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Faith-Related Programs in Dementia Care, Support, and Education

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DEMENTIA CARE, SUPPORT, AND EDUCATION

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EXECUTIVE SUMMARY

More than 5 million Americans over age 65 are living with dementia, which affects a person's ability to perform daily social and occupational activities. People with dementia and their caregivers may experience psychosocial benefits from participation in religious activities. Spirituality and religious activity can provide relief from anxiety, reduce behavioral disturbances, and improve quality of life for people with dementia and reduce burden for caregivers. Faith communities offer a range of services that incorporate aspects of spirituality and religion for people with dementia and their caregivers. These services are developed and implemented either by a faith community or an outside secular organization. This case study report focuses on initiatives developed by faith-based or secular organizations that include faith-related or spiritual components.

E.1 Methods

To obtain information about faith-related programs focused on dementia, RTI International conducted telephone interviews with staff at five dementia-related programs with religious or spiritual content: Alzheimer's Orange County's Interfaith Outreach Program in Orange County, California; Amazing Place in Houston, Texas; The Respite Ministry in Montgomery, Alabama; Twin Cities Jewish Community Alzheimer's Task Force based in Minneapolis, Minnesota; and United Methodist Church Discipleship Ministries, Office of Aging and Older Adult Ministries based in Nashville, Tennessee. In addition, RTI reviewed the research literature on faith-related initiatives within secular and faith-based organizations, health-related support for members of congregations, or outreach to members of a congregation with dementia by community-based organizations.

E.2 Findings

The five faith-related dementia programs profiled in this report work to keep people with dementia and their caregivers engaged in faith communities. Two of the programs serve as adult day centers for people with dementia. These programs--Amazing Place and The Respite Ministry--include spiritual and religious features in their programs. The other three programs support people with dementia and their caregivers in a number of ways, including through specialized religious services, support groups, and education to the community and clergy about dementia. These programs include Alzheimer's Orange County's Interfaith Outreach Program, the Twin Cities Jewish Community Alzheimer's Task Force, and United Methodist Church Discipleship Ministries.

Each of the sponsoring organizations made distinct efforts to grow relationships with the surrounding community, and in some instances reached out to other faith communities for their program involvement and support. Through outreach into the community, the programs were able to obtain support needed to run their programs. This community assistance varied for each program but typically included volunteers, use of space, or funding.

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SECTION 1 INTRODUCTION

Dementia refers to changes in memory and other cognitive skills severe enough to affect a person's ability to perform daily social and occupational activities. Alzheimer's disease, the most common cause of dementia, is a progressive brain disease for which there is no cure. In 2016, it was estimated that 5.2 million Americans over age 65 and approximately 200,000 people younger than 65 had Alzheimer's disease (Alzheimer's Association, 2016).

People with dementia and their caregivers receive support and assistance from many sources within their communities. Aid includes home and community-based services, support groups or counseling, and respite for family caregivers. Faith-based communities may supply services and support to people with dementia and their caregivers. Clergy are often considered first responders because congregants frequently approach them in times of crisis.

Religion is important to many Americans; most adults (77%) identify with some religious faith. Two-thirds of religiously affiliated adults say they pray every day and that religion is very significant to them. These adults regularly engage with faith-based organizations. Of adults over age 65, 48% attend religious services at least once per week, and an additional 25% attend services once or twice a month. Thirty percent of adults over age 65 participate in prayer, scripture study, or religious education groups at least once per week (Pew Research Center, Religion & Public Life, 2014).

Participation in religious activities may provide a number of psychosocial benefits for people with dementia and their caregivers. Studies have shown that spirituality and religious activity may provide relief from anxiety, reduced behavioral disturbances, and improved quality of life for people with dementia (Ennis & Kazer, 2013; Vance, 2004). Religious involvement, particularly church attendance for those who choose to attend, may also provide psychosocial benefits (e.g., reduced caregiver burden) to caregivers of people with dementia (Sun et al., 2009). At least one study showed a relationship between caregivers' church/synagogue attendance, support and comfort from a religious faith, and contact with a church/synagogue and positive emotional states, health, absence of psychiatric symptoms, and positive coping patterns (Burgener, 1999).

Attendance by both caregivers and people with dementia at religious services declines over time for a number of reasons. To some extent, people with dementia may not be able to physically attend religious services because of immobility. Progressive cognitive decline also affects attendance. For example, people with later-stage dementia may have difficulty maintaining focus during lengthy religious services (Kaufman et al., 2007; Pinson et al., 2010; Plunkett & Chen, 2015; Stansbury et al., 2010; Vance, 2004).

Although formal training on dementia care and support for clergy is limited, clergy use a variety of strategies to aid people with dementia and their caregivers (Stansbury et al., 2010; Tompkins & Sorrell, 2008). Vance (2004) suggests that spiritual activities, such as intense scriptural study or interactive prayer, that require the use of executive function are likely to be met with failure or frustration even in the early stages of the disease. Activities that may help in maintaining spiritual connections for people with dementia include being soothed by a familiar

song or prayer, feeling secure performing a simple religious ritual, and being awed by holding an item associated with one's faith (Tompkins & Sorrell, 2008; Vance, 2004). Faith communities may respond to the needs of individuals living with dementia by providing reminders about and transportation to worship services, a safe environment, and social support (Stansbury et al., 2010).

