

***ACT on Alzheimer's®* Evaluation**

**Caregiver Focus Group Report**

**May 7, 2015**

Deborah Paone, DrPH, MHSA

*Paone & Associates<sup>1</sup>*  
Minneapolis, MN

---

<sup>1</sup> *Paone and Associates* is an independent consulting and evaluation firm. See [www.paoneandassociates.com](http://www.paoneandassociates.com)

## Executive Summary

*ACT on Alzheimer's*® is a volunteer-driven statewide collaboration. It focuses on 5 goals to help prepare Minnesota for the budgetary, social and personal impacts of Alzheimer's disease and related dementias. One of the 5-year goals of the initiative was to: “sustain caregivers through access to and navigation of organized information about supportive services and resources.”<sup>2</sup>

Caregivers of persons with Alzheimer's disease and related dementias—usually a family member or significant other—live the journey of disease with their partners. Thus, their perspectives are important in building strategies and understanding results.

There are 34+ ACTION communities statewide--using the *ACT on Alzheimer's Dementia Capability Toolkit* that guides through a community engagement process. Many of these communities have identified the need for more awareness about the disease and about the need for caregiver support. Many of the communities are pursuing action around these priorities.

A two-year modest formative evaluation was funded to document progress and capture insights in a structured way. As part of that evaluation, a caregiver focus group was held on May 7, 2015 with four caregivers who have been active in one of the ACTION communities for a year or more. This report captures the discussion from that focus group.

The caregivers in this focus group shared the opinion that one of the greatest results of their ACTION communities' efforts had been to raise the issue and visibility of Alzheimer's disease and dementia and of caregivers. They felt that there was more awareness, conversation, and discussion about these issues. They mentioned *Dementia Friends* training sessions, film series, conferences, lectures, and other tangible evidence of the increasing number of opportunities within their communities to learn about the disease.

They also remarked that it was very encouraging to see professionals working across sectors and organizations, as a result of the *ACT on Alzheimer's* community engagement process.

Caregivers spoke about the great need for meaningful social engagement for both the caregiver and the person with the disease—and mentioned a number of programs that currently provide essential support. They each said that more is needed in this area.

When asked about measuring impact—toward an increase in “dementia-capability”—these caregivers discussed a set of domains and essential supports that will be important for the dementia-capable community of the future. These were:

- Mental and social well-being as a focus—and as an aspect of quality of life—for both caregiver and person with the disease
- Counseling for caregiver and for person with the disease
- Family communication and help with family dynamics

---

<sup>2</sup> *ACT on Alzheimer's Cumulative Success Measures*, 2011. See: <http://www.collectiveactionlab.com/sites/default/files/ACT%20LONG%20RANGE%20GOALS%20AND%20CUMULATIVE%20SUCCESS%20MEASURES.pdf>

## ACT Evaluation: *Caregiver Focus Group Report*

- Accessibility and availability of caregiver communities and networks
- Education and awareness opportunities throughout the community about dementia and about caregiving
- Transitions in care and “safety net” services—that are proactive and handled effectively
- Navigators – caregivers will have one “go-to person” who is there for the journey to help navigate the health and social services systems, even as the individual goes through the stages of the disease
- The medical care “gold standard” is followed (i.e., early detection, caregiver and individual education and support, effective follow-up; subsequent medical visits and treatments take into account dementia as an organizing principle of care)
- Polypharmacy is addressed proactively

While this ideal community does not yet exist, measures of success over time would be that these things are growing in number and sophistication. For example, that the number of caregiver support groups grows and that they are held around town at all times of day/days of week to make it easier for caregivers to access them. Also, that the caliber of medical and social services care is consistently high in organizations throughout their communities (e.g., well-trained staff, consistent, effective response).

These caregivers remarked that the greatest need they have is for acceptance and understanding. They wish to be included, empowered, and assisted—as they provide loving care to their husband, wife, brother.

The caregivers closed their group meeting by saying that their “bumper sticker” for life reads: “We’re doing the best we can!”

## Background

### **What is ACT on Alzheimer’s?**

ACT on Alzheimer’s® is a volunteer-driven statewide collaboration. It focuses 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—with a health equity lens (Figure 1). The initiative was launched in June 2011 ([www.actonalz.org](http://www.actonalz.org)).

