ACT on Alzheimer’s Community:

Latino Collaborative

Report on Activities & Progress
June 30, 2015

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Executive Summary

The Latino Collaborative ACT on Alzheimer’s® community is located in Minneapolis and is one of 34 ACTion communities using the guided community engagement process and the ACT on Alzheimer’s Dementia Capable Communities Toolkit.

This report describes the progress made by the Latino Collaborative ACTion team, from early 2014 through June 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 implementation of its priority action items as part of its’ “action” (Phase 4).

The lead agency for this effort is Centro Tyrone Guzman. The ACTion team includes representatives from other key local community organizations and agencies, including Legacy Spanish Adult Day Care, and Amigos del Mercado. The ACTion Team (7-10 members) began meeting in July 2014 and held two community information/education events (one in Spanish and one in English) in the fall of 2014.

The MAAA provided valuable technical assistance and support, as did some other organizations (e.g., Alzheimer’s Association and Fairview Southdale) and other ACTion teams (e.g., St. Paul). The ACT on Alzheimer’s website with its videos and resources supporting use of the Toolkit were instrumental in facilitating the process effectively.

The ACTion team carried out the community assessment and engagement process in December and January, interviewing community members and representatives from local organizations, focusing particularly on social service agencies, health care and community member input. There were 117 surveys completed.

The results from the analysis of those surveys pointed to two key priorities: 1) Awareness, and 2) Information and Education. The ACTion team identified several objectives and activities that aligned with those priorities, and wrote a 3-year Action Plan for their Phase 4 work.

The key ACTion team members from Centro Tyrone Guzman and two other active team members described their accomplishments, challenges and lessons learned from this effort. One challenge was with the surveys within the Toolkit. The wording, length, and structure of the questions and the responses proved unwieldy and made the interviews difficult to conduct.

This ACTion team is proud of the great work that has been accomplished in less than one year and sees tangible results in their community.
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 the Communities Leadership Groups (one of 5 Leadership Groups of ACT) and members from four pilot ACTion communities.

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. **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 are defined within the Toolkit, beginning with Awareness (see flowchart Figure 1).

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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 additional Minnesota communities to conduct 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 found on the website (http://www.actonalz.org/minnesota-communities).

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).


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

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Members of the Health Equity Leadership Group work to “embed a set of principles and values” including embracing the richness of cultural diversity and reducing health disparities into the “operational lens of all ACT on Alzheimer’s work” (See ACT on Alzheimer’s website at: www.actonalz.org/sites/default/files/.../HEidentity-purpose-082714.docx)

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.

Latinos in Minnesota

According to a 2014 report by Minnesota Compass on demographic trends in Minnesota, the number of individuals of Hispanic/Latino descent has been growing. An increasing number are children and native born—as families have settled and grown. Most of the Hispanic/Latino households are in the Twin Cities:

The number of Hispanic children in Minnesota has quintupled since 1990, and Hispanic children now comprise 8 percent of Minnesota’s under 18 population. The median age of Hispanic residents is 24 compared to 38 for Minnesota overall. Sixty-two percent of Minnesota’s Hispanic residents are native born and 91 percent of Hispanic children under age 18 are native born. About half of native-born Hispanic children have parents who are immigrants.

The Twin Cities region is home to nearly 180,000 Hispanics . . . the highest proportion of Hispanics live in southern and central Minnesota, drawn by employment opportunities in farming, processing, and manufacturing plants.

4 Source: www.ACTonAlz.org accessed on December 20, 2013.
Hispanics/Latinos are one of the fastest-growing racial/ethnic groups in the United States—with a population of 54 million Latinos in 2013 and a growth rate of 2.1% per year.\(^5\) Is there a breakdown by age of Latinos?

**Alzheimer's Disease and Dementia in Latinos**

The Alzheimer's Association notes that “Hispanics/Latinos face a higher risk of Alzheimer's disease and other dementias because (like the general population of the United States) they are living longer but have higher rate of cardiovascular risk factors.” The Alzheimer's Association also notes that other conditions, such as diabetes, high blood pressure and high cholesterol may also be risk factors for Alzheimer's disease and stroke-related dementia. Since Latinos in the U.S. have a higher incidence of diabetes, this puts them at greater risk.\(^6\)


Latino Collaborative ACTion Community

Introduction
The Latino Collaborative ACT on Alzheimer’s® community located in Minneapolis 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 by the Latino Collaborative ACTion team from July 2014 through June 2015. In that time, this ACTion team completed the “convening” phase (Phase 1), the “assessment” phase (Phase 2), and the “analysis” (Phase 3) of that work and began implementation of its priority action items as part of its’ “action” (Phase 4).

Data sources included:
- Key informant interviews (conducted in April and May, 2015)
- Meeting notes and progress reports
- Assessment survey data
- The ACT on Alzheimer’s® website (www.ACTonAlz.org)
- Centro Tyrone Guzman website
- U.S. Census Bureau
- Alzheimer’s Association national website

The shaded boxes provide direct quotes from various team members from the lead organization and ACTion team members who have been highly engaged in the process.

Community Profile
According to U.S. Census Bureau data, people of Hispanic/Latino descent comprise approximately 4.9% of Minnesota’s population, and 10.5% of Minneapolis’ population, as compared to 16.3% for the nation. People age 65 and over make up 8% of Minneapolis population compared to 13.9% for the state and 13% for the nation.

