



## Dementia Capable Communities -Sharing learning to date-

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### Objectives

- ❖ Themes: Identify commonalities and unique experience from across communities
- ❖ Lessons Learned: Discuss tips and strategies
- ❖ Highlights: Absorb process, method and Toolkit use examples from 5 ACTION communities (rural and urban)

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### Process Using ACT Toolkit

- Convene
- Assess
- Analyze (Synthesize)
- Action Plan



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### Common Themes

- ❖ Need a **strong leader(s)** to serve as coordinator or co-coordinators, as well as **several active lead members** who facilitate the work of at different phases of the process, leading team members
- ❖ Being part of a **state-wide initiative** adds momentum and importance to this "grassroots" community effort
- ❖ **Maintaining visibility** and systematic, regular, **communication** - disseminated by the coordinator to team members and to the wider community is an important element for **maintaining momentum and involvement**

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### Common Themes

- ❖ Right at the beginning, there will be a need for **education** around the concept of "dementia-capable community,"
  - ❖ why dementia is an important community issue,
  - ❖ how it affects individuals and organizations and the community (all levels).
- ❖ The work is conducted as a collective, **voluntary effort**
  - ❖ not the domain of one organization
  - ❖ Some individuals will have time allocated by their employers,
  - ❖ others provide time outside their normal job duties, often on personal time
- ❖ **Resident engagement**
  - ❖ the voice of people living with Alzheimer's disease, the caregivers and people with the disease (often not associated with an organization) is important

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### Unique Elements

- ❖ **Core** group can be small or large – as long as there is a wide net cast for "assessors/surveyors" to be involved, because a key ingredient to this effort is to **raise awareness among surveyors and as interviewees**
- ❖ An **existing task force** or group can lead the formation of a community coalition or ACTION team
  - ❖ Pros: Kicks off effort faster, already have buy-in from a group of people and organizations
  - ❖ Cons: Brings with it the vestiges of the existing or past work and roles/assumptions (can be positive or negative) and often need additional (new) people to be brought into the work—so they may feel like outsiders unless there is deliberate work to "reform" as a group

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## Lessons Learned: tips and strategies

- ❖ **Set goals** and determine time frame for the whole effort (people want to have a sense of what they are committing to)
- ❖ **Establish processes and methods** the group will use (e.g. selecting 1:1 vs. group assessments)
- ❖ Find a way to keep inviting additional participants while also not slowing down the momentum of the group – for example, **use volunteers** who can conduct assessments
- ❖ Understand **history & context - commitment**
  - ❖ Engage/respect the passionate people with history and strong involvement in community work who will come forth - also welcome those completely new who are learning
  - ❖ Work to recognize existing or past efforts as helping to add to, not compete with current efforts

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## Lessons Learned: tips and strategies

- ❖ Have **enough people** involved
- ❖ Set **realistic goals** as a group, including
  - ❖ practice with the tools (e.g. role play & provide each other feedback)
- ❖ Offer educational and other leave-behind **material** following the assessment
- ❖ Don't wait to do **data entry**
  - ❖ as soon as the assessment is completed, or
  - ❖ as they are turned in to lead
- ❖ **Involve the group** in ways that are conducive to large discussions (e.g. interpreting the results)

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## Lessons Learned: tips and strategies

- ❖ **"Digesting," training/orienting,** and **facilitating use** of the **Toolkit** is time consuming for lead facilitators, but allows the team members/surveyors to understand the process – facilitate their ability to describe the effort to others. They need to be able to answer the questions:
  - Why is this being done? Why this way?
  - How is this group effort organized?
  - Who is involved? Who is being surveyed?
  - What is this supposed to lead to?
  - When/how will this turn into action for our community?

