

Act on Alzheimer's Pilot Community: Walker, Minnesota

The ACT on Alzheimer's Initiative (www.ACTonAlz.org)

ACT on Alzheimer's is a statewide collaboration seeking to address the personal, social, medical and budgetary impacts of Alzheimer's disease and related dementias. Many sectors have come together—community members, health care and social service providers, government officials, caregivers, people with Alzheimer's disease, academics, and businesses – to better support individuals with Alzheimer's disease and their families.

A Dementia Capable Communities Toolkit was developed in 2012 through an iterative process. Four pilot communities provided input into content of the Toolkit and tested it within their own communities. The four pilot communities (all in Minnesota) were:

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

The ACT on Alzheimer's website describes the purpose for using the 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 health care professionals, clergy, service staff, and others who want to know how to best support individuals touched by Alzheimer's.*¹

The Toolkit offers four steps, following a sequential process:

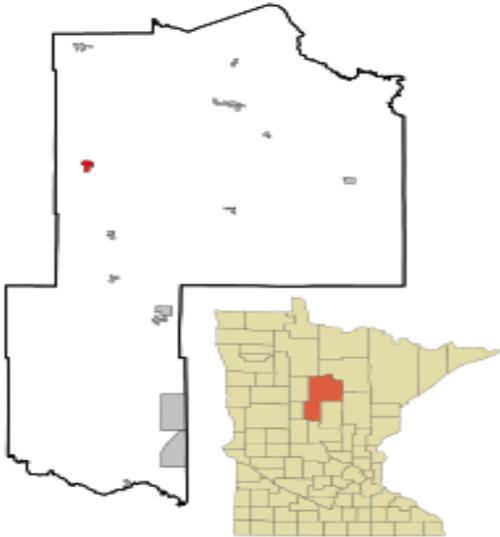
- **Convene** key community leaders and members to understand the disease and its implications for communities. Then, bring together an Action Team.
- **Assess** current strengths and gaps in meeting the needs that result from Alzheimer's disease and related dementias, using a comprehensive community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

This Report – This report provides a snapshot view of progress made (as of May 2013) using the Toolkit, focusing on this featured pilot community involved in development.

¹ www.actonalz.org Accessed on May 30, 2013.

Walker Community Background

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 Noland, 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 rolls.”

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*