

ACT on Alzheimer's Pilot Community: Twin Cities Jewish Community

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.

Twin Cities Jewish Community Background

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 Study² 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.³ 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.*⁴

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.*"

² Source: <http://www.jewishdatabank.org/study.asp?sid=18419&tp=2>

³ Source: Dr. Joshua Comenetz, Jewish Map of the United States - Comenetz 2011, <http://www.jewishdatabank.org/study.asp?sid=90195&tp=6>

⁴ (Source: <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 which 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.#

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Annette Sandler

Chris Rosenthal

Judi Marshall