly community work (3 created); also included representation in multiple ACTion communities to increase diversity and representation. ▪ Leadership Council dedicated to health equity – May/June 2015.</td>
</tr>
</tbody>
</table>

**Outcome Indicators Revisited**

As described earlier in this report, several “reach” longer-term outcome indicators were offered by the ACT leads/staff in 2013 to be considered as potentially able to be met by the end of 2015. These indicators are revisited in Table 13.

<table>
<thead>
<tr>
<th>Focus Area: Health Care Practice Tools &amp; Curriculum</th>
<th>“Reach” Indicators offered in 2013:</th>
<th>Results as of 2015:</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ 60% of organizations/individuals involved in the ACT initiative have used ACT tools</td>
<td>▪ While evidence does not support this goal of 60% of Minnesota health care organizations (that have been involved in ACT) using the ACT tools within their settings, information from those involved in the initiative does show nearly all have utilized other ACT products and resources—both professionally and personally. Furthermore many organizations and health care professionals have been exposed to the tools statewide—far beyond those involved in ACT. Finally, two major health care systems are embedding these tools, and additional organizations are working toward adoption.</td>
<td></td>
</tr>
<tr>
<td>▪ 20% of relevant organizations (e.g., health care providers, community based organizations) involved in ACT are adopting/embedding the tools and/or training</td>
<td>▪ Several instructors/faculty members are using the curriculum. The potential for additional use is high, as HRSA incorporates the ACT dementia curriculum into work on a national basis.</td>
<td></td>
</tr>
<tr>
<td>▪ At least 25 certified health care home clinics have adopted the ACT provider practice tools</td>
<td>▪ The ACT Toolkit was developed and piloted.</td>
<td></td>
</tr>
<tr>
<td>▪ Of the clinics that adopted the tools, there is a demonstrable increase in the number and rate of persons identified with AD</td>
<td>▪ Based on the 4 community pilot, the Toolkit was revised and edited.</td>
<td></td>
</tr>
<tr>
<td>▪ At least one major institution has adopted the dementia curriculum</td>
<td>▪ Many instructional guides, videos, and other technical assistance, including in-person resources through the AAAs and the Alzheimer’s Association were added to support new communities as they used the Toolkit in their community engagement process.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Focus Area: Communities</th>
<th>“Reach” Indicators offered in 2013:</th>
<th>Results as of 2015:</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ New communities begin using the ACT Toolkit and experience a streamlined process/experience as compared to pilot communities</td>
<td>▪ It appears that all ACTion communities that moved through the “action” phase of the process have undertaken at least one step that they intended, following their assessment and analysis.</td>
<td></td>
</tr>
<tr>
<td>▪ ACTion communities undertake at least one priority action step following community assessment</td>
<td>▪ ACTion community team members report increased awareness and knowledge of AD issues; however there is</td>
<td></td>
</tr>
<tr>
<td>▪ ACTion communities report increased knowledge/awareness of AD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Communities report an increase in the resources and services available to persons with AD or AD caregivers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
| | no data on community-wide knowledge change, as methods and measures for assessing this have not yet been determined.  
  - ACTion communities report that they have better lists or directories of local resources and services available to support persons with AD or AD caregivers, however there is no data to indicate that there is a wide-spread increase in resources and services being developed—though this is happening in some communities.  
  - Many community awareness building and educational efforts have occurred and are uniquely led or crafted by the community team involved.  
  - There are a few reports of additional services for caregivers, but this is an area for further work. |
| **Caregivers** |  
  - There is statewide dementia training for caregiver consultants  
  - At least 50% of Senior Linkage Line call center staff have received basic dementia training  
  - At least 25 community based organizations (with Caregiver Consultants) have been trained  
  - Caregivers report that the statewide database is supportive of AD caregivers |  
  - There has been statewide dementia training for caregiver consultants—supported by the Minnesota Board on Aging—and this state agency has utilized the ACT dementia tools and curriculum to modify its training.  
  - Senior Linkage Line staff members do have access to basic dementia training statewide.  
  - Evidence suggests that at least 25 caregiver consultants have been trained in dementia issues  
  - Caregivers involved in ACT did participate in discussions to improve the statewide database. There is no data publicly available to support any additional conclusions (i.e., that Minnesota caregivers do or do not find the database supportive of their needs) |
| **Investment in Promising Practice** |  
  - At least one health plan is paying for the evidence-based practice that was modeled as having cost savings through the ACT economic model |  
  - As of October, 2015, no Minnesota health plan has chosen to cover the NYUCI intervention that was modeled through the economic model development funded by ACT. However, the State of Minnesota does allow Title III-E Caregiver Support Services providers to include this intervention as one of the services that meets the definition of caregiver counseling and education. |
**Leahs Insights**

