Minnesota Council of Churches
ACT on Alzheimer's Action Community:
Report on Progress

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By Deborah Paone, DrPH, MHSA

Paone & Associates, LLC

Background on ACT on Alzheimer's Initiative

ACT on Alzheimer's® is a volunteer-driven statewide collaboration. It was organized to focus on 5 goals to help prepare Minnesota for the budgetary, social and personal impacts of Alzheimer's disease and related dementias. The goals include: (1) sustain caregivers, (2) raise awareness and reduce stigma, (3) invest in promising approaches, (4) increase detection and improve care, and (5) equip communities. The initiative was launched in June 2011.

In 2012 a Dementia Capable Communities Toolkit was developed by one of the leadership groups and other participants involved in ACT on Alzheimer's.

The Toolkit provides a structured process for a community to assess its own dementia awareness and resources, as well as to determine priority areas for action. The toolkit offers four clear steps and processes:[1]

1. **Convene** key community leaders and members to understand Alzheimer's disease and its implications for your community. Then, form an Action Team.
2. **Assess** current strengths and gaps in meeting the needs that result from the disease and related dementias, using a comprehensive community assessment tool.
3. **Analyze** your community needs and determine the issues stakeholders are motivated to act on; then set community goals.
4. **ACT Together** to establish implementation plans for your goals and identify ways to measure progress.

Key elements of dementia capability were defined within the Toolkit, beginning with Awareness (see flowchart Figure 1).