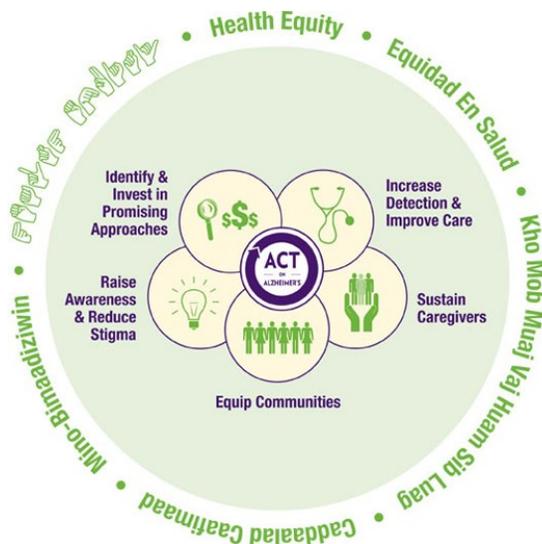


Figure 1. ACT on Alzheimer’s Goals

### **What is the evaluation?**

In 2013, a private foundation<sup>3</sup> provided a grant to fund a modest evaluation of the ACT on Alzheimer’s collaborative effort. An independent consultant (*Paone & Associates*) was hired to conduct a process or formative evaluation—to document progress, identify successes and challenges, capture insights and lessons learned in a structured way. This evaluation began with preparation of a logic model for ACTion communities (Figure 2) which briefly summarizes the inputs, outputs, interim, and longer-term results that would be expected from such a community engagement, collaborative effort.

A process or formative evaluation is done while a program is underway. It provides snapshots of information--collected in a structured way. The value of this approach is for the program directors or leaders to use the information and feedback to make adjustments in the approach as learning occurs and as the program or initiative develops and evolves.