Leaders within the initiative have recommended the following steps for the next phase in the life of this initiative:

(Source: Paone, D. 2015 – ACT on Alzheimer’s Leadership Group Chairs: Perspectives)

- Wrap in the *health equity lens* to modify/revise the tools and resources and ensure they are accessible and inclusive and engage more *individuals at a grassroots* level, especially persons of color and from diverse groups
- Enhance the *caregiver supports*—throughout Minnesota
- Foster *implementation* with technical assistance and guidance so that they are embedded into practice settings and communities
- Provide support to ACTion communities for *sustaining* their work
- Provide guidance around *evaluation* of impact

Comments were offered through key informant interviews on what should come next:

>The caregiver support pieces—this has not materialized as hoped—so we have work to do to ensure that the Minnesota caregivers experience enhanced support and guidance. There is always need for more training and keeping that going as staff turnover will always be occurring.

What we haven’t really done yet is understand what knowledge and resources can and should be embedded in the community. For example, identifying memory issues is not only the purview of the doctors—it is the community. There is a lot of community wisdom that should be more fully developed. We need to engage the family members, social service agencies, etc. It is about noticing and providing supports, not only running to the doctor to get a diagnosis. We need to talk and work more on this; especially in the non-medical arena. We need to broaden our approach and our tools. We can learn from these communities about how they support their elders and how they come together and how they cope—and strengthen those things.

The health equity work itself is one of the most significant things that happened. We are starting to see more attention to this—for example the Health Equity Report that came out of the Minnesota Department of Health. The blind spots are starting to be pointed out, and starting to be addressed. There is “intentionality” to that—which is huge. This only came about because the whole group was committed to a democratic and collaborative process with open dialogue—and a willingness to hear various
perspectives. Traditional ways of having one agenda and staying action-directed may not fit the grassroots and more relationship-based, informal, discussion-style nature of ethnic and diverse communities.

There is work to be done on a few fronts. For example, we have to learn what are the effective mechanisms from bring the provider practice tools into actual practice.

I would say on the practice tools, to have the number of health systems that are using them. It would be good to have each health system or provider have a base rate of # of people diagnosed—and compare before the implementation of the practice tools to after the use—to see if the # of people diagnosed increases. So measures would be the # of clinicians and # of clinics using the tools.

The issue in these 34 communities and beyond is how to sustain action. What happens after the ACTion item is completed, and grant ends (after Phase 4). Communities are starting to talk about this – sustainability is an issue.

We absolutely have to keep this going. We need at least a couple of years to learn how to successfully embed these tools in organizations and communities. We’re going to need the collaborative overall structure to keep having us come together—otherwise it’s too easy to default to our silos. We need a core administrative/project management/logistics driver keeping it all together.
Discussion

Collective Action/Structure

This issue was and is important to many individuals, groups, and organizations. The structure of ACT on Alzheimer’s with five clearly-defined goals, shared ownership, and strategically selected individuals/organizations created the environment that led to significant investment of time and money. The effort built off of a robust working group (the ADWG) and directly tied goals to that work. This lent credibility to the effort.

Extensive engagement of industry leaders and advocates throughout Minnesota far exceeded expectations. There was a high caliber of individuals with professional networks and serving in leadership positions who were invited to participate. More than 600 individuals and 50 organizations are estimated to have contributed—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 shared ownership, buy-in, and engagement strategy were critical factors in achieving this level of involvement. These strategies leveraged system change. As work efforts bore fruit, additional people and organizations from across the state got involved by invitation or at their own request. The management team, while stretched to respond to the growing interest within the state, successfully organized their human resources and/or contracted with experts and consultants as needed.

