St. Paul Neighborhoods’
Action toward becoming a
Dementia-Capable Community
using the
Act on Alzheimer’s®
Community Toolkit

2013 Progress – Phases 1, 2, and 3
Through December, 2013

Prepared by:
Paone & Associates, LLC
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This report

was written by Adine Stokes, LSW, Research Associate, and Deborah Paone, DrPH, MHSA, Principal of Paone & Associates, LLC for the SPN ACT community action team and for additional communities working with ACT on Alzheimer’s, toward becoming a dementia-capable community. It is intended to capture the activities of this community and share observations and lessons learned for others to use in their work.

We acknowledge and thank Georgia Lane, Coordinator of SPN ACT, and the following individuals who provided information for this report:

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Maureen Kenney, Director – Wilder Foundation, Caregiver Services
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ACT on Alzheimer’s® Community:
St. Paul Neighborhoods (Minnesota)

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This Report – Executive Summary

Six St. Paul neighborhoods form one of the communities using the ACT on Alzheimer’s® Dementia Capable Communities Toolkit to identify action steps to help address the impact of Alzheimer’s disease and related dementias. This report describes the first phases of that effort, conducted in 2013.

Data sources included:
- Meeting minutes and agendas
- Assessment survey data
- Key informant interviews conducted from October 18 – December 4, 2013 (in-person and telephone) using a semi-structured interview protocol (N= 6)
- Trend reports from local, regional, and governmental organizations
- Government websites
- The ACT on Alzheimer’s website (www.ACTonAlz.org)

There were nine open-invitation St. Paul Neighborhood Consortium ACTion Community (SPN ACT) working meetings held between the Kick-Off Forum (held on February 12, 2013) and December 17, 2013.

From February to December 2013, the SPN ACT group worked together to work through the ACT on Alzheimer’s Toolkit and process for assessing the current state of the St. Paul neighborhoods “dementia capability.”

More than 350 individuals followed the activities of the SPN ACT effort. Involvement ranged from “information only” participants who kept updated via email communication, to those who attended regular monthly meetings. Approximately one-third (90+ individuals) attended at least one of the nine working meetings.

The meetings’ content corresponded to the process included in the ACT on Alzheimer’s Dementia Capable Community Toolkit. This included: review of the Toolkit, development of lists of names of individuals who could be surveyed using the assessment tools included in the Toolkit, review of the activities completed in-between each meeting (such as the number assessments completed and the service sectors that were surveyed), review of the synthesis and results from all of the assessments, development of priority areas for action (using an iterative voting method during the meetings), and development of a work plan and timeline to launch the priority action item.

Attention from local media increased visibility and community awareness for the effort, possibly strengthening the impact of the SPN ACT group.
Regular meetings for SPN ACT members who lived and worked in the St. Paul community fostered professional and personal connections. Through attending the SPN ACT meetings, participants learned about services and special features or programs that are available to those living in the targeted St. Paul neighborhoods. Residents who are caregivers of an individual with the disease, interested local citizens, and representatives from local faith communities provided unique perspectives in addition to the representatives from local health and social service, housing, and professional service organizations.

Throughout the year, the group continued to identify key stakeholders. They maintained an open invitation approach. By welcoming newcomers and “casting a wide net” the group’s assessments covered many service sectors and included individuals with a variety of skills, knowledge about community resources, and community contacts—including those who might be willing to participate in the assessments.

By September, 127 assessments had been conducted, which were analyzed and presented to the SPN ACT group for discussion. The priority areas that arose were:

- raise awareness of the issue,
- provide more education, and
- foster early detection and diagnosis.

By November the SPN ACT group developed an action plan, reviewing the priority areas and objectives. Short and long-term goals for 2014 were identified, along with a process to accomplish the goals.

The next phase of work for SPN ACT, beginning in early 2014 includes developing and distributing a local community resource repository or list, and preparing community members to be “dementia friends.” Training will focus on how community members can positively interact with and support someone with dementia. A work plan was under development as of early December. Through the work of SPN ACT, the group hopes they will contribute to a safer, more informed St. Paul community.
Background on ACT on Alzheimer’s Initiative

ACT on Alzheimer’s is a volunteer-driven statewide collaboration. It focuses on 5 goals to help prepare Minnesota for the budgetary, social and personal impacts of Alzheimer’s disease and related dementias. The goals include: (1) sustain caregivers, (2) raise awareness and reduce stigma, (3) invest in promising approaches, (4) increase detection and improve care, and (5) equip communities. The initiative was launched in June 2011.

In 2012 a Dementia Capable Communities Toolkit was developed by one of the leadership groups and other participants involved in ACT on Alzheimer’s. The Toolkit provides a structured process for a community to assess its own dementia awareness and resources, as well as to determine priority areas for action. The process utilizing the ACT on Alzheimer’s Dementia Capable Communities Toolkit has been piloted by four communities in Minnesota and is now being used by three additional communities. More communities are preparing to use this Toolkit and process in 2014. The ACT on Alzheimer’s website summarizes the focus of this work as follows: “Community by community, we can create a supportive environment for everyone touched by this disease.” ¹ Additional information about specific goals is provided in Appendix A.

Alzheimer’s disease and related dementias are increasing in prevalence as the population ages. According to the ACT on Alzheimer’s website:²

As more and more Minnesotans live with Alzheimer’s disease and other dementias, the costs and challenges can be overwhelming for them, their families, our communities and our state. Care costs for Americans age 65 and older with Alzheimer’s disease and other dementias are projected to increase from $203 billion in 2013 to $1.2 trillion by 2050 (in 2013 dollars).

Many individuals with Alzheimer’s live alone and are at greater risk for inadequate self-care, malnutrition, untreated medical conditions, falls, wandering and accidental deaths.

Nearly 250,000 Minnesotans care for family members with Alzheimer’s disease. These caregivers provide 277 million hours of unpaid care, valued at $3.4 million yearly. The physical and emotional impact on caregivers results in nearly $9 billion in increased healthcare costs annually, including $157 million for Minnesota caregivers.

¹ Source: www.ACTonAlz.org/realities accessed on December 20, 2013
² Source: www.ACTonAlz.org accessed on December 20, 2013
Purpose – Why Participate in SPN ACT?

Aging, health, and human services representatives (who participated in the key informant interviews for this report) noted that they had been involved in conducting evaluations of the clients they serve for their own organizations related to issues of dementia. This occurred prior to the ACT on Alzheimer’s dementia capable community effort. The findings from the organizational evaluations conducted by these representatives led them to believe that St. Paul needed additional education and awareness about Alzheimer’s disease and related dementias. They say the importance of engaging in a systems-change effort. By creating an “action community” and assessing gaps, they could raise awareness about Alzheimer’s disease and mobilize communities within the targeted St. Paul neighborhoods (See Appendix B for timeline and goals).

Representatives from human services organizations who already have memory programming or other services for people living with Alzheimer’s commented that there was no reason not to participate in this effort. They described the SPN ACT effort as a “win-win,” where new collaborations could be forged and new energy could be focused on a problem that is difficult to address through a single agency or business.

The representatives interviewed remarked that they were hoping for several outcomes. Through conducting a community assessment and embarking on collective action around dementia, they were hoping for the following to be accomplished:

- stronger community engagement
- greater strides toward building community enthusiasm and momentum for systems change
- greater awareness of the importance of community solutions to address the impact on lives of people touched by Alzheimer’s
- enhanced education to increase understanding and awareness about Alzheimer’s disease.

The focus was to engage the community at large, raise awareness, and identify some solutions that would lead to improving lives of those in St. Paul touched by dementia. As the SPN ACT moves into the implementation phase of its proposed action plan, there is opportunity to engage new individuals and additional service sectors. One interviewee voiced her support for the community engagement process in this way: “Why assess and not do anything about it? We could have come up with an action plan—and could have had other organizations work with us—but it misses the point of community outreach.”
St. Paul Communities’ Profile

Demographics
St. Paul is changing demographically. St. Paul encompasses 17 neighborhoods in total. Approximately 290,770 people live in St. Paul\(^3\). People age 65+ make up 9% of the city as compared to 12.9% for the state as a whole. Approximately 22.8% of the city’s residents live at or below the poverty line.

According to the *St. Paul Trends Report*, data from the 2010 US Census indicate that St. Paul is rapidly diversifying in terms of the ethnic, racial, and cultural identity of the population. Nearly 45% of residents in St. Paul identify themselves as non-White or Hispanic. One of every six residents was born outside of the U.S. and one in four speaks a language other than English at home. The economy of St. Paul is still recovering from the recession of 2008. Positive signs of recovery include a lower unemployment rate and fewer housing as compared to 2009\(^4\).

The St. Paul Neighborhoods ACT on Alzheimer’s Coalition (SPN ACT) is made up of six neighborhoods: Highland Park, Macalester-Groveland, West 7th, Summit Hill, Summit University and Union Park. There is not a one-to-one match-up between these neighborhoods and zip code areas. The following zip codes roughly correspond to the neighborhoods within the SPN ACT catchment area (based on neighborhoods derived from earlier community development projects described in this report) are: 55116, 55105, 55104, 55103, and 55102, respectively (see Appendix C for the map).

Information derived from US Census data shows that these five zip code areas represent approximately 124,300 people. The median annual income level is lower in four of the five communities when compared to the rest of the state of Minnesota. State median income was $57,820 in 2011\(^5\).

Profile of St. Paul Neighborhoods ACT on Alzheimer’s Community\(^6\)

<table>
<thead>
<tr>
<th>Zip Code</th>
<th>Highland Park</th>
<th>Mac-Groveland</th>
<th>West 7th</th>
<th>Summit Hill</th>
<th>Summit University</th>
</tr>
</thead>
<tbody>
<tr>
<td>55116</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55105</td>
<td></td>
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<td>55104</td>
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<td>55103</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55102</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The people of Minnesota have a higher than average level of educational attainment. Over eighty percent of Minnesotans (82.4%) have a high school degree or higher, as compared to the U.S. average of 75.2%. In Minnesota, 21.8% of the population have a bachelor’s degree or higher, compared to 20.3% of the nation as a whole. In the five chosen zip code areas in St. Paul, educational attainment varies, although in most of the zip code areas, it is higher than the state average, as shown in the next table.\(^7\)

Educational Attainment\(^8\)

<table>
<thead>
<tr>
<th>ZIP</th>
<th>Less Than High School</th>
<th>High School or higher</th>
<th>Bachelor Degree or higher</th>
</tr>
</thead>
<tbody>
<tr>
<td>55105</td>
<td>2.2%</td>
<td>97.9%</td>
<td>69.9%</td>
</tr>
<tr>
<td>55116</td>
<td>5.5%</td>
<td>94.5%</td>
<td>56.8%</td>
</tr>
<tr>
<td>55104</td>
<td>10.7%</td>
<td>89.3%</td>
<td>42.0%</td>
</tr>
<tr>
<td>55103</td>
<td>27.9%</td>
<td>72.1%</td>
<td>18.8%</td>
</tr>
<tr>
<td>55102</td>
<td>6.8%</td>
<td>93.2%</td>
<td>45.6%</td>
</tr>
</tbody>
</table>

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\(^7\) Source: United States Census Bureau. [http://factfinder2.census.gov/faces/nav/jsf/pages/community_facts.xhtml?#none](http://factfinder2.census.gov/faces/nav/jsf/pages/community_facts.xhtml?#none)

The five zip code areas show growing population diversity, although they are not as ethnically/culturally diverse as St. Paul in total. In the five zip code areas, approximately 30% of the population identifies as non-White (compared to 45% for the city as a whole).

**Diversity Demographics**

![Diversity Pie Chart]

Like most communities in Minnesota, the five zip code areas that correspond to the SPN ACT community of interest have an aging population. Many households in these five areas include single person households, of which some households are comprised of a person age 65+ living alone.

<table>
<thead>
<tr>
<th>ZIP</th>
<th># Households</th>
<th>Households: living alone</th>
<th>Households: Male 65+</th>
<th>Households: Female 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>55105</td>
<td>10,883</td>
<td>4003 (36.8%)</td>
<td>249 (2.3%)</td>
<td>606 (5.6%)</td>
</tr>
<tr>
<td>55116</td>
<td>11,175</td>
<td>4489 (40.2%)</td>
<td>358 (3.2%)</td>
<td>1145 (10.2%)</td>
</tr>
<tr>
<td>55104</td>
<td>17,136</td>
<td>5,897 (34.4%)</td>
<td>364 (2.1%)</td>
<td>838 (4.9%)</td>
</tr>
</tbody>
</table>

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9 Source: SPN ACT Community meeting held on November 21, 2013. Diversity Demographics in Our Specified Neighborhoods. SPN ACT Community Forum PowerPoint, presented by Georgia Lane.

These five communities include over 13,500 individuals age 65 or older, with approximately 2,300 individuals living with dementia, and approximately 4,500 caregivers assisting them.