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Looking further at specific neighborhoods in Minneapolis—those in and around Centro Tyrone Guzman—we see that in Minneapolis’ zip code area 55404 (where Centro Tyrone Guzman is located), and adjacent area 55407, the Hispanic/Latino population is significantly higher than the state average. 
Looking at demographic and income data from five zip code areas in the central part of Minneapolis where Centro Tyrone Guzman is located, we see that the communities are more ethnically diverse and proportionately younger than Minnesota as a state (see Tables 1 and 2). 

Figure 4. Map of the City of Minneapolis. Source: www.
https://www.google.com/search?q=map+of+the+city+of+minneapolis&biw=1273&bih=723&tbn=isch&imgil=toy2AAf3tbOM%253A%253BKnZ88TzQs6DYFM%253Bhttp%25253A%25252F%25252Fwww.minnpost.com%25252Ftwo-
Profile of Latino Collaborative ACT on Alzheimer’s Community based on five zip code areas\(^7\)

### Table 1. Area Neighborhood Profile: Ethnicity, Age

<table>
<thead>
<tr>
<th>Zip Code</th>
<th>55404</th>
<th>55403</th>
<th>55407</th>
<th>55415</th>
<th>55454</th>
<th>Minnesota</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Size (estimated from 2010 U.S. Census)</td>
<td>27,121</td>
<td>14,985</td>
<td>37,881</td>
<td>2,604</td>
<td>8,125</td>
<td>5,457,173</td>
</tr>
<tr>
<td>% Hispanic/Latino</td>
<td>3,967 (14.6%)</td>
<td>698 (4.7%)</td>
<td>10,542 (27.8%)</td>
<td>129 (5.0%)</td>
<td>279 (3.4%)</td>
<td>270,545 (4.9%)</td>
</tr>
<tr>
<td>% Foreign born</td>
<td>25.7%</td>
<td>10.7%</td>
<td>20.5%</td>
<td>11.5%</td>
<td>44.8%</td>
<td>7.3%</td>
</tr>
<tr>
<td>% Age 65+</td>
<td>7.6%</td>
<td>7.6%</td>
<td>6.0%</td>
<td>3.0%</td>
<td>8.0%</td>
<td>13.9%</td>
</tr>
<tr>
<td>Median resident age</td>
<td>28.9 years</td>
<td>33.5 years</td>
<td>30.9 years</td>
<td>30.4 years</td>
<td>22.2 years</td>
<td>37.6 years</td>
</tr>
<tr>
<td>% residents speak English at home</td>
<td>67.1%</td>
<td>87.2%</td>
<td>70.5%</td>
<td>83.8%</td>
<td>48.2%</td>
<td>--</td>
</tr>
<tr>
<td>% residents speak Spanish at home</td>
<td>9.8%</td>
<td>3.5%</td>
<td>21.2%</td>
<td>5.1%</td>
<td>6.0%</td>
<td>--</td>
</tr>
</tbody>
</table>

### Table 2. Area Neighborhood Profile: Households, Income

<table>
<thead>
<tr>
<th>Zip Code</th>
<th>55404</th>
<th>55403</th>
<th>55407</th>
<th>55415</th>
<th>55454</th>
<th>Minnesota</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median Household Income</td>
<td>$22,846</td>
<td>$38,564</td>
<td>$45,540</td>
<td>$44,531</td>
<td>$13,539</td>
<td>$56,954</td>
</tr>
<tr>
<td># Households</td>
<td>24,065</td>
<td>13,849</td>
<td>37,179</td>
<td>1,577</td>
<td>6,174</td>
<td>---</td>
</tr>
<tr>
<td>% Below poverty level</td>
<td>42.5%</td>
<td>20.6%</td>
<td>23.1%</td>
<td>29.7%</td>
<td>57.2%</td>
<td>11.9%</td>
</tr>
</tbody>
</table>

\(^7\) Source: [www.city-data.com](http://www.city-data.com) (uses 2010 Census Bureau data) and [http://factfinder.census.gov](http://factfinder.census.gov); accessed June 1, 2015.
Estimating the number of people with Alzheimer’s Disease

A methodology is provided in the *ACT on Alzheimer’s Dementia Capable Community Toolkit* to estimate the number of people with Alzheimer’s disease (see box below).

As explained, it is difficult to determine the exact boundaries (zip code areas) to determine a “defined population” for the Latino community—as it is an affinity community, not one defined by geographic boundaries. For purposes of estimating a local region, we chose a geographic area including and surrounding Centro Tyrone Guzman using zip code areas as shown previously: 55404, 55403, 55407, 55415, and 55454. The total resident population of this area is 90,716. The number of people age 65 and over is 6,201. The total Latino population (all ages) living in these same zip code areas is 15,615. The number of Hispanic/Latino residents age 65 and older is 1,013.

Using the figures for the entire older resident population, the estimated number of individuals with Alzheimer’s disease living in this immediate area is estimated to be about 689 individuals (calculated as shown below). The estimate for only the Hispanic/Latino resident population is estimated to be 113 living with Alzheimer’s disease. This is likely a low estimate, as we know the incidence of the disease in Latinos is higher than in the general population.

