ACT on Alzheimer's ®
Leadership Group Chairs'

Perspectives

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Executive Summary

As part of the ACT on Alzheimer's formative evaluation, key informant interviews were conducted between late October and December of 2014 with the ACT on Alzheimer's Leadership Group Chairs. Each Leadership Group (there are six Groups) has had a defined purpose and focus, with volunteers (group members) from various service sectors, government agencies, educational institutions, industry leaders, and individuals.

The individuals serving as Leadership Group Chairs had been involved in the ACT initiative for at least three years. The interviews were to capture insights from these engaged members on the work and the results that had been achieved, as well as lessons learned about implementation and what more needed to be done.

Key themes emerged from these engaged leaders, as they discussed the ACT on Alzheimer's initiative and the activities of their respective Leadership Groups. These included:

- ***Structure/Process -*** The structure/process of ACT itself (built on the foundation of voluntary, collective action which is not owned by any single organization), as well as the caliber and credibility of the people involved—were two factors instrumental in getting people to come to the table and stay involved.

- ***ACTion Communities -*** The 33 ACTion communities—each working through a community engagement and action planning process around dementia capability—were the most tangible and visible outcome of the work overall.

- ***Tools/Resources -*** The prolific development and then testing/piloting of tools and resources was notable—much was accomplished in 3 years.

- ***Timeframe & Work to be Done*** – All of the Leadership Group chairs discussed the need to continue the work, particularly to:

  o wrap in the ***health equity lens*** to modify/revise the tools,
  o engage more ***individuals at a grassroots*** level, especially persons of color and from diverse groups,
  o enhance ***supports to caregivers*** and ***persons with the disease AFTER diagnosis*** is made—throughout Minnesota, and
  o learn effective methods/means for ***implementation*** and provide support or guidance (especially to ACTion communities) for ***sustainability***.

ACT on Alzheimer's – Background/Structure

ACT on Alzheimer's (formerly Prepare MN for Alzheimer's 2020) is a voluntary, state-wide collaboration seeking to transform the State's medical and long term care systems and communities to better support individuals with Alzheimer's disease and their families. It is a collaboration of medical, academic, community, government, business and nonprofit stakeholders across Minnesota. ACT on Alzheimer's is organized under a unique collaborative structure that is intended to foster collective ownership and accountability for furthering the ACT on Alzheimer's vision. No single organization owns, funds, or controls the initiative. Instead, the vision and goals are furthered through collective contributions of over 300 participants, including over 60 nonprofit, governmental and private sector organizations.

The governance structure includes a *Leadership Council* that provides overall direction and strategy and helps to secure human and financial resources to further implementation, as well as provides guidance to 6 Leadership Groups, a *Management Steering Committee*, that identifies cross-cutting issues and makes decisions that require quick responses to further the work, and the *Project Management* team, including the Executive Co-Leads, Project Director, and Project Manager.

Five goals were set forth in 2011 for ACT on Alzheimer's as follows:
1. Raise awareness and reduce stigma of the disease
2. Increase early identification of dementia and improve care
3. Prepare and equip communities to support residents who are touched by dementia
4. Sustain caregivers with information, resources, and in-person support
5. Identify and invest in promising approaches that reduce costs and improve care

Leadership Groups

Each Leadership Group has had a defined purpose and focus, with volunteers (group members) from various service sectors, government agencies, educational institutions, industry leaders, and individuals. Implementation plans for the first 18 months of work (mid 2011-2013) set targets for work. Thereafter, each group set additional plans based on progress made and evolving interests of group members.

The 6 Leadership Groups are:
- Awareness
- Detection and Quality Health Care
- Communities
- Caregivers
- Investing in Promising Approaches
- Cultural & Linguistic Communities Committee (added in 2012) – renamed the Health Equity Leadership Group (in 2014)

Each Group has a Chair or Co-chair and a defined membership, although others are invited to participate by current group members or through request to the Chair. The roster and contact information for each Leadership Group is maintained by the Project Manager for ACT on Alzheimer's. She also prepares and disseminates the meeting agenda, minutes, and working documents as directed by the Chairs. When the Leadership Group completes its work, information is included on the ACT on Alzheimer's website (www.actonalz.org)

Long Range Goals and Success Measures

Five-year goals were set in 2011 with some "reach" measures.[1] These included:

1) *Increase early identification of Alzheimer's disease and improve ongoing treatment based on recommended care practices* – with measures focused on health care homes and educational programs—settings in which provider practice screening and diagnoses algorithms and training would increase.

2) *Sustain caregivers through access to and navigation of organized information about supportive services and resources* – with measures focused on improving/enhancing the state-sponsored information repository (minnesotahelp.info) around dementia resources, and providing more support to caregivers through dementia-capable navigators and care coaches.

3) *Equip and engage communities in supporting individuals with the disease and their caregivers* – with measures focused on developing a community toolkit and piloting

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[1] *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

the toolkit in 3 communities—with expansion to new communities throughout Minnesota.

4) *Raise awareness about and reduce stigma regarding Alzheimer's disease and related dementias* – with measures focused on communication tools, key messages, a public website and 22 additional Action Communities that have assessed their community for dementia-capability and are showing progress toward change/improvement

5) *Establish and garner stakeholder investment in promising interventions that are projected to bend the cost curve for Alzheimer's and related dementias* – with measures focused on building an economic model that would project the direct and indirect cost of Alzheimer's disease and model promising interventions to reflect economic impact.

The Leadership Groups' activities and the outputs/results they achieved (2012 through 2014) are briefly summarized in Table 1.