### Demographic Trends in ZIP CODES: 55116, 55105, 55104, 55103, 55102

<table>
<thead>
<tr>
<th>ZIP</th>
<th># Households</th>
<th>Households: living alone</th>
<th>Households: Male 65+</th>
<th>Households: Female 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>55103</td>
<td>4,710</td>
<td>1,702 36.1</td>
<td>116 2.5</td>
<td>211 4.5</td>
</tr>
<tr>
<td>55102</td>
<td>9,230</td>
<td>4,868 52.7</td>
<td>307 3.3</td>
<td>609 6.6</td>
</tr>
</tbody>
</table>

**St. Paul Communities’ Recent History – Focus on Elder Services & Dementia**

According to the key informants interviewed, the city of St. Paul and metropolitan area experienced a programmatic boom for development and provision of elder services in the 1990s, reflecting a growing awareness of the increasing “age wave” and the need to provide home and

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community-based service options to institutionalization. This also included recognition of the rise in the number of people who would have Alzheimer’s disease or related dementias. In the late 1990’s and early 2000’s the Minnesota state legislature took action to study these issues. The legislature supported policy to foster innovative approaches to “rebalance” long-term care from institutionalization to home and community-based care. This rebalancing included the creation of the Community Services/Service Development grants developed in 2001--which have since fostered several projects in St. Paul that are precursors to the current work by the SPN ACT organizations and individual participants.

A discussion paper\textsuperscript{12} from the Wilder Foundation written in 2006 describes the following trends:

- Racial and ethnic minority older adult population growing
- More affluent older adult households
- More older adults living alone
- Working retirees
- Increased interest in family and informal caregivers

The report also described specific policy changes and programmatic incentives—some of which enhanced and some of which impeded access to home and community-based services such as:

- Stated interest by the state legislature in enhancing alternatives to nursing home placement, and development of grant initiatives to support this
- Policy changes which restricted Alternative Care grants, reducing eligibility
- Passive enrollment into the Minnesota Senior Health Options program that included many people who were eligible for Elderly Waiver home and community-based services (eligible for Medical Assistance and require a level of care commensurate with nursing home care).

The Metropolitan Area Agency on Aging covers a 7-county metro area, including St. Paul. According to the MAAA website, the organization has participated in several special projects that involved a focus on Alzheimer’s disease and involved St. Paul health care and social service organizations.\textsuperscript{13} These included the:

- Alzheimer’s Disease Demonstration Project – that provide a grant to the Payne Phalen Living at Home/Block Nurse Program to adapt the Chronic Care Networks for Alzheimer’s Disease tools and referral process to provide culturally acceptable support services to Hmong and Latino elders who have dementia, and their families.


\textsuperscript{13} Source: Metropolitan Area Agency on Aging Special Projects \url{http://www.tcaging.org/whatwedo/pastspecialprojects.html}; accessed December 27, 2013.
- Dementia Care Transitions Project – to establish better linkages between hospital and primary care clinics for follow-up when an individual has been screened at the hospital and the results indicated concerns with memory. This involved two metro area hospitals including one in St. Paul.
- Dementia Identification Project – funded by the Minnesota Department of Human Services, this project worked to teach health care professionals how to screen for early signs of dementia and provided information and referral resources to individuals with dementia and their family members.

The Sisters of St. Joseph of Carondelet, St. Paul Province (CSJ) and Presbyterian Homes and Services (PHS) have been working together to create a community resource to assist elders to age in place.

In 2009 CSJ and PHS invited health and social service organizations in St. Paul to form the Consortium at Carondelet Village (CCV), which focused its efforts on 1) supporting seamless continuity of care through care coordination; and 2) promoting meaningful engagement for seniors through fostering connections and building on the social capital of the community.  

To implement these services, the CCV entered into collaborative relationships with a variety of organizations that provide services to older adults “responding to the explosion in growth of older adults” and to work together in a “systematic way that optimizes people, technology, and other resources.” This effort was funded with support from a Community Services/Services Development Grant issued by the State of Minnesota. Part of coalition allowed the two organizations (Sisters of St. Joseph Carondelet-St. Paul Province and Presbyterian Homes and Services) the opportunity to enter into a collaborative agreement. The agreement focused on serving individuals 65 years and older in the neighborhoods of Highland Park, Mac-Groveland, West 7th, Summit Hill, Summit University and Union Park.

The Sisters of St. Joseph of Carondelet-St. Paul Province, and Presbyterian Homes and Services brought the Consortium together. Consortium members included:
- St. Catherine University, St. Paul
- Amherst H. Wilder Foundation, Wilder Community Services for the Elderly, St. Paul
- Elderberry Institute-Living at Home Block Nurse Programs, St. Paul
- Eldercare Development Partnership (SAIL)
- Eldercare Partners
- Fairview Health Services, Minneapolis
- Greater Metropolitan Housing Corporation, Minneapolis
- Health Partners, Bloomington
- HealthEast (Bethesda)

14 Source: Carondelet Village Consortium Summary 6/19/09.  
- Highland Block Nurse Program A Living at Home Block Nurse Program, St. Paul
- Jewish Family Service
- Jewish Community Center
- Kairos Dance
- Keystone Community Services
- Lumen
- Macalester-Groveland Seniors- A Living at Home Block Nurse Program, St. Paul
- Metropolitan Area Agency on Aging: Staff from the SeniorLinkAge Line, Return to Community and Planning Director
- Medica, Minnetonka
- Merriam Park Living at Home/Block Nurse Program
- MN Center for Health Care Ethics
- MN Department of Health (MDH)
- National Alliance of Mental Illness (NAMI)
- Naturally Occurring Retirement Community (NORC)
- Ordway Center for Performing Arts
- Outreach Counseling & Consulting Services, Inc.
- PRISM/Express
- Ramsey County Human Services Department
- River Bluffs Village/DARTS
- Senior Recovery Program
- Summit University - A Living at Home Block Nurse Program, St. Paul
- Seabury Assisted Living
- St. Catherine University Andrea Lee, IHM President
- St. Paul Housing Authority, St. Paul
- St. Paul Public Schools Community Education
- UCARE—MSHO MSC+ Care Management
- University of Minnesota School of Social Work
- Urban Partnership and Community Development Center
- West 7th Community Center Senior Program, St. Paul
- Wilder: Community Services for Aging, Health Promotion Classes, and Caregiver Services and Memory Club
- Wisdom Ways Center for Spirituality

This Consortium submitted an application to the Minnesota Department of Human Services under a Community Consortia initiative to bring services together around the needs of a defined population of older adults living in Wards 1, 3 and 4 in St. Paul. They received a grant for $861,000 in 2009. Summary documents describe the Consortium as follows:

Two organizations, the Sisters of St. Joseph Carondelet-St. Paul Province and Presbyterian Homes and Services entered into a collaborative agreement to serve

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SPN ACT Community Progress Report as of December 2013
individuals 65 years and older in the surrounding areas of the Highland Park neighborhood of St. Paul build and operate Carondelet Village (CV) located in Highland Park. Carondelet Village will include independent senior housing (some subsidized), assisted living housing, memory care, and a care center and will open in November 2011.

CVC has initiated contracts for care coordination services with the UCare health plan and is in active discussions with Medica. In addition, Presbyterian Home has formed a new company, Optage Primary Care. The CVC will coordinate its efforts with Optage, including an arrangement that will enable CVC nurse practitioners to provide primary care services and receive payment from the health plans and Medicare fee for service.\(^{15}\)

In 2011 the Carondelet Village senior housing campus was completed and further enhanced the community development work of these two organizations. Carondelet Village is located centrally in the Highland Park neighborhood.

In 2012, this funding was extended by a private foundation to continue this collaborative work, with a particular focus on Alzheimer’s disease and related dementias. This work on a collaborative approach to addressing needs in these neighborhoods is seen as laying the foundation for the SPN ACT coalition, based on the key informant interviews.

Launching the Effort to Become a Dementia Capable Community – Groundwork & Pre-Convening

In the spring of 2012, stakeholders from Amherst H. Wilder Foundation (Wilder) and Carondelet Village (a shared ministry of Presbyterian Homes and Services and the Sisters of St. Joseph of Carondelet) participated in a series of meetings with Olivia Mastry, Executive Lead of ACT on Alzheimer’s.

At that time, there were four pilot ACT on Alzheimer’s communities engaged in using the Dementia Capable Community Toolkit which was still under development. These communities were at different phases of conducting their own community assessments. St. Paul was positioned to be the next community to conduct such an assessment using the completed ACT on Alzheimer’s Dementia Capable Communities Toolkit.

As described, the Consortium at Carondelet Village had already had a role in bringing together organizations to collaboratively share information and focus their service coordination for seniors living in several neighborhoods surrounding the Carondelet Village residential facility.

Both Carondelet Village and Wilder had been working together in various ways, to provide programming to residents and neighbors, although much less formally than through the CCV effort.

In early 2012, Olivia Mastry approached the leadership of Carondelet Village and Wilder Foundation and offered an opportunity to co-convene a systems change effort together, focusing on dementia. Several meetings were held. The purpose was to determine if these St. Paul organizations would co-convene and initiate a dementia-capable community assessment and systems-change effort under the ACT on Alzheimer’s initiative.

Through these discussions, the group agreed that St. Paul would be an appropriate community to conduct a community assessment. Although neither organization had the financial resources to fund the change effort alone, the participants agreed that one organization would need to take the lead and serve as project manager. Private foundation funding was identified within Carondelet Village. Thus, this organization could step forward and convene the effort, serving as a lead agency.

In interviews with representatives from both organizations, the decision of who would lead the SPN ACT was decided “organically.” Discussions naturally focused on having a representative from Carondelet Village take the lead. Participants agreed that Georgia Lane could serve as team coordinator or “influencer” to convene and help shepherd the process. She would hold primary responsibility for coordinating, organizing, convening, and documenting all SPN ACT meetings. The idea was endorsed by the Board of Directors of Carondelet Village.

Once the convening organization was determined, focus centered on getting a wider scope of stakeholders involved. More stakeholders would mean that multiple organizations would be involved, often with varied incentives. Staff members from Carondelet Village and Wilder Foundation, together with staff from the Alzheimer’s Association and Olivia Mastry (ACT on Alzheimer’s), worked to determine the best approach for identifying participants and launching this effort. These organizations were already committed to the work of ACT on Alzheimer’s, understood the mission and vision of this voluntary grass-roots initiative, and could perceive the benefits of a community assessment for the neighborhoods in St. Paul.

Having well established stakeholders from prominent Alzheimer’s and aging organizations was critical at this phase of the planning effort, according to key informants interviewed for this report. These organizational representatives developed the concept and content for a pre-convening and kick-off event. The kick-off event was planned for February 12, 2013.

During this pre-convening phase when a kick-off event was being planned, SPN ACT was comprised of the following community partners: Wilder, Metropolitan Area Agency on Aging, members from the St. Paul Advisory Committee on Aging, ACT on Alzheimer’s and the
Alzheimer’s Association. Everyone interviewed agreed that this pre-convening team was important in launching a successful kick-off.

Since Georgia Lane of Carondelet Village was the lead convener, her role in these early planning meetings was to unify the community partners, and develop a plan for the launching event. Many members of SPN ACT attribute their success through to the efforts of Olivia Mastry and Georgia Lane. Ms. Mastry’s past experience guiding four pilot communities through a community assessment process in the past 12 months was particularly helpful to the group in these early pre-convening days, according to the informants interviewed.

**Kick-Off Forum**

Each member of the pre-convening group took ownership over specific aspects of the Kick-Off Forum, working on tasks that most suited their professional competencies. For example, Jim Emery, advocacy coordinator from the Alzheimer’s Association, assisted in scripting the event. Jan Mueller, vice president of government affairs at the Alzheimer’s Association, helped secure a commitment from Betty McCollum’s office along with the Lieutenant Governor Yvonne Prettner to participate in the Kick-Off. Kathryn Ringham, a Wilder social worker, identified community members living with dementia who could participate on the panel. Members of the planning group contributed to the content of the Kick-Off Forum as well. Each respondent interviewed identified the Kick-Off Forum as “impressive,” “motivating,” and “something I wanted to be a part of”—they described their efforts as purposeful and fruitful.

The ACT on Alzheimer’s Toolkit provides language for new communities to convey the concept and purpose of a Kick-Off Forum in their materials. This kind of community-wide event is described as helping the community learn more about this issue, how it affects them, and how to work together to improve the lives of people living with Alzheimer’s disease. The kick-off event is a method for the community to come together. It is a “call to action” for the community. Furthermore, the Kick-Off Forum reinforces publicly that the initiative is a grassroots, effort that is volunteer driven, and that it has state-wide partners. It is both local and statewide, with technical and resource support to become dementia capable.¹⁶

A wide representation of community stakeholders were invited to the Kick-Off Forum. Several types of media and educational approaches were used. The Forum lasted 2 hours. It included two panels of speakers, video segments (pre-recorded), demonstration of the ACT on Alzheimer’s website, and a Question & Answer session.