<sup>3</sup> The GHR Foundation. See: <http://www.ghrfoundation.org/health.html>

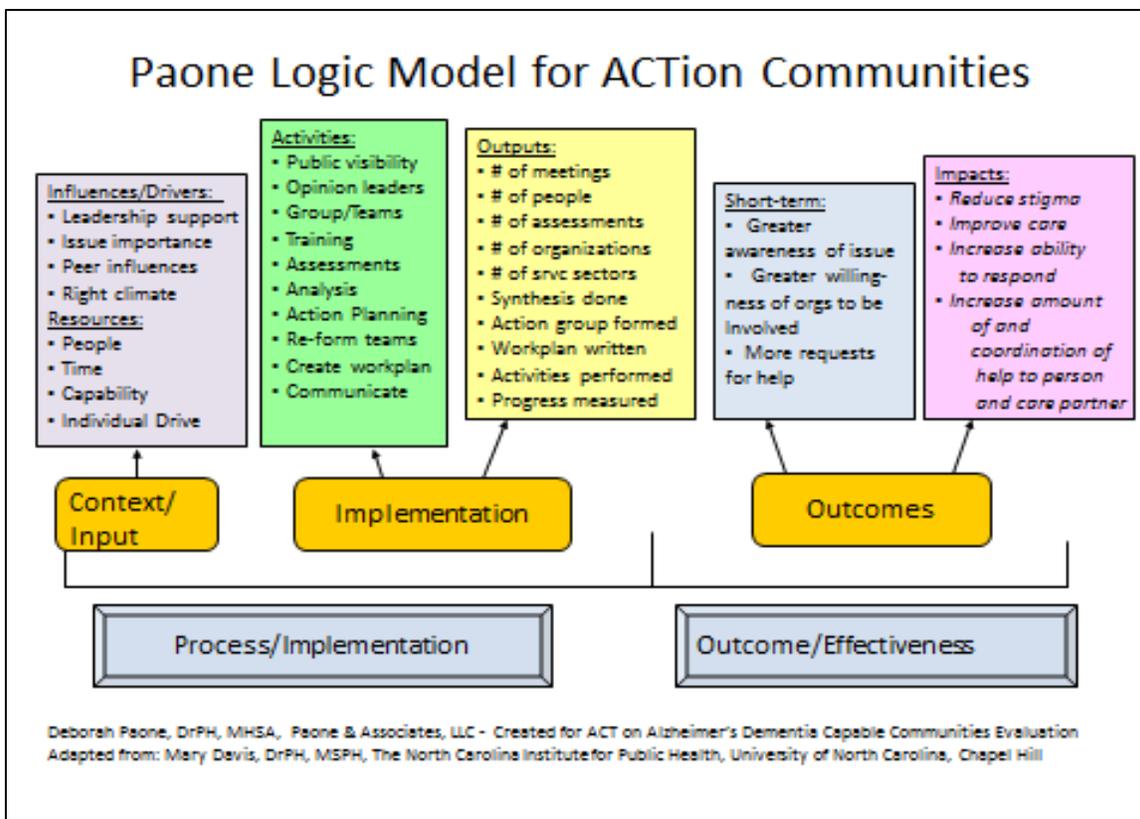


Figure 2. ACTION Communities Logic Model

### **Why a caregiver focus group?**

One of the 5-year goals of the ACT on Alzheimer’s initiative was to: “sustain caregivers through access to and navigation of organized information about supportive services and resources.”<sup>4</sup> There are 34+ ACTION communities statewide. Many of the 34+ ACTION communities (those using the ACT on Alzheimer’s Dementia Capability Toolkit and community engagement process) have identified the need for more awareness about the disease and about the needs and issues of caregivers in their communities.

Caregivers of persons with Alzheimer’s disease and related dementias—usually a family member or significant other—live the journey of disease and address daily living challenges with their partners. Caregivers are extremely important—vital. Thus, their perspectives are important in building strategies and understanding results.

A focus group is one research or evaluation method for obtaining information from a defined group of people with special characteristics or knowledge. The people participating in the focus

<sup>4</sup> ACT on Alzheimer’s Cumulative Success Measures, 2011. See: <http://www.collectiveactionlab.com/sites/default/files/ACT%20LONG%20RANGE%20GOALS%20AND%20CUMULATIVE%20SUCCESS%20MEASURES.pdf>

group should be alike in specific ways.<sup>5</sup> The focus group method provides the opportunity to obtain more detailed information through fostering in-depth thinking and discussion. The group is designed to be small to allow for issues and information to be probed in a deeper, more substantive way. This is a qualitative research method that is widely used.

In this case, the evaluator set the following criteria to select the caregiver participants so that the both of the following were true: (1) the individuals had actively participated in the work of one ACTion community and (2) the individuals were self-identified caregivers of a person with Alzheimer's disease. The criteria for invitation were:

- Person has been or continues to be a caregiver of a person with Alzheimer's disease
- Person has been active in one of the furthest along ACTion communities (i.e., the community completed Phases 1, 2, and 3 and started Phase 4 by January, 2015)—either on the ACTion Team of that community or actively involved in some component of the work (e.g., assessment/surveys, training, etc.)
- Person lives in the metro area (for convenience in transportation)
- Person had been recommended by the ACTion community Coordinator
- Person was willing to participate in the 1.5 hour group discussion

Four individuals were invited via email with a follow-up email, phone call or mailed confirmation.

The confirmation included logistics/directions and a draft set of questions--for the caregivers to think about prior to coming. No one had to complete the questions or submit anything in writing. The questions were designed to focus on what they, as caregivers and informed community members, saw as *different* in their respective communities now as compared to when the ACTion community work began, about their perspectives on *access or availability to meaningful dementia-specific resources* in their communities, and about *measures or measurement domains* that are meaningful to caregivers for evaluating impact over time (see Appendix A).

All four caregivers agreed to participate and did participate in the focus group which was held on May 7, 2015 at a local community library in a closed-door conference room.

ACTion communities represented included: St. Louis Park, the Jewish community, St. Paul Neighborhoods, and Edina. These communities had begun their work as ACT on Alzheimer's communities in 2012, 2012, 2013, and 2014 respectively. All communities had, as a goal, to raise awareness and provide education about the disease.

---

<sup>5</sup> Krueger, R. and Casey, MA. (2009). *Focus Groups: A Practical Guide for Applied Research*. California: SAGE Publications, Inc. p.6, 7.

## **Focus Group Results**

### ***Format/Methods***

The group of caregivers and the evaluator sat facing each other around a table. A small table-top easel/stand sat on the table with a large pad on it with pre-printed text--starting with a "Welcome" and a purpose statement for the focus group. The purpose statement read:

*To obtain perspective from expert, informed, involved caregivers who have been involved in one of the ACT on Alzheimer's ACTION communities – about results, impact, differences – that are meaningful to these caregivers.*

Each individual provided his/her first name, the name of the ACTION community he/she was involved in, the length of time he/she had been a caregiver, and a favorite past-time or hobby.