Table 1. ACT on Alzheimer's Leadership Groups' Work – Snapshot 2012-2014		
Group	**Activities/Focus of Work**	**Outputs/Results**
Awareness	▪ Develop and orchestrate key messages about the initiative and create identity components and communication vehicles to ensure consistency and to disseminate information and tools ▪ Provide input on the tools and products being developed by other Leadership Groups ▪ Build awareness in Minnesota and beyond via media outlets/formats and through state and national/international groups working on issues of Alzheimer's disease	▪ Changed name of initiative from *Prepare Minnesota for Alzheimer's 2020* to *ACT on Alzheimer's* ▪ Created logo & key graphics ▪ Created website as the primary information source and dissemination vehicle ▪ Consistency in look, feel, and messages across ACT products ▪ Templates to support work of ACTion Communities ▪ Extensive local, regional, state coverage, as well as some national and international coverage of the work of the initiative ▪ ACT on Alzheimer's awarded the 2013 *Age Odyssey* Policy Award by the Minnesota Board on Aging

Detection/Health Care	▪ Create a "Compelling Case" for early detection
	▪ Develop a practice algorithm for providers that lays out the pathway from screening to diagnosis, to follow-up
	▪ Identify ways to incorporate the practice algorithm into electronic medical record systems
	▪ Develop a resource to guide Care Coordinators
	▪ Develop Community Based Organization resource on Mini-Cog screening
	▪ Develop "Dementia Curriculum" as educational modules for training students (medicine, nursing, social work, etc.)
	▪ Work with MDH on Health Care Homes – to provide input into certification standards and to bring work of ACT on Alzheimer's to current certified HCHs via Learning Collaborative conferences/sessions
		▪ Full array of provider practice tools developed:
		  o Physician Practice Tool
		  o Care Coordination in Health Care Settings Practice Tool
		  o Community Based Organization Practice Tool
		  o Dementia Curriculum
		  o Dementia Trainings for Direct Staff Resource Grid
		  o Smart Set template
		  o Mid-Late Stage Tool
		  o Working with the Caregivers Leadership Group – "After the Diagnosis" caregiver resource
		  o Provider videos
		▪ Collaborated with MN Dept of Health to plan and conduct educational sessions about detection and follow-up in Health Care Home Learning Collaborative conferences (held in 2013, and 2014) attended by hundreds of care coordinators, clinicians, and administrators from Minnesota's 225-300+ certified health care homes
		▪ MN Dept of Human Services incorporates the ACT on Alzheimer's provider practice tools into the 2014 Community Services/Service Development Request for Proposals
		▪ Collaborated with University of Minnesota and Mayo regarding their use of the Dementia Curriculum in teaching/training students
		▪ On the national level, working with the Health Research and Services Administration (HRSA) to have the ACT on Alzheimer's dementia curriculum incorporated into their work to create a national dementia curriculum, as required by the National Alzheimer's Project Act Plan.

Table 1. ACT on Alzheimer's Leadership Groups' Work – Snapshot 2012-2014 - continued		
Group	**Activities/Focus of Work**	**Outputs/Results**
Communities	▪ Create a Toolkit and process to guide geographic or communities of interest to gauge their current strengths and gaps in being "dementia-capable" ▪ Pilot the Toolkit; make revisions ▪ Assist Minnesota communities who step forward to use the toolkit towards becoming "dementia-friendly"	▪ *Dementia Capable Communities Toolkit* developed & tested (2012/2013) ▪ Toolkit revised (2013/2014) ▪ 33 ACTion Communities in process of using the Toolkit – moving from Phase 1, 2 & 3 (Convene, Assess, Analyze) to Phase 4 (ACT based on plan) and beyond (2014) ▪ Funding (small grants) for these 33 communities - provide support for admin and supplies costs (effort is otherwise voluntary unless local funding exists) ▪ Funding secured for Area Agencies on Aging and Alzheimer's Association to provide technical assistance to these 33 communities ▪ ACTion Communities Learning Collaborative ½ day sessions held (2 or 3 per year) to encourage cross-site exchange of ideas and lessons learned
Caregivers	▪ Provide expert input to the Minnesota Board on Aging and MN Dept of Human Services regarding enhancements to AAA Senior LinkAge Line® call center staff training and on MinnesotaHelp.info® resource tool/database site navigation ▪ Work with the Detection/Health Care group to developed a tool to coach caregivers through the journey ▪ Advise other groups, as asked	▪ Enhanced training for Area Agency on Aging staff which is now incorporated (embedded) in training for all SLL call center staff ▪ On the provider portal of MinnesotaHelp.Info, added additional options for providers updating their information to indicate dementia programs ▪ "After the Diagnosis" resource developed, edited, printed and available on the ACT website
Investing/Economic	▪ Develop economic model to test/demonstrate the impact of using evidence-based dementia care interventions on health care costs	▪ Economic Model developed using the New York University Caregiver Intervention (NYUCI) – also known as Family Memory Care – which can be used in the future to study other evidence-based interventions as well ▪ Article published in *Health Affairs* showing a potential cost savings of $1 billion to Minnesota taxpayers and families. Article later receives recognition from the editors of *Neurology Today* as "truly revolutionary" work.