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**Calculating the number of people who are living with Alzheimer’s disease:**

Estimate your population over the age of 65 years. For this defined zip code area, there are 6,201 residents age 65+.

Divide by 9 to estimate the number of people with Alzheimer’s and related dementias. For all residents in these 5 zip code areas = 6,201 ÷ 9 = 689 people with Alzheimer’s.

Looking solely at the Hispanic/Latino residents in these zip code areas, the estimated number of Hispanic/Latino persons with Alzheimer’s is: 1,013 (persons age 65+) ÷ 9 = 113.*

*NOTE: The incidence of the disease in Hispanics/Latinos is higher than for the general population. Therefore this estimated figure of the number of people living with Alzheimer’s disease is likely to be lower than actual.

1 in 7 people who have Alzheimer’s live alone. The population of persons living with AD in this geographic area is estimated to be: 689 ÷ 7 = 98 people living alone.

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Figure 5: Formula to Calculate Number of Persons with Alzheimer’s Disease in Latino Collaborative geographic area.
Source: Formula provided in *ACT on Alzheimer’s Dementia Capable Community Toolkit* for estimating population with Alzheimer’s disease
**Groundwork & Convening**

The lead agency for the Latino ACTion community is Centro Tyrone Guzman.

Centro Tyrone Guzman has a strong history and well-developed programs for the Latino community. They particularly reach out to recent immigrants who are learning English and the social services and health care systems. Centro Tyrone Guzman helps with enhancing basic reading skills and working toward literacy.

According to Centro Tyrone Guzman’s website, it is a multi-social service agency and serves the community as “a partnership with Latino and Chicano families.” It provides education, wellness, mental health, youth and senior programs, maternal & child health, community events, and has a food shelf (Appendix A). The website reads:

*Centro Tyrone Guzman is a place where we offer respite from troubles, understanding to solve crises, education and encouragement to make change, nurturing and healing to strengthen families, art and culture to reaffirm our identity and value, and resources to build a better future.*

The mission of the organization is: *To contribute to the well-being and full participation of Latin@s through education and family engagement.* (See: [http://www.centromn.org/](http://www.centromn.org/)).

Groundwork to create the Latino Collaborative ACTion community began through efforts of a few individuals. A Spanish-speaking member of the ACT on Alzheimer’s Health Equity Leadership Group (Lili Ugaz) first initiated development. Lili, Program Manager of the Spanish language adult day care (Legacy), contacted Roxana Linares, Executive Director at Centro Tyrone Guzman.

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*I [Lili] was in the Health Equity Leadership Group. I wanted something for the Latino community—but I’m from a small organization and could not take on the lead role. I contacted Roxana at Centro as they have a broad set of services and many more employees. I thought: “Let me see if Roxana will get involved.” We realized we could do this together. We got together (Yoli too) and did the footwork.*
Lili and Roxana then reached out to individuals in their professional and personal networks, and to organizations that are visible in the community as resources to Hispanic residents. They emphasized the importance of bringing awareness about this disease to the community and helping to develop additional culturally-appropriate and Spanish-language resources about the disease and about caregivers (families) dealing with the disease.

We asked some organizations to partner with us and they accepted because they know that this is a huge need in the community.

The core team of individual staff members from Centro Tyrone Guzman were involved:

1. Roxana Linares, Executive Director
2. Sandra Reyes, Wise Elders Coordinator
3. Susana Rodriguez, Wise Elders Assistant Coordinator
4. Yolima Chambers, Assistant Administrator (Latino Collaborative Project Coordinator)

The other core ACTion team members were:

5. Betty Grant – Co-Leader, Amigos del Mercado
6. Azalea Henao - Co-Leader, Amigos del Mercado
7. Lili Ugaz, Program Manager, Legacy Adult Day Care
8. Melissa Schebloom, MSW, LicSW, Clinical Social Worker, Community Member

Most of the people on the ACTion team were there because Roxana asked them to be involved. She and Yoli are the driving force. Yoli especially was a key person as she is very capable and did a lot of the work.

The Assistant Administrator of Centro Tyrone Guzman, Yoli Chambers, has served as the ACTion community’s Project Coordinator.

In addition, Leanna Smith, Manager at the Metropolitan Area Agency on Aging, attended each team meeting to provide technical assistance, support and guidance. The Educational Manager from the Alzheimer’s Association, Debbie Richman, also provided educational materials and offered to assist in the search for materials written in Spanish.
This core group of individuals began working together as an ACTion community in July 2014. The ACTion team (8 individuals) met in July, August and September to develop their approach. The ACTion Team discussed the importance of this disease in their community and of getting the word out.

We had all the meetings here at Centro. We tried to send an agenda ahead of time. Between meetings we maintain communication through emails. One thing that was difficult was finding time to meet.

No one knows or talks very much about it [dementia]. In Spanish the word translates to “crazy.” There is a lot of stigma and many misconceptions about this disease.

It is important, since we, as Latinos, are more likely to develop Alzheimer’s than other races.

They also discovered that there are not many resources for Spanish-speakers about the disease, especially regarding local supports.

There are many resources in English but few resources in Spanish for Latino people who have Alzheimer’s and their caregivers. We need to support our community and provide resources. We need to increase the level of awareness but also provide resources where they can find support.