The evaluator displayed and read aloud a question and invited participant discussion--until it seemed that everyone had had the opportunity to provide remarks on that question. Then the next question was posed to the group. The evaluator took notes as the participants spoke. The evaluator provided a brief synopsis of the comments, to ensure the notes captured the main points of the conversation. The notes were shared with caregivers as a group electronically following the focus group, not to add to the information, but to ensure accuracy.

### ***Questions & Discussion***

Question #1: What is different in your community now, as a result of the ACT on Alzheimer's action community work? Do you have an example?

Responses:

*The collaboration between the organizations and professionals in the field is the result so far. We can see the people and organizations working together—that is important for us to see and know. We have a sense that there is forward momentum around Alzheimer's disease. We are welcomed in to be a part of this.*

*We already had a task force on Alzheimer's disease before ACT. So we were already working on awareness and community education. What has been an added boost as a result of ACT on Alzheimer's are the tools and the guided implementation process. Also, as a result of this larger initiative we were able to bring training to the faith community leaders—the rabbis. Many times people in synagogue will ask their rabbi when there is a question or issue. Some did not have training/much education on AD. The rabbi training helped open their eyes and brought the issue of Alzheimer's disease and of caregivers more to the forefront.*

*This takes a long time—to bring this issue "out of the closet." So ACT on Alzheimer's is helping to do that and also bringing more people to our effort and to help work on education and awareness events. Our committee was strengthened as a result of ACT.*

## ACT Evaluation: Caregiver Focus Group Report

*We have a network of AD caregivers in the community that is growing.*

*When I look over all the folders and materials that have been shared and the notes from the meetings, I am amazed at the number of people involved. The professionals, the community members, and from so many sectors of our community—City Council, police, church, residential senior housing, health care, social service agency, etc.—it is truly impressive. Now with the Dementia Friends training sessions being held around town—that is really spreading the information and awareness. It's exciting to see.*

*The biggest difference is the number of people talking about this and the efforts to keep the awareness growing.*

*Our community has really focused on the film series and the educational events and discussion opportunities. That is really helping to grow awareness and encourage discussion. Now other communities want to replicate our film series. So very encouraging.*

*We found out how important it is to have something concrete, like the Dementia Friends training sessions that can be held really anywhere. The scripts and materials are already to go. I've seen the great need in these senior residential buildings to have this—these awareness building and educational sessions. There are so many people living with this disease in these buildings. Whether silently, without diagnosis, or with—still it is there and everywhere. You see it—even when sometimes the younger adult family members who come for occasional visits don't see it, or don't want to see it.*

*Yes, and why do we want to bring it out and talk about it? Because it is so much healthier to get it out in the open and discuss it.*

*I am also encouraged about the breadth of organizations willing to have this be part of their outreach and education—such as the faith communities.*

**Question #2:** Are caregivers supported differently now in your community? How? How can you tell?

### Responses:

*Yes. I believe so. I myself feel more supported. There are other caregivers who I didn't know—who I've met through this process and we are reaching out to each other. Also the Center and a local church are offering education sessions and the Caregiver Support Group on a monthly basis. That support group is growing.*

*We now have some Jewish Caregiver Support groups, where we didn't before. This depends on what synagogue you belong to. We have the "Views from the Pews" sermon notes, which have been helpful to the rabbis.*

*Still there is a way to go. The caregiver of a person with AD is still not supported the way a caregiver or loved one who is caring for a person with cancer is supported. There is not that immediate pouring out and wrapping around support.*

## ACT Evaluation: Caregiver Focus Group Report

*With regard to caregiver support, I do think it is also important to take into consideration how the patient is accepting the diagnosis. Some individuals are not accepting the diagnosis. Then the caregiver has a much harder time. Of course the person with the disease does not want to talk about it. She/he may not want the caregiver telling anyone anything. That inhibits help all around.*

*That is a good point. There is also the issue of when the care partner or significant other will not accept the diagnosis. The denial goes both ways. Sometimes a care partner wants it to be anything else—my loved one received an initial diagnosis of Parkinson’s disease. His care partner hung on to that—rather than Alzheimer’s.*

*Sometimes it is this issue around mental health and the stigma associated with having behavior that is different. What people have to understand is that there are physical changes in the brain. This is a brain disease. It is not a mental illness. But still, the stigma related to behavior changes gets attached to this.*

*I see slow progress in some parts of the community—changing the mindset and talking about this openly is one of the best ways to support the caregiver at this point.*

**Question #3:** A goal of ACT is to make meaningful dementia-specific resources accessible and available. What are “meaningful dementia-specific resources” to YOU?