The two speaker panels and invited guest speakers showcased the importance of this issue (building a dementia capable community) by emphasizing the political and civic importance. The

¹⁶ Source: [www.ACTonAlz.org/convene](http://www.ACTonAlz.org/convene) accessed on April 20, 2014
invited guests, including a caregiver emphasized the human element, underscoring the personal importance of this issue. One panel showcased elected officials, and one was comprised of content experts and local leads. This was followed by a personal story where a father and son described their personal story related to their wife and mother who had been dealing with the effects of Alzheimer’s disease. The panels included:

**Elected Officials Panel:**
Mayor Chris Coleman, City of St. Paul  
Lieutenant Governor Yvonne Prettner Solon, State of Minnesota  
April Shaw, on behalf of U.S. Congresswoman Betty McCollum  
Commissioner Toni Carter, District 4, Ramsey County  
Council Member Chris Tolbert, City of St. Paul

**Content Experts & Project Logistics Panel:**
Sue Spalding, Executive Director, Alzheimer’s Association of Minnesota  
Olivia Mastry, Executive Lead, ACT on Alzheimer’s  
Dawn Simonson, Executive Director, Metropolitan Area Agency on Aging  
Georgia Lane, Team Lead, Saint Paul Neighborhoods ACT  
Bob and John Marshall, Community Care Partners

An extensive list of invitees was developed to raise awareness and ensure full. Invitations were provided through electronic mail, with a flier developed specifically for this event (Appendix D). Over 150 people attended a packed auditorium located on the campus of St. Catherine University. Many of the attendees of this event worked in the aging-service sector—particularly in social services agencies and housing and health care providers.

In addition to the scripted program, there were display tables set up outside of the auditorium featuring information from local aging services providers, including Wilder Foundation and the Alzheimer’s Association. Individuals attending had nametags and were provided refreshments.

In reflecting on this Kick-Off Forum, one interviewee commented that she was impressed with the level of community participation and the prominence of the panelists. She complimented the content for how “moving” it was for her personally. She stated:

*There were lots of people, and people involved [in it] with Alzheimer’s disease. It was a well-coordinated event, and it was nice to hear people talk about it.*
On the other hand, there was confusion about the purpose of the event and what it was supposed to yield:

_{It was ambiguous. I was unsure about the whole thing. I never totally understood the purpose of the goal of the event—[was it to] assess the area and what was going on and what was available to people? I just don’t know. I still don’t really know._

### SPN ACT Convening

Following the Kick-Off Forum, an expanded group of interested organizations identified themselves as interested in participating in the effort. The majority of the regular SPN ACT members who continued to attend meetings had heard about or attended the Kick-Off Forum. Nine meetings were held between March and December 2013. Members of the SPN ACT ACTion community team who are committed partners to the effort include:

- Carondelet Village (convener)
- Alzheimer’s Association
- Amherst H. Wilder Foundation
- Catholic Charities
- The City of Saint Paul
- Health East
- Health Partners
- Highland Block Nurse Program
- Jewish Family Services
- Keystone Senior Communities
- Lyngblomsten
- Medica
- Metropolitan Area Agency on Aging
- Nativity of Our Lord Catholic Church
- Ramsey County Human Services
- Senior Services Consortium of Ramsey County
- Stratis Health
- caregivers of people with dementia, and
- other interested local community individuals from additional faith communities, businesses, social service organizations, businesses, and housing agencies

This group of individuals and organizational representatives began their work in March. At that time they reviewed the Toolkit and goals of ACT on Alzheimer’s. They discussed their own goals and purpose for using this Toolkit and process in St. Paul.
Those interviewed for this report stated different reasons for participating in the SPN ACT effort. All agreed that St. Paul needed a specific approach or focus to understand how Alzheimer’s impacts their community and what changes need to be integrated to improve lives for those touched by the disease within their local region. Some of those interviewed described initial confusion about the purpose of conducting a community-needs assessment and the application of using the ACT on Alzheimer's Dementia-Capable Communities Toolkit. At that time, they were unfamiliar with the Toolkit or process.

Other dementia-capable communities have reported that it takes time for members to come together and work as a team/group. The community assessment process is often unfamiliar to individuals, and can be difficult for groups to understand. The initial convening stage is the time where the lead coordinator helps community members to come together, educates members about the disease, and facilitates discussion about the specific community’s needs. The lead (or technical support person) also orients members to the Toolkit and assessment process.

Before embarking on the Assessment Phase, the SPN ACT group was deliberate in facilitating a discussion about the concept of being “dementia-capable.” Content for subsequent meetings included:
- education around the phases of an ACT on Alzheimer’s community assessment: “Convene, Assess, Analyze and Act”
- further clarification what the community assessment was and how it was different from a research method or process.

For some members, this definition of “dementia-capable” and the assessment process continued to be confusing and ambiguous. Despite this ambiguity, members continued to attend and participate.

Meeting Format & Organization
There was careful organization to make the most of each SPN ACT meeting. There were nine open-invitation SPN ACT working meetings held between the Kick-Off Forum February 12, 2013 and December 17, 2013.

Attendance varied—from a low of 17 individuals to a high of 45. There were several individuals and organizational representatives who attended most of the nine meetings. The meeting content corresponded to the process included in the ACT on Alzheimer’s Dementia Capable Community Toolkit. This included: review of the Toolkit, development of lists of names of individuals who could be surveyed using the assessment tools included in the Toolkit, review of the activities completed in-between each meeting (such as the number assessments completed and the service sectors that were surveyed), review of the synthesis and results from all of the assessments.

17 Includes the Jewish community, St. Louis Park, Walker, and Willmar.
development of priority areas for action (using an iterative voting method during the meetings),
and development of a work plan and timeline to launch the priority action item (see Appendix E
for a table providing detail on attendance and content for each SPN ACT meeting in 2013).

The lead (Georgia Lane) used a specific format and process to maximize engagement and
productivity for each meeting. She was coached by Olivia Mastry (executive lead for ACT on
Alzheimer’s) and was assisted over the summer by administrative support from a Master’s social
work intern from St. Catherine/St. Thomas University School of Social Work, Meghan
Constantini.

Generally, the SPN ACT meetings followed a set format (See Appendix F for an example):

- Next meeting is announced at the end of each SPN ACT meeting, followed by a
  broadcast email to all who have requested being notified
- RSVP requested directly Georgia Lane via following a meeting reminder sent by email
  (approximately two weeks prior). In addition, some personal phone calls to specific
  stakeholders were conducted by Ms. Lane
- Meetings are held in the same place, often on the same day of the week (Thursday), and
  same time-slot if possible (2:30-4:30 p.m.)
- Starting in April, 2013 the SPN ACT group built 15 minutes in before each meeting to
  allow members an opportunity to network
- Upon arrival to a meeting, a check-in table requires each participant to:
  - create a written name tag
  - identify themselves on the master list as “present” or provide contact information
    to add stakeholder to master list
- Upon entering meeting room agenda and welcome is visible using PowerPoint
  presentation
- Each member individually greeted
- Food and beverages are accessible, visual and to the side of the room
- Tables are arranged in rounds and set up throughout the room with enough space in-
  between- allowing the entire group to participate in the meeting, and then providing easy
  opportunities for the larger group to break into small discussion groups
- Each meeting begins with a welcome to the group (Georgia Lane)
- Introduction of meeting topic (Georgia Lane)
- Note progress, and celebrate successes to date as a group (Georgia Lane or Olivia
  Mastry)
- Updates and press announcements (Georgia Lane or Olivia Mastry)
- Discussion/break into small groups
- Reconvene with larger group and share results of discussion (Georgia Lane or Olivia
  Mastry)
- Discuss next steps and identify upcoming meetings (Georgia Lane)
The meetings were only canceled due to inclement weather. Over the course of a 15-month period, two meetings needed to be re-scheduled due to two snow storms.

The SPN ACT group was identified as “an effective and efficient coalition” by the members who were interviewed for this report. According to these participants, the meetings were well organized, and meeting participants continued to attend. This regular attendance continues even though some interviewed for this report said that certain phases of the work have been onerous or confusing. Members stated that the consistency and organization helped them stayed committed to attending. Some individuals interviewed for this report identified that a 2:30 meeting time was difficult to rearrange schedules to attend, but most agreed that it was easiest to convene a meeting closest to the end of the working day as possible.

**Assessing**

The SPN ACT group was efficient in conducting the assessments of the St. Paul community neighborhoods targeted. Most of the assessments were conducted in May, June and July, with a few completed in August, 2013. Assessments covered all 14 service sectors. One hundred twenty-seven assessments were completed by 24 individuals.

**Volunteer Assessor**

For SPN ACT, volunteers from the community and organizations took a lead role in implementing surveys. The majority of the assessments were conducted by participants and organizations donating their time. Ms. Lane was paid (part-time) through a private grant to provide part-time project management support and facilitate the effort. Paid support also included the work of a summer social work intern, and technical support by Olivia Mastry. Other organizations involved in disseminating and collecting assessments in St. Paul through staff members who provided time were:

- Alzheimer’s Association
- CSJ Consociates
- Caring & Sharing Hands
- Catholic Charities
- Carondelet Village
- Comfort Keepers
- Community Members (unaffiliated)
- Health Partners
- Jewish Family Services
- Keystone Communities
- Lyngblomsten/The Gathering
- Nativity Catholic Church
- Senior Services Consortium of Ramsey County
- Stratis Health
- Union Park Representative
- University of Minnesota
- Wilder Foundation
The first meetings of SPN ACT involved orienting group members to the Toolkit. Although most of those interviewed were aware that the Toolkit was available online, they said that it was cumbersome to review electronically. They found it easier to have the Toolkit printed out. It was also helpful to have extra sector surveys ready for people who were willing to conduct assessments following a meeting. Having the physical forms in hand facilitated willingness to schedule and conduct surveys.

At the April 2013 meeting the SPN ACT group determined what other materials should be included in a “leave-behind” resource packet. Ms. Lane worked with the Carondelet Village marketing department to develop or copy materials that had been developed by the Alzheimer’s Association and from the ACT on Alzheimer’s© Toolkit:

- Assessment instructions for survey team members
- Call script
- ACT Communities info brochure
- Dementia-capable communities resource (specific to sector-i.e. businesses government, healthcare, etc.)
- A handout with St. Paul demographics;
- A summary of the St. Paul initiative;
- Identification badges for team members;
- A list of St. Paul leaders (e.g. Mayor Coleman) who have signed on to the initiative; and
- The Alzheimer’s Association® tool, “Know the 10 Signs, Early Detection Matters” (Appendix G).
- Thank you letter script

Training SPN ACT members on the Toolkit occurred through a series of educational sessions over the course of three different meetings. Individual respondents interviewed indicated that the training and orientation for the survey and the tool itself was minimal. However, meeting minutes show at least a portion of four different SPN ACT meetings included training to prepare the members to implement the surveys. SPN ACT members were able to ask questions about the surveys during the meeting or to contact Ms. Lane following a meeting.

Ms. Lane said, in retrospect, providing more opportunities for SPN ACT participants to role-play implementation from beginning to end could have been useful. Having members speak or describe to another person the purpose and objectives of the SPN ACT group (in addition to administering the survey) could have offered an added benefit to the individual conducting the survey.

Some SPN ACT members worked on their own preparation before launching into making community connections. One member comments:
It was important for me, if I was going to be interviewing people I didn’t know. I had to stop and regroup and think about the process, and what was going to happen when approaching strangers. I had to anticipate some of the issues and troubleshoot from the ground up. This helped me organize my materials and have answers ready when questions were asked. This is so important when you engage with someone who is busy!

This particular member used the information from the ACT on Alzheimer’s Dementia-Capable Toolkit (Appendix H) for a one-page call script. She modified the script to write it in her own words so it was easier to engage with people. This idea of practicing a natural introduction was reinforced at SPN ACT meetings. This member said she found it important to have her own words to describe her enthusiasm and the purpose for the effort. She was interested in engaging the individuals she was connecting with--beyond administering a survey. Cultivating relationships with those surveyed would be easier if the script was customized to the audience and the surveyor. SPN ACT meeting discussions reinforced this idea.

There were several ways to administer the survey: in-person, through electronic tools (Survey Monkey®), or over the telephone. On average, the interview took 30 minutes, although some team members indicated that sometimes it took up to an hour. Often the most time-consuming aspect of the assessment process was connecting with people and coordinating the time to complete the survey (scheduling). Having various methods available for conducting the surveys was something each team member interviewed for this report appreciated. Some surveys were conducted on the phone, while others were emailed via Survey Monkey®; some were provided in person, while others were dropped off and picked up. Each survey, once completed, was given to the social work intern to track and process.

Ms. Lane was able to secure support from her own organization to pay a social work intern part-time (0.5 FTE at three months’ effort). This support during the assessment phase was critical for the extensive data entry of surveys, preparation for and response to surveyors, and follow-up after SPN ACT meetings. In addition, technical assistance provided by Act on Alzheimer’s staff and Stratis Health was useful for analysis of the raw data and transforming that data into a synthesized format.

Many commented that Ms. Lane and her intern made themselves very accessible and available to team members when there were questions or concerns regarding the process of preparing for the interview or following a survey. Members could access Ms. Lane by phone or email, and she also made herself and her intern available to members who wanted to stop by and ask specific questions. This was useful for team members who needed assistance troubleshooting issues that were encountered.
Assignments for who would disseminate the assessment to different sectors needed to occur. The intern encouraged the group to explore many open-source cloud-based options through www.Google.com and Survey Monkey® to disseminate surveys to respondents efficiently. The intern did all of the data entry of the assessments.