Services for people with dementia and their caregivers have several relationships with faith-based communities. Programs may be *faith-placed* where an outside organization uses the faith-based community to host its secular program or *faith-based* where the faith community has developed and implemented a program with religious or spiritual content (Harr & Yancey, 2014). Collaborative arrangements also exist where the outside agency and faith-based group create a partnership to provide support or services (Campbell et al., 2007). In a study of general health programs in faith-based organizations, faith-placed programs developed by health professionals outside of a congregation accounted for the largest percentage of programs (DeHaven et al., 2004). This case study report focuses on faith initiatives developed by faith-based or secular organizations that include faith-related or spiritual components.

SECTION 2 METHODS

Information in this report was gathered in April and May 2016 through telephone interviews with program staff at five dementia-related programs with religious or spiritual content. These programs serve the needs of people with dementia or their caregivers or educate members of the community and clergy. RTI performed literature searches of PubMed/Medline, CINAHL, PsychInfo, and ScienceDirect to access peer-reviewed literature. The authors used natural language syntax queries to access grey literature in Google and Google Scholar. Literature searches and syntax queries resulted in the identification of 237 articles, of which 44 were reviewed for this paper. The articles reviewed included information on faith-related initiatives within secular and faith-based organizations, health-related support for members of congregations, or outreach to members of a congregation with dementia by community-based organizations.

Through these literature and Internet searches and inquiries to religious organizations, RTI identified 16 faith-related programs focused on dementia. RTI studied five programs that responded to requests for interviews about their programs: Alzheimer's Orange County's Interfaith Outreach Program in Orange County, California; Amazing Place in Houston, Texas; The Respite Ministry in Montgomery, Alabama; Twin Cities Jewish Community Alzheimer's Task Force based in Minneapolis, Minnesota; and United Methodist Church Discipleship Ministries, Office of Aging and Older Adult Ministries based in Nashville, Tennessee.

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SECTION 3 CASE STUDIES

The five faith-related dementia programs are profiled below in individual case studies. These programs aim to keep people with dementia and their caregivers engaged in faith communities in a variety of ways.

- Two of the case studies detail adult day programs for people with dementia that were developed by faith communities and include spiritual and religious aspects in their programs—Amazing Place in Houston, Texas, and The Respite Ministry in Montgomery, Alabama.
- The other three programs support people with dementia and their caregivers through a variety of programs such as specialized religious services and support groups and educating the community and clergy about dementia. These programs include Alzheimer’s Orange County’s Interfaith Outreach Program in Orange County, California; the Twin Cities Jewish Community Alzheimer’s Task Force based in Minneapolis, Minnesota; and United Methodist Church Discipleship Ministries, Office of Aging and Older Adult Ministries based in Nashville, Tennessee.

3.1 Alzheimer’s Orange County Interfaith Outreach Program, Orange County, California

3.1.1 Project Background, Description, and Major Activities

Founded in 1982, Alzheimer’s Orange County (AOC) is a nondenominational organization with programs open to all faiths. For the past 16 years, AOC has supported the Interfaith Outreach Program, which educates faith communities about Alzheimer’s disease and dementia and the importance of supporting people spiritually. The program also provides an opportunity for people with dementia and their caregivers to be involved in religious activities.

AOC’s Interfaith Outreach Program was developed to keep people with cognitive impairment engaged in faith communities. The Program formed an Advisory Committee made up of AOC volunteers to approach faith communities in Orange County and provide special religious worship services for people with dementia. The program invites individuals from all faiths to attend services provided and performed in the traditions of the host organization. Beginning as a Judeo-Christian effort, the program now includes Baha’i, Christian, Jewish, and Muslim communities.

The Interfaith Outreach Program is managed by the 12-member Advisory Committee and is assisted by a member of the AOC staff. The Advisory Committee hosts quarterly meetings to plan upcoming events and outreach activities. Currently, the program has three main areas of support that can be implemented by a faith community: (1) worship services, (2) dementia-specific educational programs, and (3) faith-based liaisons.

- **Worship Services**—The Interfaith Outreach Program worship services offer an opportunity for a faith community to provide abridged services for people with

dementia, in any stage of the disease, and their caregivers. These worship services are offered monthly and rotate to different faith communities. Prior to hosting services, clergy and faith community volunteers are provided guidance and formal training by AOC staff. The training helps sensitize volunteers to the need to accommodate people with dementia rather than expecting them to fully participate in a traditional service. Participating faith communities must agree to specific criteria:

- limiting the service to 20 minutes,
- incorporating music therapy with commonly known hymns,
- using only familiar texts (not new translations),
- ensuring door-to-door transportation (going beyond handicap accessibility), and
- providing a meal after the service to participants to enhance social engagement.

The majority of participants with dementia who attend the specialized worship services reside in assisted living facilities. Individuals living in assisted living facilities may stop attending worship services out of fear that they will be embarrassed or will be in situations that they do not understand. Other potential participants lack transportation or need reminders to attend. Advisory Committee members and AOC staff recruit program participants from the community and arrange for their transportation to and from worship services. Many individuals come from assisted living facilities that can provide transportation. As part of program outreach, facilities receive an annual calendar of worship services, including the locations and times of services, so they can be included in their activities calendar.