Kick-off
The Latino Collaborative had two community-wide kick-off events, one in English (October 23, 2014, with 44 participants) and one in Spanish (November 15, 2014, with 74 participants). See Appendix B for the event fliers.

We created a flier and sent it to different organizations that we partner with. Also, we posted it in our Facebook page and gave it to all our participants. Then some of staff and volunteers made phone calls explaining the event and reminding individuals to come.
At both events, the ACTion Team members introduced themselves and explained the ACT on Alzheimer’s initiative in brief, and the Latino Collaborative as a local effort to reach Hispanic/Latino residents in the area.

Two physicians were invited and presented information about the disease. The content included:

- What is Alzheimer’s disease
- The difference between Alzheimer’s disease and normal aging
- Other types of dementia
- What treatment is available to slow the process (for some patients)
- Actions that Alzheimer’s patients and families/caregivers can take after receiving a diagnosis
- The importance of maintaining a healthy diet and exercise, socialization and brain health
- Testimonials from clients with Alzheimer’s disease and their caregivers.

Following the formal presentations, the ACTion Team facilitated a Question & Answer session. Team members noted that many participants had heard about dementia and Alzheimer’s disease but did not know much about this. Team members also discovered that the Latino residents/family members of the person with Alzheimer’s disease found it difficult to discuss the diagnosis and struggled with what next steps they should take. The ACTion team distributed evaluation forms for both sessions. Results from the first (English-speaking) event show that participants valued the content. Participants rate the event as Excellent (78%) or Very Good (22%). Half of the respondents said that their awareness of Alzheimer’s disease/Dementia and the impact on the Latino community had increased a lot (Appendix C).
As a result of the Kick-off events, more individuals came forward to join the Latino Collaborative ACTion Team, including:

- Jesus Villaseñor, Parent Advocate, and staff member of PACER (Parent Advocacy Coalition for Educational Rights)
- Ana Diaz, Community member and clinician with long history of helping to address Alzheimer’s patients needs in the Spanish-speaking community
- Francisco Ramirez, Community Health Worker, Fairview Southdale Hospital

> When we started talking about this, we were surprised by the strong need and desire in the community for more information about Alzheimer’s disease and other dementias.

> It is amazing to see the interest that the community has! So far everyone wants to learn more in order to support our community.

**Technical Support & Resources**

Leanna Smith from the Metropolitan Area Agency on Aging (MAAA) provided invaluable technical support throughout the process—the value of her participation and assistance was mentioned by several of the key informants. Leanna participated in monthly meeting discussions of the ACTion Team for the Latino Collaborative, attended their community events, walked the Team through the components of the ACT community engagement process, provided an orientation on the Toolkit and analysis methods, served as a channel to ACT on Alzheimer’s resources and additional tools, and offered one-on-one guidance to the Coordinator if/when requested.

> Leanna Smith was amazing. She was always there. She showed up and gave us amazing support. She gave incredible advice.

> Leanna Smith from MAAA is a wonderful person and resource. She supported us a lot through this process. She explained the process to us and provided us different materials that helped us a lot. Her input was invaluable!

In addition to the support and guidance provided by Leanna Smith from Metropolitan Area Agency on Aging, other key supports were important in providing assistance and information. These included: the Coordinator from the St. Paul Neighborhoods Action Community Team, and team members from the Edina ACTion team—particular individuals from Fairview Southdale Hospital (Community Health).
Assessing
The ACTion team members reviewed the Dementia Capability Toolkit and the surveys (assessments). The Toolkit provides resources, guides, scripts, tips, and other materials corresponding to the four phases of work:

![Diagram of the four phases of work: Convene, Assess, Analyze, ACT Together.]

Surveys
The Toolkit has 13 sector surveys\(^8\) which vary in content (that is, the survey has questions specific to that sector)—but have a common format. See Figure 6.

![Figure 6. Toolkit Sectors and Codes]

The ACT on Alzheimer’s manager/lead for the ACTion communities had arranged to have all of the sector surveys of the Toolkit translated into Spanish. This was done prior

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\(^8\) Note that The Dementia Capable Community Toolkit had been piloted with communities that did not match the ethnic/racial composition of the Latino community.
to the Latino Collaborative team members interviewing members of their Spanish-speaking community.

[The Toolkit] had all the information that we needed to conduct this process. It explained every single step in a very clear way through videos and other documents.

Leanna coached these team members on how to present basic facts about Alzheimer’s disease and about conducting interviews in the community, using the question sets and the Toolkit guided process.

In each survey, questions ask about the current level of activity on a specific issue or function or resource, and then ask the interviewee about his/her opinion whether than issue/function/resource should be a priority for action (Table 3.)

<table>
<thead>
<tr>
<th>Level of Current Activity</th>
<th>Priority for Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Strongly disagree</td>
<td>1. Strongly disagree</td>
</tr>
<tr>
<td>2. Disagree</td>
<td>2. Disagree</td>
</tr>
<tr>
<td>3. Neither agree or disagree</td>
<td>3. Neither agree or disagree</td>
</tr>
<tr>
<td>4. Agree</td>
<td>4. Agree</td>
</tr>
<tr>
<td>5. Strongly agree</td>
<td>5. Strongly agree</td>
</tr>
<tr>
<td>0. Do not know</td>
<td>0. Do not know</td>
</tr>
</tbody>
</table>

The team set about learning about how to facilitate the community engagement process that is outlined in the Toolkit, including how to reach out to community members and those working in the various sectors, and how to conduct face-to-face interviews.