Funding/Visibility

The five goals helped focus and set parameters for the work. Funders were attracted to the goals and purpose. Significant development of products and tools occurred through the volunteer member working groups—together with contracted, targeted expertise which was funded through short-term consultation assignments. Funders and those involved could see tangible practice-based output of the collective work and the caliber of individuals and organizations involved. This in turn increased visibility and attracted additional funding to achieve specific work products.

The development of professional communication pieces and the website were also key levers that helped the initiative gain visibility and credibility. The communication efforts proactively pushed information on products and accomplishments out to an increasingly widening distribution list. This was a critical strategy, to raise visibility. This reflects an understanding of how to diffuse innovations (Rogers, 2003). Eventually, the initiative gained national attention which continued to attract more involvement in Minnesota by individuals, organizations, community representatives, policymakers, and funders.

Action Communities

The work by the voluntary ACTion communities was extensive within Minnesota. The four steps for community engagement that were set forth worked well. The scripted process made intuitive sense: (1) convene key community leaders and members to understand the disease and its
implications for communities, (2) inquire about current strengths and gaps in meeting needs
arising from Alzheimer’s disease and related dementias using a community assessment process
and tools, (3) analyze priorities and identify possible ways to respond, and (4) act together to set
goals, plan, and engage.

Another effective strategy was to extend the work statewide through small seed grants made to
communities who agreed to use the ACT on Alzheimer’s Dementia Capable Communities Toolkit
and scripted community-engagement process. Grant funding and structured technical
assistance allowed more than 30 communities to be supported over two years (2014-2015). This
far exceeded initial expectations. Having this extend statewide brought the whole initiative
additional attention and helped as a dissemination vehicle for the products and resources.

There is more to do to ensure that the ACTion communities can make the most of time and
money invested and to refine tools so that they wrap in learning from the field. Further work is
needed on how to maintain community engagement (sustainability) and evaluate/measure
impact. Research and practice literature offers guidance (Scheirer, 2005; Pluye et al., 2005;
Shediac-Rizkallah & Bone, 1998). Communities are looking for technical and funding support
and guidance in these areas.

Health Care

Through involvement of many experts, organizations, and targeted outside funding, evidence-
informed practice tools and resources were created for use in the health care field. In addition,
training and educational resources were developed to support adoption. The work was also
highlighted in state agency conferences, provider educational meetings and through multiple
training sessions held at health care organizations and other institutions. In the initial logic
model for this component, the evaluator identified a few possible markers for outputs related to
adoption/implementation such as:

- The tool/curriculum/resource is successfully integrated into the processes of the
  organization (e.g., is written into the electronic record, added to the protocol, part of the
  required training, incorporated into the educational modules, etc.);
- A set of individuals, such as physicians, students, staff, etc. experience use of the tool or
  curriculum and early response is positive;
- Post-use data analysis shows a benefit to using the tool or resource, as compared to a
  baseline before use.

These anticipated “outputs” are starting to emerge. In the two organizations that are farthest
along (HealthPartners, Essentia Health), it appears that the ACT health care practice tools have
been embedded into the EMR. The providers within these organizations are receiving training
and education to encourage detection and practice change (e.g., follow-up and referral). Self-
reports by champions in these organizations indicate that early response is positive. Each
organization is currently examining their data to determine results of these efforts.

Within Minnesota, many clinics and health care professionals have been exposed to the ACT
provider practice tools through purposeful dissemination efforts. However, adoption and
implementation of these health care tools and dementia curricula is not widespread. Adjunct
faculty and instructors from several educational institutions, such as the University of Minnesota, report that they are using the dementia curriculum in their courses as they teach medical students. The extent of the use of the curricula outside of these instructors is not known.