- Dementia-specific Educational Programs and Support Groups—AOC dementia education programs are designed to increase awareness of dementia and the supports available in Orange County. Educational program topics range from the basics of dementia to advance directives, which are presented by a faith community leader who brings a spiritual perspective on a specific subject. The host organization of each education program may limit the participants to its own congregants or may open participation to the general public. Support groups are open to the public, although approximately 85% incorporate teachings and rituals consistent with the host faith community. Support groups provide emotional support and practical information to participants, such as information about obtaining respite care. The faith community hosting the program is asked to publicize the interfaith outreach education programs, including support groups for people with dementia and caregivers, in its printed bulletins and online calendars.
- Faith-based Liaisons—Interfaith Outreach Program faith-based liaisons are volunteers from the participating faith communities who serve as a link between their community and AOC. AOC created a specific training program for faith-based liaisons. This formal dementia-specific training emphasizes the importance of

spiritual expression to engage a person with dementia. Liaison tasks include the following:

- attending an annual training session and keeping informed of advances in dementia-specific issues,
- obtaining permission from clergy to identify themselves to their congregation as a resource for individuals experiencing memory loss and their families,
- exploring and identifying opportunities for educational presentations to congregations regarding dementia, and
- attending AOC quarterly interfaith advisory committee meetings.

3.1.2 Identifying Community Needs and Outreach

Orange County is home to more than 1,000 faith communities serving more than 3 million residents. Early in the program, the Interfaith Outreach Program’s Advisory Committee recognized the importance of engaging with different faith communities, which resulted in an increase in participation of both faith communities and participants. The committee focuses its efforts on engaging the county’s 100 largest faith communities.

Advisory Committee members go to faith communities every month to provide information about the Interfaith Outreach Program. These volunteers and AOC staff also call 90 assisted living facilities monthly to invite them to participate in the worship services and send flyers to each facility’s activities and executive directors. Activity directors from the assisted living facilities recruit residents to participate in worship services. Social media coverage of these activity directors’ successes has resulted in an increased interest in the Interfaith Outreach Program.

The faith-based liaison training and support materials encourage liaisons to survey their community members about their interest in participating in services or educational workshops. These surveys help identify faith community members with dementia and those who are interested in volunteering to host worship services or education workshops.

AOC staff and the Advisory Committee recruit program participants through faith-based community education programs. For example, AOC participates in an annual spirituality conference and partners with other senior services organizations to present dementia content at community events. These activities feature clergy active in the program to help encourage new faith communities to join.

AOC staff attend monthly interfaith council meetings throughout the county to promote upcoming events. These interfaith councils are unincorporated associations of clergy and lay representatives from different faith communities within a geographic area. The councils provide platforms for organizations to highlight and coordinate interfaith projects (Orange County Interfaith Network, 2016).

3.1.3 Project Successes/Challenges

When AOC initiated its interfaith project there were no comparable programs in the community and no clear blueprint for how to proceed. In the early stages of the program, AOC adjusted the program to reduce the length of worship services, increase time for participant socialization, and add light meals. The mature program features structured worship services with formal expectations for participating faith communities, including required dementia training with AOC staff for clergy. The cost of the program to AOC is minimal because transportation is mainly provided by families and assisted living communities, and the host faith communities provide the meal and meeting space. The interfaith program is sustained by the Advisory Committee's established relationships with faith communities.

In 2016, AOC worship services served an average of 64 participants at each service, which was a 40% increase from 2015. This increase is attributed to increased recruitment at assisted living facilities and Advisory Committee member outreach.

AOC had 10 active faith-based liaisons in 2016; with continued growth of the program, it would like to increase that number to 50. Beyond linking their faith community to outside resources, liaisons have developed new faith-based support groups within their faith communities. Although it is not a requirement for participation in the program, AOC would like the faith-based liaison positions to be formalized within each faith community, for example with volunteer job descriptions.

The Interfaith Outreach Program does not formally measure participant outcomes. However, short-term improvement in participant sleep quality, mood, behaviors, engagement, and alertness are anecdotally reported. One staff liaison to the program speculated, "It is mysterious how this works so well. We can't put a label on it but if you have a person with faith-based tendencies or faith was part of their upbringing, the services can speak to a part of memory that elicits responses differently than other stimuli."

3.1.4 Lessons Learned and Advice for Future Faith-Based Projects

An organization that wants to replicate the program needs to determine whether it can implement the program with enough flexibility to meet the needs of partnering faith communities. Organizations spearheading a faith effort must understand and respect the needs of faith communities being considered for inclusion in the program.

A variety of strategies can contribute to the program's success. A new program would benefit from support staff with 6-8 hours a week dedicated to implementing the program. AOC suggests that organizations delegate staff responsibility to a person with an understanding of both organized religion and the spiritual needs of people with dementia and their caregivers.

Establishment of a committee of 10 or more volunteers, representing different faith communities, to allow for roles and responsibilities to be shared is also recommended. For example, having multiple volunteers trained in each program responsibility allows individuals assigned to some of the more intensive activities, such as recruiting and tracking responses for services each month, the opportunity for an occasional break from those tasks. Recruitment requires calling assisted living facilities, caregivers, and clergy four times a month to gather

attendance plans and encourage participation, which can be wearing. Similarly, having three to four people available to assist at services should an assigned volunteer become unavailable ensures that programs are not canceled or postponed.

3.1.5 Products That Other Organizations Might Use

- Sample Abridged Worship Service for Persons with Dementia in Mid-Late Stage
- Sample Recruitment Flyer for Abridged Worship Services
- House of Worship Requirements for Abridged Worship Service
- Job Description, Interfaith Committee Member
- Job Description, Faith Community Liaison
- Training Manual, Faith Community Liaison

Products may be requested by contacting Patty Yuen at pyuen@rti.org.