[1] http://www.actonalz.org/act-together Accessed May 1, 2015

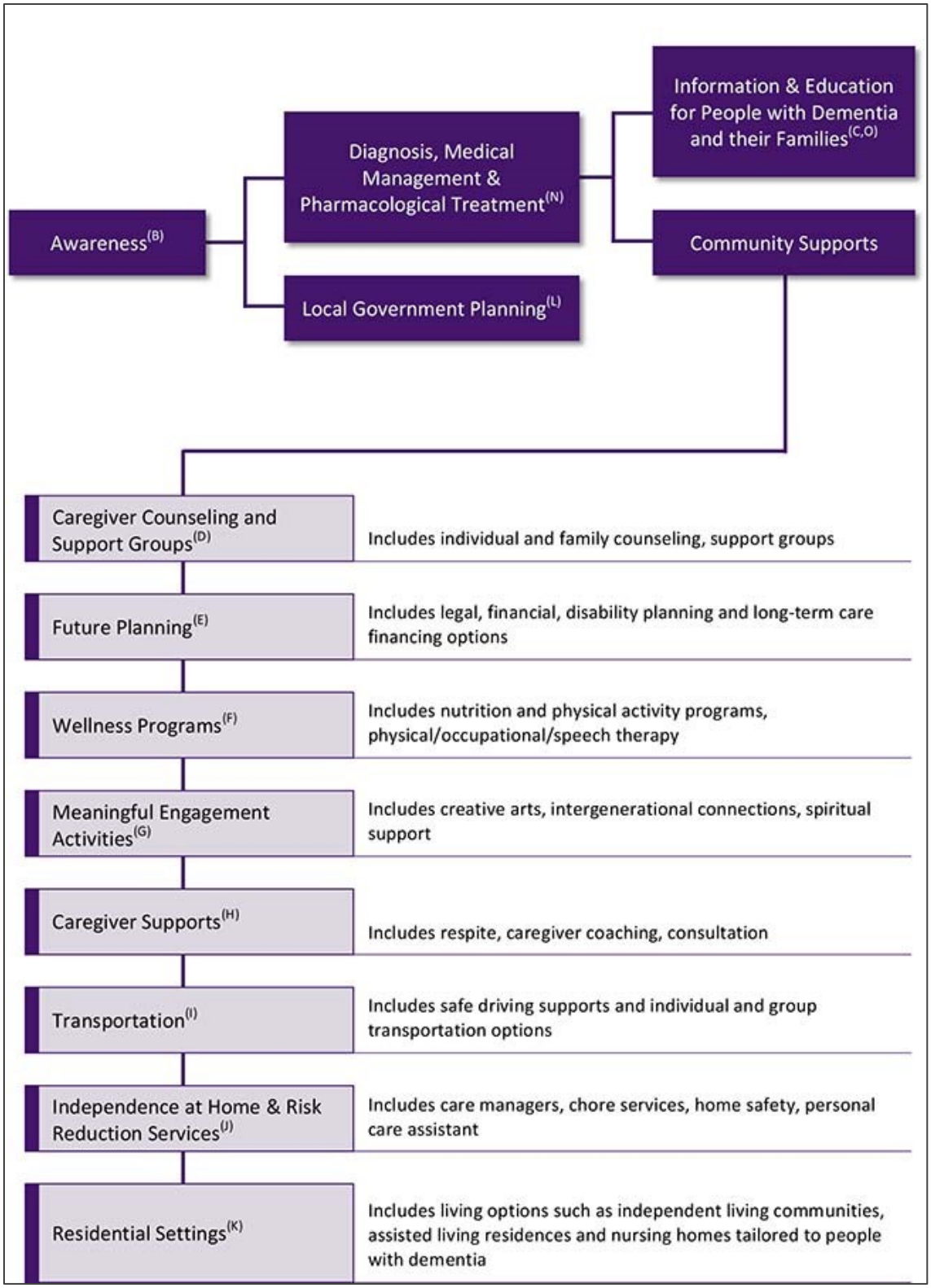

Figure 1. Key elements of a dementia-capable community (Source: ACT on Alzheimer's website: www.actonalz.org, Accessed April 15, 2015).

The process and Toolkit was piloted by four communities in Minnesota in 2012 and 2013 (finalized in 2013).[2]

In 2014 ACT on Alzheimer's leadership secured outside funding to support and engage Minnesota communities in launching this community assessment and engagement process. As of April 2015, there were 34 ACTion communities within Minnesota who had responded to the request for grant proposals and were awarded funding. The ACT on Alzheimer's® website summarizes the focus of this work as follows: "Community by community, we can create a supportive environment for everyone touched by this disease." [3] Additional information about specific goals of dementia-capable communities is provided in Attachment 1.

In 2014 the ACT on Alzheimer's leadership also added the lens of health equity – and endorsed a call to action—to enhance the tools and work of the initiative across the 5 goal areas (See Figure 2).

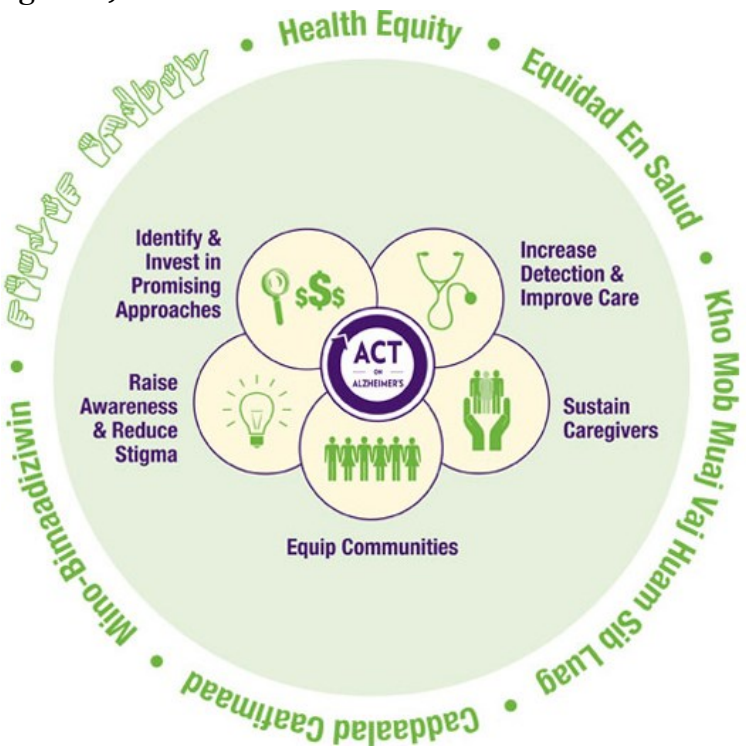

Figure 2: ACT on Alzheimer's Goals through a Health Equity Lens. *(Note: Translation of Health Equity, clockwise from the top: English, Spanish, Hmong, Somali, Ojibwe and American Sign Language)*