Early implementation efforts in health care organizations suggest several important factors, such as a visible champion(s), top leadership support, and organizational-specific data analysis to demonstrate the potential value to the organization and practitioner of the tools and practice changes required to use them. Dissemination and implementation is a current and ongoing area of focus for this working group that has been leading the effort to develop the health care tools.

Policy Influence

ACT members created an economic model and utilized the model to conduct an analysis of one intervention (New York University Caregiver Intervention) showing cost savings to Minnesota. Authors published the findings in a credible industry journal (Health Affairs). The State included this intervention as a covered service under the Title III-E Caregiver Services and Supports service 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 chose to cover this intervention within their product lines of business, and the cost savings did not accrue within the timeframe parameters to allow this intervention to be included under Medicaid.

ACT gained significant traction on a national basis as well—in terms of influencing work planned or underway by organizations such as HRSA, NAPA, NQF, and other organizations as described. Although this was beyond the scope of the original focus on Minnesota, it highlighted the state’s efforts in front of many influential groups and experts, and provided additional leverage for systems change.

Top Accomplishments

The evaluation findings point to the top 5 accomplishments of ACT as:

1. Significant involvement of leaders, experts, sectors, communities, and individuals throughout Minnesota who provided thousands of hours of unpaid, voluntary time and expertise in a collective action structured approach
2. Securing $2 million in funding to support the work
3. Voluntary engagement of 34 communities in Minnesota working at the grassroots level and utilizing the Dementia Capable Community Toolkit (also a significant work product of the initiative)
4. Development of health care practice tools and resources such as training modules, videos, webinars, and other materials to support adoption of these tools
5. Robust communication and effective use of all type of media to raise visibility of the effort — well beyond the state of Minnesota—which led to policy influence at the national level and additional funding.

Key factors around the success of this effort as observed were:

- Issue of importance to many
Extensive voluntary engagement by individuals and organizations of high credibility and caliber through personal invitation

A management structure that supported action and the member working groups

Funding

Robust communication and efforts to use all types of media and outreach to raise visibility of the effort

Tools development and dissemination

The importance of having a collective action management structure that engages volunteerism as well as core funding—as happened in the first phase of this effort—cannot be overstated. This structure seems to have been a critical ingredient. It is unclear how the initiative would move forward without it.

**Next Stage Efforts**

Based on the evaluation findings, the next stage in the development toward goals would focus on:

1. *Implementation Support* - Attention to implementation so that the tools are implemented and the benefits are realized (there is a strong body of research and practice on how to effectively implement and embed innovations/new practices).

2. *Robust Evaluation Approach* - Need for an overarching evaluation approach that is supported—at the community and organizational level—to set measures and methods for discerning changes as a result of efforts. This includes evaluation support to guide the communities and organizations in what can be measured, how, when, and how to learn from each other so that it is incorporated back into the next stage of work. This would include qualitative and quantitative methods in order to provide a more complete picture of effect.

3. *ACTion Community & Peer Learning Support* - Continued support to communities that have reached and completed Phase 4—they need additional support and guidance to move to the next stage and re-form/transform or continue to move ahead on their action plans. They also represent a rich source of knowledge and information on how to work at the grassroots level and about strategies and techniques and activities that were successful. This knowledge should be captured and shared.

4. *Developing Caregiver Supports and Meaningful Engagement Services* - A greater focus on growing the supports, services, and meaningful engagement programs for persons with the disease and for caregivers. This may involve funding, policy/advocacy, and technical assistance. As others have stated, if this doesn’t reach the person with the disease and his/her caregiver, what has been accomplished?

5. *Inclusive Engagement* - Greater attention to how to effectively engage and support diverse communities as well as caregivers and persons with the disease. This may include offering additional resources in order to reach these individuals and support their ability
to become involved or stay engaged. Their representation will enhance the final work products and infuse the effort with important perspectives.

