

Act on Alzheimer's Pilot Community: St. Louis Park, 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.

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

St. Louis Park Community Background

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 age 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 JFCS, 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.

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."#

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