[2] A description of the experience of those four pilot communities is found at: http://www.actonalz.org/sites/default/files/documents/FINAL%20Pilot_Communities%20Composite%20Report-%20%20Paone%20June_2013%281%29.pdf

[3] Source: www.ACTonAlz.org/realities accessed on December 20, 2013

Alzheimer's disease and related dementias are increasing in prevalence as the population ages. According to the ACT on Alzheimer's® website:[4]

As more and more Minnesotans live with Alzheimer's disease and other dementias, the costs and challenges can be overwhelming for them, their families, our communities and our state. Care costs for Americans age 65 and older with Alzheimer's disease and other dementias are projected to increase from $203 billion in 2013 to $1.2 trillion by 2050 (in 2013 dollars).

Many individuals with Alzheimer's live alone and are at greater risk for inadequate self-care, malnutrition, untreated medical conditions, falls, wandering and accidental deaths.

Nearly 250,000 Minnesotans care for family members with Alzheimer's disease. These caregivers provide 277 million hours of unpaid care, valued at $3.4 million yearly. The physical and emotional impact on caregivers results in nearly $9 billion in increased healthcare costs annually, including $157 million for Minnesota caregivers.

[4] Source: www.ACTonAlz.org accessed on December 20, 2013

Introduction

The Minnesota Council of Churches is one of 34 ACTion communities using the guided community engagement process and the ACT on Alzheimer's Dementia Capable Communities Toolkit. This community engagement process guides a community action team as it identifies current resources, strengths and gaps within its community and plans action steps, based on findings.

This report describes the progress made through this work, from Fall 2014 through August, 2015. In that time, this ACTion community completed the "convening" phase (Phase 1), the "assessment" phase (Phase 2), and the "analysis" (Phase 3) of that work and began working on the Action plan (Phase 4).

Data sources included:

- Key informant interviews (conducted in May, July and August, 2015)
- Meeting notes and progress reports
- Assessment survey data
- The ACT on Alzheimer's® website (www.ACTonAlz.org)

Groundwork & Convening

The lead agency for this ACTion community is the Minnesota Council of Churches. Coordinator Helen Jackson Lockett-El, formerly with MCC, facilitated the work to engage MCC member churches. She found the issue of Alzheimer's disease an important one to begin to address.

> *The things that sparked my interest were that there was such a stigma around the disease. In addition, I have compassion for caregivers as well—they are dealing with the repercussions of the silence and denial in the faith community, often in isolation.*

The Minnesota Council of Churches has 24 member denominations that "represent the regional governing and administrative bodies of Mainline Protestant, Historic Black, and Orthodox judicatories." The mission of MCC is: "To manifest unity in the church and to build the common good in the world (See: http://www.mnchurches.org/).

The MCC mission is to bring denominations together around issues that are relevant to all lives from a faith perspective and unite around these issues.

The MCC member churches, together with the MCC organization, work together to address social justice issues as part of their work. For example, in 2013, the MCC reported many "Mission Impact" service accomplishments (see Appendix A) including: delivering *Graceful Journey* presentations to 51 congregations, and engaging 9 churches in strategic ministry through *Congregations of Care*.

According to interviews with key members involved in this Action team work, the MCC's *Graceful Journey* training and presentations to many member churches was instrumental in setting the groundwork for this ACT on Alzheimer's project—at least in the view of some of the participating team members.

I had taken the Graceful Journey training offered by the Minnesota Council of Churches and that was really good. That was a few years ago. There were four of us who did that. It was very well planned and presented. When I heard about the MCC sponsoring training—this time on dementia—I thought it might be like the Graceful Journey program.

The *Graceful Journey* project is conducted by MCC in partnership with the Twin Cities Medical Society (sponsoring *Honoring Choices Minnesota*) and the Bush Foundation. It is provided in either two 90-minute presentations or four 45- minute sessions in adult education forums. The purpose is to foster dialogue around end of life as a natural part of life's journey (See Appendix B for more details).