3.2 Amazing Place, Houston, Texas

3.2.1 Project Background, Description, and Major Activities

Amazing Place, a daytime wellness center, was founded in 1996 by St. Luke's Methodist United Church in Houston, Texas. Its mission is to provide fellowship, memory care, and wellness for adults with mild to moderate memory loss and to support their families and the community. Center activities include creative and cultural arts, civic service, fitness, and spiritual activities.

Fifteen churches govern and help fund Amazing Place—a \$2.2 million per year nonprofit organization. Amazing Place is licensed to serve about 60 participants a day. In 2010, Amazing Place opened a freestanding LEED Silver-certified 13,700 square foot building, which includes a chapel, art studio, game room, fully functional kitchen, family conference and training rooms, and an expansive courtyard. Because of Houston's large geographic size, transportation and traffic present problems for participants. To attend the program, most participants use a county-subsidized cab service or are dropped off at the facility by family members, 60% of whom are still working.

The program operates Monday through Friday for 10.5 hours daily. Participants, ranging in age from 49 to 98, attend between two and five days per week. The 25 staff members provide activities geared to the personal interests, hobbies, and experiences of participants. They also offer support services and information to family members. The professional staff includes registered nurses, a social worker, and a culinary director.

Amazing Place benefits from the services of 350 volunteers, each of whom completes an application and 2.5 hours of training. Each volunteer is subject to a background check.

Volunteers can assist in a number of ways, including providing entertainment, assisting with or leading activities, interacting with participants, or working on office administrative or clerical tasks.

In 2015, Amazing Place served 420 people in the day program. The staff customizes care plans for individual participants and meets routinely to review the plans. An interdisciplinary consultation service—“Next Step”—also assists families with care planning when it becomes necessary for a participant to transition out of the program.

Amazing Place incorporates faith-based features into daily activities. Each day Amazing Place offers a Bible study class for participants. This activity allows participants to share their knowledge of the Bible and their faith even with their challenges related to dementia. Participants also read devotions every day before lunch. Amazing Place holds church services once a month for participants. Although Amazing Place is governed by Christian churches, it is committed to serving those of other faiths or no religious affiliation. Volunteers from different denominations often take the lead during activities and conduct special programs for holy days.

In addition to providing services to participants with dementia, Amazing Place provides support to caregivers through counseling and referral services from an on-site family services director and licensed social worker. Amazing Place also offers support groups, family social events, and dementia education and training programs including Powerful Tools for Caregivers and Stress-Busting Program for Family Caregivers™. Caregivers receive monthly newsletters with a calendar of participant activities and articles about managing various aspects of dementia as a caregiver. They also have access to an extensive array of information on the Amazing Place website, such as lists of caregiver support resources, how-to guides, and names of local neurologists, geriatricians, and other organizations that provide support services.

3.2.2 Identifying Community Needs and Outreach

To help reduce stigma and identify people with dementia and their caregivers who could benefit from its services, Amazing Place developed programs to broaden awareness of brain health and dementia in the community. Amazing Place outreach activities include a speaker’s bureau, consisting of a registered nurse, an activities director, and a community and church liaison, which provides free programs about dementia and brain health. These programs are offered to professional and social organizations, churches, and companies. Speakers address many topics, including healthy aging, memory issues, early-stage memory loss, and nutrition and exercise for brain health. Amazing Place has strong relationships with the medical and aging community and works closely with the local Alzheimer’s Association. These relationships result in program referrals from physicians, churches, and the Alzheimer’s Association.

Amazing Place has a participant population that mirrors the aging population in the Houston area. Participants are predominantly White, but the center also serves those from the Asian, Latino, and African American communities. To help recruit underserved and low-income populations, scholarships are offered to help with tuition costs.

As part of the Amazing Place evaluation process, which ensures ongoing quality assurance and program improvements, anonymous caregiver surveys are conducted each year.

Amazing Place also conducts interviews with participants to solicit feedback on programs. To understand the needs of the community, a community and church liaison works with other churches on a regular basis to determine their dementia care needs. In 2016, Amazing Place launched a council of congregations to advise the board of Amazing Place and to encourage communication between Amazing Place and its sponsoring congregations.

3.2.3 Project Successes/Challenges

The main challenges of Amazing Place are its operating costs and attracting people to attend the program. Amazing Place has an expensive operating model and it needs a community-wide financial commitment to sustain the program—the average cost per person per day is \$154, but tuition is \$90 per day. Amazing Place chooses to exceed licensing requirements by employing highly trained nurses and other professional staff, which contributes to its high operating costs. The program relies primarily on two revenue streams: participant fees and contributions from the community. Some participant fees are covered by long-term care insurance policies and reimbursements from the Department of Veterans Affairs. For those who are unable to afford participant fees, Amazing Place has a scholarship program. In 2015, Amazing Place provided \$190,000 in scholarships.

Even more challenging than high operating costs is reaching people in need of services. The director explained that there is sometimes tremendous denial and reluctance to accept a diagnosis of dementia when people are in the early stages, which is when individuals can benefit from the structure and stimulation of a day program. In an effort to attract participants and generate referrals, Amazing Place markets its services by sending printed materials and e-newsletters to donors, volunteers, and medical professionals. Newspaper ads and direct mail campaigns are also used to reach the broader community. However, the best marketing is when participants and caregivers share their program experience with friends or their physician, which generates referrals and increases awareness of the program.