Closing Thoughts

Evaluation of community coalitions presents special challenges. Since the coalition often relies heavily on volunteer time of those engaged, the infrastructure, planning, and reporting capacity may be under-resourced. As the coalition members meet, discuss, and welcome new members, the purpose, activities, and scope may morph or become scattered. Evaluating the effort is difficult as plans evolve. Initial goals, objectives, and measures put forth may be found to be too lofty or not on target. If evaluation questions, focus areas, measures, and data collection efforts have been crafted around these initial goals/activities, then the evaluation will increasingly seem irrelevant to the coalition members. Furthermore, evaluation is seldom incorporated into the work of the coalition as a key output of the group. It may be relegated to one individual or left to the end of the work effort (Francisco, Paine, and Fawcett, 1993; Fitzpatrick, Sanders, and Worthen, 2011).

On the positive side, formative evaluations are meant to evolve with the initiative. As “snapshots” of progress are taken and discovery of challenges or successes occurs, this information is fed back into the group. In this way the evaluator is a full member of the core team.

Based on information from the key informant interviews, community coordinators, learning collaborative participant feedback, Leadership Group chairs, and others—it appears that many of those involved in this initiative are ready to measure progress in a more structured way. A working group around evaluation met four times between April and July 2015 to begin the thinking and discussion necessary to build a cohesive approach with sound measures and data sources. However, voluntary engagement of members from all the Leadership Groups as well as funding would be needed to support work on this component. There is a window of opportunity to build consistency across communities and organizations, employing meaningful measures and standardized methods.

Focus areas suggested for further evaluation of this initiative have been suggested within this report. In particular:

- measuring the synergy and development of community coalitions/teams working on this issue as they sustain effort and what builds their capacity to be successful,
- examining the increase in identified local caregiver supports and meaningful engagement programs for persons with AD in the given communities over time,
- examining how health care practice tools are being embedded within Minnesota primary care clinics and other settings,
- tracing the rise in detection and referral to community services, and
- calculating the resources (e.g., in-kind time, dollars) devoted to working collectively across silos and addressing the effects of this disease in communities.
These are some possible indicators of progress that could show trends over time toward stated goals.

One key issue that coalitions and organizations will continue to face is that of attribution of the observed results to the efforts of ACT on Alzheimer’s. Many of the activities described in this report had deeper roots—a longer time history—that emerged from complementary efforts. In addition, many organizations, such as clinics, senior housing organizations, community social service agencies—had previously begun to address dementia training or capability in their settings and will continue to do so. ACT made the most of these existing efforts. Though the issue of attribution to the ACT on Alzheimer’s effort (cause and effect) may be difficult to ascertain, perhaps this is not critical. As long as implementation is fostered in these focus areas and periodic snapshots of progress show desired improvement—then there is benefit. To determine the critical success factors that were necessary ingredients of that improvement can be the focus of a more in-depth evaluation.
Conclusion

Community coalitions are described as alliances for a common purpose. The story of ACT on Alzheimer’s is one of collective action among individuals and organizations --willing to be engaged for an extended time period around an important issue. This willingness, collective accountability, strong project management, skilled communication, and credible tools development, have been the hallmarks of ACT on Alzheimer’s from June 2011 through October 2015. The initiative achieved impressive results in less than four years.

Notable were the 34 Minnesota ACTion communities that came forward to work toward becoming “dementia-capable.” This involved hundreds of people and organizations working together across sectors. The communities relied on hands-on technical assistance as well as videos and tutorials and important peer learning opportunities.

The involvement of individuals in the ACT working groups is now largely completed. The ACTion communities continue their efforts, though their grant funding runs out in 2015. The ACT on Alzheimer’s initiative is evolving. Many individuals have expressed interest in continuing this collective action effort. Funding has been allocated to move some of this work to existing organizations, such as the AAAs and the Alzheimer’s Association, as well as the state government agencies and provider-associated organizations.

Members involved in ACT will determine if they retain some kind of collective action infrastructure to be reconstituted and refocused on next stage development. If they do go forward as a collective action initiative, additional funding would be needed.

The evaluation findings suggest several next steps:

- 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.

In this report, I have utilized the kinds of measures and methods advised by other researchers in evaluating coalitions to document activities and determine progress. I have tapped into several data sources and collected primary data to gather evidence and draw some preliminary conclusions. Methods were largely qualitative, although some quantitative data were available.