Table 1. ACT on Alzheimer's Leadership Groups' Work – Snapshot 2012-2014 - continued		
Group	**Activities/Focus of Work**	**Outputs/Results**
Cultural and Linguistic Communities Committee; renamed *Health Equity*	▪ Focus attention on diversity; work to enhance the work of ACT that includes a "health equities" lens ▪ Review work of other ACT Leadership Groups and provide feedback ▪ Develop vision and "Call to Action" for health equity to add to the ACT goals and vision ▪ Provide guidance to ACT Leadership Council ▪ Support work to fund diverse ACTion communities through grant process	▪ Identified/recruited members from various cultural communities to form a Health Equity Leadership Group ▪ Created document titled "Preamble" which outlined principles and values in fostering health equity in dementia-related care and activities ▪ Created a"Call to Action" (Reviewed American Indian Elder Rights Declaration and MDH Health Equity Reports) ▪ Worked with ACT staff to redesign ACT logo to include vision of health equity ▪ Health Equity embedded as a fundamental value and goal in ACT initiative ▪ Met with chairs of Investing/Economic, Caregivers/Public Awareness, ACTion Communities and reviewed, provided input on revising ACT tools & Toolkit – including adding health equity information, principles, and questions for consideration in the curriculum fo health professionals ▪ Supported funding applications for culturally-specific dementia-friendly community work (3 created) ▪ Representation in multiple ACTion communities -- from African American, Native American, Latino, Deaf, Southeast Asian, LGBT communities and agencies and initiatives that serve culturally-specific communities, e.g. JCC and St Paul Neighborhood Dementia-Friendly Community. ▪ Leadership Council meeting to be dedicated to health equity in May 2015.

Evaluation Component: Key Informant Interviews with Leadership Group Chairs

A private foundation[2] is funding a modest process/formative evaluation of this initiative to document progress toward the ACT on Alzheimer's goals and objectives. As part of this evaluation, key informant interviews were conducted between late October and December of 2014 with the Leadership Group Chairs. Interview questions were mailed prior to the interview. All were conducted by phone. The interviews generally took 1 hour each. The focus of the interviews was on the key activities and the outputs/results that had been achieved. Chairs were also asked to comment on lessons learned about implementation, what more needed to be done, and how to measure results. A summary of the responses is provided first, offering common themes, followed by the detailed responses.

Summary/Common Themes

Key themes emerged from these engaged leaders, as they discussed the ACT on Alzheimer's initiative and the activities of their respective Leadership Groups. These included:

- *Structure/Process -* The structure/process of ACT itself (built on the foundation of voluntary, collective action which is not owned by any single organization), as well as the caliber and credibility of the people involved—were two factors instrumental in getting people to come to the table and stay involved.

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- *Tools/Resources -* The prolific development and then testing/piloting of tools and resources was notable—much was accomplished in 3 years.

- *Timeframe & Work to be Done* – All of the Leadership Group chairs discussed the need to continue the work, particularly to:
    - wrap in the *health equity lens* to modify/revise the tools,
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[2] GHR Foundation

Detailed Responses

Q: **Overall, how would you evaluate the work of ACT?**

The growth of the initiative, and the engagement of 33 communities to examine their dementia-capability, is significant.

I think my comments will be consistent with others. I've been shocked at the amount of tangible outputs that were created through the ACT initiative. I've never seen anything like this. Regarding output – a benefit of this leadership group structure has been the professional connections across organizations. It's been really neat. Tremendous sharing across organizations and this continues.

From the beginning with just 20-25 leaders to the present—we much more than tripled the number of people and organizations—this is really significant. The coming together of collaborators; the networking and growth—this is an important outcome.

The health equity work itself is one of the most significant things that happened. We are starting to see more attention to this—for example the Health Equity Report that came out of the Minnesota Department of Health. The blind spots are starting to be pointed out, and starting to be addressed. There is "intentionality" to that—which is huge. This only came about because the whole group was committed to a democratic and collaborative process with open dialogue—and a willingness to hear various perspectives. Traditional ways of having one agenda and staying action-directed may not fit the grassroots and more relationship-based, informal, discussion-style nature of ethnic and diverse communities.

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I would say I think ACT has been particularly effective in bringing together organizations in the aging and health care communities around the issue of AD – at an unprecedented level. Really extraordinary in bringing organizaitons together and uniting them around a specific issue. This was a new form of collaboration; seeing results in a fairly short timeframe. Another hallmark has been really strong communication—this concerted effort to keep everyone informed and involved--at all levels—the Leadership Group, Steering, management, etc. The communication pieces are succinct, yet informative and manageable.

It is amazing what has been done in a short amount of time; people coming together voluntarily and working in a non-competitive way. This is really impressive.

ACT is doing wonderful work. The Community work is probably the most beneficial, because it is bringing awareness to the issue. Also having so many organizations and individuals involved—it is remarkable, the length of time that folks have stayed involved. That it is a statewide collaborative is fabulous. The education and toolkits for the doctors and the communities is phenomenal information. Hopefully all this will trickle down. We need to keep pushing this out and keep the momentum going.

Personally, it's been incredible. I don't know of any similar effort that has had so much buy-in and produced so much in such a defined period of time and kept up momentum.

The ACT structure itself –right management, getting the right people involved. It's worked really well. Cut down the noise and the process. The structure liberated folks in the cooperative. I think it's been inspiring.

I would evaluate it very highly.

I think that, having been there from the beginning, the whole ACT initiative (and all of the tentacles) has gotten a lot more success than anyone anticipated. The sum of the parts has exceeded expectations. What ACT did was build-in portions that will be sustainable. There are pieces of the work that will have a life of their own regardless of the structure. That is a very rare thing. We don't know now how much the tools will be used now or in the future. How far the tentacles have reached – I don't know how we could really capture or assess that. We talk about the end products and replication of the model/approach. Example Citizens League – having "Aging Conversations." We talked about the collaboration model of Act on Alzheimer's. We will know or sense the impact in hindsight, most likely.