A related effort within the MCC congregations has been the Congregation of Caring initiative. One team member explained that her church has adopted the Congregation of Caring approach. This is described further in the MCC website:

The MN Council of Churches, in partnership with Project Compassion, has created Congregation of Care training for churches to enhance or develop their caring ministries. Congregation of Care is a distinctive system of support in the community of faith that involves the whole community, inspiring active involvement with congregants during critical times, such as hospitalization following surgery, living with illness, caregiving, aging, dying, death and grief. It seeks to enhance and develop a caring, compassionate congregation on the basis of deeply held religious beliefs, sustainable caring, education and support for members that will result in a cultural transformation of the congregation.

The objective of the training is to build a shared understanding with pastors (ministry leaders) and leadership teams on how to integrate caring and preparing for illness, caregiving, end of life and grief into a community of faith. Churches are invited to send a team of 3-4 people to attend the training, which consists of a one-day introductory workshop and three partial-day workshops, as well as homework and assessments. Minnesota Council of Churches Graceful Journey will provide coaching, support and opportunities to learn and share.

The Congregations of Care process is similar to the ACT on Alzheimer's process—in which tools were provided that involved surveys and assessments of congregations, to discover the members' level of awareness and actions with regard to important end of life and grief, caregiving, and related issues. A gap analysis was done to determine actual need and each congregation was able to create an action plan.

So I reached out to churches that had participated in this process and the Congregation of Care training. Each church had done work toward building a caring and compassionate congregation already.

Those team members who had participated in this Congregations of Care training felt that it helped them understand more fully the challenges that caregivers of persons with various types of terminal illness face—including Alzheimer's disease. Thus, they believed that additional training about Alzheimer's disease would be "a natural follow-up."

Helen Jackson Lockett-El convened seven member churches in September of 2014 to introduce the *ACT on Alzheimer's*® initiative and to engage representatives in a discussion about Alzheimer's disease and caregivers.

Attending this informational and discussion meeting were representatives (congregational members of these churches and/or staff members):

1. Sunrise United Methodist
2. Dayton Avenue Presbyterian
3. First Presbyterian Church, Mankato
4. Mayflower Community Church
5. Oak Grove Presbyterian Church
6. Plymouth Congregational Church
7. Westminster Presbyterian Church

The meeting was held in the Twin Cities. The meeting began with a presentation of factual information about Alzheimer's disease and dementia, including the 10 Warning Signs. Kate Houston, Metropolitan Area Agency on Aging Planning Director, and Helen facilitated the meeting. They provided an overview of the ACT on Alzheimer's initiative, described the Dementia Capable Community Toolkit and process, and introduced the individuals present to the opportunity to conduct such as process within their own congregations.

As part of that first meeting, Helen walked through the Dementia Capable Community Toolkit. Despite the fact that the ACT on Alzheimer's initiative was described as a community engagement process, some members of the team did not fully understand what would be expected of them. They did not understand that they were forming a Working Group to follow a scripted/guided process.

> *I guess I didn't understand what this was really all about. It is only now that I understand this is a process we're supposed to follow to work as a team to address building a more capable community. Being that we were from four different churches and from different geographic areas of the state, I think this was a very difficult starting point.*

> *One member of our church reached out to a few of us who had various experiences with dementia to attend the sessions with her. To be honest, we thought we were attending a session sponsored by MCC to teach us how to do a better job in our church. We were not clear this was a multiple-session commitment with "homework" and that most of the ideas were to come from us.*

Though participants had different expectations about the purpose and focus of the initial meeting, good discussion ensued at that first meeting. Individuals shared stories and spoke about the impact of the disease and generated many ideas that could be part of the community action efforts. Some of those ideas included: creating an Awareness Sunday, putting together sermon notes about the subject, and conducting a "pew survey" to get a sense from each congregation about their perspectives on this issue.

Helen presented the Toolkit and talked about the church representatives conducting surveys of their congregations. Representatives present from the different churches agreed that they would take a look at the surveys and the Toolkit to see how or whether

they would be able to conduct this assessment in their congregation. Kate and Helen provided materials for these team members to use as they went back to their churches and described the project.