3.2.4 Lessons Learned and Advice for Future Faith-Based Projects

Amazing Place continues to include spiritual content in daily activities and to develop other aspects of the program. For example, Amazing Place added art and creative writing programs to attract and provide more stimulation for those with less severe symptoms of dementia. To raise awareness of the program, Amazing Place works to cultivate relationships, especially with referring physicians and other organizations. Relationships with sponsoring congregations are also valued because these connections provide financial and leadership support, while Amazing Place serves as an important resource for their congregants. Overall, the director indicated that the faith-based association allows for a high degree of trust, and participants find Amazing Place comforting because they are in a supported and safe environment.

3.2.5 Products That Other Organizations Might Use

At the time of the case study interview, products were not available for Amazing Place. However, information on Amazing Place can be found at <http://www.amazingplacehouston.org/>.

3.3 The Respite Ministry, Montgomery, Alabama

3.3.1 Project Background, Description, and Major Activities

In 2012, the Senior Pastor and congregants at the First United Methodist Church in Montgomery, Alabama, started a day program for people with dementia and their families. In an effort to fill a gap in services, the First United Methodist Church provided startup funding of \$50,000 to establish The Respite Ministry. The Respite Ministry is a community project open to people of all faiths, presently serving Buddhist, Catholic, Episcopalian, and Jewish participants. The Respite Ministry program is primarily volunteer based; the only staffing support comes from First United Methodist Church, which funds the salaries of the program director and one part-time assistant.

The Respite Ministry's 120 volunteers, from eight churches and two synagogues, provide more than 10,000 hours of service per year. Volunteers perform a variety of tasks including providing supervision to clients and leading activities such as music, dance, Bible study, arts and crafts, and intergenerational activities. Prior to serving the program, volunteers undergo a background check and are required to attend a 4-hour training course developed by The Respite Ministry. The training covers the basics of Alzheimer's disease and communicating with people with dementia.

The Respite Ministry operates 4 days a week, from mid-morning until early afternoon, and includes a hot lunch. Respite Ministry programming, which is aimed at participants with memory loss from Alzheimer's disease or related dementias, consists of socially interactive mental and physical activities. To attend, participants must be able to use the restroom independently and participate in a group setting. Typically, up to 20 people with dementia attend daily, with 15 volunteers running activities, and a total of about 40 people with dementia per week. Participants pay \$30 per day, if they are financially able. To better meet the needs of underserved communities, the Respite Ministry solicits donations from the public and maintains a scholarship fund for those in need. Since the beginning of the program, The Respite Ministry has awarded more than \$45,000 in respite scholarships.

Participants attend The Respite Ministry between 1 and 4 days a week. To reduce stigma, all participants are made to feel like and act as volunteers by assisting and encouraging other participants. The Respite Ministry director explained that an observer would notice little, if any, difference in the involvement in activities between volunteers and participants. Everyone sits together in the group, with matching name tags. Respite Ministry volunteers and participants work together to identify activity roles for the participants that support success and feelings of contribution, including serving food, assisting with drinks, and helping fellow participants navigate the classrooms. The director believes this integrated structure is an important aspect of the success of the overall program. Sessions are also called "classes" so participants feel they are involved in a life-long learning program. The Respite Ministry does not have programs for people with more advanced dementia but refers caregivers to home health services or the Area Agency on Aging.

Activities offered by The Respite Ministry include those typical of a secular adult day center as well as faith-based and spiritual activities. A short devotion starts each day, and

spiritual activities include a prayer group, fellowship, service projects, and Bible study. Attendees also have the opportunity to participate in the Side by Side Choir consisting of Respite Ministry participants, volunteers, and caregivers. The choir performs hymns and secular songs and practices regularly in 10-week sessions to prepare for public performances. Because the participants might be isolated from other regular church services, twice a month The Respite Ministry holds special services in a nonjudgmental environment. These special services are inclusive and specifically tailored to be welcoming for program participants and their families. Those who attend can actively participate in the service or just observe. The Side by Side Choir and special services are a way to bring caregivers back into the faith community and demonstrate the community's commitment to supporting them.

The Respite Ministry provides the opportunity for caregiver respite during the day so they can address their needs and offers emotional support to caregivers through a caregiver support group. A bimonthly support group is led by an experienced counselor and provides attendees with information regarding available community resources, nursing home options, and information on Alzheimer's disease, including how to manage difficult behaviors. The ministry also has a weekly yoga class open to all caregivers and volunteers. Caregivers are also welcome to attend sessions, lunch, and church services with participants.

3.3.2 Identifying Community Needs and Outreach

The Church's Senior Pastor actively works to recruit people from the community into the respite program and communicates with other denominations for outreach. Community trust in the church helps enrollment and fosters goodwill toward the project within the congregation. Volunteers and families build awareness of the program through word of mouth, which has increased understanding and acceptance of Alzheimer's disease and dementia within the congregation and aided in the growth of the program. To raise the public profile of The Respite Ministry, a professional video was made and can be shown to caregivers interested in the program, other congregations, and at various caregiver and professional conferences.

3.3.3 Project Successes/Challenges

The Respite Ministry's positive environment entices participants, who may be socially isolated, to attend the program, and to establish a routine. Caregivers report that The Respite Ministry has made respite care affordable, and they believe the program allows them to keep loved ones at home longer.

A major challenge of The Respite Ministry is convincing caregivers to accept help. Often caregivers ask their family member with dementia if he or she wants to attend the program, and the person declines. In an effort to overcome this challenge, the Respite Ministry asks local neurologists for referrals to the program. The Respite Ministry also collaborates with a nurse practitioner who writes a "prescription" for program attendance, which often makes both the person with dementia and the family caregiver more accepting of the program.

