Act on Alzheimer’s Pilot Communities’ Use of the Dementia-Capable Communities Toolkit*
Composite Report

Prepared by Paone & Associates, LLC
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Under a grant from GHR Foundation

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Background

**Act on Alzheimer’s**

*ACT on Alzheimer’s* is a statewide collaboration\(^1\) seeking to address the personal, social, medical, and budgetary impacts of Alzheimer’s disease and related dementias. The collaborative, formerly known as “Prepare Minnesota for Alzheimer’s 2020,” grew out of the work conducted by the Alzheimer’s Disease Working Group—which was initiated by the Minnesota State Legislature in 2009 and facilitated by the Minnesota Board on Aging (providing its report and recommendations in January 2011).

Within the voluntary effort called *ACT on Alzheimer’s* (launched in June, 2011) many sectors have come together to participate in this effort—people with Alzheimer’s disease, family caregivers, medical care and social service providers, government officials and policy experts, researchers and academics, and businesses, advocates, and civic organizations—to better support individuals with Alzheimer’s disease and their families.

The ACT on Alzheimer’s website reads (as of June, 2013):

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*The collaboration has more than 150 participants, including some 50 nonprofit, governmental and private organizations, and works toward five goals:*

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

Development of a Dementia Capable Community Toolkit has been part of the work of this collaboration. The Community Toolkit was developed under funding by Greater Twin Cities United Way, by individuals engaged in one of the five leadership groups within the structure of the ACT on Alzheimer’s initiative (the Leadership Group on Preparing Communities). The members of this Leadership Group, together with a

\(^1\) Please refer to the website ([www.ACTonAlz.org](http://www.ACTonAlz.org)) for current information and resources, as this web site is continually being updated.
consultant staff expert from Stratis Health developed the Community Toolkit. The executive lead had this to say about the Toolkit development:

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

The process for creating the Toolkit included examination of current literature on community engagement and crafting a set of tools and a process for administration community-wide. Representatives of four pilot communities came forward to assist in the effort. Each of the pilot communities provided input into content for the Toolkit and subsequently provided feedback in iterative cycles as the Toolkit was refined. Each community was then asked to test it within their geographic area or their community of interest.

These four pilot communities (all in Minnesota) were:

1. St. Louis Park
2. Twin Cities Jewish Community
3. Walker
4. Willmar

The four pilot communities differ in several ways. Three communities were geographically defined (St. Louis Park, Walker, and Willmar), and one was a community of interest (Jewish Community). Two of the geographic communities (Walker and Willmar) are in greater Minnesota, outside of the Twin Cities. The St. Louis Park and the Jewish communities are within the Twin Cities metropolitan area.

The Toolkit development and piloting occurred in late 2011 and throughout 2012 via an iterative process. Each of the four communities provided input and suggestions during and after the development of the various versions of the Toolkit. The community then chose a timeframe for using the assessment tools and conducted an assessment of their own community’s dementia capability—understanding that this would be a cursory view at one point in time.

The ACT on Alzheimer’s website describes the purpose for using the Community Toolkit as follows:

*To give your community a process for coming together and planning how to become dementia-capable. This process will strengthen your community, improve overall services, support caregivers and prepare*

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² Stratis Health is the federally-designated Quality Improvement Organization in Minnesota
Steps for Use
At time of this report, the Community Toolkit offers four steps, following a sequential process:

1. **Convene** key community leaders and members to understand the disease and its implications for communities. Then, bring together an Action Team.
2. **Assess** current strengths and gaps in meeting the needs that result from Alzheimer’s disease and related dementias, using a comprehensive community assessment toolkit.
3. **Analyze** community needs and the issues stakeholders are motivated to act on to set community goals.
4. **ACT Together** to establish implementation plans to achieve goals and measure progress.

This Report: Progress to Date

**Evaluation “Snapshot”**
An evaluation team from Paone & Associates, LLC was contracted under a grant from the GHR Foundation to take a “snapshot” of the four pilot communities and document lessons learned to date. Paone & Associates provides strategic program development and evaluation. The evaluation team for the review of the four pilot communities was comprised of Deborah Paone, (Principal), and Lisa Edstrom, Jeanne Schuller, and Adine Stokes (Research Associates).

A key informant interview structured protocol was developed based on interviews with the ACT on Alzheimer’s leads and review of materials from the “Preparing Communities” Leadership Group within ACT on Alzheimer’s. A member of the evaluation team first conducted key informant telephone interviews with the executive lead and project manager from ACT on Alzheimer’s and with the staff expert lead from Stratis Health to discuss the development and use of the Community Toolkit in 2012 through early 2013. Two Research Associates then conducted telephone interviews using the structured interview protocol with the Community Coordinator and two other individuals (usually a co-leader) from each pilot community (April and May, 2013).

This Composite Report summarizes the work done to date, identifies common findings and themes across the four communities, and provides the community-specific individual reports that provide additional detail. The individual reports are also being provided to each community coordinator as stand-alone documents for their use.

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4 Ibid.
Common Findings

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

• Pilot-testing community coalitions were formed out of an existing task force or working group that had been created with an identified interest in addressing Alzheimer’s disease or dementia in some way (although, in one case members from the existing working group formed a new group specifically to help develop and test this Toolkit).

• The need for education around dementia was a primary driving force for creation of the existing task force or group. Respondents said that their task force or group had already had several years of experience with offering educational and awareness-building sessions/events to their respective communities.

• All of the groups were receptive to the invitation to be part of the Pilot Community Toolkit development and testing as part of the ACT on Alzheimer’s initiative.

• Each community had a coordinator as well as several active lead members who facilitated the work of the whole group or taking a lead in one part of the process (with additional group members and other volunteers participating).

• The work was conducted as a voluntary effort—while there were individuals employed by various organizations, almost all of the effort occurred outside their normal job duties.

• The Toolkit development represented a large component of the total work effort by these four pilot community coalitions during the timeframe examined (2012-early 2013).
Processes and Steps

**Groundwork and Convening Phase**
The pilot communities began their effort by establishing the coalition (forming or reforming the group of individuals who would participate to develop and test the Toolkit). Each coalition/work group had, as members of the group, a combination of individuals who were doing the work with some time approved from their employers (“paid staff”) and individuals who were independent volunteers. These individuals were often highly educated and well-versed in the issues of Alzheimer’s disease. Members included professionals in the field of aging, health care and medical services, housing, business, law, spiritual care, and other sectors, as well as retirees. Within all four pilot communities, personal interest/passion for addressing the issue of Alzheimer’s disease and building dementia capability was the reason that individuals had committed time to this effort. Thus the group members were internally motivated.

None of the community coalitions held a public kick-off event at the beginning of the process. Rather they worked together to identify and invite individuals to participate as a member of the coalition/workgroup, based on their knowledge of the community and their professional and personal networks.

As coalition members came together, they clarified the coordinator role and determined how they would work together. A single coordinator or two co-leaders were identified as the key point people within each pilot community. The community coalitions functioned democratically. The identified community coordinator facilitated a consensus process around key decisions and content discussions. As time went on a small core group emerged. These were the individuals most involved in the work; with point people designated to take a lead on one or more aspects of the process.

Each of the coalitions/groups received information about the ACT on Alzheimer’s effort, met with the executive lead and with the staff expert from Stratis Health, and reviewed material and resources related to conducting a community assessment. In some cases they reviewed material and resources about Alzheimer’s disease (e.g., on early warning signs and disease stages and progression) to determine what information might be useful to leave with individuals being interviewed.

**Assessment Phase**
Because communities were assisting with both the tool development and the pilot testing, their first task was to read and respond to each version of the toolkit and the collateral material. This was a “roll-up-your-sleeves” lengthy process of going back and forth on content, format, focus, definition of terms, and other aspects of the Toolkit. Although this was a time-consuming process, it did enhance the understanding of the four pilot communities’ coalition/workgroup members about what it means to be “dementia-capable.” The downside of this method was that it created process-fatigue.
and some members left the coalitions or suspended their involvement during this phase. This also impacted the number of people involved in the next phase of work—which was to actually conduct the assessments within their communities.

The assessments were conducted in many different ways—as groups, one-on-one, and in pairs (teams of two assessors per interviewee). Methods used included conducting the interview using the question set in-person or over the telephone. In a few cases the assessment survey was completed by one individual and mailed or handed in, without an assessor posing the questions.

Group interviews were a means of reaching more people who may not have had the time to participate otherwise. However, group interviews did not provide much rich feedback or stories. Nor could the interviewer develop a relationship as much through group interviews. For these reasons the 1:1 interviews/assessments were preferred by most interviewed for this report.

The assessments took from 15 minutes to more than 2 hours to complete, with 40 minutes to an hour being the norm. This range is based on recollection of the coordinators, since the time to complete each survey was not recorded by all assessors.

Coalitions had various ways of distributing the assessments among their members, with the most often reported method being letting each person choose who they would interview from a comprehensive list generated by the whole coalition.

The timeframe to conduct all of the assessments varied from three months to six+ months. Some assessments were still being conducted at the time of this report.