> *We had some great discussion that first meeting. There were some strong viewpoints and personalities. But we didn't think the Toolkit was really designed for us—for faith communities. However, we did agree to try.*

During and following the meeting, members expressed some consternation about the surveys and their focus. The fact that none of the surveys were written for a faith community was of concern. As members reviewed the survey questions, they discussed the need for a different set of questions if they were to conduct assessments within their communities. Helen agreed to pull together a set of questions that would be a modified survey tool for these church representatives to conduct interviews. Helen created questions that were relevant for the faith community group—more exploratory in nature (see Appendix C).

> *The questions on the surveys were not relevant to the faith community. If we are looking to churches to be seen as a community—then it is difficult to use this Toolkit as it is.*

Assessing

In November 2014 the Action team met again. Three churches had decided not to continue with the work of the community assessments, as they did not have the staff or volunteers available to do the work.

The remaining four churches were:

1. First Presbyterian Church, Mankato
2. Mayflower Community Church
3. Oak Grove Presbyterian Church
4. Westminster Presbyterian Church

> *The survey itself as written was fairly clumsy—in terms of workability in a church setting. A lot of folks responded with some version of: "same answer as the previous question." This happened several times. The questions didn't get at how a church might differ from other organizations in how it supports people.*

Phone and in-person interviews were conducted by members from each church. In total, group members completed 34 surveys.

The members discussed their experiences in conducting assessments using the modified question set developed by Helen.

They described a number of challenges they had faced, including finding people willing to be interviewed, scheduling a call or meeting, finding enough time as volunteers to conduct the survey, and the difficulty with the survey questions themselves.

> *One thing that didn't work was surveying church leaders only about what support is provided—*[this] *is only half of the picture. It didn't give us any information about what the needs of the congregation are—how many members have dementia? How many are caregivers in the home? How many are caregiving from afar? What would they find most helpful? Do they need rides to church? Respite care? Calls from a pastor? A Befriender? Education? A night out?*

The group from these participating churches agreed that if ACT on Alzheimer's wanted to have faith communities involved in the work, then there should be a survey that is created specifically for communities of faith—with perhaps a set of questions for the pastor or lay leaders, and a set for lay congregational members. They pointed to the set of surveys that had been developed for the healthcare sector. A similar attention to faith community structure, service, and orientation should be attempted. The group said that they would try to conduct more surveys in December and early January, 2015.

> *Despite the survey questions, the experience of surveying church leaders was in and of itself valuable . . . because it got our church* [members/leaders] *talking and raised awareness of how many people in our community were grappling with dementia.*

This Action team shared ideas and discussed what would be helpful to them to raise awareness of this issue. For example, the group talked about having prepared sermon notes around dementia and caregiving. Helen Jackson Lockett-El prepared a sermon outline and shared that with the group. This could be used to build a sermon.

We talked about how many resources we already had in place that could be brought to bear if we thought about them differently. This last point was really important, because our congregation is really active and engaged—and the idea of creating a whole new structure to address an issue in the congregation was overwhelming and exhausting to most of the leaders we interviewed.

Analysis

In February 2015 members of the Action team met again. There were three churches now involved:

- First Presbyterian Church, Mankato
- Mayflower Community Church, Minneapolis
- Oak Grove Presbyterian Church, Bloomington

Those involved included:

ACTion Team Members
From First Presbyterian Church, Mankato:

- Janet G.
- Joyce P.

From Mayflower Community Church, Minneapolis:

- Kay K.
- Ann C.
- Kay H.

From Oak Grove Presbyterian Church, Bloomington -

- Doodee B.
- Sue G.
- Beth H.
- Jane J.
- Kathy H.
- Nancy K.

Each church contact person had sent the hard or an electronic copy of the completed surveys to Helen. Helen had Mary W., the MCC administrative support staff member, put all the data together. Once the data were tabulated, Helen sent out the survey results and asked the representatives from each church to look at their own data.

Representatives from the three remaining churches met to analyze the results of the surveys, and choose up to two priority areas for action.

Also participating was Kate Houston, MAAA, who continued to provide technical support and guidance in the process.

In discussing the results from their interviews, the team members said they saw and heard stories of fear, denial, and lack of knowledge about Alzheimer's disease and dementia. They also heard about the stigma associated with the disease and of the difficulties faced by family caregivers.