The ACTion team split up the work among themselves.

Each of our ACTion team members created a list with all their possible contacts who could complete the survey. Our goal was to reach three sectors: health care, social services, and community members.
Two team members worked on reaching out to the health care sector, four reached out to community members, and Centro Tyrone Guzman worked on the social service agencies.

To reach community members, Centro Tyrone Guzman staff asked people who walked through the door (particularly for senior programs) if they would participate in the interview.

While the guided community engagement process that is laid out in the Toolkit was very helpful to the team members, the language and length of the surveys/assessments within the Toolkit proved difficult for this community to work with.

The language and wording was definitely a huge challenge for us. We are so happy that ACT on Alzheimer's translated this document for us -- but it was still hard to understand the wording.

The experience of this ACTion team was that the survey questions were too detailed, there were too many of them, and they assumed that the interviewee had knowledge they did not have. Several of these key informants described the challenges with the surveys as they were written.

Yes, we did use the surveys. We received different comments about the open questions. Some people said “my answers were the same as the ones before”.

In each survey interview that we did, we needed to explain each question in a very deep way, giving examples (especially with the community) because it was hard [for them] to understand. Also, the part when people needed to indicate their “level of agreement” for each question—this was difficult.

It is really hard to know the difference between “very low” and “low” or “strongly disagree” and “disagree.”
The team member interviewing members of the business community voiced problems with the length of the survey questions in particular.

For example, I did the business sector surveys—I had maybe 5-8 minutes. For someone who is busy and at their place of business, these long survey questions were too detailed. I didn’t end up using them. I did more of an open-ended conversation.

The detail was too much. There was a question: Does your community know anything about Alzheimer’s Disease? They would answer: “No.” Should it? “Yeah, we should do something.” But that was about as far as it could go.

A team member noted that the survey questions assumed some knowledge about the disease, aging, caregiving—and these assumptions did not match the community.

It’s one thing if you are interviewing a group of people who are very involved with elders—but these folks were not—many said they didn’t know anyone with memory issues.

A team member also noted that it was very difficult to reach the health care sector, as the doctors and nurses were often too busy to participate.

**Analysis**

The key administrative support team member from Centro Tyrone Guzman, Yoli Chambers, entered in all of the survey data (N=117). She also created a document to compile all of the comments, typing each one in. During this process she noted some common themes/similar comments. She also used the matrix which is available on the ACT website to help graph the results. The tabulation yields a matrix (see Figure 7) which highlights the areas that are considered to be high priority, but that currently have a low level of activity.
In March and April of 2015 the ACTion team came together to review the results from the surveys, and to analyze these results and brainstorm possible action steps.

After compiling all of the data, I completed the Assessment Priority rating and explained the results to our ACTion team.

It was interesting because through the surveys we confirmed what we were thinking at the beginning—that there is a huge lack of information and there are not enough resources in Spanish for the community.

Working with Leanna Smith to examine the results, the priorities for action focused on: (1) increasing community awareness and (2) increasing information and education to the Spanish-speaking community. Appendix D provides the priority table listing action items and number of surveys.
Action Planning

Goals

The ACTion team set forth two priority goals as follows:

#1) Awareness

Prepare the Minneapolis Latino community to actively engage in creating a safe and respectful environment for individuals with dementia and Alzheimer’s and their caregivers by coordinating activities designed to: raise awareness, garner support, and encourage open and non-judgmental dialogue about community members’ experiences with dementia and Alzheimer’s disease.

#2) Information and Education for People with Dementia and their Families

Foster a safe and respectful environment for Latino Minneapolis residents with dementia and their caregivers, by engaging the broader Latino community in activities aimed to: educate about Alzheimer’s disease and dementia, reduce stigma, and increase access to information and resources.

Objectives

The ACTion team met as a group and provided different ideas about specific objectives under these goals, and about how they could implement activities that address these goals.

- Training/Education - The first objective they set forth was to train local professionals on topics related to Alzheimer’s disease and dementia—as a start they focused on having members of their own ACTion team get additional training from the Alzheimer’s Association.

- Workshops - The second objective was to increase the capacity of Latino community members to identify early signs of Alzheimer’s disease and dementia. A target of 5 workshops targeting local Latino residents was set.

- Local media – The third objective was to raise broad public awareness of dementia and Alzheimer’s in the Latino community. The team focused on local television and Univision stations/media outlets to reach the Latino Minneapolis community.

- Creative activities – The fourth objective they set was to engage Latino community members in fun and creative activities that educate and inform about dementia and Alzheimer’s. These would include such things as a theater/play production, arts & crafts activities such as crocheting, and nutrition and exercise sessions.
Spanish-language resources – The fifth and sixth objectives they set were to provide information and support in Spanish to Latino individuals with Alzheimer’s Disease and dementia and their caregivers and to increase access to Spanish language resources. This would include a joint Spanish language presentation on “Living with Alzheimer’s disease,” working with Fairview Southdale Hospital. It would also involve distributing written educational materials to Latino clients (such as those who participate in programs at Centro Tyrone Guzman, Amigos del Mercado, Legacy Adult Day Care, PACER, and others). Finally this would include creating a list of local resources for Spanish-speakers—including whom to contact and where to go (location, hours, eligibility).

