Act on Alzheimer's Pilot Community: Willmar, MN

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.

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

Willmar Community Background

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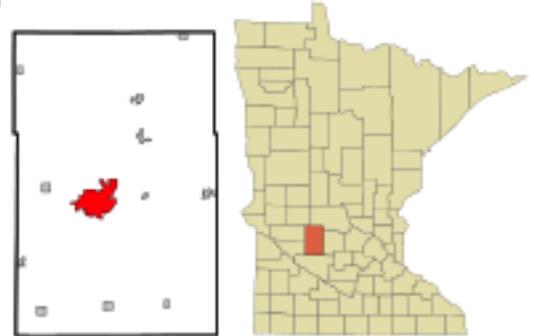
Persons age 65+ living alone make up 12.4% of households. The median age in the city is 33.8 years and 15.8% of the population is 65 years of age or older (3,098 people). The prevalence rate for Alzheimer's disease nationwide is estimated to be approximately one out of every nine people over age 65.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

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)

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 now the community is 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.#