Despite their commitment to a community assessment process, feedback about the surveys themselves was not positive. SPN ACT team members interviewed said that the survey “seemed like it had never been read out loud to another person before” because the language was so awkward. Individuals said that the wording seemed to be “leading” the respondent. The questions were written in such a way that they assumed that the respondent had knowledge of Alzheimer’s disease and dementia. Some team members reported this was a barrier and caused them concern. They said that they didn’t want to assume the respondent knew about Alzheimer’s, but they didn’t want to insinuate the person didn’t “know anything about Alzheimer’s” either. A SPN ACT member who facilitated several in-person surveys found the tool to be lacking in another critical area. She commented:

“When asking people about their concerns related to Alzheimer’s…there was feedback and stories which the toolkit did not have a place for us to capture their stories. Questions triggered people to remember stories or ideas that were important, and I don’t know what will happen to that information. There wasn’t anywhere to put it, and I don’t know what will happen to that information because we can’t use it in our analysis.”

However, the process of implementing the surveys, overall, was positive for both the SPN ACT group and the sectors interviewed. A lessoned learned from one SPN ACT member regarding conducting community assessments was not to be fearful about contacting new people and “going outside of one’s comfort zone” in terms of the service sectors one selected or the way the survey was conducted. One respondent said:

“I am an introvert and I am not comfortable talking on the phone. I decided it was best to go out of my comfort zone [to connect with people with whom she was not familiar and do the survey in person]. . . . Not everyone did this. . . But I thought it was important for me to branch out. I wanted feel prepared and I thought the best way would be to take the information directly to them, rather than do the survey on the phone. They would have the information I wanted to give them, and we would have cultivated the relationship.”
Others reported it was exciting to see how many people were actually surveyed. This fact alone helped some aging-service professionals feel more connected to their community, and they reported feeling reinvigorated to conduct their work. One interviewee reported:

> You knew we were all really together - in that sense of working together to be try to do things in a group like that in a group process . . . somewhat orchestrated and wide open in a lot of ways galvanized being part of a more visible community.

Ms. Lane also commented that this was a unifying activity for the SPN ACT group:

> People liked that this was a guided tangible task that they could complete. The St. Paul Neighborhood ACTion community was able to share their experience with one another during meetings, and the process was an awareness-raising process within itself.

Despite the concern about the survey language, SPN ACT members did not report negative feedback from individuals who were contacted. Ms. Lane’s name was the contact for all materials left behind and she received no calls.

Another concern about the assessment process was the time it took. Some members said that there was a lot of preparation leading up to the community assessments being conducted. However, the SPN ACT members recognized the importance of ensuring that everyone understood the larger context and not just the task at hand. If members interpreted the task at hand as only administering the survey, the community engagement and community change opportunities could be lost. For example, the SPN ACT team had to determine the capacity of the group to engage diverse communities, like the African American community within the six neighborhoods. Discussion and informal evaluation within the group was also time-consuming. The group was able to discuss and recognize their strengths and limitations and where they had gaps. This analysis helped a member from African American faith community begin a larger conversation about developing a separate ACT community of interest – meeting the specific gap within this community regarding representation by persons of color.
A breakdown of the assessment conducted by SPN ACT is shown below:

**SPN ACT Community Needs Assessment Overview (as of August 2013)**

<table>
<thead>
<tr>
<th>Sector-Based Surveys</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Day Programs</td>
<td>5</td>
</tr>
<tr>
<td>Caregiver Supports</td>
<td>4</td>
</tr>
<tr>
<td>Community Members</td>
<td>24</td>
</tr>
<tr>
<td>Community Members (Faith)</td>
<td>12</td>
</tr>
<tr>
<td>Action Team</td>
<td>3</td>
</tr>
<tr>
<td>Employers</td>
<td>2</td>
</tr>
<tr>
<td>Legal Council</td>
<td>2</td>
</tr>
<tr>
<td>Local Government</td>
<td>8</td>
</tr>
<tr>
<td>Residential Settings</td>
<td>9</td>
</tr>
<tr>
<td>Social Service Agencies</td>
<td>9</td>
</tr>
<tr>
<td>Transportation</td>
<td>2</td>
</tr>
<tr>
<td>Ancillary Health Providers</td>
<td>5</td>
</tr>
<tr>
<td>Clinics</td>
<td>19</td>
</tr>
<tr>
<td>Home Health Agencies</td>
<td>9</td>
</tr>
<tr>
<td>Hospitals</td>
<td>14</td>
</tr>
</tbody>
</table>

**SPN ACT Assessments Stats:**
- 127 Surveys Completed across 14 Sectors
- 64 Organizations completed surveys
- 24 SPN ACT team members were on survey teams (conducted surveys)
- 68 individuals participated in meetings

**Tracking Involvement**
Following each meeting, the attendance record and notes regarding decisions made were typed and entered into a project organizing format. This helped Georgia identify those organizations/individuals who were regularly involved and those who were not present. Some individuals had expressed interest but needed a personal outreach to get involved. Ms. Lane made these calls and this was an effective strategy.

Ms. Lane developed a coding system to track organizational and individual engagement which helped her stay on top of this issue. This served as a kind of “inventory” for each person’s engagement in the SPN ACT effort. Ms. Lane commented that this method helped her team be mindful of how members were contributing, and where there were gaps. In addition, the system served as a reminder to extend invitations and requests for participation to stakeholders and to thank those who were actively involved in moving the effort forward. Maintaining communication and using phone, email, personal meetings, and other ways of keeping the connections to stakeholders was key. This inventory of activity and “coding” by participant helped foster stakeholder communication and engagement.
### Categories for SPN ACT Member Inventory/Engagement, based on Actual Involvement or Stakeholder Role

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Assessor: someone who assisted in completing the community assessments, but may not have attended SPN ACT meetings</td>
</tr>
<tr>
<td>TM</td>
<td>Team member: a SPN ACT member who attends meetings regularly (2+ meeting)</td>
</tr>
<tr>
<td>C</td>
<td>Collaborator: has indicated an initial interest, continues to receive updates about the group and engages a group of stakeholders with SPN ACT activities with a low investment of time for both parties</td>
</tr>
<tr>
<td>C+</td>
<td>Community collaborators that possess many connections and likely hold a position of power or are affiliated with a powerful organization</td>
</tr>
</tbody>
</table>

Note: after assessments were completed and priority areas chosen, SPN ACT needed to change the coding system because the team recognized that those were actively engaged in the assessments may not necessarily invest their effort in the next phase, action plan and implementation.

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### Synthesis

To analyze the data, completed surveys were e-mailed, faxed, or dropped off directly to Georgia Lane at Carondelet Village. The part-time social work intern was the lead person responsible for taking the forms and entering the results into the Dementia Tools assessment matrix (provided by ACT on Alzheimer’s). The support from the social work intern was essential to processing the information and producing a quick turnaround of the data for the group as a whole to assimilate. Entering the assessments and processing the data took approximately eight weeks. The process worked best when surveys were processed immediately as they came in. The SPN ACT team could scan and email completed surveys, submit Survey Monkey surveys, fax in the raw data, or drop it off. Data coding and entry included recording who conducted the survey and when, as well as how the survey was administered and how it was provided (e.g., electronic copy via Survey Monkey®, Word document via email, hard copy, etc.) All surveys printed or kept in raw (handwritten on paper) form. This allows reference back to a specific survey to determine if narrative information that was captured could be useful in the future.

While the assessment matrix provided a systematic way to enter the data and process the information, there were limitations in the tool. The following limitations were noted:

- The survey tools themselves were described as difficult to “process and manipulate.” Each survey is a Microsoft Word document. All information needs to be put into the matrix manually.
• The matrix does not allow for tracking narrative data in a cohesive way. The survey form does not lend itself to capturing this raw data, and the matrix does not have the capacity to categorize this data.

• Narrative comments and stories were recorded in a comments section, but it was difficult to find a way to combine, synthesize and analyze the narrative data. Again, this was all done by manually. The group benefitted from hearing this narrative feedback during the SPN ACT meetings.

Technical support during this synthesis phase included Deb McKinley from Stratis Health and Mary Ek, project coordinator from ACT on Alzheimer’s. Both Ms. McKinley and Ms. Ek were able to assist by answering data and survey processing questions. The social work intern interviewed indicated assistance from McKinley and Ek was useful to ensure that she stayed “out of the weeds” and keep her tasks aligned with the overall goals.

Some of the tasks required during this part of the process were described as “onerous.” This may be unavoidable, as each survey form must be reviewed and the data entry checked by a person to ensure that it was entered accurately. Narrative comments must be reviewed by a person to help with interpretation of meaning. That is, to match the narrative comments to the survey responses.

**Action Planning**

Following synthesis, the SPN ACT group began interpreting the information for action planning (September 2013). Georgia Lane reviewed a PowerPoint that included matrices containing all the compiled data on all 14 service sectors. As a full group SPN ACT members reviewed the high and low priorities and the areas where there is high or low action currently within the St. Paul community (see graphing matrix on the following page). SPN ACT members were counseled that the focus for their next phase of effort and to analyze these results should be on the top right hand quadrant, where there is high priority, but low action.
During the September meeting, group members discussed emerging themes, gaps and priorities as indicated by those surveyed, and their own perceptions of what is needed in St. Paul to build a dementia capable community.

The October 2013 meeting included full group and individual voting to identify the top priority areas and ideas for action. The October meeting also included a description of the process that would be used in November. Participants would develop specific outcomes or deliverables to meet the identified priority areas.

The SPN ACT members voted on their top five picks from the nine areas listed below:

1. Information and education for people with dementia and their families (Education Category)
2. Increase wellness programs and risk-reduction programs (Resource Access Category)
3. Increase meaningful activities for people with dementia (Resource Access Category)
4. Transportation options (City Planning Category)
5. Training in early detection of dementia and caring for people with dementia (Education Category)
6. Increase dementia awareness and knowledge in the community (Education Category)
7. Improve dementia-related resources tailored to our diverse populations (Resource Access Category)
8. Increase the level of living options for people with dementia (City Planning Category)
9. Improve our community’s contingencies for people with dementia in its disaster planning (City Planning Category)

The democratic voting process resulted in five priority areas:

- Priority #6 (dementia awareness and knowledge in the community): 16 votes
- Priority #1 (information and education): 14 votes
- Priority #5 (early detection and caring for people with dementia): 9 votes
- Priority #3 and #4 (meaningful activities and transportation): 6 votes each
- Priority #2 (wellness programs and risk reduction): 5 votes

Potential action items were brainstormed for these five priority areas. During the November meeting, the action items were written on large flipcharts and put up around the room.

Each individual was asked to pick his/her top three action items (a person was allowed to assign all three of his/her votes to the same single item). SPN ACT members were coached by Olivia Mastry, facilitator, to use the following principles to guide their votes:

- “Are we doing the right thing first?”
- Our action items should foster the Dementia-Capable Communities goal.
- We need to reach our target audience (people directly affected/indirectly affected).
- We should focus on what is doable in a short period of time, a “quick win.”
- We need clear, measurable outcomes.
- We should build off of what other people are doing.
- What will have the most impact? We want the most “bang for our buck.”

During the November 2013 forum, two table leads were identified for each of the three priority areas. The role of the table leads was to help the group members to flesh out an Action Plan. Members were asked to consider what is urgent and fits St. Paul. Action items should be affordable, doable, meaningful, and “SMART” (that is, specific, measurable, achievable, relevant, and time-bound).

During this phase of the process, some of the ambiguity about SPN ACT that members had experienced lessened. As the group brainstormed different action items to meet the priority areas, they were more enthusiastic.

One member who was interviewed commented (after delivering criticism about the time to train and deliver the survey) that she recognized the difficulty of getting important issues to “rise to
the top efficiently,” and followed this by stating, “I have been in so many situations where we have tried to complete an analysis like this and failed. [In contrast] this process worked efficiently, without having people feel that they weren't being heard.”

**Key Themes**

**Leadership and Technical Assistance**

Georgia Lane was identified as a champion of the effort. Olivia Mastry was also identified as a key facilitator. Both women were named as being vital to the creation, growth, and development of the SPN ACT group.

Although Lane credits Mastry with her role in advancing the effort of the SPN ACT group, one St. Paul community member who participated in SPN ACT made the following observation:

> “Georgia had a lot of great support, but she was just phenomenal – she was skilled at listening and pulling together what was said. I was impressed with her student as she rose to the occasion. I think Georgia had something to do with that too though, she was a great support.”

Ms. Lane’s role as the convener of the group was clearly understood by all participants interviewed for this report. She was seen as a leader. Ms.Lane’s leadership style was democratic and open. She allowed space for group creativity, and feedback and was offered democratically – this openness has provided participants various opportunities to establish their role as well.

Stakeholders from SPN ACT who were interviewed were aware of the unique position the group held in the overall development of the state-wide ACT on Alzheimer’s effort. The SPN ACT group benefitted from the technical assistance from ACT on Alzheimer’s staff, like Mastry. One respondent commented to this point when referencing future support:

> “Olivia Mastry has consistently been there and totally engaged with everyone involved. I think the idea is that Olivia [Mastry] won’t always be present every time that a community convenes, and that was an advantage that we had. But, as each new community convenes, they will have the wisdom of the other communities who have been there.”
Connecting to External Stakeholders and Efforts
Throughout the year, Ms. Lane conducted additional meetings to engage stakeholders with community influence. She reached out to those who would not only benefit from learning about SPN ACT, but might be able to assist the group or connect the group to other stakeholders and coalitions.