Another challenge is that the program does not provide transportation but does have a bus available for program use. Many variables associated with provision of transportation, including

hiring and training a driver, arranging for volunteer bus monitors, and establishing a travel route, have proven difficult to overcome.

The Respite Ministry does not formally assess program outcomes, but the University of Alabama at Birmingham's Memory Center has plans to measure the impact of its volunteer model on participants. The success of The Respite Ministry within the greater community became a catalyst for other Alabama communities to start their own similar programs, including the First Methodist in Dozent, Canterbury in Birmingham, Jewish Services in Birmingham, and Auburn United Methodist in Auburn.

3.3.4 Lessons Learned and Advice for Future Faith-Based Projects

The director of The Respite Ministry noted that faith communities already have many of the resources needed for day services and support groups, including availability of facilities, financial stability, and a wealth of available volunteers. The Respite Ministry is not expensive to operate because it is run largely by volunteers; it is sponsored by the church, and there are no expenses other than food and the salaries of the director and one assistant. To replicate this work, a community could develop a program that has a smaller or larger scope than The Respite Ministry. Most congregations in other locations have access to members who can volunteer in a respite program. The program director explained "People can't imagine an Alzheimer's ministry being happy, but there's humor and joy...in a ministry like that. Everybody just feeds off each other. I've got volunteers who have never volunteered a day in their life, and now they are addicted to this and come all of the time. They just feel so needed."

3.3.5 Products That Other Organizations Might Use

- Job Description, Respite Director
- Consent Form
- Field Trip Form
- Medical Form
- Policy & Procedure Manual
- Start-Up Checklist

Products may be requested by contacting Patty Yuen at pyuen@rti.org.

Additional information on The Respite Ministry can be found at <http://www.fumcmontgomery.org/respite/>

3.4 Twin Cities Jewish Community Alzheimer's Task Force

3.4.1 Project Background, Description, and Major Activities

Founded in 2007, the Twin Cities Jewish Community Alzheimer's Task Force (Task Force) is sponsored by Jewish Family and Children's Service of Minneapolis. The mission of the Task Force is to help Jewish agencies, organizations, and synagogues provide education, support, and programming regarding memory loss for the Jewish community. The Task Force works to raise awareness and reduce stigma associated with Alzheimer's disease and dementia and focuses its work on how, as a faith community, it can educate families on available resources and on the importance of getting an accurate and thorough diagnosis of dementia. A staff person employed by Jewish Family and Children's Service of Minneapolis leads the Task Force and is aided by volunteer members of the community who are responsible for a number of tasks, including providing guidance on developing activities related to Alzheimer's disease and helping to find financial resources. Professional staff and a group of approximately 25 volunteers run the Task Force programs.

As many as 25 congregations, with between 30 and 1,500 families per congregation, have participated in Task Force programs. For those who are unable to attend, Task Force members provide video recordings and related documents. The Task Force operates its programs with grant funds received from Act on Alzheimer's[®], private donations, and funds from Jewish Family and Children's Service of Minneapolis. Other community organizations provide support through outreach or participation in the Task Force programs, including the Minnesota Rabbinic Association, Jewish Family Services of St. Paul, Shalom Community Alliance, and local Jewish community centers.

The lead staff person for the Task Force explained that conducting programming related to dementia through a faith-related community is different than running the program through another entity such as local government. For example, local government program staff may not be as connected with personal concerns of program participants as their faith-related community. In faith-related communities people often turn to clergy for guidance when they are in need of advice and they trust the clergy to keep personal information private.

Since its inception, the Task Force has conducted many activities, all of which take place in Jewish settings, such as congregations or Jewish community service agencies. For example, two area synagogues hosted a film series with movies about dementia and family relationships. In 2013, the Task Force worked with the Act on Alzheimer's[®] initiative, a statewide collaboration in Minnesota to prepare the state for the multiple effects of Alzheimer's disease and related dementias on the population, helping to test and revise its tools. Act on Alzheimer's[®] tools are designed to assist providers in treating and managing care for people with dementia and supporting caregivers, as well as guiding communities in their efforts to become dementia friendly.

Recent activities of the Task Force include Dementia Friends, teen, and rabbi training; a caregiver conference; and a film series.

- **Dementia Friends Training**—The Task Force developed the Dementia Friends training, which educates the Jewish community about dementia. There are about 25 Dementia Friends trainers. Typically, the trainer is a member of the congregation where the session is located, which helps to increase attendance and gain support from the congregation’s clergy.
- **Teen Training**—Teen Training is an adaptation of the Dementia Friends training designed to teach teenagers about Alzheimer’s disease and dementia. The sessions occur during religious school at Jewish congregations for teens about 16 years old. Topics include how to support a parent who is a caregiver for someone with dementia and how to have conversations with people with dementia, who in some cases will be the teens’ grandparents.
- **Rabbi Training**—In 2015, the Task Force conducted a training for rabbis, which included a panel of caregivers of people with dementia. The Task Force worked with the chairperson of the Minnesota Rabbinical Association to schedule the training during one of the Association’s regular meetings. On an ongoing basis, the Task Force distributes bookmarks with resources for people with dementia and their caregivers and the Alzheimer’s Association’s 10 Warning Signs.
- **Caregiver Conference**—The mission of the caregiver conference is to provide a Jewish perspective to caregiving for family members of people with dementia, lay leaders, rabbis, and professionals. Information at the conference is presented through vignettes on practical approaches for caregiving, tactics for taking care of the caregiver, and current research about dementia. In May 2015, the first caregiver conference used a video of caregiver vignettes as a learning tool (“Keeping the Spirit Alive,” 2015). There were 325 attendees at the first caregiver conference, most of whom were family caregivers. The next caregiver conference is scheduled for spring of 2017.
- **Film Series**—In both 2015 and 2016, the Task Force hosted a series of three films attended by about 150 individuals. Each of the sessions included a short overview of dementia basics and available community resources, an introduction to the film with a “Hollywood reality check” where a dementia care specialist discussed medical inaccuracies portrayed in the film, the film viewing, and a facilitated discussion. The mission of the film series was to raise awareness and reduce the stigma of Alzheimer’s disease and related dementias and to bring the community together to show support within the faith community. After the first film series in 2015, the Task Force created a replication guide for developing and conducting the program.