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### Lessons Learned: toolkit

- ❖ **Walk through the entire Toolkit** and plan for the various phases of work
  - ❖ The ACT on Alzheimer's effort provides estimated guidelines to establish time-frames
  - ❖ There are different phases of the work, so different people can take the lead for a limited time (help avoid burn-out)
  - ❖ Consider when need outside help for certain tasks/duties
  - ❖ See beyond the survey phase to the priorities and Action planning – set groundwork for next phase

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### Lessons Learned: group dynamics

- ❖ **Team-building**, rounding out representation, ensuring people have opportunity to ask questions, and **intentional effort to achieve group cohesion** are all important
- ❖ **Draw on different talent/expertise** among group members as the process continues to have different individuals assist/lead in a component where their talent is **tailor-made for the task** at hand. If that skill set or talent is not within the assembled group, bring it in from outside the group. This helps to show that the effort is not "owned by" or dependent on one person or one organization

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### Lessons Learned: challenges

- ❖ **Time, focus, balance, group process . . .**
  - balancing ACTI work with other employment and organizational priorities
  - coordinator workload
  - adapting to fit the community group's desired approach/interest while following Toolkit
  - trying to define the concept of "dementia capable communities" for the local area
  - dealing with orientation and communication with new members who may come in at any time
  - Maintaining group momentum and involvement
  - communication, outreach - keeping residents, businesses, wider community aware

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## Process Step #1: Convene

- ❖ Walker example:
  - Pre convening phase
    - Foundational work two years prior with "Dementia Competent Community" group (DCC)
    - DCC declined to participate - new ACT group formed ("Walker Community Coalition")
  - Convening
    - Utilized some of the groundwork developed by DCC
    - Volunteers knowledgeable about Alzheimer's disease, so "hit the ground running"




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## Process Step #1: Convene

- ❖ St. Paul Neighborhoods Act (SPN-ACT) example:
  - Pre convening phase
    - Involved key stakeholders - behind the scenes
    - Foundational work years prior
  - Convening
    - Public Awareness Kick-off - visibility
    - Full invitation list- e.g., service and housing providers, health care systems, individuals with interest, community groups (e.g. faith), practitioners, neighborhood resources, advocates, caregivers, etc.




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## Process Step #2: Assess

- ❖ Jewish Community example:
  - "Digested" the Toolkit
    - Survey team members took time to rehearse; discussed & explained *their* community objectives along with administering survey
  - Implementation methods
    - In person - 1:1, or 2:1 allowed for an interviewer and a note-taker or over the phone
    - Enhanced cohesion/connectedness of the survey team and the person surveyed
    - Not a scientific survey - grassroots, community assessment




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## Process Step #2: Assess

- ❖ St. Paul Neighborhood example:
  - Meeting format allowed for regular discussion of St. Paul neighborhood and ACT on Alzheimer's
    - Provided survey team members with common language to discuss group objectives with community members surveyed
  - Worked with other communities and mentors
    - Utilized data from Jewish Community transportation surveys from same zip codes and integrated into their results
    - Part of a state-wide effort, so learned about other communities' experience, lessons, phased approach




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## Process Step #3: Analyze

- ❖ St. Louis Park example:
  - Data entry compiled by 2 volunteers – 1 lead
    - Redundancy in data entry process helps ensure accuracy, and problem solving if issues arise
  - Drop box or cloud-based computing utilized to gather and store data in central location – accessible




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## Process Step #3: Analyze

- ❖ St. Paul Neighborhood example:
  - Leadership to maintain momentum, troubleshooting and reporting back to stakeholders
  - Interviewees, survey team
  - Convene larger meeting to share results - Transparency for group participants
    - Opportunity to understand the final result of the process
    - Engage the group to commit to Action Planning phase through helping them understand the results of their analysis




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### Process Step #4: Action Plan

- ❖ Walker Community example:
  - Results shared with the full group
  - Next steps involved determining which organization/s would take the lead to implement segments of the Action Plan
- ❖ Implementing Dementia Capable education in surrounding community
  - Identified lead source for community members and professionals with questions about Alzheimer's disease
  - Community perception - work will benefit everyone




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### Process Step #4: Action Plan

- ❖ St. Paul Neighborhood example:
  - Convene small group discussions
    - Options – which action plans were resonable solutions
    - What was the best fit for St. Paul
  - Use seasoned and new group members to form working group/committees to develop action plan framework
  - Invest in the process by drawing on the commitment and knowledge of skilled participants




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### Questions

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