The funding of this formative evaluation by a private foundation as requested by ACT leadership demonstrated commitment to documenting progress and feeding it back to participants and community leaders. Hopefully, this evaluation sets a foundation for future efforts.
References


*Paone & Associates, LLC*


ACT on Alzheimer's Final Evaluation Report


ACT on Alzheimer’s Final Evaluation Report


See: http://www.actonalz.org/evaluation%20reports

These reports and materials were produced by Deborah Paone and colleagues of Paone & Associates, LLC, under contract with Presbyterian Homes and Services which acted as the fiscal agent for ACT on Alzheimer’s® for the evaluation from 2013-2015. Funding for this evaluation was provided by the GHR Foundation. This was a formative/process evaluation to assist ACT project leads to take stock of progress, capture lessons learned, and adjust their course of action, if needed. The Evaluator previously was a participant in a Leadership Group and in the Leadership Council of the ACT on Alzheimer’s initiative from 2011-2013, and was, therefore, familiar with the components. She also co-led one of the 34 ACTion communities (Edina) through the community engagement process (2014-2015). This provided significant advantage as an embedded evaluator for conducting the examination and interpreting the results.

<table>
<thead>
<tr>
<th>#</th>
<th>Title of Report/Document (not same as pdf filename)</th>
<th>Date</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Logic Model for Adoption of ACT Practice Tools &amp; Curricula</td>
<td>May, 2013, revised January, 2014</td>
<td>One slide graphic (in PowerPoint) – provides a simplified depiction of a logic model for the adoption of ACT on Alzheimer’s practice tools and resources. Includes assumptions around (1) context, (2) implementation, and (3) outcomes - short-term effects and longer-term impact.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Four Pilot Communities: Willmar, Walker, St. Louis Park and Jewish Community: These are the four pilot communities that provided comment on a draft of the ACT on Alzheimer’s Dementia Capable Community Toolkit and used it to conduct a community assessment process. Each formed a community working group. They conducted assessments of dementia awareness, strengths and gaps within different sectors of their community. This was done in a piecemeal fashion, since the sections were being written as the community went along. The groups offered many recommendations to the ACT Toolkit designers, which were then incorporated into the next version of the resource.</td>
</tr>
<tr>
<td>2.</td>
<td>ACT of Alzheimer’s Pilot Community : Willmar, MN</td>
<td>June 2013</td>
<td>Report -This report describes the work of a community team from Willmar (MN), one of four pilot communities. The group began their work in 2011. Challenges and successes were shared.</td>
</tr>
<tr>
<td>3.</td>
<td>ACT of Alzheimer’s Pilot Community : Walker, MN</td>
<td>June 2013</td>
<td>Report - One of four pilot communities. Walker (MN)’s experience from 2012 through early 2013 is profiled. Challenges and successes are reported.</td>
</tr>
<tr>
<td>4.</td>
<td>ACT of Alzheimer’s Pilot Community : St. Louis Park, MN</td>
<td>June 2013</td>
<td>Report - St. Louis Park (MN) community team was one of the four pilot communities. The report describes their work, accomplishments, and barriers.</td>
</tr>
</tbody>
</table>
5. **ACT of Alzheimer’s Pilot Community: Twin Cities Jewish Community**
   - June 2013
   - Report - The Twin Cities Jewish Community is a community of affinity, and was another pilot community. This report describes how members were highly engaged in reaching out to the rabbinical community as they used one survey section and a portion of the draft Toolkit. Challenges and successes are offered.

6. **Pilot Communities’ Use of the Dementia-Capable Communities Toolkit: Composite report**
   - June 2013
   - Report - This report synthesizes the results across the four pilot communities that helped develop and test the ACT on Alzheimer’s Dementia-Capable Communities Toolkit. The report identifies common findings and themes, and offers lessons learned and advice/tips for other communities interested in conducting this community engagement process. The report also includes each individual community report to provide more detail.

7. **Use of Dementia-Capable Community Toolkit: Evaluation**
   - July 11, 2013
   - PowerPoint - This slide deck was presented as part of the orientation and early work of the fifth ACT on Alzheimer’s community—the St. Paul Neighborhoods Community Action Team. It offers learning from the initial four pilot communities.