Providing leave-behind material to the interviewee enhanced the value of the interview as an educational opportunity and helped underscore the importance of this issue. Likewise, positive feedback from those being interviewed and from others within the community was important to capture.

**Analysis Phase**

Only one of the four communities had completed the analysis phase at the time of these interviews, although all communities had been working to enter the results of the assessments in spreadsheets or tables. The one community that completed the analysis phase was in the process of setting up an action plan for moving forward. This community commented that the process for entering data and then interpreting data from the assessments can be lengthy. Both quantitative and qualitative information must be organized and analyzed in a structured or systematic way.

In anticipation of this next phase, the following comments and suggestions were made by the community representatives interviewed:
• Trained volunteers for data entry/analysis would be valuable support.
• The data entry and analysis takes time—the more assessments, the more time needed—and could be overwhelming. One person should be designated to oversee the analysis phase.
• Entering data immediately following the assessment is highly recommended.

Lessons Learned/Advice for Others

From the Pilot Communities’ Experiences

The Toolkit is primarily geared for geographic communities and not communities of interest (e.g., a faith community, ethnic community or other population group). Adaptations or other changes to the tool will be necessary to make it more workable for these types of communities.

Barriers identified included time and focus—that is balancing ACT work with employment or other demands, losing group momentum, adapting the tool to fit the community group’s desired approach or parameters of interest, and trying to define the vague concept of “dementia capable communities.”

Working together as part of a pilot community was of great value. There was a sense of pride at being involved with this effort. The process itself cemented group cohesion. Members felt bonded with one another. This strong camaraderie may be an “asset” to drive the work during the next phases of the process.

Other successes identified were the newly streamlined and accessible tools that were created as a result of this Toolkit development input, the creation of a group method for “dividing and conquering” the process, and the expanded utilization of volunteers.

Tips for other communities embarking on this process were offered. Advice included:

• Have a very strong coordinator or co-coordinator leads
• Team building is critical
• Get a kick off going

Advice/Tips for New Communities:

• Have a very strong leader/Coordinator or co-Coordinators
• Team-building and group cohesion is critical
• Walk through all of the Toolkit and plan for the various phases of work, perhaps bringing in different talent/expertise among group members that is tailored to the task at hand
• Ensure you have enough people involved
• Set realistic goals as a group, including timeframes
• Practice with the tools; role play and provide each other feedback
• Offer educational and other leave-behind material following the assessment
• Do data entry as soon as the assessment is completed, don’t wait
• Involve the group in conducting the analysis and interpreting the results
- Practice administering the tool
- Be prepared to engage fully with respondents
- Have educational “take away” materials to leave with the person
- Embrace creative solutions to problems and obstacles
- Don’t get overwhelmed by the content or volume of work to complete
- Set realistic and attainable goals
- Do not get discouraged by the tool or process
- Spend time investigating the assessment tools and determine which tools apply to your specific community—you may not want to/need to do all of the assessments, and you need to think about how the assessments are done
- Set goals and determine timeframe
- Establish the processes and methods you want to use, for example selecting 1:1 vs. group assessments
- Consider the use of volunteers— in order to build community engagement—but be prepared for utilizing them effectively and managing their needs
- While it is good to have passionate people with a history and strong involvement doing this work, it is important to think through how new volunteers and other professionals can “come and go” and contribute throughout the various phases of the initiative—this will aid to keeping up the momentum. (New members may energize the process)

More Advice:
- Build a bigger team from the start, to allow for some shrinkage of the group over time
- Select volunteers with specific skills
- Bring diversity onto the group; ensure community representation
- Communities should pick the assessment areas and scope of their assessment process
- Communities differ in the amount of technical assistance they will need
- Involve the group in conducting the analysis and interpreting the results
- The process of conducting the interviews and completing the assessments raises awareness; it builds momentum for “what’s next”

From the ACT on Alzheimer’s lead and Toolkit consultant
The executive lead, program manager and consultant were interviewed in March, 2013 about their perspectives on lessons learned. These comments are from those interviews:

We have learned many things from the efforts of these four pilot communities that can inform future communities, such as:
- You need a very strong local champion to do this work; having co-leaders is best; plus several committed individuals who are willing to be in it for the long haul.
- Communities, too, may be more or less action oriented.
- With regard to the convening step - it makes a big difference if you build a bigger team from the start.
- Building the team will need to include selecting volunteers/participants with specific skills sets. Some people may be very interested in Alzheimer’s but not so
interested in conducting a community assessment. They may not be trained for this and can easily go “off script.” Alternatively people who are used to scientific rigor and community-based research will find this lacking—because this is different than a research project.

- Bringing diversity to the table and onto the working group conducting assessments (to ensure the reflection of the full community) will be important so that there is not a lopsided or distorted picture of the community.
- As this is an ongoing (and somewhat lengthy) process, there may need to be additional people added along the way from one phase to another.
- We have found that this is not a stand-alone, do-it-yourself process. There will need to be some technical support. Each community will be different in terms of the level of technical support and guidance they might need.
- Communities can make this their own—can pick and choose the components depending on the size and scope of what they want to accomplish; this needs to be flexible and adaptable.
- Even the process of doing the assessments raises awareness within the communities; it builds the momentum for “what comes next.”
- The analysis process and action phases are still being explored—we will be learning about how this assessment translates into prioritization and action—we don’t know how this will unfold yet.
- Sometimes even defining the community is hard—people are mobile and where they live is not often where they work—and areas overlap, services extend across town or city boundaries.
- Sharing stories is a powerful tool. It motivates people—including the team conducting the assessments and the community at large. It provides the reality of why this is important to self, neighbors, friends, and the whole community.

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Deborah Paone, Lisa Edstrom, Adine Stokes, and Jeanne Schuller
Focus Report #1: Twin Cities Jewish Community

In 2004 a survey of the Jewish population was conducted in the Twin Cities (St. Paul and Minneapolis metro area). The 2004 Twin Cities Population Study estimates that 40,000 Jewish people live in 19,000 households, with an additional 8,700 non-Jewish persons living in the same households. According to the North American Jewish Data Bank, which conducted this survey in 2011, the Twin Cities (or more specifically, Minneapolis) are ranked 90th in the nation for the percentage of the population that is Jewish. It is estimated that 50% of the 40,000 Jewish people in the Twin Cities are unaffiliated – that is, they do not actively interact with the Jewish community.

In the Twin Cities, it is estimated that there are 7,500 Jewish people over the age of 65, and that 938 have an Alzheimer’s disease. There are approximately 1,040 Jewish people over the age of 85, and of those, 520 are estimated to have Alzheimer’s disease.

Foundation: The Twin Cities Jewish Community Task Force on Alzheimer’s disease

In 2007, three caregivers from the Jewish community approached the Community Engagement Department of Jewish Family and Children’s Service (JFCS) of Minneapolis with the idea to form the Twin Cities Task Force on Alzheimer’s disease.

This Task Force arose from an identified need for the Jewish community to generate awareness around Alzheimer’s disease and the issues faced by families living with the disease. The Twin Cities Jewish Community Task Force on Alzheimer’s disease is comprised of professionals in the aging services area, caregivers and other community members, including staff from JFCS and JFS of St. Paul and volunteers. The group includes people who are young adults to an individual who is in his 80’s. Members are from St. Paul and from Minneapolis, from the Reform, Conservative and Orthodox Jewish community. The Alzheimer’s disease Task Force’s mission is to guide Jewish agencies, organizations and synagogues to provide education, support and programming regarding memory loss for the Jewish Community.

Annette Sandler of JFCS describes the early passion and purpose for this group that grew from small ideas with a big vision. For example, the person within the group that is diagnosed with Alzheimer’s disease who wanted an innovative model of support for people with Alzheimer’s: “He really, really wanted the Jewish community to invent something similar to [Lyngblomsten’s] The Gathering.”

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7 (Source: [http://www.actonalz.org/jewish-community](http://www.actonalz.org/jewish-community))
Many activities generated by the group focused on the development of one-time educational offerings tailored to different stakeholder groups in the Jewish community.

From 2008 to 2011, the following activities occurred:
- Mt. Zion Synagogue began a support group
- Task Force group offered presentations to Sholom Home West and East on “Alzheimer’s disease and the Jewish Community”
- JFCS hosted to “Empowering the Caregiver” conferences in 2010 and 2011
- Task Force convened awareness and educational meetings with congregational nurses and with the Minnesota Rabbinical Association (MRA) members
- The Task Force planned activities for the Jewish community, such as hosting/organizing several opportunities to watch the HBO documentary *The Alzheimer’s Project*, providing a tour of the Minneapolis Institute of Art and conducting an education conference for caregivers.

In 2012, ACT on Alzheimer's approached the Task Force to request the group to assist in the development and testing of a “Communities Toolkit” that would focus on assessing the dementia capability or awareness at the community level. The Task Force enthusiastically agreed to participate.

### Activities and Progress - October 2012 through May 2013

In 2012 the Task Force began their work with the ACT on Alzheimer’s Initiative. The group is co-lead by Annette Sandler of JFCS and Chris Rosenthal of Jewish Family Service (JFS). Both facilitators conduct this group as a function of their jobs. While both consider their time with this initiative as a function of their jobs, the time commitment for working with the Task Force exceeds the threshold of time commitment for their positions. Therefore, often the work required for the effort had to be outside of normal working hours/days.