> *I think that, having been there from the beginning, the whole ACT initiative . . . has gotten a lot more success than anyone anticipated.*

Q: Regarding your Leadership Group work, what were the top outputs of this Leadership Group?

Detection & Health Care: We had a very busy productive group. The 7 provider and other practice tools that were created and vetted. Provider practice tool, EMR decision support tool, implementation guide for health systems, mid-to late stage tool, Tool for caregivers, Community organizations, Tool for patients and families. Educational modules/curriculum and the development of the presentation slide deck – to more widely disseminate to physicians and social workers. We are also creating 3 minute videos – almost all finished – on 3 different screening instruments – all with real patients. Mini-Cog; SLUMS, MoCA. On the web site we will be able to measure usage statistics. Also how to deliver a dementia diagnosis, how to do care consultation from a social worker point of view. Those can stand alone—another output. Providers, like anyone, once they see something being done – make it more real.

Health Equity: A number of those involved in the ACT initiative recognized that there was an opportunity and need to make a difference in communities of color and other groups, particularly those groups that have been traditionally underserved. This includes, for example those who have unique needs or perspectives, such as the deaf community, ethnic minorities, non-English-speaking communities. We identified and recruited people to participate from these and other diverse communities. We came together. We had to create some momentum, since we had not been part of the Leadership Council from the beginning.

We discussed the concerns and issues of various diverse cultures and groups. What were common issues? We used facilitation practices that focused on relationship-building, creating mutual understanding of our different and our shared experiences.

We wrestled with finding the right balance between policy and practice impact. We did not only want to influence the work of the Leadership Groups. We worked to assure that the overall initiative truly represented all of the communities impacted by AD.

This emphasis on policy impact led us to review the Native American Elders Declaration of Rights, and the Minnesota Department of Health – Health Equity Report. From this we developed a Call to Action focused on health equity and a Preamble stating the principles and purposes of this work. We also intentionally began engaging other Leadership Groups, beginning with the Detection and Health Care group—to actively comment and revise their tools and work products.

Communities: Deciding that a Communities Toolkit would be the way we could help Minnesota communities work together to become dementia-friendly, then developing that Toolkit. We were very intentional about this—having a Toolkit and process. We looked at the literature, and drew on the experience of the Lifetime Communities work. The Toollkit was structured, but not too bureaucratic or burdensome. The second part of that was the funding—recognizing that having a little money to support the community engagement work would be key. Then having so many communities actually engage. We weren't sure that many would step forward. The willingness of leaders to volunteer and help facilitate the work in their communities and the sector involvement—all of those things have been important.

Outputs include the increased resources available to communities and the assistance available to them for working through the Toolkit and process. Now this work is evolving as the communities have best practices—they can learn from each other and share successes.

Caregivers: I think that originally our group wanted to focus on caregivers as a large and invisible community. We needed to give voice to their needs. We came up with a list of many of problems they deal with. A big part of what we wanted to do is increase the awareness; increase understanding of the caregiver.

The original Working Group didn't have a caregiver component. That made it difficult to incorporate the caregiver voice in this group, as ACT was building off of the recommendations of that Working Group. It was not clear how the caregiver would be incorporated; perhaps it

should have been woven into all of the groups, rather than a stand-alone. The other groups had specific deliverables and an organized framework with funding to move those things forward. Because we are individuals, without the backing of big organizations or funding behind us, we turned into a reviewer group for other efforts. We had some very important suggestions. Our Leadership Group has discussed many of the common issues that arise during the course of disease. David made a phenomenal matrix where he went through the stages of the disease. ID, Early, Middle, Late, End of Life. This was very important work.

Early on we were hoping to have a caregiver coach for each caregiver. We have supporting information on how important that is. It helps avoid isolation, crisis. It provides timely supportive resources for caregivers. So our group was focused on 2 things: (1) competent, consistent care management from beginning to end for each caregiver, and (2) access to easy, navigable information that is not overwhelming, but adequate to the specific task or need. We are definitely not there yet. Obviously, this has policy and payment implications. As we all know, change happens at a glacial pace when you are talking about big systems—such as health care or government. I believe we did influence thinking and hopefully future policy.

We also talked about self-help for the caregiver. We ended up doing a lot through the DHS and helped with teaching on training for the Tiers for caregiver consultant and phone line staff. We spent a lot of time reviewing Minnesotahelp.info database. We reviewed it extensively and made many recommendations. I am not sure how much it was changed. We looked at the Navigator. We reviewed the brochures going out (the After the Diagnosis brochure, for example). So we were a resource to other Leadership Groups.

ACT is listening to caregivers. We are still at the table. We are still asking the question about how all of these things are trickling down to the caregivers. How are families experiencing these things? I feel that might be the last piece...it has to change the experience of the caregivers and persons with the disease. This is where those other things (tools, etc.) come together. We have laid the groundwork. There is still work to be done here. More advocacy is needed. We are working to get more health networks and health plans on board—this is all good (that they recognize the issues)—but they are not at the point of saying "here's your prescription for a caregiver coach."

Awareness: *This has been a tremendously productive group. We have three primary areas were we've worked: (1) the identity and messaging—transforming from PMA 2020 to ACT on Alzheimer's, (2) the website, and (3) the resources – from scientific, research language to more lay language.*

Economic: *We did the bulk of our work in 2012 and 2013. It has been very exciting, interesting, lots of new "ah-hahs." Important questions for research –e.g., how do you determine numbers, what does the evidence say, how do you define costs? What prevalence figures to use? What models and methods and examples are there around making economic determinations and analyses? We had a good turnout in every LGp meeting. An intangible is how folks took this home and used it. However, it is expensive to do this work. Research costs money. At the end of the day we have a unique model. We have publications. We have*

citations. We identified, studied, published. But that didn't move the dial to the investment part. I'm political, so it is not a surprise. The investment is long term and that is rarely done in policy – mostly short term focus, by necessity. So more work to be done.