The ACTion team set forth these objectives and goals in a three-year written Action Plan. They then presented it to other members of their professional network, asking for feedback and opinions on the best way to reach out and to implement the plan.

With our plan, the community will be more aware and will be able to identify if they need help. Because even though we know there is no cure for Alzheimer’s we know that an early diagnosis can help a lot and we can support the family.

The Action Plan includes key activities, lead accountabilities, a timeframe, and measures. The Team is committed to measuring progress. For example, they have an evaluation form that is distributed to participants after every presentation, workshop, and event.

We have set a lot of goals and high standards. That is impressive and quite a lot. We seem to really be doing a lot. We do have momentum. I think it will be really remarkable what we end up doing.

I would say that getting people engaged is an important point. More visibility is the first step. That is the primary focus of our plan going forward. Raise awareness, start the conversation.
The Team discussed the need to spread the work across organizations. While Centro Tyrone Guzman is taking the lead and is involved in many of the activities, they also are going to be partnering with the other ACTion team member organizations and with additional organizations, including:

- Adagio Holistic Therapies
- Alzheimer’s Association – MN/ND Chapter
- Fairview Southdale Hospital
- Minneapolis Institute of Arts
- Teatro del Pueblo
- United Way – Twin Cities

They are also working to engage the Sheriff’s Office and the Police departments in Minneapolis.

**ACTion Community Results to Date**

ACTion team members and the Coordinator point to many accomplishments and early successes thus far. In less than one year (July 2014- June 2015) the work of this ACTion community has included:

- Putting together a lists of names of local individuals and organizations and reaching out to request their involvement in this initiative
- Creating the ACTion Team
- Dividing up various functions between ACT team members
- Deciding how to talk about this within the community
- Reviewing the ACT Toolkit and community engagement process as outlined in the Toolkit
- Planning and hosting the community meetings and events
- Working on outreach, particularly in defined sectors, to determine who to interview and how to conduct the surveys to gather information about gaps and priorities
- Gathering information about Alzheimer’s disease and resources for the Latino community
- Conducting the surveys
- Determining how to analyze the information gathered (and doing so)
- Discussing the results as a small group and identifying the two priorities
- Setting forth objectives
- Brainstorming possible action steps
- Landing on the action steps to pursue and writing an Action Plan
- Submitting the Phase 4 grant
Beginning to pursue some of the Action Plan activities, such as:
- The original play and theatrical production ("El Orden del Desorden")

In addition, Centro Tyrone Guzman and the Latino Collaborative have participated in a Twin Cities Public Television documentary that has featured this community’s efforts and provided a client story of a Latina caregiver (See: Late Life: Facing Dementia – TPT Co-Productions with Allina Health found at: http://video.tpt.org/video/2365494190/).

Responding to the question about the impact and results to date, team members expressed surprise at how much their efforts are bringing forth community members and fostering discussion.

We have surprised ourselves with the impact.

Team members reflected on the many accomplishments. They expressed many positive feelings about the progress that had been made.

I’m very proud of how we have come together, and very proud of our accomplishments. We definitely needed the organizational structure and depth of resources that Centro has behind them in order to do this.

Lessons Learned/Advice/Reflections

The Coordinator described the advantages of being part of a coordinated effort—part of the larger ACT on Alzheimer’s initiative. The Health Equity Leadership Group discussions that Lili Ugaz participated played a large part in establishing this ACTion community. Having the scripted community engagement process and the technical assistance and seed money through ACT was important to provide guidance and some funding. The assistance of the MAAA was critical and very appreciated. The scripted, guided process within the Dementia Capable Community Toolkit allowed the Team members to follow a well-defined course. In addition, the information and sharing from other ACTion community leads was helpful.

Advice that the Coordinator and team members offered included:
- Choose a lead organization with capacity and deep ties/services in the community
- Build a strong ACTion team
- Be prepared for the time commitment—especially the assessment process
- Maintain good communication with the community and try to involve as many people and organizations as you can
- Read the whole Toolkit and go on the ACT on Alzheimer’s website and view the videos, resources, etc.
- Keep everything organized

I would say it’s successful. It is pretty well organized. However, the work has been done by a fairly small group of people.

I have learned that people will gather together to help each other when they understand that there is a need. That is very encouraging. Even if we don’t have all of the answers and resources—they will help.

Challenges these Team members encountered are similar to those of other ACTion communities, particularly those with ethnically and racially diverse populations. These included:
- The language and terminology used in the Toolkit, particularly the survey wording, length, question content and response scale
- The lack of culturally relevant resources
- The complexity of the assessment and analysis process, and
- The time commitment this process took

In the case of Centro and Legacy—they have a pool of seniors and families already. So that outreach and engagement was easier. Extending beyond that group is part of the real challenge and next steps.

Team members discussed sustainability and impact, as well as how to keep the momentum going.
Team members discussed the importance of having culturally-relevant and Spanish language resources—including materials, programs, services—for both the family/caregivers and the person with the disease.