To be eligible to conduct any of the aforementioned trainings, community volunteers took the online Act on Alzheimer’s[®] training, completed additional training with one of the staff members involved in the project, and observed educational sessions before conducting any sessions on their own.

3.4.2 Identifying Community Needs and Outreach

The Task Force conducted surveys of those in the Jewish community to determine their needs related to Alzheimer's disease and dementia. Members also met with clergy, education directors and executive directors of synagogues, and others to evaluate the information gathered and develop a workplan to address identified needs.

To evaluate the programs, the Task Force conducted surveys after events asking about the usefulness of the program and whether attendees' dementia knowledge improved. In particular, the programs received high ratings in the usefulness category.

Outreach techniques differ depending on the activity. Little outreach was needed for the teen training because the students were already attending the religious school where they received their training. Outreach for the film series required extensive outreach. Although one congregation hosted the film series, the Task Force partnered with eight congregations to publicize the events, including through the electronic newsletter of the host congregation. For the caregiver conference, the Task Force marketed the event for about a year. Publicity for the conference included sending invitations, placing newspaper advertisements and articles written by caregivers, and posting the registration information on websites of various Jewish organizations. Some rabbis in the community also mentioned the event in their sermons during important Jewish holidays.

3.4.3 Project Successes/Challenges

Challenges included providing transportation and respite care so that people could attend events. The Task Force continues to experience challenges in reaching the Jewish community that is unaffiliated with a congregation. Although they have started conducting Dementia Friends training in some of the Jewish Russian communities, the Task Force has not determined a way to reach other underserved populations through this program.

Securing funding for the Task Force is a challenge. The Task Force received a grant from Act on Alzheimer's[®] and funds from private donors and other agencies. The sponsoring agency, Jewish Family and Children's Service of Minneapolis provided additional funding to help sustain the program.

3.4.4 Lessons Learned and Advice for Future Faith-Based Projects

A well-respected community organization and dedicated volunteers with an interest in the cause were critical to program implementation. As a religiously defined activity, the support of the community's clergy was crucial. A key to success is determining program features that are aligned with the community's needs through a survey or other mechanism. Both the outreach collaboration between the Task Force and local Jewish organizations that publicized events and the involvement of clergy in getting the information to the congregation contribute to the program participation levels.

3.4.5 Products That Other Organizations Might Use

- Alzheimer's Disease Task Force Job Description

- Film Series Replication Guide
- Bookmark on 10 Early Detection Signs and Local Resources

Products may be requested by contacting Patty Yuen at pyuen@rti.org.

3.5 United Methodist Church Discipleship Ministries Office of Aging and Older Adult Ministries

3.5.1 Project Background, Description, and Major Activities

For the last 25 years, the Office of Aging and Older Adult Ministries of the United Methodist Church Discipleship Ministries has assisted church leaders across the United States in their work with the aging population, including how best to serve people with dementia and their families. More broadly, the Discipleship Ministries is an agency of the United Methodist Church and “connects leaders with needed resourcing, training, consulting, and networking that support spiritual formation...” (United Methodist Church, 2016a). Although the Office of Aging and Older Adult Ministries serves Methodist clergy and congregants throughout the United States, requests for dementia program assistance primarily come from areas that are located in the southeastern part of the United States. The major source of funding for this work comes from World Service dollars, which is a portion of the funds collected by Methodist churches through weekly offerings.

The focus on older adults developed because of a concern that Methodist Churches could not meet the needs of aging congregants. In response, the Discipleship Ministries set up a resource center that provides information on aging issues for the entire church community. Discipleship Ministries receives many requests for information on dementia, and a key issue is addressing the view that people with cognitive impairment have fewer spiritual needs. The Discipleship Ministries works to provide meaning in life and assists caregivers in coping with their grief and loss.

Some of the dementia-related projects of the Office of Aging and Older Adult Ministries include webinars, workshops, and written materials, and a video series is in development. The director of the Office of Aging and Older Adult Ministries, who is a trained hospice chaplain and also has experience working in a parish church, is primarily responsible for the development and delivery of these programs.

- Webinars—Discipleship Ministries conducted three webinars specific to Alzheimer’s disease and dementia. Webinar topics include types of dementia and current research, how to approach communication in the different stages of Alzheimer’s disease, and spiritual opportunities for churches to engage people with dementia and their families, such as special worship services or support groups. A webinar in development will focus on church-based respite care programs, some of which may focus on caring for people with dementia. The webinars, with typically 100 registrants, are free and Discipleship Ministries posts the recordings on its website.