> *The fact that we were attending the sessions with other churches helped us see that each congregation would have different needs and would have to go about supporting folks in different ways. It made our conversations a lot richer.*

> *Kate Houston was a resource to us and was instrumental in guiding us as we worked through the Toolkit and dealt with other challenges around time constraints and different church priorities.*

Action Planning

Results indicated that the churches' congregations needed more information and awareness-building around dementia and caregiving. Members of the team also decided that a list of resources would be helpful—particularly for those churches that have parish nurses and assist people one-on-one.

> *So education, awareness-building, and reaching out to caregivers—those were the priorities we selected. In addition, the group agreed that a resource page specifically for the faith community should be created and that it should be housed and maintained by MCC.*

Each church was asked to determine their next steps and possible action items to pursue within their congregation, with pastoral leadership blessing.

> *They handed the reins over to the participants* [team members], *which made the experience interesting, but it was frustrating at the same time. Many of the ideas we left the sessions with originated with us and had to be executed by us.*

Some members said they wanted to be trained as a Dementia Champion in order to offer Dementia Friends sessions within their church. Some talked about intergenerational activities—such as having youth interview a person with dementia or a caregiver as part of his/her confirmation class or service project. Some team members were interested in conducting a pew survey – having members drop the short survey in the basket after church services. Some were interested in hosting/showing films, such as "I'm Still Alice" or "Alive Inside," as part of the awareness-building events, where the general public would also be invited.

Members from each church needed to go back to their church and consider what they could lead, get others to be involved in, or delegate to others. They also had to consider current and ongoing programming. They determined that this effort needed to fit into existing structures and programming—such as a Sunday educational hour or existing support group format.

Action steps emanated thereafter from each church on its own, based on the interests of the team members and pastoral leadership, time availability, and how the proposed activity fit into the larger programming of the church (i.e. calendar). Examples of action steps include: having individual members trained as Dementia Champions, including information about Alzheimer's disease and caregiving in the church newsletter, and setting up plans to do a survey of the congregation's needs (forthcoming – fall, 2015).

> *Our church had already been doing a caregiver support group, and we have continued to do that. I and a colleague were trained as Dementia Champions, and she and I have done one session for deacons and elders where 10 people came and one session for the congregation where 7 people came.*

> *We include information in our monthly newsletter and featured a story about this project and the issue of AD and caregiving.*

Lessons Learned/Advice

The key informants involved in the facilitating this work offered several lessons learned and recommendations for moving ahead. These are offered below:

- *Develop specific faith community survey* - Team members felt that the Toolkit surveys did not fit the faith community focus/orientation.

- *Include more orientation to the community engagement nature and process as well as expectations of the ACTion team* – Team members noted that more work to have them come together as a team would have been helpful. Some did not understand the community engagement process. Others were interested, but had little volunteer or staff support from their church—given the many priorities, heavy demands, and number of existing programs that their churches were dealing with already.

- *Clarify the need for many volunteers to be engaged* – The few individuals who attended the three action team meetings were, essentially, those who needed to go back and implement the process and do the work. It was too much work for these individuals, who were primarily volunteers (not staff members).

> *Our team did not really come together with other churches as a result of this process. We did have discussions and provided feedback, but our contact did not extend beyond that . . . We formed a team at our church, but have not met with the other churches since then.*

> *Speaking just for myself, I did not understand this project or the process very well. I didn't know we needed to be organized as a team to move this along. We were not really organized. There were some strong opinions and some didn't want to fit into a tight process. So the church representatives really were thinking of what would be valuable/useful for their own church—not so much that we were a team working collaboratively. We never really got that we were a team, I think. Maybe there could have been more ground-work laid or more time spent on building our group.*

However, the members really appreciated learning more about the disease and the issues caregivers face. They did see the applicability and want to increase the number of people from their church who will learn about this disease. In addition, the ideas and "free-flowing" discussions among the church members present were stimulating for the participants. This may lead to further work together around this issue.