An example of a meeting of this type is the August 2013 meeting with City Council Member, Chris Tolbert. Georgia Lane was accompanied by other SPN ACT members to this meeting. These members included: Margaret Belanger, CSJ (Carondelet Village Board Member), Amy Moser of St. Paul Community Ed (Advisory Committee on Aging member), Mary Livingston of St. Paul Parks and Recreation (Advisory Committee on Aging member), and Beth and Roger Maulik (community members living with Alzheimer’s disease). The meeting was productive as Council Member Tolbert expressed his support and commitment to helping find ways to link SPN ACT work with the city’s planning efforts. During this meeting it was identified there was needed to be a more formal mechanism to share information between the 17 St. Paul District Councils and city agencies. This could be an objective that the SPN ACT identifies as a larger systems-change effort. The results of this meeting were shared with the SPN ACT members at the next SPN ACT meeting held in September 2013.

While the SPN ACT group was convening, assessing, and synthesizing their results, other coalitions and groups in and around St. Paul area were also completing complementary work. The following complementary coalitions or initiatives identified by SPN ACT group members included:

- St. Paul Mayor’s Advisory Council on Aging: *Communities for a Lifetime* Initiative (ACOA)—which was being led by SPN ACT members Mary Livingston, Amy Moser and Kathy Kelso
- City of Saint Paul 2015 Strategic Planning Process - which will take into account the rising 65+ population and includes SPN ACT member Donna Drummond. SPN ACT hopes to learn more about city planning and to make dementia-capable communities a part of strategic plan.

There have been efforts to keep these initiatives connected and make sure participants are informed of one another’s activity.
Communication and Visibility

One important element that was actively pursued by SPN ACT members (particularly the lead, Ms. Lane) was to raise visibility of the effort within St. Paul—through articles in local papers, and even through pursuing ceremonial recognition of the effort. The SPN ACT was in the news several times during the year (see list below and refer to the Appendix).

**SPN ACT in the news:**

- Two articles in the Catholic Spirit—(one found here):  
- February 6, 2013 St. Paul City Council presentation
- February 12, 2013 St. Paul Resolution declaring ACT on Alzheimer's Awareness and Kick-off Day
- Highland Villager. Regan Smith, June 26, 2013 (Appendix K)

A leader within the CSJ community from Carondelet Village shared her thoughts regarding measuring the impact of efforts to focus on people with dementia:

You can measure [the] number of people who come in, and x number of programs held. We know that there are x hundreds of people with [Alzheimer’s disease] within five miles. We can measure . . . all the ways we get the word out, the phone calls we get, the number of people who walk in the door, the evaluation from each program in terms of usefulness and value to them.

Then there are things you can’t measure—things like meaningfulness of interactions. Relationship-based . . . these moments happen because of what was designed. There is a gut-level connection. “I found a new friend.” “I felt heard, understood.” These things. The narrative feedback hits an emotional level. We need to remember to collect the stories so that the dry statistics come alive.

**Enabling Resources**

Many resources were used in this effort. What was identified by the stakeholders interviewed for this report as most beneficial were:

- Small operating budget to pay for paper needed to print the surveys;
- Technical infrastructure to capture, store and analyze the data;
- Committed community influencer or project manager who oversees and directs the entire process;
- Technical support from an outside entity (not a stakeholder), and
- A regular meeting space.

Having a Master’s-level social work intern to assist with the assessment phase was critical for Ms. Lane and the SPN ACT group.

Carondelet Village received support from the Presbyterian Homes and Services marketing department that Ms. Lane was able to tap into – accessing the content expertise and resources of this department to assist in developing materials for the SPN ACT group, particularly to support the community assessments, and in promoting the initial kick-off event and community forum to review assessment results. For example, the department assisted in creating a packet of information that the team members could leave for individual survey respondents. This packet included a folder with information about ACT on Alzheimer’s, a description of the purpose for the community assessments/surveys, and the intended outcomes from the effort (See Appendix).

Posting this information electronically, and capturing which member provided which survey to whom, has been useful from a historical perspective. It was useful for the intern as she kept track of surveys and sectors. Ultimately, the SPN ACT group preferred a different method, but the leadership was able to benefit from the organization.

**Challenges**

There were challenges faced by SPN ACT members, but they did not pose a roadblock to accomplishing the assessments or moving toward an action plan. One challenge was the weather, which included a number of snowstorms coinciding with scheduled meetings and surveys appointments. Another challenge was how to capture and address the needs of all of the residents of these St. Paul neighborhoods, especially minority groups—whether these individuals were being reached through the process. The ethnically and racially diverse groups were not well represented early in the process.

There was a challenge to achieving group cohesion identified by many interviewed arising from the “open door policy” for the SPN ACT group to take all comers. Though the open, democratic style provided ongoing opportunity for newcomers to get involved and feel welcome, interviewees said that the complexity of the concepts could be difficult for a newcomer. It is hard to get new people up to speed if they have not participated in the previous steps. Individuals who self-identified as a working “Team member” were unsure about who was also serving as a working “Team member.” These individuals did not get to know each other’s strengths or perspectives as much as if the group had had a consistent core. With larger numbers of attendees and variable consistency in attendance, this issue that was seen as most important. Another challenge voiced by interviewees was that the group was primarily comprised of women (little
gender diversity) who were employed in the aging services or human services sector (little sector diversity). The good news about this was that many people already knew each other. The negative side of this was that it is possible that the assumptions and determinations made by the SPN ACT group may not accurately reflect the wider community. This might also limit the ideas or potential solutions that were generated.

A related challenge was to keep people focused and following the process. New members, in particular, brought ideas to the group that were not feasible or in line with the results of the assessment.

Another challenge mentioned during the interviews concerned two of the integral concepts in the ACT on Alzheimer’s initiative, described 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 each respondent interviewed expressed an initial phase of confusion, particularly in conceptualizing what a dementia-capable community was. They also questioned why conducting a convenience sample of interviews would help measure anything that would be useful to 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.

Some members of SPN ACT (particularly those not working in the aging services sector) said that they did not have sufficient knowledge to understand the nuances around gaps and strengths. Some also felt unprepared regarding background in Alzheimer’s disease and caregiving. They felt their lack of awareness or knowledge was problematic when conducting interviews. Ms. Lane and other members interviewed recognized that many types of training could be offered to ACT/Action community members early on that were not offered within the SPN ACT experience.

Providing basic information about what community resources exist, the nature and symptoms and issues of Alzheimer’ disease, and the challenges that are faced by those living with and caring for those with the disease could be quite useful early on, said those interviewed. One group member remarked that though the process had been inspiring, and although she “learned immensely” from her involvement, she was concerned the solutions derived “did not go deep enough, or have enough impact.” Another member commented that this process was social justice in “true life,” providing an equal voice to all who participate and work to develop a solution together.

Reaching more people and organizations, particularly key stakeholders was another challenge. Service sectors and organizations sought out for additional involvement were: faith communities (especially within diverse cultural groups), agencies and advocacy groups serving culturally
diverse communities, the business community, health systems and health plans, and city employees. Georgia Lane noted that these stakeholder groups may need to see more tangible benefits from participating. Their motivations or the type of involvement they are comfortable with may differ from individuals from the senior services and housing sectors. Communication messages and methods must be tailored to these stakeholder groups.

An example of how the use of technology was not successful for the group is the electronic sign-up sheet that the intern created for SPN ACT members to allow individuals to choose their community assessment contacts. The sign-up was meant to be an efficient and effective way to reach more members and allow each member to choose individuals from different sectors to provide with the community assessment. This sign-up was posted in www.google.com Google Drive® cloud service. Some organizations could not access the cloud service because of firewall restrictions imposed by their organizations. Some SPN ACT identified in individual interviews that they did not understand the purpose or utility of accessing information in this way. It turned out to be most effective to provide the SPN ACT participants a paper sign-up at a meeting to help provide structure to the meeting participants.

**Lessons Learned/Advice**

During the key informant interviews, members had clear opinions about what was most useful and what they learned:

- A community assessment is an art, not a science.
- An interviewee cautioned, “This is not a research study with protocols that need to be followed, but there is a process to it.”
- Dementia-capable is a concept that is fluid – meaning based on the beholder; people need some concrete examples
- Learning about process and conducting the community assessment can be overwhelming, because of the volume of information to take in—do not be overwhelmed!
- Attending meetings for one purpose can help participants learn about other aspects of the community and make different professional connections. The groundwork and convening phases can provide great opportunities and help community members learn about new services in the community without much additional effort.
- It may seem like a lot of work, but organization and structure can help participants feel welcome and will not distract from the intended meeting purpose. Excellent organizational skills are a must.
- Include as many people as possible in these early phases, cast the net wide. Learn what skills people have and what they can contribute. Not every participant can, or should,
involved in every step of the assessment. But it is necessary to have tools to keep all who are interested engaged and informed about challenges and progress. Additional suggestions for engaging members included deriving membership beyond those who are “invested,” like clinicians and aging-service providers; ensuring there is an even representation of men and women, caregivers and people with dementia; and including stakeholders who may not traditionally be engaged in systems change efforts.

- With regards to engaging and cultivating community members, there is a limit. “There is only so much engagement you can do before you start to stalk people, and if they don’t want to participate in meetings, people can sink their teeth into different aspects of the projects.”
- Consistency of key members is helpful for process integrity. Ensuring a 12-month commitment for the convening organization and leads is important.
- Lay early groundwork to have individuals have a more solid concept of what a “dementia-capable community entails” through offering specific examples. Specific solutions that other communities have created could be shared with the group, or examples of a dementia-capable community could be demonstrated.
- There are some issues with maintaining an open-door policy that includes a large group. This can be problematic. As a leader, Lane needed to be decisive and give members tasks and jobs, using smaller groups in meetings and outside of meetings to make key decisions. Lane concluded that having a core group of people or staff/volunteers available to help with the work required between meetings is essential.
- The volume of the information can also be overwhelming. Allow one person to manage the project and ensure that information is framed in a way that it is digestible and understandable to a lay audience. One comment from those who were not aging-service providers or clinicians was that there was a longer orientation process for those who may not be as familiar with the industry as a whole. One SPN ACT member suggested offering a survey to test new members’ knowledge and then matching them to electronic resources or people who could fill in those gaps. This idea would allow the group not to lose momentum or be bogged down because they are continually bringing new members up to the current level of baseline knowledge.
- All members interviewed shared the sentiment that this process, even when executed efficiently, takes patience. One member stated, “Keep your focus and be present in whatever phase you are in—don’t overthink it!” Creating a sense of community should be enjoyable and all members agreed that keeping the process light and fun can help when members are struggling for clarity around issues, or frustrated with unexpected results from outcomes. The SPN ACT members realized early on that this process was an art, not a science, and the toolkit provided a lot of direction. One respondent commented, “Follow the toolkit, but be flexible. This assessment needs to be adapted for each community, and only the community can determine which aspects of the assessment will work.”
Another solution to the issue of using members to their full capacity would be to restrict the meeting policy and not allow “all comers” or anyone who responds to the email. Rather, this approach would evaluate and categorize the member, and direct him or her to resources if necessary. Then determine how and where best to plug them into the phase of assessment or action.

Another issue identified by several members of the SPN ACT group was that there is a great need for awareness, across all communities throughout the state. Since the assessment is cumbersome and time-consuming, one member commented, “Would it not make sense to implement the action plan to build awareness rather than conduct the assessment at all?” Some from the SPN ACT group would argue that this critique doesn’t fully integrate the purpose of the assessment phase, which is to make new connections in the community. This objective needs to be clarified.

Reaching out to other groups who have completed an assessment, or to the ACT on Alzheimer’s staff and leadership group members, can be very beneficial. There is no need to reinvent the wheel. An example of this is the SPN ACT group utilizing data gathered by the St. Paul-area Jewish Pilot Action Community. Since the SPN ACT group was not successful connecting with transportation providers, the Jewish community shared their data.

An unintended benefit for the SPN ACT members was how much they personally and professionally benefitted from being involved in this effort. Many believed they were joining as professionals to provide their experience and recommendations for the group. In the course of the year, many SPN ACT members made connections they wouldn’t have normally have made and created opportunities for collaboration outside of the SPN ACT group. For example, Leah Hanson, Ph.D., from HealthPartners, spoke at Carondelet Village, and collaborations with Wilder have formed to offer caregiver programs. Many seasoned service providers had not experienced this type of collaboration with a coalition partnership. One member commented, “You find people who are organically passionate about this—good things will come from that.”

Next Steps

Although Georgia Lane continues to be the lead for the SPN ACT group, other organizations have come forward as partners to move toward action steps and implement activities. These organizations will help complete the work plans and will be involved in determining outcomes and deliverables.