8. **Framework for Examining ACTion Communities – Paone, 2013**
   - Sept (Revised Dec) 2013
   - Word document - This document lays out a framework and the Evaluator’s assumptions underlying the formative/process evaluation around measuring progress of the ACTion communities.

9. **Logic Model for Dementia Capable Communities, ACT on Alzheimer’s 2013-2015**
   - December 2013
   - One slide graphic (in PowerPoint) - This graphic provides a simplified depiction of a logic model for ACT of Alzheimer’s communities working with the Dementia Capable Communities Toolkit. The model lays out assumptions about issues and factors around: context, implementation (activities and outputs), and short and longer term outcomes expected as the communities work through their community engagement process.

10. **Dementia Capable Communities – Sharing Learning to Date**
    - January 22, 2014
    - PowerPoint - This slide deck was part of a webinar presentation to the Minnesota Area Agencies on Aging to support them as they were oriented to the ACT on Alzheimer’s Dementia-Capable Community Toolkit. Lessons learned from the four initial pilot communities were shared.

11. **St. Paul Neighborhood Consortium ACT on Alzheimer’s Dementia-Capable Community ACTion**
    - February, 2014
    - Report - Six St. Paul neighborhoods formed the fifth community (St. Paul Neighborhoods Action Community Team) using the Dementia Capable Communities Toolkit. This report describes the first phases conducted in 2013, including:
### Team (SPN-ACT): Report on 2013 Progress

Convening, conducting surveys in a community engagement process, reviewing results, and identifying priority areas for action. Two priorities included: (1) raise awareness about community resources through creating a St. Paul-specific, culturally appropriate resource package, and (2) improve community members’ skills/knowledge about the warning signs and how to interact with people with dementia—through *Dementia Friends* training sessions.

### 12. SPN ACT Progress Update & Evaluation Next Steps

**February, 2014**

**PowerPoint**

This slide deck was presented to the St. Paul Neighborhoods Action Community Team (SPN ACT) and the community at large to provide a progress report. The deck also describes a self-assessment survey that would be electronically distributed to members. The purpose of the survey was to take stock of the functioning of the team itself, to help the Coordinator make any mid-course corrections needed.

### 13. Survey of Participants as “Early Adopters”

**May, 2014**

**Report**

This report provides findings from a survey of individuals involved in *ACT on Alzheimer’s* working and strategy groups. The survey was conducted to capture information about how the ACT on Alzheimer’s initiative had impacted individuals active in this initiative, and whether they had adopted or used its products, tools and resources. Respondents included those who were in the Leadership Groups, Leadership Council/Executive Committee, Management Steering Committee, and other sub-Committees or working groups. It was assumed that these participants represented “early adopters” of the ACT-developed tools and resources. Overall, responses were positive. The report provides a picture of engaged individuals who had provided significant time, content expertise, and energy toward developing the resources generated by the initiative, as well as bringing others into the work and making the work known.