It is very important to receive this information in your language, and in a culturally appropriate environment, where you feel you are welcome—where you can ask different questions about it--where you can feel like you are at home and you have a family to support you without judging you.

Team members talked about the unique needs of their community as well as the needs and issues they have in common with all people. One team member discussed the issues as being “systemic”—not particular to the Latino community—and therefore need to be addressed at a systems level.

I don’t see this as being able to be sustained after the grant ends—not without some funding. Unless there are additional grants, I’m just not sure.

One has to be positive. I would say: “Don’t get discouraged. You are rowing, and making progress. Sometimes against the current. However, we are rowing together. We are moving forward. Everybody’s efforts come together. That all accomplishes something.”

We are a lot further than we thought we’d be a year ago.

There is a difference. Those in the Latino community are talking about this.

Regardless of the outcome – regardless of what can be measured, be pretty humble about measuring impact. Anything small is not really small. Things do happen and are moving along. Everything is good. One person learning about AD is good. Never feel discouraged. All we do is progress.
There are a lot of issues that are systemic. They are not particular to the Latino community. Such as awareness of this as a brain disease, what are the signs, how to get a diagnosis, what your physician should do to arrive at a diagnosis, what kind of follow-up should happened, what kind of help should be provided to caregivers, etc. These issues are not unique to the Latino community—I mean we can’t take on the whole health care system. We can do what we can do to build awareness and educate in our community.

Meanwhile, there has to be a bigger effort at the systems level. There has to be a big push into policy. Setting some requirements for health care. We can’t do it all from the grassroots.

Team members envisioned how the dementia-capable community will look and feel once it is a reality.

What is most important to the Latino community about this effort is that we are a community across sectors and organizations and people. That is key. We want to get the people involved. We work as part of the community.

This illness impacts everyone and it impacts the Latino community even more. We’re more at risk. You cannot think this will not affect you. Everyone has a relative; mother, father, grandmother. So long as people are fearful and do not talk about this— that will not build resources. I think that is part of the incentive— not fear, but knowledge. Of course we hope that they will find a cure. But until then, we have to educate and build awareness and more resources.

A measure of success will be when the Latino community can talk about “I see some signs of my relative that may have dementia” – and a friend or a neighbor brings the 10 Warning Signs flier.

When the doctor responds. When the referrals to community resources on Alzheimer’s are given and there are Spanish-speaking caregiver support groups, respite care, Alzheimer’s Association and other Spanish-speaking caregiver consultants. When people have enough knowledge, not feel ashamed, and can advocate for attention and address this issue.
Conclusion

In less than one year, the Latino Collaborative ACTion Team has successfully moved through the first three phases of the ACT on Alzheimer’s dementia-capable community engagement process and is in the midst of phase 4—community action.

Centro Tyrone Guzman has served as an effective lead organization—with a long history of serving the Latino community—and also having capable staff capacity and a professional network, which was tapped to bring together a working team of 7-10 people and organizations. The Project coordinator, Yoli Chambers (Centro Tyrone Guzman), not only was an integral ACTion team member, but provided the hands-on administrative and data support, maintaining documents, organizing the agenda and meetings, facilitating the surveys/assessments, and ensuring communication. Leanna Smith from MAAA provided invaluable technical support and guidance.

The ACTion team is encouraged by the strong showings at community events and educational sessions. It is also encouraging that additional people, organizations, and resources are coming forward to be part of the work of building awareness, and extending the education and information to the Latino community.
Appendix A: Centro Tyrone Guzman

Vision: To create a vibrant, diverse and inclusive Latin@ community that belongs and contributes to the social and economic vitality of Minnesota. (Source: Centro website; www.centro.org )

Here at Centro participants have said to us many times: “I feel at home here.”

That aspect is so important—because we are talking about a person’s roots, traditions, language, culture. . . all of these aspects play a really important part in everyone’s life. [When] you feel comfortable and safe, you feel you belong to that place.

For example, an older mother participates in our Wise Elders Group—she has Alzheimer’s disease. When her daughter found us she was extremely happy, as her mother does not speak English, and also because Centro is a Latino organization. The daughter was trying to find support but couldn’t. They both needed to feel comfortable talking and expressing concerns and ideas.

Now her mother has friends here and she has a lot of fun every time she is here. She has the opportunity to sing her favorite songs and do her favorite activities.
Appendix B: Community Event Program Fliers

Hablando de Alzheimer’s y Demencia

Reconociendo los síntomas
Mejorando el cuidado
Entendiendo el impacto en la Familia y Comunidad
Rompiendo estereotipos

LO LOGRAREMOS CON TU AYUDA!
Sábado 15 de noviembre
10:30 am – 1:00 pm
CENTRO 1915 Chicago Av So.
Minneapolis, MN 55404
Para registrarse llame a Sandra Reyes al: 612-874-1412

Raising Awareness about Dementia & Alzheimer’s

Recognizing the symptoms
Increasing detection
Raising awareness
Reducing stigma
Improving care
Impact on Family and Community

WE CAN ONLY DO IT WITH YOUR HELP!
Date: Thursday, October 23
Time: 5:30 pm – 7:00 pm
Place: CENTRO 1915 Chicago Av So.
Minneapolis, MN 55404
For more information please contact Yolima Chambers at 612-874-1412