Both Annette and Chris were joined by a team of committed and passionate volunteers in the pilot development and testing of the Toolkit. The group was comprised of three caregivers, one person with Alzheimer's disease, several volunteers, a representative
from the Orthodox Jewish community, a Rabbi from the MRA, a Ph.D. student and three paid staff (from JFS of St. Paul, JFCS, and Sholom Home). The group functioned very democratically. Therefore, although there are paid staff members who have taken a lead role in managing the deliverables of the project and maintaining momentum, all decisions are made by consensus.

**Groundwork and Convening**

The ACT on Alzheimer’s website defines the initial phase of “groundwork and convening” as an opportunity to gather group members together and determine direction. In the pilot Twin Cities Jewish Community, the Task Force on Alzheimer’s disease was already assembled and key stakeholders had active roles. The Task Force was structured and members said they were ready to work on the Toolkit for the ACT on Alzheimer’s initiative.

There was not an official campaign or kick off that occurred within this community. No one interviewed could determine why this did not occur, except to recognize that the group deemed an activity like this unnecessary. It is also possible that because this Task Force was already assembled and had worked together for years, the kick-off was less of a priority.

The individuals interviewed for this report said that the champions of this effort were the three caregivers who approached JFCS in 2007 with an interest in addressing issues related to Alzheimer’s disease. In addition, interviewees recognized the efforts of Annette Sandler and Chris Rosenthal, with Chris acting as the chair of the Task Force and Annette serving as the manager. Both Chris and Annette shared responsibility for facilitating the overall work effort and helping group members make progress. Those interviewed said they believe there is enough momentum and interest among the remaining members that a lack of staff presence from the two Jewish family organizations would not prevent the group from advancing.

Other members from the Jewish community were initially approached to join the work group. Active recruitment was less important as word-of-mouth communication among the Jewish community helped inform and engage others. Likewise an article in *American Jewish World* discussing the work of the Task Force helped with recruitment, such that more people came forward. In fact, some of those who approached the group later were asked to wait until the work of the Task Force transitions to the Action Phase. It is hoped that these new members will bring added energy to this next phase and the necessary action planning that is required.

Because the Task Force members had direct or professional experience with Alzheimer’s disease, they felt that disease-specific training/education for members was not necessary. Some members of the group did experience trepidation, however, when faced with the prospect of administering the assessment from the Toolkit. To remedy
this, Chris and Annette conducted role-playing sessions. They administered the tool that was going to be used in individual interviews with each member in the group watching. Thus each member participated as an interviewee in a mock session and practiced the administration of the survey themselves.

During the groundwork phase, the Task Force made the decision to complete only a portion of the Toolkit. They chose the “Awareness” Community Member Survey (CM) as most relevant to their community of interest. They administered this survey to Rabbis and Cantors in a cross section of synagogues. In total, 42 surveys were completed.

Assessing

The ACT on Alzheimer’s Community Toolkit defines this phase as an opportunity for the group to assess community gaps and strengths to meet the needs of people living with Alzheimer’s disease. The Task Force members intentionally worked through the surveys, one by one. They parsed out sections of the Toolkit in phases, choosing what surveys to administer by group consensus. Each member of the Task Force was involved in these decisions.

With the Twin Cities Jewish Community, most of the assessments were administered individually, in-person or over the telephone. This phase lasted approximately three months from beginning to delivering the final results to Annette Sandler for analysis.

Before each interview took place, the Task Force members took time outside of administering the survey to explain to the interviewee the goals of the Task Force, the purpose for the survey, and what ACT on Alzheimer's Initiative is. This was done while the interviewer requested the interview, and again before the survey was administered.

No one who was asked to complete the assessment with the Task Force declined to be interviewed. Participants were informed that the survey could take up to an hour, and this did not pose a barrier for subjects to participate. After the assessment was complete, a thank-you note was sent.

Task Force participants noted that they used a lot of paper to conduct these assessments. This Toolkit is dense, and multiple surveys are needed, even for one section.

The Task Force members found that the assessment process brought up the need for some education among some interviewees. They came up with the idea of leaving a “take-away” for individual survey respondents. Annette found it useful when the tool was administered to have “The 10 Warning Signs of Alzheimer’s” available for the surveyor as a “cheat-sheet.” They found this sheet to be a helpful leave-behind educational piece for the participant (informant) who answered the survey questions.
Travel was not an issue, as most people stayed in their own area to administer the assessment. Most appointments for surveys were set up over the telephone or by email. Some Task Force members conducted the surveys in-person if it was convenient.

Many members of the Task Force teamed up to co-interview each individual respondent. Those who teamed up reflected that they felt this was a richer experience and found a greater connection with the individual interviewees. When probed why this was the case, the reasons provided were:

- the interview team parsed out the roles, allowing one to act as scribe, while the other could focus solely on asking the questions
- the dual-person added to a feeling of group cohesion/connectedness
- the dual-person team could tag team and fill in or add to the discussion

The dual-person format did add to the time commitment, however. When only one Task Force member conducted the survey the time to administer ranged from 15 to 30 minutes. However when the assessment was a team effort, the time to administer was at least an hour. In some cases, when the interviewee was a caregiver the time to administer the survey doubled (up to 2 hours).

Many respondents were interested in the process and indicated that they would like to track the progress of the Task Force Pilot Community. Individual interviewers have agreed to follow up with the individual respondents as the data is analyzed and the action plan is developed.

One member of the Task Force recognized that through administering the survey, alliances were built and developed with a key stakeholder group, the Rabbis, Cantors and administrators. Because of this allegiance through the survey process, it may be easier to involve this group in an action plan because they have invested in the analysis portion of the process.

Individual interviewers processed the raw surveys to ensure the format was legible and usable.

Annette provided this comment about the process:

[After] completing the surveys, what we have found is that the data we have from the surveys gives credence to why the action plan is taking place...connecting analysis will help drive the process forward.
Analyzing

After all the assessments were complete, members of the group had to ensure that the data collected was gathered in one location. Most surveys were given directly to Annette Sandler, who took responsibility for compiling the data. In other cases the results were emailed, or submitted into a Drop Box account in a Word document. Annette was the sole member of the Task Force who compiled each survey and entered the data into the grid for analysis.

Annette reported that the staff resources allocated were needed for facilitating this analysis process. However, this phase was cumbersome. Since she was the only person working on this portion she found it to be time-consuming—approximately five hours to compile. Initially, the process was tedious as each survey needed to be plotted and results hand-tabulated. Plotting the data by hand was challenging. Annette recommends entering the data immediately following administration of the survey. She hypothesizes that following this protocol will save time in the future. Additionally, the process of entering the data is much easier now with the added tools provided. It is likely that the team members themselves will be responsible for entering individual survey data in the future.

Because the Task Force will be choosing additional assessment tools to complete, they recognize that one or more volunteers may be engaged for this compilation and analysis phase of using the Toolkit. Now that many of the analysis tools generated by ACT on Alzheimer’s have been completed, a volunteer who wants to be engaged and has competency in this area would be a good match for this work.

To date, only one meeting of the Task Force has occurred where the group was able to see all the survey data plotted out on the grid. As a group, they analyzed the data and discussed their interpretations. Some pre-action planning occurred during this meeting, as a few areas of interest were strongly identified through the analysis.

Working together over the past three months to administer the surveys was an experience in with the Task Force grew closer. One Task Force member said that the group had a true sense of accomplishment. Group members felt that they were at the forefront of this work—within their community and in the state. Each member of the Task Force interviewed indicated that the process brought the Task Force members closer—there was a sense of unity as they advanced into the Action Phase. The group intends to recruit new volunteers in this phase as well.
Action Planning

The Task Force will be reconvening to determine the results of their work and what action steps the findings suggest are a priority for the community. Each Task Force member interviewed expressed their excitement for this part of the process. Much of the work leading up to this phase has been helping to inform the group, but they indicated they are all ready to begin.

The Task Force only had one meeting in this phase of the process. At this point, they would best be described as occupying a “pre-action planning” phase, since only one meeting has occurred where all data was available for the group to analyze. The group identified key themes to focus on for the next meeting. The data showed that education, awareness, and stigma reduction are key areas of interest. At this point the group identified possible stakeholder groups who could be targets for education—such as the MRA and youth groups. These findings will shape the direction of the Action Plan phase.

Since JFCS and JFS are still key players in the Task Force, these organizations will continue to take a lead role in the Action Planning phase. Additionally, a member from the MRA will begin to attend future groups meetings, and there will be continued presence from the staff coordinator from Sholom Home Care and Hospice. It is too early to say which organization from this Task Force, or from the Jewish community as a whole, will take a lead role in the action planning or implementation.

Lessons Learned, Overall Reflections, Advice

To date, there have been four organizations involved in the process, JFCS, JFS, MRA, and Sholom Home Care and Hospice. However, since the Action Planning phase has not occurred, this is not a complete assessment, and other organizations may join this effort.