Q: What have you learned works in terms of implementation or dissemination?

Detection & Health Care - We learned that it is a lot easier/faster to create a best practice tool then to implement it. Also there is a challenge with depth of implementation. What seems to work best is to those leaders who can actually make policy changes. It is a lot harder to do than it sounds. In my organization we were able to find several providers to pilot some tools, but it is a lot harder to implement system wide. Find champions – works especially in smaller organizations. In systems there is value in having one clinician say to another – this is useful. Clinicians – we need them for content expertise – but they are not always drivers of change. It is a slow process. We worked in our own Dept. of Neurology. The tools are available in our whole dept—our Chair is on board. Lessons learned are more tangible. This gives the tools and us more credibility. The Smart Set is also embedded in Neurology.

You have to be persistent. Can't just give up. Keep bugging people enough and showing them the value. It is a lesson in Public Relations—you need the right message. We had to talk about detecting dementia not for treatment—but for quality indicators. We found some success with that. There are 85 quality measures that doctors are rated on…e.g., Diabetes – on patient management – that come into play. Dementia wasn't on this list – clinicians didn't want to add one more measure. So we talked about dementia as a hidden barrier to patient compliance to any ongoing treatment. Showed base rates – on how common this is as a secondary condition. That was the message that resonated. This is because it directly impacted their practice. The other thing they said: This is great, but if we detect this condition, then what? Need tools for follow-up and help. Therefore, on the intervention side we pointed to the Care Coordinator tool. Easy button EMR tool – a whole piece on the management – includes education – I don't have to memorize the medications or dosages, because there is education above each box you can click. You don't have to dig out the # of the Alz Assn. Lingo about driver evaluation.

Health Equity: We are learning more about each community and its unique issues and challenges. For example, the Somali community, the Latino community— how they see and deal with or interpret memory loss and dementia. This led us to see how communities share information and how they discuss this issue. The Community Toolkit and the typical presentation and process may not work for all. For example, there was a doctor who hosted a community discussion about Alzheimer's. He did a call and response type of format—

> *We are learning more about each community and its unique issues and challenges. . . we have just started to hear the voices of communities of color and diverse communities.*

which really engaged the audience/community participants. He did a small group table-top exercise on memory—people were chosen and did the memory exercise. This was also engaging. They did not hand out evaluations—these were done verbally as a group. This approach to evaluation took into account different education levels/reading levels, dialects—it really worked.

We have just started to hear the voices of communities of color and diverse communities. Some of the communities most affected by Alzheimer's are just starting to get involved and have a dialogue. So we know this is going to take time—and we have to give it the time it needs. Implementation is not a linear process.

Communities: *We've learned that having the Toolkit tested and then revised based on the experience of real communities was important. Having grants that could fund communities was critical for dissemination and then engagement. The role of the AAAs was also important to bring this possibility to the communities in Minnesota.*

We are just beginning to learn what works on implementation and dissemination – there is still a huge learning curve on what the dementia friendly community is and what the Toolkit is all about. The first round of applicants – they knew what they wanted to do – evolved more into a community engagement process. However, in the next round, the focus was on having the assessment tell the community what it wanted to do. The idea was to build off of the surveys and assessments. So it was not as clear for them at the beginning. Some communities are now moving into Phase 4 and just starting to implement an ACTion item. We see that many times the goals come back to building more awareness as to what is there in their own community. They are finding out there are a lot of resources available but people don't know about them. So this is one important finding.

> *We are just beginning to learn what works on implementation and dissemination— there's still a huge learning curve on what the dementia-friendly community is . . .*

We do need a movement to continue implementation – there is going to be a point where the majority of the tools and things will be done and then it has to sustain itself at some level. We want to get the tools implemented into health systems. We want to ensure that there is follow-up after diagnosis. For the diverse communities, we definitely have some work to do. We also want this to continue, to be self-sustaining, in the communities that have taken action.

Caregivers: *Unlike the other Leadership Groups, we are a collection of individuals more than organizations. We relied on the Department of Human Services and where they wanted to or could go. Our presence and advice was important, but we ourselves cannot implement. Some things have a significant cost – who is going to pay for what caregivers really need? Going forward we need policy and advocacy support--some coalition or group that will advocate for the needs of caregivers and help direct resources toward their needs. Research is showing that*

the person-to-person coach, a person who could help, listen, guide, is needed. We need to simplify all of our systems and make it easier for the caregiver to get human to human help that is consistent and ongoing. Most caregivers don't reach out until crisis.

I believe in the importance of embedding. That is huge—so refining the products and focusing on adoption, implementation, and embedding—that is the next important piece. The health equity group will be a great force for this—making the tools and processes more amenable to community use and to all types of diverse populations.

__Awareness:__ We've learned that having people with a personal connection to the issue makes this important to them. We've learned that having the administrative and organization components, together with regular communication—is key. The meetings are efficient, well-organized, they start and stop on time. They are directed and focused on producing. The information and decisions are then communicated widely. It is tangible.

Implementation is the $10,000 question. How to get champions embedded in the health systems. How to get the tools embedded.