A grant was submitted to the ACT on Alzheimer’s on December 9, 2013 (Appendix L). Organizations who helped in completing this grant application were the Alzheimer’s Association, Wilder, HealthPartners, Lyngblomsten, Nativity Catholic Church, and a
representative from the African American Faith Communities. Letters of support were provided by HealthPartners, Medica Community Outreach for State Public Programs, and Carondelet Village Board of Directors.

**Conclusion**

Overall, these first phases of moving toward a “dementia-capable community” using the ACT on Alzheimer’s process and tools were effective in St. Paul. Over the course of roughly 12 months, more than 330 individuals were regularly informed and approximately 90 were regularly engaged in the St. Paul effort. Participating members said the effort was effectively managed and that the action plans being generated for the next 12-18 months have promise. The action plans are complementary, offering opportunities for cross-benefit. Members say that the work done to date is already helping to raise awareness. The SPN ACT’s work has been featured in the local newspaper, faith-based newspapers, and district-council newspapers. It is hoped that these connections will continue.

Positive feedback was given by each respondent interviewed for this report. Many of their observations were shared in this report. The organization of the project, upfront and behind the scenes work by the lead coordinator, and access to assistance were important facilitators.

This project continues to create a buzz in the community. This is a grassroots effort and is seen as successful. Service providers feel engaged and new community members continue to arrive to learn what is happening. Lane commented:

> 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 in, and you will be surprised and who attends the group.
Goals of Dementia Capable Communities

- People with dementia can live safely, with as much independence as possible in the setting most conducive to their physical, mental, cognitive, emotional, and spiritual health
- People with dementia are treated with respect
- People with dementia-like symptoms can receive accurate and timely assessment, diagnosis, treatment, support and care
- Families/friends/care partners of people with dementia have easy access to information and resources, such as education regarding symptoms, disease processes, self-care, and providing care
- Resources and Supports are geographically, financially, and culturally available, and accessible
- All segments of the community:
  - Recognize the early warning signs/symptom
  - Understand how to interact with persons with dementia
  - Know basic communication adaptations or accommodations
  - Know that dementia is a disease

February 12, 2013: Convene a community kick-off event to raise issues of dementia for communities, identify ACT process and call community to action

October 2012-January 2013: Work with Convener (Carondelet Village) and others to identify broad base of community stakeholders, including elected officials, employers, faith communities, and providers; invite them to a kick off community event

September-October 2012: Meet with PHS, Carondelet Village, and Wilder to identify Convener and establish pilot status

March 2013: Convene follow up stakeholders to review SPN process and timeline and seek ongoing commitment of

March-April 2013: Orient SPN on Assessment process and assign responsibilities for completing Assessment

April-June 2013: SPN members conduct Assessment and synthesize results

July-September 2013: SPN reviews Assessment results and prioritizes 1-2 year community goals for which it will seek buy-in and engagement

SPN executes on plan and measures progress in partnership with ACT

September -December 2013: SPN develops implementation plan, including success measures, budget and responsibilities and begins to implement priority dementia goals

YEAR 1

ST. PAUL NEIGHBORHOODS ACTION COMMUNITY TEAM

Process Flow and Timeline for Action Community Team Convened by Carondelet Village

YEARS 2-3

Appendix B.
Appendix C

Maps of St. Paul Area Codes (highlighted portion indicates neighborhoods encompassed in SPN ACT)
ST. PAUL NEIGHBORHOODS
ACT on Alzheimer’s
KICK-OFF FORUM
sponsored by Carondelet Village
St. Catherine University Recital Hall
Tuesday, February 12, 2013
3:00 – 5:00 p.m.

Welcome & Program Introduction
Georga Lane, Carondelet Village
Margaret Belanger, CSJ, Carondelet Village Board Member

Elected Officials Panel
Mayor Chris Coleman, City of St. Paul
Lieutenant Governor Yvonne Prettner Solon, State of Minnesota
April Shaw, on behalf of U.S. Congresswoman Betty McCollum
Commissioner Toni Carter, District 4, Ramsey County
Council member Chris Tolbert, City of St. Paul

Content Experts & Project Logistics Panel
Sue Spalding, Executive Director, Alzheimer’s Association of Minnesota
Olivia Mastro, Executive Lead, ACT on Alzheimer’s
“ACT” Video
Dawn Simonson, Executive Director, Metropolitan Area Agency on Aging
Georga Lane, Team Lead, Saint Paul Neighborhoods ACT
Bob Marshall, Community Care Partner

Q & A Discussion

Thank You & Closing Remarks

Final Call to Action

Reception
Please join us for refreshments in the lobby
Special Thanks

ACT on Alzheimer's Leadership Council
Alzheimer's Association of Minnesota
Amherst H. Wilder Foundation
Carondelet Village Board Members
    Margaret Belanger, CSJ
    Dan Lindh, President, Presbyterian Homes & Services
City of St. Paul
St. Paul Advisory Committee on Aging
CSJ Province Leadership
    Meg Gillespie, CSJ
    Katherine Rossini, CSJ
    Jean Wincek, CSJ
Metropolitan Area Agency on Aging
Minnesota Department of Human Services
Ramsey County
### Appendix E

**SPN ACT 2013 Meetings - Summary**

<table>
<thead>
<tr>
<th>Date</th>
<th>Objective</th>
<th>Next Steps</th>
<th># Attendees</th>
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<tbody>
<tr>
<td>Mar 18, 2013</td>
<td>Build team cohesion, understand concept of dementia capability in St. Paul., familiarize team with assessment tools and identify key contacts to conduct</td>
<td>Action Team members were encouraged to contact Georgia with further suggestions and potential additions to the Action Team. Georgia and Olivia will focus on the concern that was raised around providing some creative (electronic survey) approaches to canvassing physicians and other health providers in the St. Paul Neighborhood Community. Next meeting: April 11, 2013</td>
<td>39</td>
</tr>
<tr>
<td>Apr 25, 2013</td>
<td>Build team cohesion, review process and timeline, sign up for sector assessments, identify gaps, review Action Team assessment, and determine next steps.</td>
<td>Georgia will set a meeting date for mid-July. Georgia will work with Nancy Shatek-Suek and Mary Beckman to get a press release in the Highland Villager. Georgia will create for the leave behind packet: • Demographics in St. Paul • Summary of St. Paul Initiative • St. Paul leaders who have signed on to the initiative Mary will send Georgia the following documents: • 10 Warning Signs • Walker “leave behind” template • Business Case • Summary of ACT on Alz. Georgia will create identification badge for those doing the assessments Georgia will add to the May 7th Agenda • Why be part of the assessment? What are the direct benefits to you and your community?</td>
<td>29</td>
</tr>
<tr>
<td>May 7, 2013 9:00-11:00</td>
<td>Review sector sign ups, identify gaps, finish Action Team assessment, and determine next steps</td>
<td>Reach out to Employer list of assessors and ask them to use the Community Assessment instead (send Community Assessment to them electronically). Update Google Docs sector assessment sign-up sheets with additional information gathered at meeting. Create special “assessor” email group (subgroup of full Action Team). Draft media release and send SPN ACT information to contact at Highland Villager and to Team Members. Team Members share media release with appropriate newsletters (faith communities or other). Reach out to Health Partners/Allina representative and orient them on Survey Monkey Assessment. Email them the language to use in an email along with the link to the survey. Have St. Paul demographics of diverse populations (65 and older) available for next meeting. Reach out to Katherine Ringham at Wilder for assistance in gathering this data. Create an electronic leave behind packet and send to group. Complete specified assessments, update completion date on Google Docs. Send Assessments to Georgia Email “check-ins” on progress, issues and updates and ask for assessments to be sent as they are completed (Cheerleading for the assessment team!)</td>
<td>18</td>
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**Paone & Associates, LLC**

SPN ACT Community Progress Report as of December 2013
<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Action</th>
<th>Description</th>
</tr>
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</table>
| June 4, 2013      | 2:30-4:30pm   | Review completed assessments, share updates and lessons learned,      | - Georgia will forward the MINNPost article to the Action Team.  
- Update Google Docs sector assessment sign-up sheets with additional information gathered at meeting.  
- The Action Team will access the sector assessment sign-up sheets and look for and fill in gaps.  
- Olivia will send Georgia a contact for Allina.  
- Georgia will send Paula Fischer the Home Health Survey Monkey link.  
- Olivia will take the Diverse Groups Sector Sheet to the ACT on Alz Cultural/Linguistics Advisory Group for feedback/suggestions.  
- Nancy Shatek-Suek will send Georgia the church bulletin insert once it has been created. Georgia will make it available to the group and anyone who is interested in customizing it for various religious communities.  
- Parichay Rudina will review the clinics sector to see if all zip codes are represented. |
| July 11, 2013     | 2:30-4:30pm   | To review assessment results, identify emerging themes, and determine  | - Add 1-page overview of survey results and priority goals to synthesis presentation and share with team.  
- Turn in all pending assessments to Georgia by July 31st.  
- Enter assessment results as they are received (including survey monkey results).  
- Ensure that first-hand accounts of what it is like to live with dementia or be a caregiver are shared and maintained as a focal point of our work.  
- Provide 3-4 options for actions under each priority area, identifying those options that already have resources that could support the efforts. |
| Sept. 12, 2013    | 2:30-4:30pm   | To review survey results and nine identified priority areas, and to   | - Review attached document: “Priority Areas and Possible Actions Resources”. Send feedback and suggestions to Georgia Lane.  
- Schedule a meeting for broader community in Mid-November to announce priority goals and discuss potential action plan. Smaller planning committee meeting is scheduled for October 10th.  
- Distribute invitations and spread the word to community stakeholders for Community Forum meeting mid-late November (planning committee, publicity, invites, process). |
<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Activity Description</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oct. 10, 2013 2:30-4:00pm</td>
<td>To plan for the SPN ACT Community Forum on November 21, 2013.</td>
<td>Connect with specified table leaders to review role and action plan template. Write and grant application once available. Distribute invitations and spread the word to community stakeholders for Community Forum meeting mid-late November.</td>
<td>17</td>
</tr>
<tr>
<td>Nov. 21, 2013 2:30-4:30</td>
<td>To establish the SPN ACT Action plan by identifying our actions and process steps, lead team members, and action plan timelines.</td>
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<tr>
<td>Dec. 17, 2013 2:30-4:30</td>
<td>To review the work plan and budget, identify team leads and work group members, and determine next steps.</td>
<td>Review revised action plans and outreach list. Provide feedback or additions to Georgia. Convene team leaders 1/10/14. Develop preliminary content for resource packets. Review and modify content for Dementia Friends and Dementia Champions training. Electronic review of resource packet and training contents.</td>
<td>unknown</td>
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**ST. PAUL NEIGHBORHOODS ACTION COMMUNITY TEAM ORIENTATION MEETING**

Tuesday, March 19\(^{th}\), 2013 3-5 p.m.

Location: Carondelet Village, 525 Fairview Ave S., St. Paul, MN 55116

**MEETING OBJECTIVE:** Orient Action Team to the Community Tool Kit and outline process and steps for supplementing the Action Community Team and conducting the Community Assessment

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Presenter/Questions/Input</th>
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<tbody>
<tr>
<td>3:00-3:10 p.m.</td>
<td>Welcome and Introductions</td>
<td>Georgia Lane and All</td>
</tr>
<tr>
<td>3:10-3:30 p.m.</td>
<td>Review</td>
<td>Olivia Mastry/Georgia Lane/Questions/Input by All</td>
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<tr>
<td></td>
<td>• Four Phases of Community Action</td>
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<td></td>
<td>• St. Paul Neighborhoods Timeline</td>
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<td>• St. Paul Neighborhoods Action Team Charter</td>
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<tr>
<td>3:30-4:15 p.m.</td>
<td>Review of the Community Tool Kit with Special Emphasis on the Assessment</td>
<td>Olivia Mastry with Questions/Input by All</td>
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<tr>
<td>4:15-4:50 p.m.</td>
<td>Discussion:</td>
<td>All</td>
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<td></td>
<td>• Who is needed to Conduct the Assessment and Do We Need to Supplement the Team?</td>
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<td></td>
<td>• Develop Plan and Accountabilities for Completing the Assessment</td>
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<tr>
<td>4:50-5:00 p.m.</td>
<td>Outline Next Steps and Next Meeting Date</td>
<td>All</td>
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<tr>
<td>5:00 p.m.</td>
<td>Adjourn</td>
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**Next meetings are schedule @ Carondelet Village on and Thursday April 11\(^{th}\) 3-5 PM**

*Light refreshments will be served*
Have you noticed any of these warning signs?
Please list any concerns you have and take this sheet with you to the doctor.
Note: This list is for information only and not a substitute for a consultation with a qualified professional.

1. Memory loss that disrupts daily life. One of the most common signs of Alzheimer’s, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. What’s typical? Sometimes forgetting names or appointments, but remembering them later.

2. Challenges in planning or solving problems. Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. What’s typical? Making occasional errors when balancing a checkbook.

3. Difficulty completing familiar tasks at home, at work or at leisure. People with Alzheimer’s often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. What’s typical? Occasionally needing help to use the settings on a microwave or to record a television show.

4. Confusion with time or place. People with Alzheimer’s can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. What’s typical? Getting confused about the day of the week but figuring it out later.