> *I think that the pastors and senior leadership need to get behind this issue and see this as important. It has to be visibly supported by the pastors as an issue that needs attention—dementia and caregiving.*

> *I am recommending that more people get trained as Dementia Champions, as I am involved in running the support group and am involved in the Congregation of Care activities—it has to be adopted by more than a few people.*

> [Is this effort being sustained or is it evolving?] *Yes, to both. We have formally established ourselves as a group with a mission statement and a spot in our church structure. We are a team associated with the pastoral care network within our congregation. We recently participated in a conference with TRUST and other churches and we are planning to invite a couple of other churches to our October workshop. Right now our efforts are concentrated on how we can best serve our own congregation.*

Conclusion

Based on the responses of these three engaged faith communities, there is a clear need within faith communities for information and education about Alzheimer's disease. However, this issue is one of many. Resources to address the needs of individuals and caregivers, even within the congregation, are few. Volunteers from the congregation are those who are tapped to provide education, support, and outreach. They are responding to this call for service. The recommendation of these faith community volunteers to *ACT on Alzheimer's* is to modify the Toolkit surveys and add resources that are more tailored to those from faith communities.

Appendix A: Minnesota Council of Churches Information

The Minnesota Council of Churches Ecclesiology, which was adopted in November, 1993 reads:

> *By participating in the Minnesota Council of Churches, we express our trust in the triune God to lead us to a fuller expression of the unity of the churches. Our conviction is that all churches have graces to offer and receive.*
>
> *Our membership in the Council testifies to our self-esteem ("In Christ, we have something to say") and to our humility ("In Christ, we have much to learn").Rejoicing in our common baptism and lamenting our inability to feast together at the Table of our Lord, we commit ourselves to support the Minnesota Council of Churches because we know the recognition of unity requires a common seeking, grounded not just in theory but in life together, not just in periodic cooperation but in sustained fellowship.*
> *We acknowledge that a council of churches does not know in advance the precise nature of the unity we seek to manifest; its task is to encourage, orchestrate, and assess our seeking.*
>
> *We expect the Minnesota Council of Churches to remind us constantly that unity is of the Church's essence, more than a worthy goal to be pursued if time and resources permit. The nature of the unity itself will be a surprise.* (See: http://www.mnchurches.org/about/membership.html. Accessed July 20, 2015)

Appendix B: Graceful Journey Project

Graceful Journey Project - From the MCC website. Found at: http://www.mnchurches.org/respectfulcommunities/endoflife.html

A Public Health initiative - A Partnership of MN Council of Churches, Twin Cities Medical Society and Bush Foundation

Talking about death is difficult, but one of the most appropriate places for this sensitive conversation is church. The tenets of our faith provide redemptive healing, hope and support. We live in the bounty of God's grace and we ought to die in like manner. We are all aging together regardless of our age. With the aging of the baby boomers Americans are facing an unprecedented demographic shift. And although most people want to avoid thinking, talking, and making decisions about the end of life, the consequences of not having the discussion can be stressful for pastor and congregants and family. With Graceful Journey people learn how to have those conversations, and to make decisions on the basis of deeply-held religious beliefs, surrounded by a caring community of faith.

Graceful Journey helps people think about decisions that need to be made at the end of life, offers tools to talk about and make those decisions, and encourages congregations to provide care that helps families experience the end of life as a graceful journey. Graceful Journey can give you and your congregation the tools to begin the conversation with family and loved ones. Fill out an interest form or contact MCC at (612) 230-3344.Graceful Journey is a project of the Minnesota Council of Churches in partnership with Honoring Choices Minnesota.

The following congregations have already hosted a Graceful Journey presentation:

AARP, Minneapolis
Ascension Episcopal Church, Stillwater
Augustana Lutheran Church, St. Paul
Beaver Lake Lutheran Church, Maplewood
Berean Baptist Church, Burnsville
Bethel Lutheran Church, Northfield
Brooklyn Park Evangelical Church, Brooklyn Park
Chaska Moravian Church, Chaska
Chisholm United Methodist, Hibbing
Christ's Community Church, Maple Grove
Crest View Lutheran Home, Columbia Heights
Dayton Ave. Presbyterian Church, St. Paul
Diamond Lake Lutheran Church, Minneapolis
Elim Lutheran Church, Robbinsdale
Epworth United Methodist Church, Minneapolis
First Lutheran Church, St. James
First Presbyterian Church, Hibbing
First Presbyterian Church, Stillwater
First United Methodist Church, Sartell
Northfield United Methodist Church, Northfield
Oak Meadows Senior Living, Oakdale
Oasis Church, Rochester
Our Savior's Lutheran Church, New Ulm
Our Savior's Lutheran Church, Stillwater
Peace UCC, St. Cloud
Plymouth Creek Christian Church, Plymouth
Prince of Peace Lutheran Church, Brooklyn Park
Progressive Missionary Baptist, St. Paul
Redeemer Lutheran Church, St. Paul
Roseville Lutheran Church, Roseville
Sacred Heart Parish, Sauk Rapids
Salem Lutheran Church, Minneapolis
Saron Lutheran Church, Big Lake
Shiloh Missionary Baptist Church, St. Paul
St. Cecilia's, St. Paul
St. James Lutheran Church, Crystal
St. John's Lutheran Church, Annandale
St. John's UCC, Faribault