When asked about group size, two of the Task Force members indicated that there is a maximum capacity for efficient and effective working groups. They identified that more than 12 members would likely make decision-making within the group difficult, with 10 being a perfect number.

At times the survey tool itself was identified as a barrier to conducting an assessment interview. Each member of the Task Force identified that the tool itself did not lead well to an in-person process. The tool was described as “clunky” because certain questions were phrased awkwardly. Often, individual interviewers would rephrase the question for conversational flow. In addition, some of the questions from the survey did not fit exactly for the population interviewed, and therefore questions were modified to meet the specific needs of the Jewish community the needs of the interviewee group as a whole.
A challenge identified was that the Toolkit is likely best utilized with a geographic community as the target. The needs and identity of the Jewish community are very different, as a community of interest, than the needs of a geographic community. For example, membership in the Jewish community is determined differently, and cultural and religious factors differentiate the Jewish population from their geographic non-Jewish neighbors. Task Force members referenced the uniqueness of the Jewish community.

Judi Marshall, an original member of the Task Force commented that this difference impacts the overall community assessment:

*The overall process shifts and it makes a difference because of the kind of community, the approach was challenging for us because it was a religious community and the tools were not written with that in mind.*

Another barrier Task Force members identified was the explanation of “dementia-capable communities.” Although each identified that administering the assessment was effective in helping to raise awareness, the survey respondents said this “vague concept” was slightly challenging.

The Task Force members provided other tips for new communities who wish to undertake this work:

- First, the Assessment Toolkit can be daunting, and the group members cautioned that the size and scope of the activity should not pose an imagined barrier. Each Task Force member emphasized that any group will tailor the tool to fit their distinct competency and needs for that community.

- Second, when the plan is to administer each survey individually, practice with another person and read each question aloud to determine the flow of the question; establish an average time to administer the survey and consider working as a team of two to conduct the survey, as this helps build a stronger relationship with the interviewee.

- Third, be prepared to answer questions and engage fully with the respondent you are interviewing, and leave behind educational information.

Task Force members interviewed said a successful approach was to complete the assessments using an individual, in-person method. By asking about the 10 Warning Signs of Alzheimer’s and leaving materials with interviewees, there was a physical reminder of the experience. In addition, respondents identified the very act of having a specific conversation about dementia with a Task Force member who was informed and
passionate about creating change in their own community was a remarkable experience – one that gave them a role as a catalyst for this change effort.

Judi Marshall concluded with a final lesson for any community, religious, geographic or otherwise, who initiates the Community Assessment:

*This was one tiny area, and if I think of making a community dementia capable, this is one tip of the iceberg ... It takes a village to really care for people ... and we’ve only just begun to talk to some of the people in the village ... we want to keep interviewing people to learn more.*

All interviewed respondents agreed that the assessment implemented by this group was the first of its kind for the Jewish community in the Twin Cities.

Acknowledgements

_Thank you to the Jewish Community for their engagement, to the Task Force for their work, and to those participating in these interviews:_

*Annette Sandler*
*Chris Rosenthal*
*Judi Marshall*
Focus Report #2: St. Louis Park Community

St. Louis Park is a city in Hennepin County, located to the west of Minneapolis. In the 2010 census, the population of St. Louis Park was 45,250. Of this, 13 percent, or 5,965 people were over the age of 65. Using prevalence rates, an estimated 746 people in St. Louis Park are likely to have Alzheimer’s disease among those aged 65 and older. Of those with Alzheimer’s, it is estimated that 107 individuals live alone. According to county health statistics from 2013, 15 percent of adults living in Hennepin County do not have adequate social supports (Source: County Health Rankings, found at: www.countyhealthrankings.org/app/minnesota/2013/hennepin/county/outcomes/overall/snapshot/by-rank)

St. Louis Park’s city motto is “Experience Life in The Park.” The city has a high proportion of Jewish residents. Community and faith organizations reflect this demographic, as St. Louis Park includes a Jewish community center and four synagogues. It is estimated that of the Jewish population in the greater Minneapolis area, around 38 percent reside in St. Louis Park. Many of the Jewish people in St. Louis Park are of Russian descent, having immigrated to the United States from former Soviet States. Russian is the second most spoken language in the city after English (Sources: St. Louis Park history site, found at: http://www.slphistory.org/history/jewishmigration.asp; and Wikipedia.org, found at: http://en.wikipedia.org/wiki/St._Louis_Park).

Foundation: The Successful Aging Initiative

In 2009 the city of St. Louis Park and Park Nicollet Foundation co-developed “The Successful Aging Initiative” (SAI). The Park Nicollet Foundation was interested in supporting a community effort that would convene local organizations and individuals around a specific need. The main intent of the SAI group was to gather, on a monthly basis, a group of interested community members, retired professionals, companies and organizations dedicated to improving community competency around aging issues. Also affiliated with the Successful Aging Initiative is a federal demonstration project, Nurturing our Retired Citizens (NORC) of St. Louis Park and Hopkins. Although the two organizations are not connected, they share a similar mission and focus to support an aging population.

In addition to educating the members of SAI, of which there are on average 30-60 regular attendees (over 150 members on the roster) the SAI co-sponsors community education sessions that further educate the community about issues around aging. For example, there have been monthly education topics around senior transportation, senior safety in the community, medication, and advance care planning. The SAI co-sponsors community programs tailored for seniors, like balance classes and other wellness activities (Sun Sailor, March 14, 2013). The SAI has been involved on a city level, making recommendations to the city council regarding supporting services that can
make the lives of the senior residents better, such as advocating for senior door-to-door transportation.

**Activities and Progress – 2012 through May 2013**

In early 2012, Mary Birchard, former Alzheimer’s Association Executive Director, was invited to speak to the SAI group and provide education on Alzheimer’s disease, and to discuss an initiative called ACT on Alzheimer’s (formerly PMA2020).

The ACT on Alzheimer’s leadership were looking to create a Community Assessment and Action Toolkit and to test this toolkit in a number of communities. The invitation was initiated to St. Louis Park. Jonathan Lips, SAI member and community estate planning and health care attorney, encouraged the SAI to focus on Alzheimer’s disease and take part in this effort. Mary’s session to the SAI group was well received, and Annette Sandler of Jewish Family and Children’s Service (JFCS) proposed to the larger group that a smaller Task Force task force should be formed to initiate the ACT on Alzheimer’s Toolkit and become a Pilot community. From this interest the St. Louis Park Dementia Capable Task Force was formed out of a group of 12-15 individuals.

The coordinator of this Task Force has been Jonathan Lips. Annette Sandler of JCFS, and Susan Maris Stodolka, a memory care professional, have been integrally involved as well. These three individuals were interviewed for this report.

Additional members of the group include an employee of Park Nicollet Foundation, a staff member from Metropolitan Area on Aging (MAAA), a retired doctor and his spouse, home-care agency staff, an employee from Sholom Home Care and Hospice, and an estate planning professional.

The St. Louis Park Dementia Capable Task Force was deeply involved with all phases of developing and editing versions of the ACT on Alzheimer’s Community Needs Assessment Toolkit in 2012. This was an iterative process that was described as “somewhat tedious and cumbersome.”

The assistance of the NORC group was also used during this editing and re-tooling for the community needs assessments. One member from the NORC group was so
influential in editing initial drafts of the assessment, her opinion about the flow and composition of the questions was used as a barometer to measure if a question was effective.

Task Force members interviewed said they were mostly pleased with the final results of the Toolkit but noted that the months and energy dedicated to refining the Toolkit was difficult for many members of the group because the Toolkit was “something of a moving target.” Some interviewed for this report suspected that a few committee members were lost during this editing phase.

**Groundwork and Convening**

The ACT on Alzheimer’s website defines this initial phase as an opportunity to gather key stakeholders to determine if implementing a project like the Community Toolkit is feasible. Within St. Louis Park and the Alzheimer’s Task Force, this process was not as necessary, since many of the key stakeholders had already identified their interest in community change efforts and in Alzheimer’s disease. Since many of those who decided to form the Task Force were experts in the field (some were specialists in Alzheimer’s disease), they did not need much education or background regarding the issues.

Groundwork and convening for the St. Louis Park community was defined by a four to five month period where many of the activities were dedicated to refining the Community Toolkit.

No formal kick-off event was held to initiate the work of the Task Force. All respondents asked agreed that the development of the Task Force from the main SAI was much more organic, and a kick-off celebration was not necessary.

Any member from the SAI was invited to join the Task Force. When the Task Force formed, approximately 12-15 people indicated interest. The group has shrunk slightly since then, with six attending every meeting, and another two or three people attending some of the meetings. As stated previously, this group also draws on the expertise of the NORC advisory committee.