*The most meaningful dementia-specific resources are those that provide something meaningful and relevant for both the caregiver and the person with the disease.*

*For example [Evaluator’s Note: The participants provided these examples as a group, building on each other’s comments]:*

- *The docent tours and SPARK Tuesday Tours at the MN Historical Society and the Walker*
- *The Giving Voices Choir*
- *The Concerts at MacPhail*
- *The films series and discussions*
- *The Alzheimer’s Association Early Stage Meetup, such as the trip to Minnehaha Falls*
- *The Living Well course—that does separate the person with the disease from the caregiver, but we each get to spend time with others on something enjoyable or on ourselves as caregivers*

*We laugh a lot and support each other. We can all be ourselves and still be together. We are enjoying life together again during these programs and outings. We feel normal and accepted. That goes for the person with the disease and the caregiver. This is an important thing for us.*

*Yes, we can’t give up on life. We still have an identity beyond the disease.*

*There are also the very important day programs—like The Gathering. So needed! Respite and rest for the caregiver. There is meaningful activities and fun engagement for the person with the disease too. So we are both supported. This is phenomenally important.*

*We have to also include the Caregiver Support Groups. Those are absolutely a lifeline.*

*Yes, I couldn't survive without my support group.*

*It is important to be supported. I am not the live-in care partner, but had to step in when the significant other care partner just could not. He had valued the intellect of my loved one. It was just too hard for him to accept. So that is doubly hard. Acceptance is so important.*

Question #4: ACTION communities want to measure impact on caregivers and persons with dementia as part of their evaluation of results around dementia capability. What do YOU believe are important measurement domains or measures for evaluating impact on caregivers and people with the disease?

Responses:

[Evaluator's Note: The participants provided these measurement domains and measures as a group, building on each other's comments.]

*We will give you things that we think should be in place in a dementia-capable community. The measures and domains will come from these things. The dementia-capable community should attend to and should include the following:*

- *The **mental health and emotional well-being** of the caregiver and person with the disease. Are they calm or anxious? Feel positive or negative? Feel overwhelmed or supported? So caregiver and individual mental and emotional well-being is a domain to keep front and center.*
- ***Quality of life** is a related but broader domain – of caregiver and of person with disease as he/she moves through the stages. Quality of life is from the person's perspective.*
- ***Counseling & family communication/family meetings** – this trips up many—how communication is or is not handled in the family network. Those family dynamics can play heavily into the situation and make it much worse or better. There needs to be counseling support with coaching about communication that is offered almost automatically or at trigger points. This needs to be baked into the community response. Both the communication and stress management support.*
- ***Caregiver communities and networks.** Other caregivers are actually some of my biggest supports. We help each other. Yes, through support groups and through online communities. This is a big way we share information. That needs to be fostered. How do caregivers even find each other in a community?*

- How **transitions** in setting or needs and medical or other **crises** are handled with care of both person with the disease and of the caregiver—needs of both. This is another marker of a prepared community. This is also tied to the idea of having set
- **Safety nets**—that is, there are plans in place for various scenarios and these “safety nets” are known and resourced and practiced. Like a fire drill. Everyone knows what to expect and someone is accountable for response. This has to be funded.
- **Navigators**- right along with the safety net plan is the navigator role. A social worker or other defined, prepared navigator who helps the caregiver and person with the disease to navigate the system of medical and social services, community resources, etc. Don't expect the caregiver to do this! He/she is already overwhelmed. There is already so much information out there—too much. We need a one source, one call person.
- That the disease is normalized. The domain would be **education, awareness, information** (sessions, events—on a regular basis). This would be built into the fabric of the community at many levels and in many places.
- We want to be assured and believe that our community **medical care providers are using the gold standard for memory care**—that they have trained their staff/clinicians in the disease and in communication, caregiver, and polypharmacy and other issues. That they know enough of the community resources to actively connect caregivers to them. That this is consistently of high caliber.
- **Communication from health care providers**— every person deserves timely and respectful communication. This is in person, over the phone, and over the Internet. Why can't we have virtual visits and tele-health visual and auditory response from the medical and social services providers? We need that.
- **Polypharmacy and medication reconciliation**. The use of pharmaceuticals can exacerbate the disease effects. So this needs to be a domain/measurement area for assessing dementia capability in a community.