5. Trouble understanding visual images and spatial relationships. For some people, having vision problems is a sign of Alzheimer’s. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. What’s typical? Vision changes related to cataracts.
6. New problems with words in speaking or writing. People with Alzheimer’s may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a “hand clock”). *What’s typical?* Sometimes having trouble finding the right word.

7. Misplacing things and losing the ability to retrace steps. A person with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. *What’s typical?* Misplacing things from time to time, such as a pair of glasses or the remote control.

8. Decreased or poor judgment. People with Alzheimer’s may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. *What’s typical?* Making a bad decision once in a while.

9. Withdrawal from work or social activities. A person with Alzheimer’s may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. *What’s typical?* Sometimes feeling weary of work, family and social obligations.

10. Changes in mood and personality. The mood and personalities of people with Alzheimer’s can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. *What’s typical?* Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you have questions about any of these warning signs, the Alzheimer’s Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.

For more information, go to [alz.org/10signs](http://alz.org/10signs) or call 800.272.3900.

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Once you’ve identified the leaders and key stakeholders in your community, it’s time to ask them about what activities are occurring in the community, and what they perceive to be the current resources, needs, and opportunities within the community. This call script is intended to help community team members kick off their fact finding conversations in order to answer the questions in the Community Needs Assessment and to develop an accurate picture of your community’s progress toward being dementia capable. The script is only a guide. Change it as appropriate to fit your needs.

Community Call Script

Hi <name>. I’m <your name and role>. [Community] is coming together to understand how well the community serves people with dementia and to explore how we can act together to be a dementia capable community.

<Reference’s name> suggested you might be a good person to talk to gain a perspective on how well local <e.g., financial planners> are prepared to meet the needs of people with dementia and their families and how we can make improvements.

Would you be willing to share your perspective? Do you have time to talk now or can we arrange a time to talk?

The prevalence of Alzheimer’s disease and related dementia is rapidly increasing. Recognizing that [Community] has a growing older population, we need to prepare our systems and communities for the spiraling needs related to the disease. The <community team name> is working to help <community name> be prepared to support people with dementia and their families. Have you heard about this community effort?

If no: The state of Minnesota has identified dementia as a looming issue that will have/is having a major impact on all communities in the state, including <community>. 1 in 9 people over the age of 65 has Alzheimer’s disease. For people over 85, 1 in 3 people will have the disease. If you’re like me, you’ve known someone who’s lived with dementia—it’s tough.

The <community team name> is trying to assess how well <community> is positioned to provide supportive options that foster quality of life for people with dementia and their families.

Your input would be invaluable.
Appendix I

**Blank Template used at November 21, 2013 for small group discussion**

**SPN ACT Priority Area #1  ** **AWARENESS**

Develop community awareness of Alzheimer’s disease and related dementias to provide the foundation for recognizing individuals that might have dementia and for identifying supports for them.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Actions/ Process Steps</th>
<th>Lead Person &amp; team members</th>
<th>Desired Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Raise awareness and reduce stigma of dementia among general population.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2 Raise awareness about community organizations and resources available to people with dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**What do we hope to achieve?**

**Date/Timeline**
Appendix I

*Blank Template used at November 21, 2013 for small group discussion*

SPN ACT Priority Area #2 **INFORMATION AND EDUCATION**

Provide people diagnosed with dementia and their caregivers with education about the disease and information about services and supports available in the community.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Actions / Process Steps</th>
<th>Lead Person &amp; team members</th>
<th>Desired Outcome</th>
<th>Date/Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Increase dementia education, training, and support for individuals with AD/OD and their caregivers</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2.2 Improve community members’ skills/knowledge about the warning signs and interacting with people with dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix I

Resource Packet Action Plan—see revised action plan

<table>
<thead>
<tr>
<th>Priority Area #1</th>
<th>Objective</th>
<th>Goal #1:</th>
<th>Desired outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>AWARENESS</td>
<td>Raise awareness about community organizations and resources available to people with dementia;</td>
<td>Create St. Paul-specific, culturally appropriate resource package and distribute to targeted audiences;</td>
<td>Community members are aware of available resources in the community, and know how to access them.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Process steps</th>
<th>Timeline</th>
<th>Team Lead &amp; members</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Develop team leads and workgroup</td>
<td>Dec 2013</td>
<td>Team Leads: Kathy Klietz &amp; Wilder with support from the Alzheimer’s Association.</td>
</tr>
<tr>
<td>2) Identify local resources &amp; determine content of packets, including culturally appropriate materials.</td>
<td>January-Feb 2014</td>
<td>Kathy Klietz, Georgia Lane &amp; Wilder with support from the Alzheimer’s Association.</td>
</tr>
<tr>
<td>a. Package will be customizable; can use as little or as much info as is relevant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Identify core pieces to be included in each resource package (contacts, FAQ’s, signs &amp; symptoms)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Include simple tri-fold brochure and bookmark with 10-signs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Include disease-specific information (difference between normal aging and AD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Include “human” contacts when possible (list phone #s, names, hours)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Include tips for communication with PWD.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Include talking points on how to disseminate and use package.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Determine target markets (faith communities, cultural communities, district councils, leadership groups, schools, businesses, City employees, pharmacies)</td>
<td>Dec 2013-Feb 2014</td>
<td>Work Group develop names and contact list. (see attached grid)</td>
</tr>
<tr>
<td>4) Pilot package with cultural communities and other audiences as needed.</td>
<td>March 2014</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Call the Senior Linkage Line to test utility of resource packet. Include recommended questions for caregivers or FAQs.</td>
<td>March 2014</td>
</tr>
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</tr>
<tr>
<td>6</td>
<td>Create a resource packet dissemination plan to streamline the outreach process.</td>
<td>March-April 2014</td>
</tr>
<tr>
<td>7</td>
<td>Identify and partner with host organizations willing to post materials on their websites free of charge.</td>
<td>March-April 2014</td>
</tr>
<tr>
<td>8</td>
<td>Distribute packages to target audiences.</td>
<td>April-Dec 2014</td>
</tr>
<tr>
<td>9</td>
<td>Quarterly review to obtain feedback, evaluate contents and dissemination process, and modify as needed.</td>
<td>April-Dec 2014</td>
</tr>
</tbody>
</table>
## Appendix I

### Dementia Friends Action Plan

<table>
<thead>
<tr>
<th>Priority Area #2 INFORMATION AND EDUCATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Objective</strong></td>
</tr>
<tr>
<td>Improve community members’ skills/knowledge about the warning signs and interacting with people with dementia</td>
</tr>
<tr>
<td><strong>Action</strong></td>
</tr>
<tr>
<td>Prepare community members to be “dementia friends”, who agree to receive training on interacting with, and if possible, supporting or helping someone with dementia. (They receive training from “dementia champions”.)</td>
</tr>
<tr>
<td><strong>Desired outcomes</strong></td>
</tr>
<tr>
<td>Community members will have reduced stigma and improved skills for interacting with people with dementia.</td>
</tr>
<tr>
<td>People with dementia will feel more supported and understood when out in the community.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Process steps</th>
<th>Timeline</th>
<th>Team Lead &amp; members</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Develop team leads and workgroup.</td>
<td>December 2013</td>
<td><strong>Team Leads:</strong> Georgia Lane &amp; Julie Pfab, with support from the Alzheimer’s Association. <strong>Team Members:</strong> See attached spreadsheet</td>
</tr>
<tr>
<td>2) Familiarize with UK “Dementia Friends” program structure and training materials.</td>
<td>December 2013</td>
<td>SPN ACT team members at 12.17.13 meeting</td>
</tr>
<tr>
<td>3) Review local volunteer training programs (Lyngblomsten, Alzheimer’s Association). Modify and customize training materials and resources as needed.</td>
<td>Jan-Feb 2014</td>
<td>Georgia Lane &amp; Julie Pfab, with support from the Alzheimer’s Association.</td>
</tr>
<tr>
<td>4) Define “Dementia Friend” and “Dementia Champion” for St. Paul. Include qualifications for being a “Dementia Champion”</td>
<td>Feb-March 2014</td>
<td>Georgia Lane &amp; Julie Pfab, with support from the Alzheimer’s Association.</td>
</tr>
<tr>
<td>5) Share draft content and definitions with team members for review and feedback. Modify as needed.</td>
<td>Feb-March 2014</td>
<td>Team members</td>
</tr>
<tr>
<td>6) Determine target audiences (faith communities, cultural communities, district councils, leadership groups, schools, businesses, City employees, pharmacies). Likely Audiences: Condo Association, St. Paul Public Housing, Library System, Neighborhood Communications to Neighborhood Block</td>
<td>Jan-March 2014</td>
<td>Work Group develop names and contact list. (see attached grid)</td>
</tr>
<tr>
<td>Step</td>
<td>Description</td>
<td>Timeframe</td>
</tr>
<tr>
<td>------</td>
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</tr>
<tr>
<td>7)</td>
<td>Identify experts who can conduct the Champions training (train the trainer).</td>
<td>Feb-March 2014</td>
</tr>
<tr>
<td>8)</td>
<td>Identify potential Dementia Champion Teams</td>
<td>Feb-March 2014</td>
</tr>
<tr>
<td>9)</td>
<td>Establish target #s of dementia friends to be trained.</td>
<td>Feb-March 2014</td>
</tr>
<tr>
<td>10)</td>
<td>Establish training schedule.</td>
<td>March 2014</td>
</tr>
<tr>
<td>11)</td>
<td>Advertise trainings to target audiences and broader community.</td>
<td>March-November 2014</td>
</tr>
<tr>
<td>12)</td>
<td>Conduct trainings and track progress.</td>
<td>April-December 2014</td>
</tr>
<tr>
<td>13)</td>
<td>Quarterly review of contents, obtain feedback from Dementia Friends. Modify as needed.</td>
<td>April, June, September 2014</td>
</tr>
</tbody>
</table>
Appendix J

Purpose: ACT on Alzheimer's used for SPN ACT handout (2-sided, bookmark size)

What is ACT on Alzheimer’s?

ACT on Alzheimer’s is a statewide collaboration designed to prepare Minnesota for the budgetary, social, and personal impacts of Alzheimer’s disease. ACT on Alzheimer’s involves over 150 multi-perspective stakeholders (including Mayo Clinic, Stratis Health, and MN Department on Aging) who seek to accomplish ACT on Alzheimer’s vision through five principal avenues:

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

2) Sustain caregivers through access to and navigation of organized information about supportive services and resources;

3) Equip and engage communities in supporting individuals with the disease and their caregivers;

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

5) Establish and garner stakeholder investment in promising interventions that bend the cost curve for Alzheimer’s and related dementias.

©2013

The rapidly increasing prevalence of Alzheimer’s in Minnesota is an urgent call for us to prepare our systems and communities for the complexities related to the disease.

- 1 in 9 people over the age of 65 has Alzheimer’s disease or other dementia.
- Minnesota will experience a 15% increase in people living with Alzheimer’s disease over the next 15 years.
- People with Alzheimer’s disease spend an average of $175,000 of their own money over the course of their disease. Medicare and Medicaid will spend $1 trillion per year on Alzheimer’s care by 2050.
- The rapidly expanding issue urgently calls communities to prepare for the spiraling needs related to dementia.

What Can We Do?

St. Paul is one of five communities in Minnesota to be chosen as a pilot community for the ACT on Alzheimer’s initiative. Our team will focus on enhancing dementia capability in the following 6 St. Paul neighborhoods: Highland Park, Mac-Groveland, West 7th, Summit Hill, Summit University, and Union Park.

We will specifically help to equip and engage organizations, businesses, and individuals in supporting people living with Alzheimer’s disease and their caregivers. If you would like more information about the ACT on Alzheimer’s initiative, would like dementia related resources, or to discover ways you can be a part of equipping St. Paul in becoming a dementia capable community, please contact Georgia Lane at (651-695-5102) or glane@preshomes.org
Appendix K

Rising to the challenge
St. Paul neighborhoods prepare for Alzheimer’s

By Regan Smith

One in nine people over the age of 65 has Alzheimer’s disease or other form of dementia. And if that number sounds high, consider this: By the time they reach the age of 85, fully half of all U.S. residents will have some form of dementia. Minnesota is expected to see a 15 percent rise in the disease over the next 15 years.

Despite these harrowing statistics, research has shown that most cities and states are woefully underprepared to serve their older residents’ increasing needs. It is this slowly brewing crisis that inspired the statewide ACT on Alzheimer’s initiative to pick St. Paul as its fifth pilot city to work on improving the lives of Alzheimer’s patients and their families. The newly formed St. Paul Neighborhoods Action Community Team (SPN ACT) is focusing on enhancing the lives of people with dementia in the Highland, Macalester-Groveland, West 7th, Summit Hill, Summit-University and Union Park neighborhoods.

“We’re lucky to live in a community that already has so many services and programs for seniors, but with these numbers on the rise, our social systems are just not set up to handle the new realities of this disease,” said Georgia Lane, SPN ACT coordinator and Dementia Pathways program director for Carondolet Village, the Highland senior housing facility where the SPN ACT meetings are convened.

ACT on Alzheimer’s, which is composed of more than 50 groups, was formed in 2009 at the mandate of the state Legislature. The organization’s main mission is to create “dementia-capable communities.” With the help of its partner organizations, local politicians and other members, ACT guides its pilot programs through a four-phase process: Convene, Assess, Analyze and ACT Together.