Paone & Associates  June 30, 2015
Appendix C: Kick-off Evaluations

### Evaluation Report for Kick of Event Alzheimer's

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Excellent</th>
<th>%</th>
<th>Very Good</th>
<th>%</th>
<th>Good</th>
<th>%</th>
<th>Poor</th>
<th>%</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>My overall reaction was</td>
<td>14</td>
<td>78%</td>
<td>4</td>
<td>22%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Workshop format was</td>
<td>13</td>
<td>72%</td>
<td>5</td>
<td>28%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Opportunity for discussion was</td>
<td>5</td>
<td>28%</td>
<td>9</td>
<td>50%</td>
<td>4</td>
<td>22%</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Length of workshop was</td>
<td>10</td>
<td>55%</td>
<td>7</td>
<td>39%</td>
<td>1</td>
<td>6%</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

As a result of participating in this event, my awareness of Alzheimer's disease/Dementia, and the impact on the Latino community has:

<table>
<thead>
<tr>
<th>Response</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased a lot</td>
<td>9</td>
<td>50%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased somewhat</td>
<td>7</td>
<td>39%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remained the same</td>
<td>2</td>
<td>11%</td>
<td></td>
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<td></td>
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</table>

As a result of participating in this event, I feel comfortable sharing information about Dementia and Alzheimer's disease.

<table>
<thead>
<tr>
<th>Response</th>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
<td>72%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Possibly/but would need more information and/or education</td>
<td>4</td>
<td>22%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No/but I would like to learn more</td>
<td>1</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No I don’t think I can share information about Dementia and Alzheimer's disease</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix D: Assessment Priority Rating - Dementia Capable Community Key Elements - Latino Collaborative

### Key Element: Alzheimer's/Dementia in Your Community

**Assessment Question:** Current Level of Activity/Priority for Action

<table>
<thead>
<tr>
<th>Activity Level</th>
<th>Action Priority</th>
<th>%</th>
<th># respondents</th>
<th>Total of people surveyed in this question</th>
<th>Sectors</th>
</tr>
</thead>
<tbody>
<tr>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Key Element: Awareness

<table>
<thead>
<tr>
<th>Assessment Question: Current Level of Activity/Priority for Action</th>
<th>Activity Level</th>
<th>Action Priority</th>
<th>%</th>
<th># respondents</th>
<th>Total of people surveyed in this question</th>
<th>Sectors</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Our community currently provides adequate awareness building on dementia to the general population. Providing awareness building on dementia to the general population should be a priority for action in our community.</td>
<td>Low</td>
<td>High</td>
<td>100%</td>
<td>4</td>
<td>4 Surveys</td>
<td>AT</td>
</tr>
<tr>
<td>6a. Indicate your level of knowledge of the warning signs of dementia/increasing community members' knowledge about the warning signs of dementia should be a priority for action in our community.</td>
<td>Low</td>
<td>High</td>
<td>68.80%</td>
<td>62</td>
<td>90 surveys</td>
<td>CM LG</td>
</tr>
<tr>
<td>6b. I have good skills for interacting with people with dementia. Increasing community members' skills for interacting with people with dementia should be a priority for action in our community.</td>
<td>Low</td>
<td>High</td>
<td>53.33%</td>
<td>48</td>
<td>90 surveys</td>
<td>CM LG</td>
</tr>
<tr>
<td>6c. Indicate your ability to make referrals to support services for people with dementia and their families. Increasing community members' ability to make referrals to support services should be a priority for action in our community.</td>
<td>Low</td>
<td>High</td>
<td>74.40%</td>
<td>67</td>
<td>90 surveys</td>
<td>CM LG</td>
</tr>
</tbody>
</table>

### Key Element: Information & Education for Caregivers of People with Dementia

<table>
<thead>
<tr>
<th>Assessment Question: Current Level of Activity/Priority for Action</th>
<th>Activity Level</th>
<th>Action Priority</th>
<th>%</th>
<th># respondents</th>
<th>Total of people surveyed in this question</th>
<th>Sectors</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Our community currently has adequate awareness of the resources that can assist with locating support services for people with dementia and their families. Raising community awareness of the resources that can assist with locating support services for people with dementia and their families should be a priority for action in our community.</td>
<td>Low</td>
<td>High</td>
<td>100%</td>
<td>4</td>
<td>4 Surveys</td>
<td>AT</td>
</tr>
</tbody>
</table>

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**Legend:**

- **Red:** Gap/Opportunity
- **Blue:** Neither strength, nor opportunity
- **Green:** Strength
- **Yellow:** No assessment data to support

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**Total surveys completed 117**

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*Paone & Associates*  
*June 30, 2015*
Appendix E: Original Play – Information, Flier, Photo

EL ORDEN DEL DESORDEN, Saturday, May 30, 2015 - 11 am - 1 pm

An original play designed to educate the community about the ten warning signs of Alzheimer's disease. Written by Silvia Pontaza, the play was based on true stories from each of the participants. They all have had a family and/or a work experience with people who have this disease. This story stresses the impact of this disease and the hope of the treatment. The play is about three different families with a common situation, their mothers have Alzheimer’s.

The play is in Spanish but has English subtitles.