After agreeing to participate as a Pilot Community, Olivia Mastery from ACT on Alzheimer’s provided direction to the Task Force regarding their role as a Pilot community. Olivia described the Pilot Community Assessment Toolkit as a tool that is meant to provide a snapshot of the community. She differentiated this Toolkit and process from a research project or comprehensive community mapping process. This is neither research nor comprehensive mapping—it is just a starting point. The assessments are intended to aid in providing direction to the Task Force, and hopefully will inform the group about areas of distinct competency for the community at large, and where there are gaps in service or knowledge.
The St. Louis Park Pilot Dementia Capable Task Force has been a democratically-led group, with each member bringing his or her skills to assist the growth and development of the group’s initiatives. For example, an electronic shared file system within the “cloud” for integrating group documents was a joint effort undertaken by a few members to benefit all members in processing their assessments. This effort was led by Michael Aguirre.

The group had a high level of capability within its membership for performing the community assessments and doing an analysis. Most members of the Task Force are dementia specialists, and therefore dementia specific training was not necessary. Also, administering a survey assessment was not a daunting task for any of the Task Force members, as individuals interviewed for this report indicated that the group is comprised of highly educated professionals working in client-centered professions.

**Assessing**

The ACT on Alzheimer’s Community Toolkit defines the “Assessing” phase as an opportunity for the group to gather information directly from service and other sector representatives from the community. This would provide a set of information about community gaps and strengths in addressing the needs of people living with Alzheimer’s disease. Some initial assessments began late in 2012, although the majority of the work was focused over a four month period in 2013 with the final assessments completed in late spring.

The St. Louis Park Dementia Capable Task Force spent the fall and winter of 2012 determining which portions of the assessment to administer within St. Louis Park and how they wanted to administer the tool. They also made the assignments among their Task Force membership – to set up interviews and take certain sections of the Toolkit (surveys).

The Task Force members reported that identification of key stakeholders groups was determined within the group, and then, as a group, an agreed-upon interview format was discussed and determined. The consensus was to conduct group interviews rather than one-on-one interviews. This was seen as a time-saving method to gather information and opinions.

The Task Force has been deliberate and intentional about how and when to conduct large-group surveys, and there seems to be a preference for this method for efficiency of survey delivery. For example, with the St. Louis Park Business Council (a group of approximately thirty members of St. Louis Park business owners), the Task Force felt it would be much more effective to use time in an already-scheduled meeting and administer the assessment to a large group simultaneously.
To gather the responses from the “Awareness Assessment,” the Task Force requested that the SAI assist in organizing a facilitated group session that was held during a regular meeting. Jonathan Lips took the lead for this assessment, and he reports that the entire group broke into smaller groups to answer the surveys.

Other assessments have been conducted in smaller groups, by handing out the assessment to a small group of individuals to complete on their own. Very few of the assessments were conducted in person, with the Task Force member interviewing the interviewee.

Regardless of the method used, each Task Force member who was charged with administering a survey would set the meeting up—usually by phone or email. Before giving the survey, the facilitator/interviewer took three to five minutes to provide some basic information about ACT on Alzheimer’s, and about the concept of dementia-capable communities.

One Task Force member thought that having information to leave with the interview group describing ACT would be quite useful. Respondents interviewed for this report indicated that many of the public-awareness materials developed by ACT on Alzheimer’s appear to be useful and would have been helpful. They note, for example the glossary of terminology used is now available on the ACT on Alzheimer’s website.

Given the range of formats and methods used to administer surveys, there is no average or typical time duration for conducting the surveys. In general, the surveys have taken individuals from 20 to 60 minutes to complete.

At time of this report, responses from individual assessments were still in the process of being completed and compiled. Task Force members recommended that this assessment phase of the process take no longer than three months, and ideally only two months. Losing group momentum was a large concern among all interviewed for this report.

**Analyzing**

The St. Louis Park community had just initiated this phase of compiling and analyzing the information at the time of these interviews.

Since Annette Sandler has completed the analysis for the Jewish Pilot Community, she took the lead on analyzing the St. Louis Park Pilot Community data sets. With the help of Michael Aguirre from MAAA, a Drop Box account was created so that the completed forms and other documents could be shared and stored in one central location. Michael and Annette completed some initial work for this portion of the project, but since the St.
Louis Park Pilot Community had not yet completed all assessments, the analysis of the
data was not finished.

The group estimated that the assessments and data analysis would be completed by June. The group members interviewed reported that the assessment phase has been energizing. The express hope that additional members may re-join the group, once the analysis is complete. These members will participate in action planning.

**Action Planning**

The Task Force will reconvene once the data entry is completed to analyze the information and determine findings. Based on these results they will discuss what the key focal areas will be for moving forward. The St. Louis Park community is eager to begin this phase. Key stakeholders interviewed anticipate that this part of the process will be underway soon.

When one Task Force member was probed about issues she believed could be priority areas of focus, she identified the following possibility: “the Pros and Cons of early detection.” In other words, it may be that there will be a need for education about early diagnosis and detection. She remarked that people diagnosed early have the full right not to disclose their illness, and as a group they will need to determine what the line is between helping and keeping illness private. Therefore, it is likely some of the areas of focus may be stigma, privacy and education.

**Lessons Learned, Overall Reflections, Advice**

Barriers identified by the group related to the process of participating as a both a developer and tester of a new tool. The process of working with various iterations of a tool under development was difficult at times.

However the respondents said that they felt pride that they were part of an innovative statewide effort. A strength noted is that the Dementia Capable Task Force remains largely intact and continues to collaborate with the larger Successful Aging Initiative.

The group identified that embracing a group philosophy of “divide and conquer” can be helpful when the process is overwhelming. Additionally, one individual interviewed for this report commented that having the support from the larger SAI group has been an asset to this smaller Task Force. The SAI agreement to take this effort on and elevate dementia-capable communities as a priority issue, at the broadest, most abstract level that we could work on as a group, will help in the future if barriers are faced by the greater St. Louis Park community. The larger group has rallied around this important focal area.
ACT on Alzheimer’s Pilot Communities: Composite Report – June 2013

Respondents said that each community will likely use the Toolkit in its own way—it must continue to allow for flexibility and adaptation.

Tips offered when embarking on this process were: embrace creative solutions, don’t get overwhelmed by the content or the volume of work to be completed, and set realistic and attainable goals.

Task Force members reflected that this whole process has been a meaningful experience. They have enjoyed working with one another—on something that has the potential to be useful with a broad impact on the community. This was described by Jonathan Lips as a “shared joint venture paying dividends for the community going forward.”

Acknowledgements

Thank you to the St. Louis Park Community for their engagement, to the Dementia Care Task Force for their work, and to those participating in these interviews:

Annette Sandler
Jonathan Lips
Susan Maris Stodolka
Focus Report #3: Walker Community

Walker is a small, rural city located in Cass County, in the north central part of Minnesota with a permanent resident population of 941. Situated on Leech Lake, Walker is a popular summer vacation destination, when the community welcomes “snowbirds” and retirees. A portion of the Leach Lake Indian Reservation is located in Cass County and Native American culture is prevalent in the community.

According to the 2010 Census, the city population is 88.0% White, 7.2% Native American, and 5% other or two or more races. There were 452 households. 48.0% of all households were made up of individuals and 23.4% had someone living alone who was 65 years of age or older. In 2010 the median age in the city was 49 years, with 25% of the population at age 45 to 64, and 30% age 65 years or older. Estimates suggest that 35 of these seniors (3.8% of the population) are currently living with Alzheimer’s disease.

The 2013 county health ratings place Cass County 87th (last) in Minnesota’s health outcomes measures. This county has very high early mortality and morbidity rates and reports an obesity rate of nearly 30%. Health data trends indicate an increasing number of adults reporting that they are physically inactive and a rising number of avoidable hospitalizations under Medicare. (Source: US County Health Rankings, Found at: www.countyhealthrankings.org/app/minnesota/2013/hennepin/county/outcomes/overall/snapshot/by-rank)

Foundation: The Dementia-Competent Community Group

Community leaders and residents as well as health care, social services, and housing providers in Walker have been recognizing the growing needs of the aging population for more than 20 years. During the late 1990’s, a senior housing campus was developed called May Creek Lodge. Over the years, questions and concerns about memory loss were posed by families and community members to the senior housing campus staff. As a result, an informal working group was formed called the “Dementia-Competent Community Group” (DCC). This group met for two years and laid the groundwork for the pilot testing of the ACT on Alzheimer’s Community Assessment work in 2012 that is the focus of this report.
Activities and Progress - October 2012 through May 2013

A group of ten individuals calling themselves the “Walker Community Coalition” launched an effort to pilot-test the ACT on Alzheimer’s Community Toolkit for assessing dementia capability and awareness in the community of Walker Minnesota on October 11, 2012.

Led by Melanie Deegan from May Creek Lodge, a senior living community, and Jane Baker, a retired teacher and volunteer, the Coalition conducted community assessments using the pilot survey instruments developed by the ACT on Alzheimer’s leadership group focused on community engagement.

The pilot testing involved: reviewing the Community Toolkit in various drafts and providing feedback, and also using the Toolkit to conduct assessments, and then analyze the results.

The assessment process started in early November 2012 and continued through January 2013. A lead participant collected all of the assessments and synthesized all of the information by the end of April, 2013. The group reports that the challenges and barriers were balanced by the rewards of a job well done and the feeling of common purpose that was shared by the Coalition. A community meeting to share results was held on May 6, 2013.