__Economic:__ I learned a lot about the value of publications and evidence-based research. How you make assumptions on population health. How you create such a model and what it can be used for. We also learned it is difficult to translate research into effective policy changes--some entities want to take this on as their own—loses the benefit of collaboration. Also, what do you mandate? Who gets the money? Different players have different perspectives. So there are issues in ownership and control issues.

Regarding implementation, clearly the people around the table were not the policy implementers – they were the health economists. There wasn't really a hand-off from completing the model and publication to what happens next. Who takes it from here? Regarding dissemination, publication is great—a good awareness building of a model and economic arguments that could eventually influence change, policy. There may need to be other ways to get to the health plans or other potential payers – to disseminate and inform in a way that spurs action.

Also, there are long term benefits of the published research on a more global scale. The model and summary results will potentially be used in all sorts of future research and we can only surmise that there will be a ripple effect and a continuation of the themes brought forward with the publication.

Q: How would you measure results and impact?

__Detection & Health Care:__ I would say on the practice tools, to have the number of health systems that are using them. It would be good to have each health system or provider have a base rate of # of people diagnosed—and compare before the implementation of the practice tools to after the use--to see if the # of people diagnosed increases. So measures would be the #

of clinicians and # of clinics using the tools. Regarding the Health Care Homes (HCH), the state can't mandate the use of these tools, but they could have mandatory reporting on some metrics—getting dementia indicators on that list, such as the # diagnosed with memory loss, the # of cognitive screens done or the percentage of patients with cognitive screens. There is one related to caregivers, and that is a start.

We are piloting the slide deck and using an evaluation form that asks questions such as: What was useful? Who was the audience? Would practice change happen as a result? We have open-ended questions. The evaluation forms are going to Emily for compilation and analysis.

> *Key things still need to be accomplished, such as having this be more community-led by individuals*

Health Equity: *There are three areas of impact: first, the enthusiastic adoption by two of the Leadership Groups of the health equity principles. Second, the work we've been able to accomplish in embedding health equity principles and cultural responsiveness into the provider tools. Finally, I would say the growth in more than 30 communities engaged—bringing forward vital discussions and action. Key things still need to be accomplished, such as having this be more community-led by individuals, not only the professionals and determining how to embed health equity principles within their community planning. The demographics of the professionals don't match the demographics of the residents/communities yet—there is an imbalance.*

Communities: *We should look at the level of engagement of the people and organizations who come to the table. Look at the breadth of the community sectors that are engaged. Regarding impact, we should look at whether the communities were able to identify priorities and move to project implementation work. Did they get to one or more action steps?*

> *When the community work gets to the caregivers— that's when this has paid off.*

I would say overall, it is the bringing together all of our organizations in one place. We all have a stake in this issue of AD – how it is impacting our organizations, our staff, our clients, our company. We want to also measure what happens to the caregivers—what happens after they get the diagnosis.

We have to see diagnosis earlier—more doctors aware and using the screening tools. We have to have the philosophy of early detection embedded throughout the State of Minnesota. Then we have to get local resources—additional services in the community—social workers, caregiver supports. It has to be accessible, local for caregivers.

Caregivers: *When the community work gets to the caregivers – that's when this has paid off.*

We have some more work to do on learning from caregivers and incorporating their valuable perspectives and responding to them. Examples include:

- o *On the provider practice tools and looking at the process flow – when someone suspects they have the disease, the ACT tools strongly encourage early detection and contact with the physician. The protocols are about screening and diagnosing. After the diagnosis there was one paragraph about the caregiver. Very little about the caregiver in this. We worked on the "After the Diagnosis" brochure, which was an important resource. However, there are still missing pieces on the process flow that the system supports—how the PWD and the caregiver find out about local services, resources and get connected to them with guidance.*

- o *Another example may be seen in the Community Toolkit—it is great to focus on the service sectors, but there is really no survey instrument designed to capture the gaps/resource availability/dementia capability perspective of the AD caregivers living in that community. Those caregivers may be the most knowledgeable about navigating in that community, therefore a survey that is designed to capture their insights might be a good addition to the Toolkit*

What ACT accomplished was impressive, as follows:

- ▪ *33 communities are fully engaged – that's huge. A critical mass. Local level changes are happening. We always talked about raising awareness and changing the culture and helping more sectors to get involved. This is helping to do that.*
- ▪ *The creation/process – Practice guidelines--tremendous. The process was as important as the resulting tools.*
- ▪ *All kinds of ripple effects. DHS funding dementia-capable health care homes and other Influence around the state*
- ▪ *Creation of the overall dementia curriculum – this allowed us to create the dementia capability training series for AAAs and care consultants, also to educate professional and preparing them.*

Helps put the caregiver stuff in context. When you have a multi-faceted agenda, there will be key things that rise to the top.

Awareness: I think I'd measure it in two ways: (1) how many health systems and other entities are using the tools, and then (2) what is happening in the communities using the Toolkit—what is the action. We went from zero to thirty-three communities. That is impressive.

Economic: The ripple effect of the Health Affairs publication and the development of our economic model– the national influence—federal organizations and policymakers read these publications too. Having Minnesota in the positive spotlight is a big deal – we don't know how far that will influence/go.

Q: Do you have ONE example related to a change you have seen ---that you can share?

Detection & Health Care: Yes. We've seen that Neurology in our organization is starting to screen all patients over age 65. We have seen an increase in # of referrals to Neurology from primary care physicians. Also physicians are taking on more of the ordering of lab tests, neuro-imaging, etc. They are following up with these diagnosis tools; this is very encouraging.

Health Equity: Yes, we have seen the formation of this Health Equity group—also that it is more universal, not only based on color/ethnicity.