SPN ACT launched the first phase of the project with an event in February at Carondolet Village. Among those in attendance were St. Paul Mayor Chris Coleman and Minnesota Lieutenant Governor Yvonne Prettner Solon, who are committed to helping see the project through the three-year process.

“After you convene your group, the next step is to go out and do community surveys, gathering information on what people’s perceptions are on the needs of Alzheimer’s patients. This is a crucial step in both collecting data and spreading awareness,” Lane said. “Not many people realize how widespread the disease is. We have 4,500 people in Highland Park alone who are going to be touched by dementia.”

Roger Maulik, a Highland resident and SPN ACT team member, is one of them. His wife Beth’s family has a history of Alzheimer’s, and her brother, who has been diagnosed with the disease, is currently being cared for at Carondolet Village.

“Sadly, when someone says, ‘My brother has Alzheimer’s,’ people
Beth Maulik, whose family has a history of memory loss, receives special support from husband Roger, who is active in a local consortium focusing on dementia and Alzheimer’s disease. PHOTO BY BRAD STAUFFER

tend to move away because they don’t understand it,” Maulik said. “Our experience has made us much more aware when we see other people who are dealing with dementia. You have a stronger feeling for what these people are going through when it’s so close to your own family.”

A lack of understanding about dementia is one of St. Paul’s most significant public health issues, Lane said. Since early detection is one of the most essential parts of treating the disease, educating people about the symptoms of dementia and creating a bridge between the health care systems and community resources is one of SPN ACT’s goals. The group also wants to make sure people with Alzheimer’s have transportation, housing, health care, financial and legal planning, and advance care planning.

“Getting people connected to the right services at the right time is our biggest gap, along with education and awareness,” Lane said. “People might go to the doctor and be told they have dementia, but because they don’t hear the word Alzheimer’s they don’t take it seriously. People are either in denial or they may get information or medication, but they don’t have the follow-up or support after they leave the doctor.”

After completing the first phase of the program, SPN ACT plans to hold another large meeting this fall where it will begin to assess the situation and identify which gaps in dementia preparedness are the most important to focus on. The group will then develop an action plan. The outcome might involve new legislation, a request for additional government funding or the creation of specialized education and outreach programs.

The SPN ACT team includes Carondelet Village, the Wilder Foundation, Metropolitan Area Agency on Aging, St. Paul Advisory Committee on Aging, St. Paul Emergency Medical Services, Ramsey County, Alzheimer’s Association, Catholic Charities, Health Partners, Allina, Fairview, Keystone Senior Communities, and other organizations, faith communities, businesses and citizens.

Those who want to learn more about dementia or get involved in the SPN ACT initiative are invited to attend its next meeting, which is scheduled from 2:30-4:30 p.m. Thursday, July 11, in the Carondelet Village auditorium, 525 S. Fairview Ave. To register or for more information, contact Georgia Lane at 651-695-5102 or glane@preshomes.org.
NARRATIVE

1. Summarize dementia capability work completed to date, including involvement in local, regional or other initiatives. Indicate which activities were conducted using the Dementia Capable Communities Toolkit.

PHASE ONE: Initial work to convene the St. Paul Neighborhoods ACT on Alzheimer’s Team began in September of 2012. A planning committee was established, that was comprised of representatives from the following organizations: Carondelet Village (Convener), Metropolitan Area Agency on Aging, Amherst H. Wilder Foundation, Alzheimer’s Association, City of St. Paul Advisory Committee on Aging, and ACT on Alzheimer’s. To begin, we defined our community to focus primarily on the following St. Paul Neighborhoods: Highland Park, Mac-Groveland, West 7th, Summit Hill, Summit University, and Union Park. Our planning team identified a broad base of community stakeholders and held a kick-off event in February 2013 which had approximately 150 attendees and a distinguished panel of elected officials and experts on Alzheimer’s disease. St. Paul City Council showed their formal support by passing a resolution declaring February 12, 2013 “ACT on Alzheimer’s Awareness and Kick Off Day”. Our kick-off created great momentum that led to a rapidly growing Action Team with 50 + members.

PHASE TWO: Our assessment phase took place March-June 2013. We continued to build our team, provided training for the assessment process and reviewed the scope of the project. 24 team members volunteered to conduct surveys. Electronic and hard copy resource packets were provided for the survey team to use, which included an introduction to SPN ACT, local demographic information, “10-signs” brochure, assessment instructions, and call scripts. Once completed, surveys were turned in to the project coordinator and entered into the synthesis tool. By July, 127 surveys were completed across all 14 community sectors.
PHASE THREE: The results were analyzed in summer 2013. Action priorities were identified and presented to a wider audience in the community in fall 2013. Based on results from the community surveys and with input from the community, our team identified 3 priority areas: Awareness, Information and Education, and Medical Management/Early ID. Two objectives were established under each one of these priority areas. A list of potential action items was generated for each objective.

PHASE FOUR: In November 2013 we moved into phase 4 as we hosted a broader community forum to build our action plan. We reviewed our established priority areas and objectives, reviewed potential actions, developed preliminary process steps, and then voted for the top two actions, which are reflected in the work plan. Implementation of this work plan will be our primary focus area in 2014.

Throughout our process, we have endeavored to align with the work happening with the St. Paul Communities for a Lifetime project, as well as the evolving work with the East St. Paul African American ACT on Alzheimer’s initiatives. We intend to stay informed of the work happening with both of these initiatives and find ways to collaborate where appropriate.

2. Describe how the activities proposed in the Work Plan will advance your community to become more dementia capable, referencing use of the ACT on Alzheimer’s Dementia Capable Communities Toolkit where applicable to your community.

We intend to invest 100% of the grant in Phase 4 towards action plan implementation. Throughout our four phases, we have been creating community awareness and providing information and education about Alzheimer’s disease and related dementias. By convening our team and conducting assessments, we initiated community conversations and had materials available to educate community members on the impact and prevalence of dementia in our neighborhoods. The toolkit provided a structured process to guide us through the phases of community action and continues to be essential to our collaborative process as we look forward to implementing our
work plan. We anticipate that the action resources listed under “Dementia-Friendly Communities” in the toolkit will be particularly valuable in the development of our proposed activities.

The activities outlined in our work plan include creating a St. Paul-specific resource packet and establishing an informal network of volunteer “Dementia Friends.” These concrete action steps will help St. Paul become more informed, safe, and respectful of individuals with dementia and their families.

- The St. Paul-specific information packet will help raise community awareness of local resources and improve access to these resources. The packet will be up-to-date, accurate, and appropriate for diverse cultural groups. It will include contact information for local resources, tips for communicating with persons with dementia, and other helpful tools to be determined by the action team. The packet will be distributed to targeted audiences such as local faith communities, businesses, government officials, and schools.
- The network of Dementia Friends will help reduce stigma and increase the number of local individuals committed to supporting, interacting with, and creating a sense of belonging for persons with dementia. Patterned after the successful U.K. Dementia Friends model, our befriending program will utilize existing best practices to inspire community members to help make St. Paul more dementia capable.

3. Identify the current project partners and outline their roles and commitments to implement the project. If applicable, indicate additional partners to be recruited on your Action Team. Attach at least 3 letters of commitment, one of which may be from the lead agency.

Throughout our process we have had a diverse group of community members and organizations involved in our work. To date, we have 320+ individuals on our contact list, and 90+ individuals who have attended meetings and/or assisted in completing surveys. We have had an “open door” policy to ensure ongoing energy and engagement with our work.

A number of organizations have demonstrated ongoing commitment. These key organizations include: Alzheimer’s Association, Amherst H. Wilder Foundation, Carondelet Village (Convener), Catholic Charities, The City of St. Paul, Health East, Health Partners, Highland Block Nurse Program, Jewish Family Services, Keystone Senior Communities, Lyngblomsten, Medica, the Metropolitan Area Agency on Aging, Nativity Catholic Church, Ramsey County Human Services, Senior Services Consortium...
of Ramsey County, and Stratis Health. As we move forward with implementing our action plan, we anticipate that our list of collaborators will continue to evolve. We also hope to obtain deeper engagement with organizations such as The City of St. Paul, local businesses, or targeted faith communities as we offer our awareness and education activities outlined in the work plan.

See attached letters of support from:
- Carondelet Village (Margaret Belanger)
- Medica (Kari Bailey)
- Health Partners (Ann Brombach)

WORK PLAN

Complete the following work plan to describe the significant milestones your Action Community will achieve, the key steps to reach them, the person(s) or title(s) of those who will be responsible, and target dates for completion. A milestone is a significant benchmark in your project such as completing the community assessments, synthesizing results, or holding a community event to share findings. Indicate which Phase of the Dementia Capable Communities Toolkit the milestone relates to.

For applicants requesting funds to carry-out Phases 1, 2 and/or 3 of the Toolkit, include only those milestones. Applicants requesting funds for Phase 4 should include only Phase 4 milestones and must state the priority area goal(s) to be implemented. Applicants may request funds to support work activities to achieve up to two (2) identified priority area goals; however, at least one (1) priority area goal must be accomplished by December 2015.

This section is worth a maximum of 10 points.
**ACT on Alzheimer's**

**Project Work Plan**

*Phase 4 applicants only* – State up to two (2) priority area goals, of which at least one (1) must be achieved by December 2015:

**Priority Area Goal 1: Awareness** Raise awareness about community organizations and resources available to people with dementia

**Priority Area Goal 2: Information and Education** Improve community members’ skills/knowledge about the warning signs and interacting with people with dementia

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Steps to Complete</th>
<th>Person or Title Responsible, Organizational Affiliation, If Any</th>
<th>Target Dates for Completion</th>
<th>Toolkit Phase (Indicate 1, 2, 3, 4 or N/A)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal 1: Create St. Paul-specific, culturally appropriate resource package and distribute to targeted audiences</strong></td>
<td>1. Develop team leads and workgroup</td>
<td>Team Leads: Kathy Kleitz, (Community Member) Therese Buckley &amp; Kristen Oshyn (Wilder) Georgia Lane, (Carondelet Village) with support from the Alzheimer’s Association</td>
<td>Steps 1-7 Dec 2013-March 2014</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2. Identify local resources &amp; determine content of packets, including culturally appropriate materials.</td>
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<tr>
<td></td>
<td>a. Include disease-specific information (difference between normal aging and AD)</td>
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<td></td>
<td>b. Include “human” contacts when possible (list phone #s,</td>
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</table>
c. Consider including tips for communication with PWD

3. Consult with MAAA staff, Mnhelp.info and Alzheimer’s Association in compilation of resource packet.

4. Determine target markets (faith communities, cultural communities, district councils, leadership groups, schools, businesses, City employees, pharmacies)

5. Pilot package with cultural communities and other audiences as needed.

6. Call the Senior Linkage Line to test utility of resource packet. Include recommended questions for caregivers or FAQs.

7. Create a resource packet dissemination plan to streamline the outreach process.

8. Identify and partner with host organizations willing to post materials on their websites free of charge.

9. Distribute packages to target
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<tr>
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<tbody>
<tr>
<td><strong>Goal 2:</strong> Create an informal network of “dementia friends”, which is a volunteer network of individuals who agree to receive training on interacting with, and if possible, befriending someone with dementia.</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Develop team leads and workgroup.</td>
</tr>
<tr>
<td>2.</td>
<td>Familiarize with UK “Dementia Friends” program structure and training materials.</td>
</tr>
<tr>
<td>3.</td>
<td>Review local volunteer training programs (Lyngblomsten, Alzheimer’s Association).</td>
</tr>
<tr>
<td>4.</td>
<td>Modify and customize training materials and resources as needed.</td>
</tr>
<tr>
<td>5.</td>
<td>Define “Dementia Friend” and “Dementia Champion” (similar to a volunteer speaker’s bureau).</td>
</tr>
<tr>
<td>6.</td>
<td>Identify experts who can conduct the Champions training (train the trainer).</td>
</tr>
<tr>
<td>7.</td>
<td>Establish target #s of dementia friends to be</td>
</tr>
<tr>
<td></td>
<td>Team Leads: Julie Pfab, Carolyn Klaver, &amp; Cindy Albing (Lyngblomsten) and Georgia Lane (CV) with support from the Alzheimer’s Association.</td>
</tr>
<tr>
<td></td>
<td>Steps 1-6 Dec 2013-Feb 2014</td>
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<td></td>
<td>Steps 7-10 March-Apr 2014</td>
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<td></td>
<td>Steps 11-12 Apr-Dec 2014</td>
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</tbody>
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Paone & Associates, LLC  SPN ACT Community Progress Report as of December 2013  68
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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>8.</td>
<td>Determine target audiences (faith communities, cultural communities, district councils, leadership groups, schools, businesses, City employees, pharmacies).</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Establish training schedule.</td>
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<td>10.</td>
<td>Advertise trainings to target audiences and broader community.</td>
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<td>11.</td>
<td>Conduct trainings and track progress.</td>
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<td>12.</td>
<td>Quarterly review of contents, obtain feedback from Dementia Friends. Modify as needed.</td>
<td></td>
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References

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