Gethsemane Lutheran Church, Virginia
Glenwood United Parish Congregation, Glenwood
Gloria Dei Lutheran Church, St. Paul
Grace Lutheran Church, St. Paul
Hennepin Avenue UMC, Minneapolis
Hibbing Rotary, Hibbing
Holy Trinity Lutheran Church, Minneapolis
House of Hope Lutheran Church, New Hope
House of Prayer Lutheran Church, Oakdale
Immanuel Lutheran Church, Amelund
Lake Harriet United Methodist Church, Minneapolis
Lumen Christi Catholic Church, St. Paul
Mayflower UCC, Minneapolis
Normandale Hylands UMC, Bloomington
Normandale Lutheran Church, Edina
St. Mark Lutheran Church, St. Paul
St. Mary's Greek Orthodox Church, Minneapolis
St. Nicholas Episcopal Church, Richfield
St. Odilia Catholic Church, Shoreview
St. Stanislaus Catholic Church, St. Paul
Sunrise United Methodist Church, Mounds View
Trinity Lutheran Church, Sauk Rapids
Trinity Lutheran Church, Stillwater
UMC Parish Nurses, St. Cloud
United Lutheran Church, Red Wing
Wesley United Methodist, Hibbing
Westminster Presbyterian Church, Minneapolis
Zion Evangelical Lutheran Church, Pat Tommet
Zion Evangelical Lutheran Church, Minneapolis
Zion Lutheran Church, Cottage Grove

Appendix C: MCC Survey Questions (To interview members of the congregations involved and pastoral and lay leadership)

Short Form

1. Would you be interested in playing a greater role to help us implement this project in our community?
2. Could you suggest other organizations/groups in our community who could take part in this project?
3. Are there any other suggestions or ideas that you can give me as we prepare to get this project started?
4. Are there any questions you would like to ask me?
5. Would you like me to be in touch with you again to let you know how the project is progressing and how to help ensure our community is becoming more dementia-capable?

Long Form

1. Have you had personal experience with someone with dementia?
2. What opportunities do you see for the community members to know the warning signs of dementia?
3. What opportunities do you see for awareness-building on dementia to the general population (congregation)? What barriers do you see?
4. What opportunities do you see for community members to have good skills for interacting with people with dementia? What barriers do you see?
5. What opportunities do you see for church leaders to make referrals to support services for people with dementia and their families? What barriers do you see?
6. What opportunities do you see for building community awareness of the resources that can assist with locating support services for people with dementia and their families? What barriers do you see?
7. What opportunities do you see for having a dementia-related resource tailored to our diverse and underserved populations? What barriers do you see?
8. What opportunities do you see for meaningful activities tailored to people with dementia living outside a formal care setting? What barriers do you see?

For caregivers

1. Is education and training provided in your community about Alzheimer's disease and care needs?
2. Is information about services and supports in the community offered?
3. What do you see as barriers or opportunities for education and training on dementia and dementia care for caregivers?
4. What do you see as barriers or opportunities for providing counseling/support groups for caregivers of people with dementia and/or their families? Would you be interested in playing a greater role to help us implement this project in our community?
5. Could you suggest other organizations/groups in our community who could take part in this project?
6. Are there any other suggestions or ideas that you can give me as we prepare to get this project started?
7. Are there any questions you would like to ask me?
8. Would you like me to be in touch with you again to let you know how the project is progressing and how to help ensure our community is becoming more dementia-capable?