We have developed the Call to Action and the Preamble—this is influencing policy and having direct impact on the tools and discussion within the other Leadership Groups.

Communities: I would say the increase in understanding of Alzheimer's disease and of caregiver issues by the Area Agencies on Aging is one change I've seen.

Breaking down the stigma—for example I'd like to see in these ACTion communities a change, so that it's okay to go out in public—having that be discussed in so many communities—that can have a lasting impact.

Caregivers: The 32 communities. Awareness is growing. As these and other communities becoming more aware of the disease, people will accept the disease more and realize what a burden and problem it is. ACT bringing together partners; this has been really crucial.

There are a number of health care systems that are implementing a part of ACT—specifically the provider tool. It is a distinct change. The Mini-Cog is being widely implemented. Health care homes are looking at this. Also, there are changes in the behavior in the agencies and organizations involved in ACT – They share resources, open dialogue, work together. It is happening much more readily.

I'm involved in the Jewish community. There was a full rabbinical training across synagogues. One of the synagogues is doing a 3-week movie series. There is great attendance and discussion afterwards. Just in the first one 90 people came and of the participants/audience, 9 people came forward with their needs, of which 3 were actually in crisis. This work has also appeared in the Jewish World News, so it reaches far beyond one community. In May we will have a Dementia Conference.

Awareness: Yes, I do. I went to a health system—and the people there did not know I was involved in the work and we talked about Alzheimer's—they went and got the tools and showed them to me—said that they were some of the best developed pieces they'd seen.

Q: Where do things go from here?

I think it is a great idea to have the Health Summit—now that the tools are done. Getting the health system leaders around the table all at once. I also believe a Speaker's Bureau will have change practice. Grand Rounds, offering CME credits. Offer them tangible tools and see them in use. I'm also pleased with the Health Equities Leadership Group being formed, and helping to focus on diverse communities and groups. Our Leadership Group is working with theirs. We are working together to identify goals and resources and priorities. We want their input and perspective reflected in the tools or to have additional stand-alone tools.

We absolutely have to keep this going. We need at least a couple of years to learn how to successfully embed these tools in organizations and communities. We're going to need the collaborative overall structure to keep having us come together—otherwise it's too easy to default to our silos. We need a core administrative/project management/logistics driver keeping it all together.

There are lessons to be learned from other initiatives regarding implementation and sustainability—research and literature on this.

We will have a Health Leadership Summit and perhaps we can also have a Community Leadership Summit—of equal magnitude and importance. We need to bring in more grassroots community involvement. We need more time.

We need to help communities to galvanize around health equity principles as well as enhance their cultural responsiveness.

> *We absolutely have to keep this going. We need at least a couple of years to learn how to successfully embed these tools in organizations and communities.*

What we haven't really done yet is understand what knowledge and resources can and should be embedded in the community. For example, identifying memory issues is not only the purview of the doctors—it is the community. There is a lot of community wisdom that should be more fully developed. We need to engage the family members, social service agencies, etc. It is about noticing and providing supports, not only running to the doctor to get a diagnosis. We need to talk and work more on this. Especially on the non-medical arena. We need to broaden our approach and our tools. We can learn from these communities about how they support their elders and how they come together and how they cope—and strengthen those things.

What is staring to percolate—particularly among the communities that piloted early on and those who are in Phase 4 of action—is to ask "What's next?" They want to come together and meet as a cohort. Share their knowledge, experience, tools, learning.

Also, there is work to be done on a few fronts. For example, we have to learn what are the effective mechanisms from bring the provider practice tools into actual practice. The caregiver support pieces—this has not materialized as hoped—so we have work to do to ensure that the

Minnesota caregivers experience enhanced support and guidance. There is always need for more training and keeping that going as staff turnover will always be occurring.

Yes, the issue in these 32 communities and beyond is how to sustain action. What happens after the ACTion item is completed, and grant ends (after Phase 4). Communities are starting to talk about this – sustainability is an issue.

We just had a Steering Committee – everyone wants it (ACT) to continue. As someone said, we've set the framework but haven't built the house. We all recognize that the Infrastructure of ACT is the glue that keeps things going. It can go on without any specific individual at this point. We have enough foundation. For example, Olivia was so important initially, but now we can build from what she helped create. There is a natural life cycle for every initiative. We are at a transition point that is natural, expected. The good news is that there are so many that still want to be table. The work is what drives people. It is not dependent on one or two people.

What is starting to percolate— particularly among the communities that piloted early on and those who are in Phase 4 of action—is to ask "What's next?"

At that meeting we also recognized the need to redouble our efforts to ensure this is reaching caregivers. We modified our graphic and added a bubble at the top – "ensure that caregivers and people with dementia benefit from the ACT efforts." We have more resources now on the professional side—is it reaching the caregiver?

We need to get the tools and resources refined, adopted, implemented and embedded. We continue to need the overall orchestration of this. Innovation happens, but then they have to be folded into long-term planning and funding. They have to get to the point where everyone with the disease and every caregiver benefits. Year after year we deliver more services, but very few people who need the services get them.

Caregivers don't have an organized voice. They don't see themselves as caregivers. They don't like the term. There is no public voice for that constituency. The problem is with the word. You are a husband/wife/daughter. You are not leaving that role. It is a piece of what you do in your role. We are never going to fix that problem. Wilder did a whole initiative around trying to convince people they are "caregivers"—yes, but the first role is husband, wife, son, daughter—it is very personal. What you call people isn't as important. Get rid of the fear. Normalize this condition and this journey.

We have to fix the systems around these caregivers—not expect the caregivers to take the lead and navigate our processes or systems.