- **Workshops**—In most instances, individual churches provide workshops at clergy breakfasts, church dinners, or community events, and occasionally the director gives presentations at larger events such as the Festival of Wisdom and Grace in North Carolina. Workshops are varied and topics addressed include how the church can respond to members with dementia and their caregivers, the importance of respite care, education on brain health, pastoral care, and caregiver support. In particular, the workshop on how churches can respond to members with dementia includes information about Alzheimer’s disease and dementia such as prevalence of the disease, various types of dementia, and effects on caregivers. In addition, the workshop focuses on spiritual care opportunities for churches including suggestions for worship. A goal of the workshops is for individual church leaders and clergy to take information back to their communities and use it as needed.
- **Written Materials**—The Discipleship Ministries produces newsletter articles on a number of topics including respite services, memory cafes, and caregiver support. The fall 2015 issue of Discipleship Ministries’ Spiritually Aging Gracefully Empowered newsletter was dedicated to caregiver support and featured a number of articles about dementia. The director also contributes articles for other newsletters in different agencies of the church.
- **Video Series**—A video series on dementia is in development and is being created in partnership with 12 people who are involved in direct services for people with dementia. Included in the video series will be spiritual and worship resources for people with dementia. A companion guide will be published to accompany the video series.

3.5.2 Identifying Community Needs and Outreach

The Office of Aging and Older Adult Ministries did not conduct a formal needs assessment or survey to determine the specific needs of clergy around the topics of dementia and caregiving. Rather, the director used his experience as a member of the clergy to design the program. To assist in determining the areas of highest need, the director monitors and logs requests for information from individual churches and examined the results of a few community surveys conducted by others.

To reach as many people as possible with workshops and webinars, the director typically promotes sessions through print and web-based methods and in-person interaction. The director advertises workshops through social media and discussions with leaders and staff of individual churches. To further publicize workshops and webinars, the director sends newsletters and e-mail notifications to 8,000 people who participated in Discipleship Ministries programs in the past.

Implementation of clergy workshops has shown that it is not uncommon for the clergy’s personal fear of their own aging and possible memory loss and their discomfort visiting congregants with dementia to hinder participation. In an effort to recruit more clergy participants, the director is planning to adjust the language used in program descriptions to appeal to the clergy and alleviate some of their fears.

Beyond the formal programming of the Office of Aging and Older Adult Ministries, the director makes additional resources available to clergy and families. When requested, the director offers one-on-one consultation for clergy. Topics covered in the one-on-one consultation include, but are not limited to, how to:

- support congregants dealing with dementia in their families,
- provide pastoral care to people with dementia,
- respond to behavioral symptoms of congregants with dementia, and
- address communal grief as a congregation sees a member of the church affected by dementia.

The director also recommends pastoral care books and videos and provides handouts related to the needs expressed by clergy members. When families approach the Office of Aging and Older Adult Ministries with concerns related to dementia, the director sends them articles, books, or videos on various aspects of dementia. He also recommends that they contact their local Area Agency on Aging for a list of available local services.

3.5.3 Project Successes/Challenges

Two projects in particular have furthered the goals of the Office of Aging and Older Adult Ministries. The first is an article titled *The Dementia Friendly Church*, posted on the Discipleship Ministries website which generated interest from many churches (United Methodist Church, 2016b). In response to inquiries, he was able to provide a list of questions to help churches determine if they are dementia friendly. The questions focused on a number of areas, including assessing the physical safety of the church, simplifying activities, and providing needed supports for people with memory loss. The second effort was workshops held at the Festival of Wisdom and Grace. These workshops resulted in a number of people contacting the director afterward seeking additional resources related to dementia. The Office of Aging and Older Adult Ministries suggests that stigma associated with dementia may keep people from attending programs and, as such, stigma reduction efforts merit inclusion in all aspects of their programs.

3.5.4 Lessons Learned and Advice for Future Faith-Based Projects

Through the years, the Office of Aging and Older Adult Ministries learned a number of lessons related to dementia programming. Clergy attending these dementia programs like concrete information as opposed to theory-based sessions. Faith communities are built around relationships, so a large portion of the Office of Aging and Older Adult Ministries' work is focused on how to manage family dynamics through the course of dementia. Much of the education provided to the clergy focuses on the church playing a role in alleviating the stress of family caregiving and reassuring family caregivers and people with dementia that they are valued members of the community. Another essential component of this work is educating clergy about the process of grieving before and after a person dies from Alzheimer's disease or another form of dementia.

3.5.5 Products That Other Organizations Might Use

- Dementia Care for Churches Webinar Slides
- The Dementia Friendly Church Article

Products may be requested by contacting Patty Yuen at pyuen@rti.org.

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SECTION 4 CONCLUSION

The organizations sponsoring these five programs recognized the need for dementia programming in their communities, either to directly assist people with dementia and their caregivers or to educate clergy and the community. Based on these varying needs, the programs were developed and are being implemented differently. Three of the programs are faith based in that they were initiated by faith-affiliated organizations, and the remaining two were initiated by secular organizations. The programs distinguish themselves by including faith-related components in their work with people with dementia, their caregivers, clergy, and the community.

Through these programs, each sponsoring entity expanded on existing relationships and developed new relationships with other faith communities and in some cases the general community. In working with others in their communities, the programs often received assistance by way of volunteers, use of space, funding, and other resources. Some of the interviewees suggested that including faith-related components in their programs or operating from a faith-based organization was a benefit in that they were already a trusted resource that people turned to for assistance. The work of the five programs profiled in this report, along with the assistance they received from others, demonstrates the dedication to addressing some of the needs of people with dementia, their caregivers, the community, and clergy.

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