### 14. Self-Assessment Survey Results by Saint Paul Neighborhoods ACTion Team (SPN ACT) March-May, 2014

**July, 2014**

**Report**

This report provides the results from the self-assessment survey conducted of one community’s (SPN ACT) team members. The content for the survey development was based on research literature related to how effective coalitions function and what factors drive success. Thirty-two active SPN ACT members responded. Results showed strong positive feedback on members’ understanding for the purpose of the work, and support for how the effort had been organized, their opportunity for involvement, and the
<table>
<thead>
<tr>
<th></th>
<th>ACT on Alzheimer's Final Evaluation Report</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.</td>
<td>ACT on Alzheimer's Dementia Capable Community: Report on Progress, Cambridge, MN</td>
</tr>
<tr>
<td></td>
<td><strong>Report</strong></td>
</tr>
<tr>
<td></td>
<td>This report provides information on the Cambridge (MN) Action team which began its work in May, 2013. Two Coordinators worked with a team of more than 23 individuals. The team completed the first three phases of work by mid-2013, and members were ready to focus their attention on priorities for action. These priorities included (1) providing information to health care providers to enhance their ability to offer information and follow-up resources immediately after diagnosis, and (2) working with first responders.</td>
</tr>
<tr>
<td>16.</td>
<td>Overview &amp; Update on ACT on Alzheimer's Formative Evaluation</td>
</tr>
<tr>
<td></td>
<td><strong>Word document</strong></td>
</tr>
<tr>
<td></td>
<td>This document provides an abbreviated (3-page) update and synthesis of findings to date from the evaluation through late 2014.</td>
</tr>
<tr>
<td>17.</td>
<td>SPN ACT Dementia Training Evaluation and Trainers’ Survey (2014)</td>
</tr>
<tr>
<td></td>
<td><strong>PowerPoint</strong></td>
</tr>
<tr>
<td></td>
<td>This slide deck describes results from the Dementia Friends training session evaluations (N=42) and the Dementia Champions training sessions (N=27) through late 2014. All training sessions were conducted as part of the SPN ACT community action team work. Responses describe motivations of individuals who signed up for training, as well as their suggested changes to the content or format of the training, challenges and successes they’ve had, lessons learned, and what they have observed regarding impact to date.</td>
</tr>
<tr>
<td>18.</td>
<td>ACT on Alzheimer's Leadership Group Chairs: Perspectives</td>
</tr>
<tr>
<td></td>
<td><strong>Report</strong></td>
</tr>
<tr>
<td></td>
<td>As part of the ACT on Alzheimer’s formative evaluation, key informant interviews were conducted between late October and December of 2014 with the ACT on Alzheimer’s Leadership Group Chairs. Each Leadership Group (there were six groups) had a defined purpose and focus, with volunteers (group members) from various service sectors, government agencies, educational institutions, industry leaders, and community leaders as well as individual caregivers or residents. The individuals serving as Leadership Group Chairs had been involved in the ACT initiative for at least three years. The interviews were to capture insights from these engaged members on the work and the results that had been achieved, as well as lessons learned about communication. Most said that they were committed to staying involved.</td>
</tr>
</tbody>
</table>
implementation and what more needed to be done. Key themes emerged from respondents, as they discussed the ACT on Alzheimer’s initiative and the activities of their respective Leadership Groups. These themes included: strength of the collective action structure and process, identification of the engagement of 34 communities as the strongest and most tangible output of the work to date, prolific development of tools and resources, and need to continue the work.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>19.</td>
<td><strong>St. Paul Neighborhoods Action Community Team (SPN ACT): Report on Progress – Snapshot #2</strong></td>
<td>March, 2015</td>
</tr>
<tr>
<td>20.</td>
<td><strong>SPN ACT: Evaluation Results</strong></td>
<td>March, 2015</td>
</tr>
<tr>
<td>21.</td>
<td><strong>ACT on Alzheimer’s Evaluation: Caregiver Focus Group Report</strong></td>
<td>May, 2015</td>
</tr>
<tr>
<td>22.</td>
<td><strong>ACT on Alzheimer’s Community - Dr. Solomon Carter Fuller (North Minneapolis): Activities &amp; Progress as of May, 2015</strong></td>
<td>June, 2015</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td></td>
<td>toward building community awareness and to increase the availability of local resources that address Alzheimer’s disease in the African-American community.</td>
</tr>
<tr>
<td>23.</td>
<td><strong>ACT on Alzheimer’s Community- Latino Collaborative: Report on Activities &amp; Progress June 30, 2015</strong></td>
<td>June 30, 2015</td>
</tr>
<tr>
<td>24.</td>
<td><strong>Minnesota Council of Churches ACTion Community Progress Report</strong></td>
<td>September, 2015</td>
</tr>
<tr>
<td>25.</td>
<td><strong>Adoption/Implementation of ACT Tools Case Example: HealthPartners, MN</strong></td>
<td>October, 2015</td>
</tr>
<tr>
<td>27.</td>
<td><strong>Evaluation Appendix &amp; Instruments Repository</strong></td>
<td>October, 2015</td>
</tr>
</tbody>
</table>