Groundwork and Convening

The ACT on Alzheimer’s website defines this initial phase as an opportunity to gather key stakeholders to determine if implementing a project like the Community Toolkit is feasible.

The opportunity to participate in a Community Assessment was presented to the community of Walker by the ACT on Alzheimer’s Leadership Group on Preparing Communities. The ACT on Alzheimer’s Leadership Group was seeking pilot communities to help develop and then test a Community Assessment and Action Planning Toolkit. Since Walker already had an active Dementia Competent Community group that was invested in exploring the issue of building the capability of the community to address the needs of persons with Alzheimer’s disease and their families, this DCC group was approached to serve as the group to test out the Community Toolkit for ACT on Alzheimer’s.

After consideration, the DCC group participants declined this offer. They felt it would be a good time and opportunity for transition to a new group of leaders and involve additional stakeholders in the effort.
I’m not sure why, but everyone was busy and they had been on the group for two years. This was a good time for them to transition."

The pilot testing of the Community Toolkit began with the creation of a new group, called the “Walker Community Coalition.” The Coalition was launched at an organizing meeting held on October 11, 2012.

Melanie Deegan coordinated the Coalition and Jane Baker served at the Lead for the project. Melanie is an employee of May Creek Lodge, a senior services community with memory loss services. Jane is a community volunteer and retired teacher. There were 10 people who participated in this ACT on Alzheimer’s Community Toolkit pilot effort. The group was made up of primarily community volunteers along with 3 staff from the senior living campus, a representative from the Central Minnesota Council on Aging and a representative from Lutheran Social Services (who later dropped from the team due to travel distance). Ann Nolan, the owner of May Creek Lodge, played a key role in recruiting volunteers and contributing staff time to this effort. All three participants noted that she had personally asked them to be involved.

She laid the ground work for this due to her concern for those with Alzheimer’s…it was important to her that this was not viewed as a May Creek project, but rather a community project.

The background work done by the Dementia Competent Community group formed the foundation for the piloting of the ACT on Alzheimer’s Community Toolkit. The opportunity to use a structured tool and process was appealing to individuals who had been active in other community efforts and to new participants who were recruited.

We were amazed and our volunteers were unbelievable – all retired from various backgrounds. This is the plus side of being in a small town community – a lot of pride and people are willing to work.

Attending this first meeting were the conveners (Melanie Deegan and Jane Baker) and several volunteers with varied backgrounds. This first meeting was the “kick-off” of the effort. The group did not have a public awareness campaign or any other public event.

It was still not so well organized and we were not aware that we should even do a “kick-off”, we did send some information to the local press.

The groundwork and convening activities took place over the winter months, and involved identifying key stakeholders, dividing up work and interviews, learning more about Alzheimer’s disease and studying the ACT toolkit. Melanie coordinated the activities and served as liaison to the ACT on Alzheimer’s Leadership Group. Jane led the assessment and analysis work.
After the convening meeting in October, the group began meeting about every 4 weeks. The first two meetings were brainstorming sessions about who the key stakeholders were in Walker and also focused on the first cut of the questionnaires in the tool kit. The group discussed whom they each felt they could interview and they divided up the interviews. This was mostly based on individual background and experience (business, health care, city government).

This group met a second time and reviewed all the sections of the toolkit and the expectations, going over the steps in the process and deciding how to move forward. During the second meeting they also discussed how to go about actually doing the assessments, how to use the ACT tools and how to conduct an assessment. They noted that they had questions for the ACT leaders, and that they appreciated the rapid response. One participant noted that she did a lot of research on the topic on her own; educating herself on Alzheimer’s using the Internet. She made copies of other materials she found and brought them to the group.

It then took about 4-5 weeks to get all the volunteers organized to start the assessments. The group also relied on the education and experience level of those involved, assuming that most people could pick up and conduct these assessments based on their past professional lives. They had a brochure that they used and they “just did the work.”

The group developed a list of those to be interviewed from within the community. Once this list of interviewees were chosen, each assessor got to choose whom to interview—as some already had personal or professional relationships.

**Assessing**

The assessments were conducted from December 2012 to February 2013. Participants reported that the assessment process went fairly well for the group, yet they realized along the way that the assessment tool was being interpreted in various ways and modified from time to time by the assessor. Being a small community benefited the group as many of the assessors were familiar with the key stakeholders. All of the interviews were local and thus the travel time and distance was minimal.

As the group worked, they compiled results and compared notes on how they “did things.” The three participants agreed that each person used the tools or “interpreted” things a bit differently. Noting some differences, this group spent time then reviewing and summarizing their assessments after they were completed.

The assessments/interviews were divided based on who they knew and those who were also most familiar with a certain sector of the community, such as healthcare. They
tracked all of this on an Excel Spreadsheet—which they put together as this was not yet part of the Toolkit.

_We first just went by those people that we knew and then we connected by phone. It worked really well._

Some individuals sent an email with the questions ahead of time. The assessors went out in pairs, although two of the participants noted that they did several assessment interviews on their own. The time for assessments ranged from 30 minutes to 45 -60 minutes. The volunteers in the group did all of the assessments and no other volunteers were recruited.

Key facilitators of the assessment process included:
- the usefulness of a call script for calling and setting up interviews,
- the structure of the assessment tool itself with defined survey questions, and
- the brochure describing the ACT on Alzheimer’s initiative.

It was also important to have access to the facilitators and content experts involved in the ACT on Alzheimer’s tool development, including Olivia Mastry and Mary Ek (Act on Alzheimer’s) and Deb McKinley (Stratis Health).

Feedback from the community was very positive. In general the participants reported that conducting the assessments peaked interest and some expectation for future action. Most reported that people were not surprised that dementia would be an issue for the community and they were supportive of this focus. Everyone assessed said they knew what Alzheimer’s disease was and could describe some of its symptoms. Those who had experienced Alzheimer’s in their families shared personal stories and deep thoughts about what should be offered in the community.

_It's a sensitive issue for many people and it's still hard for many to talk about._

Most respondents wanted to know more. Assessors were pleased with the overwhelming community interest and support and the useful feedback they received during the assessment process.

The assessors compiled summaries of their assessments, spending time informally analyzing their interview forms. The assessments were then given to Jane, the lead.

**Analyzing**

Jane collected all the forms and the individual assessors’ summaries. Jane did all the work and reported: “I reviewed all of them and I tried to use the tool.” Jane was the only person to work with the synthesizing tool. She did all the work compiling and
aggregating the results. The participants agreed that this was time-consuming and Jane reported that the synthesis and analysis took about 20 hours. She finished this work in late April.

The biggest hurdle noted by the participants was that the information did not transfer well for them. What was on the assessment survey form did not fit the synthesizing tool (this was attributed to the tool not being fully developed). The concerns expressed were related to not having all the information transferred well.

_We did not want to lose information; we wanted an accurate picture of what our community was saying._

The initial interview questions were not included in the synthesis tool and this made it hard for them to understand what was critical to the analysis. Jane thought that there was strong narrative (qualitative) data, but the tool asked for more quantitative data. In some cases she felt she needed to go back and get this quantitative data. The focus on specific sectors in the Toolkit on areas (sectors) was good, helpful and useful. One participant noted that the interviews themselves were catalysts—among members of the Coalition and among individuals being interviewed. Conducting these interviews—taking the time—reflected a genuine concern to do something and gave the assessor a sense of responsibility to “do a good job”.

**Action Planning**

The participants noted common themes arising from the community assessments. Top issues were identified as:

- The need for ongoing community education and training that also addressed questions and fears about the disease – overcoming the stigma,
- understanding the financial impact and addressing the cost of services and how those affected could get assistance with the costs, and
- the need for centralized resources – a one stop shop and a resource guide, and transportation services.

A meeting with the ACT on Alzheimer’s leadership was held on April 29, 2013 and a report to the community meeting was held on May 6, 2013. The findings of the assessment were shared with the community, providing an opportunity for community member engagement in the action planning steps. The Coalition participants indicated that their work is complete.

Regarding the next steps on action planning and implementation, they said that they are not sure who or what organization will take the lead. There is more interest from Cass County now and they may step forward.
Lessons Learned, Overall Reflections, and Advice for Others

Challenges

The challenges for the group were primarily focused on the utility of the synthesizing tool and also the difficulty connecting with the large Native American population.

The many changes in the Toolkit itself and the process developed impacted the usefulness and application of the Toolkit. The evolution of the tools proved to be difficult to navigate, as it was hard to use the Toolkit when it was being developed and changed. “The interview tool changed and then it did not tie to the synthesizing tool.”

Some of the changes were fast and volunteers felt “left out” of the information. For example, in referencing the initiative name change from Prepare Minnesota for Alzheimer’s 2020 to ACT on Alzheimer’s, one participant stated: “I had to find out about it online.”

Cold calling for interviews was hard for some. Once positive responses were received, however, it got easier. Working together as a group became a valued support system.

Advice for Others

Participants noted the importance of the group or team. Getting the whole team involved and carefully building the team was noted as critical to success.

It’s a timely process so getting people who are committed to the cause and understand the time commitment is important.