*You know, the biggest thing is ACCEPTANCE and not feeling alone. Understanding. That all the medical and social services and other professionals realize this is a big deal and they are part of helping the person and caregiver's reach an effective, individualized approach. It is not “diagnose and done.”*

Question #5: How would you like your community to measure progress as it moves forward?

Responses:

*I would like to see some of the things we talked about being developed. More of these things.*

*Yes, and also as a measure, who is coming to the meetings and events, and why? Are they getting involved? Is this growing?*

*I'd like to see more people with the disease and their care partners (who we know are living in our communities already) come forward and be open to participating.*

## ACT Evaluation: *Caregiver Focus Group Report*

*If the number of calls to the Help Line were increasing—that is a measure that they are asking for help and reaching out more.*

*More support groups and memory and caregiver programs in the community.*

*That care consultation/navigator role gets developed and resourced.*

*That there are more chat rooms/blogs/other online or virtual communities being fostered too.*

*That where-ever a caregiver goes, they consistently get help.*

Closing: Anymore final words you want to share or add?

Responses:

*Yes, we have words of meaning for this:*

*Acceptance.*

*We are coming to a new place.*

*We are included.*

*We are empowered.*

*There is unconditional love.*

*We all agree that our bumper sticker should be: “**We’re doing the best we can!**”*

## **Discussion**

These informed and involved caregivers provided keen insight about the progress of their ACTION communities and how they are seeing the effort raise awareness—a key goal. The caregivers discussed the importance of meaningful activities and programs for both the person with the disease and for caregivers. They remarked that communities still have a way to go, but that they are encouraged.

These caregivers offered a comprehensive list of what they believe will be essential services and supports in the dementia-capable community of the future. Measurement domains, such as quality of life, how transitions are handled, consistent and “high caliber” medical and social care/support, were offered by these caregivers as important for evaluating success in the future.

This information can be used by the Leadership Groups for ACT on Alzheimer’s and by ACTION communities to help guide future efforts to ensure that the caregiver perspective is taken into account when designing next steps.

## Appendix A

### ACT on Alzheimer's Evaluation – Caregiver Focus Group Confirmation

Hello! Thank you for agreeing to participate in our caregiver focus group/discussion to capture insights from knowledgeable caregivers like yourself. Each person has been selected and invited by the ACTion Community team Coordinator (from your ACT on Alzheimer's community) as a person who has been involved in the ACTion community meetings/work and also as a person with experience in caring for a person with Alzheimer's disease or dementia in your community. So we will tap into that knowledge and experience. Several communities are represented by the group of caregivers who will attend that day.

I am Deborah Paone, Evaluator for ACT on Alzheimer's overall—and have been involved in the initiative as a volunteer since June of 2011 and also now a consultant.

#### **Caregiver Focus Group – May 7<sup>th</sup>, 2015 from 2:00-3:30**

(Introductions at 2:00 and start by 2:10 with finish by 3:15 and wrap up if any lingering questions)

**Location: Edina Library, 5280 Grandview Square, Edina, MN 55436** (see attached directions location info)

**Facilitator & Key Contact: Deborah Paone, Evaluator - Phone: 952-200-6810**

---

The focus areas for our group discussion will include such topics as:

- 1) What do you see is different in your community as a result of the ACT on Alzheimer's Action team work? (Give an example of a “before” and “after”)
- 2) Are caregivers supported differently now in your community? How? How can you tell changes have happened?
- 3) In your experience, have you had the access and availability to “meaningful and dementia-specific resources” that you and your partner wanted/needed?
- 4) What was your pathway in your community to getting the resources/help you needed? Do you think this pathway would be different for newly diagnosed individuals now?
- 5) ACTion communities would like to measure impact on caregivers and persons with dementia related to the services and programs and care available in their community. How do you think communities can best measure this impact? How would you like your community to do that?