I can't speak about what is happening in the provider world, but the national and international recognition is continuing and reaching further.

There may be marketing and other communication materials that the Awareness LG can put together for communities—we see that they have communication needs that are not fully met. It does take time and money. Perhaps there can be templates and more ready-made pieces for them. Maybe a statewide campaign or a big community awareness effort.

We have to fix the systems around these caregivers—not expect the caregivers to take the lead and navigate our processes or systems.

Where things go partially depends on what the framework is going to be for any additional ACT on Alzheimer's related work. If, for example, the Naylor transitions results are published—we have a lot of people interested in that; we could do the economic analysis on that. My hope is that an ad hoc group would raise some funds to get the next intervention through the model to identify value.

The other thing is – we do have a model/research on this caregiver support. We don't own it. It's free for someone to take and utilize. We could team with others. We need to have that kind of collaboration for the best work product. Negotiation and collaboration – especially if it touches on policy work and funding– has to be collaborative.

My fear is if the whole structure goes away, we cease to exist as a collective. And the ACT lens gets clouded.

Q: What are your overall lessons learned for the ACT on Alzheimer's initiative as a whole?

Detection & Health Care: It is helpful early on to have decision-makers at the table. Get them at the table early. We need senior administration drivers. Also, our Leadership Group was smaller and more manageable with content experts—that helped us be more efficient in developing the tools. Then we could bring it to other groups for their input, e.g., caregivers, consultants who work with mid to late stage—they made brilliant suggestions. So it is an iterative process – develop, refine, test, refine, develop another tool, etc.

It is helpful early on to have decision-makers at the table.

Health Equity: It takes a lot more time than you think it would take for an effort such as this, but it is worth the effort. People need to expand their vision. We have such poor representation of communities of color overall. This awareness is starting to sink in. We need to pace this work. It will not happen overnight. If you see how long it took the Health Equity

group to form and become a leadership group – it took us 18 months just to form and have our principles.

Everyone regardless of their ethnic or cultural background can be an advocate for health equity principles and help decrease health disparities. Creating cross-cultural and multi-ethnic collations takes time, communication and energy. We have yet to create that across all the Leadership Groups, so the "majority" participants must not give in to apathy. Trust takes time to build and trust is what is needed to help communities of color, Native Americans and cultural groups to feel like they WANT to be at THIS table in order to create something beneficial for themselves.

Communities: *I still think it is really a fascinating initiative in that it is a collaboration--voluntary in nature. The idea that no one organization owns it seems very important. And yet, despite that, the initiative has been able to make decisions, follow-through and have action happen. Key ingredients have included: Olivia and her leadership, the caliber of the representatives involved—people of high integrity. The credibility and maturity of persons who are involved. They have deep knowledge and long-standing relationships. They have made a commitment to the issue and to doing something together. Many of the roles that people are in--they've been in these roles for some time and they know each other – high credibility. Due to the many years of working together, there is a strong history and strong level of trust. Professional and personal relationships were tapped. These are accountable, passionate people.*

> *I think this worked in part because the structure was really unique— because everyone owned it, the buy-in was much greater.*

Another thing was that the ACT initiative built off of the Alzheimer's Disease Working Group—that early foundation was important. Also that the Alzheimer's Association was able to participate but not have to lead—they could step aside and allow the democratic collective action process happen—this was significant too.

I think this worked in part because the structure was really unique--because everyone owned it, the buy-in was much greater.

Caregivers: *For me, personally, I am learning so much—and I was already a person well-versed in this issue. I've grown more. I see the implications for policy. I'm more political now and ready to do advocacy work. I'm ready to help more to give caregivers a voice. That said, I want to say how much I appreciate the true concern and honest desire to improve the situation—that has been shown by everyone involved. Everyone is putting so much of their own time and effort into this. As a family member it makes me feel so good. We are at the forefront at the nation.*

We learned that a personal ask of the right people to participate in a defined way, with the structure of the administration/management behind the "ask," works. Olivia and others worked their personal and professional networks to get all of these people participating. You need the right, passionate people who are collaborative in nature—non-territorial.

All of the work that's been done is necessary to get the momentum. The groundwork is now laid. Tremendous foundation. Made a huge start. But we're not finished.

Awareness: My organization sits at a lot of different tables, working with many different groups and committees. This ACT has so much more happening than most. What makes this different is the voluntary collaborative nature of the structure and commitment of people. It is an important component—key ingredient for the success that we've seen. It can't be owned or even led by only one organization. The structure and process have to be both efficient and democratic. We accomplish things and people still have a voice. That is energizing.

Economic: The collective action approach does work. That is the overall lesson. I also know and believe that you need a strong cheerleader –Olivia is exceptional. She knows each of the people on the Leadership/Working groups – who they are, what they are doing. Olivia asked many people to come to the table – personal asks. She did most of that. She had a very strong network. She knew who to ask or knew who would know who else should be at the table. She made it the place to be. It did become kind of competitive. People wanted to join. Part of that was the function of who had said yes, and Olivia's leadership style and engagement. The strategy was to get the right people in the room, the right talents – the facilitation, the communication was provided to take away the administrative burden and let people focus on the work. The work was targeted and the discussions were very current – and directed. It's hard to manage large groups – so breaking this down into smaller groups – and smaller still if needed – but then tying that back together. That was part of the structure/strategy too. The meetings themselves were orchestrated into getting to outcomes. Administrative support for getting the agendas and materials out – didn't have to take minutes, but could participate. This made it all possible.

> *The groundwork is now laid. Tremendous foundation; [we] made a huge start. But we're not finished.*

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