Recruiting good volunteers who had time and would be able to deal with the process was also critical to success. Others suggested that it might help for interviewers to tailor and refine questions – depending on who is being interviewed.

Understand your community and what you are trying to get at. For example you don’t ask about public transportation when there is none. You learn as you go. Each group will have their own dynamic and some will emerge as leaders and others will take on other roles.

For the coordinator this work was time consuming. If it is not part of a person’s regular job, it may leave them feeling challenged to find the time needed to make this initiative successful.
There was so much. It was getting hard to know if I was doing what I was supposed to...I was overwhelmed and a little lost. It is not just a Toolkit, it’s a process!

Success

The participants were proud that the community of Walker “got to do this.” Other noted successes included having the opportunity to work together on something important, and getting useful information from the community.

The participants noted that they are still processing their work.

This process has been successful for us overall. Before, with the DCC Group, we were just coming up with our own ideas of what the community needs, now we know what the community says they need. #

Acknowledgements

Thank you to the Walker community for their engagement, to the Coalition for their work, and to those participating in these interviews:

Melanie Deegan
Jane Baker
Tanis Beadle
Focus Report #4: Willmar Community

Willmar is a vibrant and growing city located in Kandiyohi County, approximately 90 miles west of Minneapolis. Known to locals as the “Willmar Lakes Area” for its popular recreation and vacation activities, the city has an aggressive economic development plan that is creating new businesses and new job opportunities. This has encouraged an influx of young professionals and families. According to the 2010 census, the city population is 19,610, an increase of nearly 7% over the past 10 years. About one-third of households in Willmar are made up of individuals living alone (any age).

Persons age 65+ living alone make up 12.4% of households. The median age in the city is 33.8 years and 15.8% of the population is 65 years of age or older (3,098 people). The prevalence rate for Alzheimer’s disease nationwide is estimated to be approximately one out of every nine people over age 65. That means in Willmar an estimated 344 people over age 65 may have the disease.

In 2008, a Community Assessment survey conducted by United Way identified the following community strengths for Willmar:

- A high level of community involvement and participation, including voting and volunteering
- Service providers and funders who work together to identify and resolve issues for the whole community
- Long-term residents who are committed to improving quality of life in the community
- New community members who bring cultural diversity and strengthen the workforce

(Source: [http://www.unitedwaykc.org/documents/UCAN_1-08.pdf](http://www.unitedwaykc.org/documents/UCAN_1-08.pdf))

According to the 2013 county health statistics, Kandiyohi County is ranked 12th out of Minnesota’s 87 counties in overall health outcomes. Health status areas flagged for improvement include an increasing adult obesity level (29% compared to state average of 26%), and 24% of adults over 18 reporting inactivity compared to the 19% state average. (Source: County Health Rankings, found at: [http://www.countyhealthrankings.org/app/minnesota/2013/kandiyohi/county/outcomes/overall/snapshot/by-rank](http://www.countyhealthrankings.org/app/minnesota/2013/kandiyohi/county/outcomes/overall/snapshot/by-rank))
Foundation: The West Central Dementia Awareness Network

The community of Willmar had already identified that Alzheimer’s disease and related dementias (and other cognitive impairment issues) were rising in its population.

A group of providers, consumers, advocates, and other stakeholders met with Mary Bauer (from the Alzheimer’s Association) and discussed the issue of Alzheimer’s, their concerns about raising awareness, and their current efforts. They realized that many of them were already conducting separate educational efforts—but that they could have a bigger impact if they worked together. As a result, a small group of health and social services providers gathered together in July 2009 and formed the West Central Dementia Awareness Network (Network). This group formed to address the need for increased community awareness, education and support relating to dementia and Alzheimer’s disease.

This Network included: individuals from long-term care facilities and specialized memory units as well as assisted living providers, social workers, Area Agency on Aging representatives, individuals from home care agencies, representatives from two block nurse communities, a parish nurse, and a representative from a medical clinic. The purpose for the Network was to advance education and awareness about dementia and Alzheimer’s disease.

Initially many thought without designated time or money, they would not make much of a difference. However, the leaders were encouraging and persistent. Lori Petersen, an employee of Golden Senior Living senior campus was one key champion. She recalled:

I just kept driving that we did not have to put in a lot of time and effort if we all worked together. We could use churches to host our events, utilize local newspapers and ask if they could do a story and ask those who attend to possibly give a free will donation to help cover the expenses. Our first event unfolded into something that the community is now aware of.

Pooling limited resources, the group planned their first community educational event. The overwhelming response suggested that the need for information and education was even greater than the group had anticipated. Since 2009, the group has grown to 15 members representing a diverse population of individuals and organizations, all with a shared focus on Alzheimer’s disease. In 2010 and 2011 Network events and educational activities became familiar occurrences in the Willmar community.

Motivated by their motto “education is power”, the Network was approached as a viable organization for helping to develop and test the ACT on Alzheimer’s Community
Toolkit. The group felt this was consistent with carrying out their focus on providing the Willmar community with education and support for families, caregivers and professionals.

Since beginning the ACT pilot work (in 2011), the Network has also maintained their regular Network activities, hosting 6 educational events and assisting the Alzheimer’s Association in providing a series of 5 opportunities throughout the summer and fall of 2012.

**Activities and Progress – Fall of 2011 through May 2013**

In the fall of 2011, the *West Central Area Dementia Network* (Network) engaged in an effort to pilot-test the ACT on Alzheimer’s Community Toolkit for assessing dementia capability and awareness in the community of Willmar, Minnesota. Two leaders (from a housing provider and medical center) served as coordinators to shepherd the effort. Since the Network was already formed (as an existing collaborative group of providers, consumers and other stakeholders) they did not see the need to add new members and conducted the work themselves. The Network reviewed and provided feedback on various versions of the Community Toolkit as it was developed and revised. The assessments were conducted in a piecemeal fashion, as instruments or sections of the tool were designed. The assessments were 95% completed in May of 2013, and the Network began the synthesis process the end of May, with hopes of analyzing the information in June. Some of the members of the original Network collaborative group no longer participate, due to job changes or members moving out of the area.

As a pilot community, the Network has served as a model for other groups and individuals in their community as well as across Minnesota—promoting the idea of community engagement and self-assessment and encouraging others to join the ACT on Alzheimer’s efforts.

**Groundwork and Convening**

In the spring of 2011, the statewide Communities group (*Preparing Minnesota for Alzheimer’s 2020* – later changed to *ACT on Alzheimer’s*) was being formed. Andrea Carruthers, an employee of Affiliated Community Medical Center and Lori Petersen, from Golden Living Centers were approached to serve on this statewide board. In learning of the board’s desire to seek some communities to pilot the project, Andrea and Lori brought this opportunity back to the West Central Dementia Awareness Network (Network) and all agreed that piloting the project would be a good fit for our group.

Recognizing that piloting the ACT on Alzheimer’s Community Toolkit would bring value to their purpose and work, they agreed to become the Willmar area “action team.”
We felt we could provide wonderful feedback to the ACT on Alzheimer’s leadership group and to Stratis Health on the developing Toolkit.

In early 2012, the group convened in a local restaurant for a Network meeting. The leaders shared what ACT was trying to accomplish with the Toolkit and the assessment surveys. The action team was made up of the existing Network membership. Without any public announcements or kick off activities, the action team went to work.

Given their existing structure, the team did not see a need to recruit new members or volunteers. There was also concern about the amount of time it would take to recruit new members and many felt we could adequately do the job on our own.

There was no plan of action identified at this time. One participant stated, “It [the Toolkit] was not all developed yet.” The Network members saw their role as “developing and testing” the Toolkit. The Network members simply added these new tasks (Community Toolkit development and assessment activities) to their existing meetings where the focus had primarily been on education and building awareness. The work was coordinated by Lori and Andrea.

The team leaders and a few others reviewed the emerging Toolkit content and resources. Copies were shared and each member took a section to review; each had a follow-up assignment. They all agreed to continue meeting on a monthly basis. They would spend part of the meeting planning their next educational event and part of the meeting making revisions and suggestions to the Toolkit, which Andrea and Lori would then share at the next ACT Preparing Communities Leadership Group meeting.

Even though participation in the Network is considered related to their job duties for many of the members, the work on the ACT project went beyond the normal expectations. For many involved with the Network, the ACT project was not part of their regular jobs.

We shared our comments, concerns, questions for 3 or 4 different “generations” of the toolkit assessment. Each network member had a special area to assess. We continued to meet on a monthly basis, and suggestions/concerns would be shared with Andrea and Lori who in turn who bring that feedback to the monthly ACT meetings in the Twin Cities. We also utilized emails to keep other Network members in the know.

The time to review and provide recommendations on the Toolkit was described as a time dedicated to frequent “back and forth” with the ACT leadership. Participants characterized this time as “plowing the way,” for others. They noted that each revised
version of the Toolkit was easier to understand and work with and they were proud of this contribution to the field.

Assessing

The assessment process began in an informal manner. Participants stated that since they were a Pilot Community, there was no real plan in place for how to start this process. It was not laid out or structured. Because of this, there were many questions and some difficulties.

Initially, there were challenges with both the assessment survey questions and with the process. For example, when the assessors met with attorneys, they found the legal sector respondents did not know what the questions meant. Sometimes appointments were made to conduct the interview, but time would run out and respondents would not have time to complete the interview.

Some assessments were done by phone and some in person. The geographic distance to cover could be a challenge, so phone interviews were preferred in those cases.

Initially the assessments were quite labor-intensive and could take up to an hour. The group agreed that this was not going to work for them or the people they were interviewing. Some assessors took 30-40 minutes, others only 10-15 minutes. They also discovered during this time that the questions were redundant and responders would simply repeat the same answers 4-5 times. Though this was frustrating, the group again acknowledged their role as a pilot, made suggestions and continued improving their work processes.

The participants used paper tools to start with and frequently referred to dealing with these early tools as being the most difficult part of the process.

The group recalled realizing a need for some collateral, such as a flyer, or something to leave behind after interviews. Network members were clearly pleased when ACT developed these resources as a result of their recommendations.

Being a small community, there were times that members of the Network were able to answer the assessment questions as representatives of a service sector. For example, the adult day member could more or less self-assess.

Understanding how to talk about dementia and its impact was not challenging for the group. The group was already familiar with the issues and characteristics of Alzheimer’s disease and related dementias and individuals were comfortable talking about these issues.
While the group initially believed it would be faster for them to do this work themselves, they soon discovered that having volunteers to support the effort would have been a welcome addition.

*We were a group of working professionals, so everyone was trying to squeeze this in to our already busy day. If we had a group of community volunteers it might have been faster.*

Some Network participants who came later to the work found it to be an overwhelming project to understand and confessed that there were perhaps many details they either didn’t know or did not complete adequately.

In some cases the size of the community was an asset. Individuals participating in the Network and in this community assessment process had many professional and personal connections. This made the assessments easier. They already enjoyed the trust and connection with many of those that they called upon. Assessors selected areas and sections of the tool that they were most comfortable with and where they had existing connections and then proceeded with phone calls and face-to-face interviews. The Network also found that sending out the questions in advance for the interviewee to review seemed to work well as there was an opportunity for those interviewed to collect their thoughts and responses.

The feedback they received from their interviews helped to keep activity at the forefront and affirmed their work. They were pleased to find that those interviewed thought that the assessment work was very necessary. It appeared that the group was especially excited to learn that even the hospital representatives learned about many aspects of Alzheimer’s and of their community that they did not know. During the assessment process, member of the community who were being assessed also became more aware of what was available. They shared feedback such as:

*This is exciting, please get in touch with me and please keep me updated.*

Even with all this positive feedback and energy, over time the group was growing weary. As stated earlier, this was due to the fact that the Network was involved in an iterative and repetitive process of testing, making revisions, retesting, making additional revisions and finally utilizing components of the Toolkit. Those interviewed believe that a community that began the process today would have a different experience. Presumably using the modified, streamlined tool would be faster/easier.

**Analyzing**

The process of compiling results became an issue for this group as the commitment began to deteriorate.
We had an issue where our group was falling apart, people were getting burnt out and we did not want to push people.

During the summer of 2012, Andrea Carruthers retired from ACMC and her colleague, Caryn McGeary, assumed the role of co-lead with Lori Petersen. Lori also experienced employment transition during the process, moving from her role at Golden Living to a new position at Bethesda, a senior campus in Willmar.

The Network is currently in the analysis phase of the work. Due to overall work demands and transitions of some members, the Network momentum has slowed and the group commitment has fallen off. The remaining members were challenged by the time required to complete this work.

Even with the loss of some Network members due to job changes, there have been a few members who have remained faithful and have worked with Lori and Caryn to “complete the project.”

As of the time of this report Lori and Caryn stated that they have been gathering all of the interview sheets and have begun to plot the answers on the synthesis tool. Some of this process (analysis and synthesis) seems very complex.

Feedback from some individuals is that this could be too much for many volunteer participants to perform unassisted. This would require additional education, training, and time to do well. It might be too much for small communities or groups. One idea offered was to find a person with a background in data analysis or research and evaluation.

It’s just a huge process [the analysis work] and like anything else it’s a huge need and huge part of healthcare – you have to look at your whole community.

While Willmar is a community that does have a lot of retirees and volunteers, they also have students that intern locally and the group is brainstorming about how to incorporate this data gathering and synthesis work into student/retiree projects. Ideas for accessing future support in data analysis include approaching nursing students or medical students in the area who are involved in public health projects or have an interest.

Action Planning

Although this effort is still in the analysis phase, initial findings are informing the remaining Network members. The biggest need identified thus far is education of paraprofessionals and information for bankers, grocery stores and other business sites.
The current challenge is recruiting more resources to move these initiatives forward. The group plans to pursue action planning upon completion of the analysis phase.

Requests for more education rose to the top for this community and frequently came from business owners, hairdressers, and local cafés. The Willmar business community would like to be better prepared and able to recognize dementia and be more aware of ways to diffuse difficult situations. The group shared that most often in the business and retail settings there exists a level of expectation about what behavior is acceptable. People with dementia may appear to be functioning normally, and then they start talking or responding “funny” and the community feels unprepared to deal with this behavior.

The group also recognizes a need to continue creating opportunities for community members to talk about memory loss. In working with the general public, the group discovered that there is a stigma about Alzheimer’s disease that is similar to how people reacted to cancer and AIDS, “if we talk about it we might get it.” The Network recently contacted the local news and they are working with a reporter to write an article about the ACT on Alzheimer’s Community Toolkit effort, detailing the Network’s involvement and sharing what they have learned about the community needs.

*If we can get the word out about the things we have learned and get more people to come on board, then we can get rolling on this.*

The participants agree that this project should have an action plan, but one is not currently in place. They hope to complete all the data analysis by mid-2013 and then plan to gather feedback from their larger group and community. Action plans will follow so that they are prepared for fall education events.

When considering who should take the lead on moving this work forward, the participants agreed that grant dollars would allow for some resources (i.e., paid staff or consultant hours) to be designated to the cause. This could take the form of hiring a part time “community champion” – or to tie the activity to a current position. There could be other not-for-profit groups that would take a stronger lead in the effort, such as the Area Agency on Aging (AAA) or the Alzheimer’s Association. The Network would like to see a stronger presence from public health as they believe this would bring a common neutral voice. By engaging these and other stakeholders, the Network would have a stronger platform. This would aid in disseminating information and educating the community.
Lessons Learned, Overall Reflections, and Advice for Others

Considering their work from the perspective of community stakeholders created many opportunities for learning and reflection for the Network members. The group credited participation in the process for making them think more critically about the areas that needed education, citing the experience with the legal community, an area they had never considered but realized needed to be involved in the discussion. When reflecting specifically on the Toolkit, the participants noted the challenges of their early involvement and the difficulty they had in the beginning just accessing the Toolkit. They expressed genuine pride about their work—noting that the tools are now more streamlined and accessible. They believe the ACT Toolkit should work well for new groups.

Completing the ACT Toolkit work themselves, while being fully employed was a big challenge for group members. As such, they recommend that groups seek out a dedicated, strong and committed volunteer champion (who is not employed full-time—or can incorporate this role into their current job duties) to act as coordinator. Recruiting others who share their commitment and concern was also a frequent recommendation. The participants reflected that their group was made up of professionals, with similar backgrounds, and while this was helpful to them in some respects, the value of including individuals who have been affected by Alzheimer’s disease was missed. They expressed the value in finding good volunteers and recognized the potential contribution of retired persons who would perhaps have more time to work on a project such as this.

The idea of holding a formal kick-off event was singled out as an “awesome” suggestion to add to the process. A formal kickoff was not part of the Willmar start-up, however, when they began the process, their “task” was to test the toolkit...and many suggestions and ideas like this had not been incorporated into the project. The group suggested that planning at initiation about structure and work plans would be very important.

It was recommended that future groups dedicate ACT work as its own project plan and work group, rather than incorporating the work into a busy existing group, as Willmar attempted to do. The group also suggested that the ACT leadership consider creating a template of a realistic implementation process with time lines included, as a timeline might perhaps keep group momentum moving forward and assist in planning efforts.

The most frequently cited challenges for this group related to the time commitment and balancing the ACT work with full time employment demands. The amount of information and detail was somewhat overwhelming for the group members and while the tool may now be better refined, future groups should be aware that it still takes time. Furthermore, groups considering this work should understand that they don’t have to do every category.
The Network expressed pride in their pilot role and their involvement as a Pilot Community. They expressed satisfaction knowing that the work they did would contribute to new community initiatives:

*So if I was a brand new group – it would be great to do all of it, but if you wanted to even start with half of the [categories], that’s better to not do any at all...*

*It’s been empowering to see that this is something that communities will pick up and use and make something of it.*

The Network’s best advice to others:

*Don’t get discouraged; don’t think you have to do the whole thing. Get a kick off going, get the newspaper following you, try to remember to check all the tips we put in the tool kit, and if you follow that it will go quite well for you.*

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