

Memory Cafés in Massachusetts



**Percolator Memory Café Network
Quarterly Idea Exchange
December 8, 2021**

Today's Agenda

1. Housekeeping
2. Announcements
3. Today's topic: how guests living with dementia can help design and guide memory cafés
 1. DAA Board panel: Mike Belleville, Laurie Scherrer, Jackie Pinkowitz
 2. Percolator survey results
 1. Effective practices at many memory cafés, with 6 mini-presentations
 2. Your challenges
 3. Discussion about your questions
4. General discussion
5. Next idea exchange: **Thursday, March 10, 1:30 – 3:30 pm EST**

Housekeeping

- This meeting is being recorded. The recording will be available at www.jfcsboston.org/Percolator in approximately 1 week.
- Please activate your video if you are able to do so.
- Please keep your audio muted unless you are speaking.
- Please use the chat box or “raise hand” function to share your questions and comments at any time.

Say hello! Please type your name and location into the Chat box.



Percolator Updates

- Has your café been meeting as a “hybrid” – with a group in person and a group online at the same time? Contact Beth to share what you’ve learned at our March 10th idea exchange!
- Looking for your feedback! New Percolator survey coming soon.



Percolator Updates

- Massachusetts cafés – PLEASE review your listing at www.jfcsboston.org/MemoryCafeDirectory

Directory of Memory Cafés in Massachusetts

This directory has been developed to help you find memory cafés in your area. You are welcome to attend as many as you wish!

We are pleased to list the following organizations and websites as a public service. They are not endorsed by JF&CS and this is not an exhaustive list. Any questions or concerns about any Café listed below should be directed to the contact person indicated.

If you would like to add or edit any information on this list, please fill out the form at the bottom of this page, or contact [Beth Soltzberg](#).

Thank you to
Rachel Birtwell,
Emily Williams
and Tali Frank!!

Updates



Percolator Updates

- All Percolator resources are free and can be found at www.jfcsboston.org/Percolator
 - In-person and virtual/hybrid café toolkit (includes list of promo ideas)
 - PSA videos (English, Portuguese, Spanish)
 - Recorded how-to videos
 - Guest artist/activity facilitator directory
 - Join the email list



Your Updates

- Maria Skinner



Your Updates

- Please share your news – briefly, please!



Percolator Survey:

**How people living with dementia
can be more involved in the
design, leadership and
implementation of memory cafés**

Plan for discussion

- Introduction of Dementia Action Alliance Board Members
- Overview of survey results: who responded, your current practices
- Deeper dive into current practices: 6 quick presentations
- Your challenges
- Your questions, and responses from DAA Board Members
- General discussion

Dementia Action Alliance Board Members

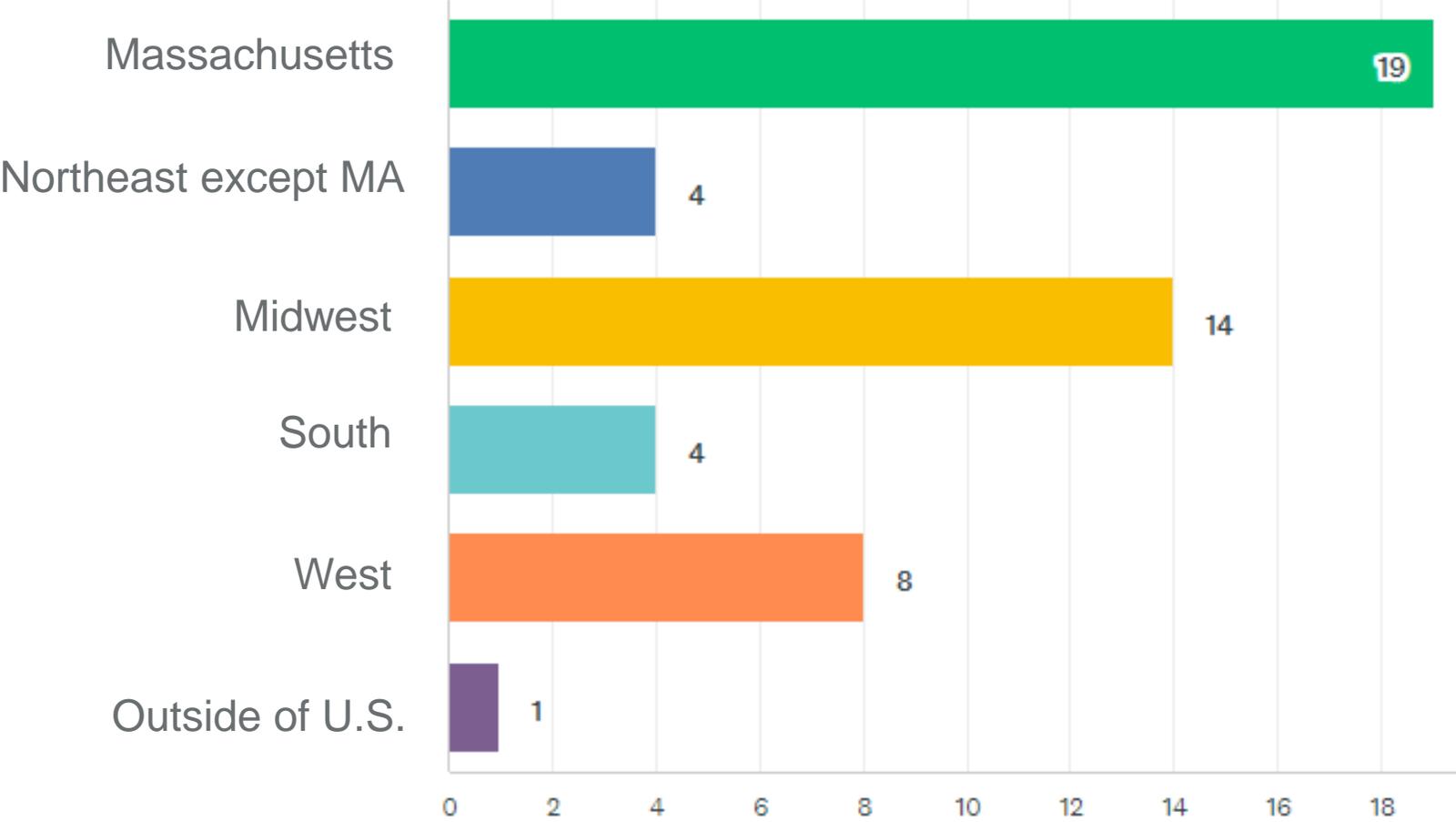
Welcome!

- Mike Belleville – An advocate since his diagnosis at age 52, Mike is living with Lewy Body Dementia and is active in many organizations, sharing his personal experience and his technical expertise.
- Laurie Scherrer – An advocate and international speaker since her diagnosis with Early Onset Alzheimer's & FTD in August of 2013 at the age of 55, Laurie is a Dementia Mentor and is active in many support groups. Visit her website: dementiadaze.com,
- Jackie Pinkowitz, M.Ed. – Board Chair Dementia Action Alliance, past Chair of CCAL-Advancing Person-Centered Living

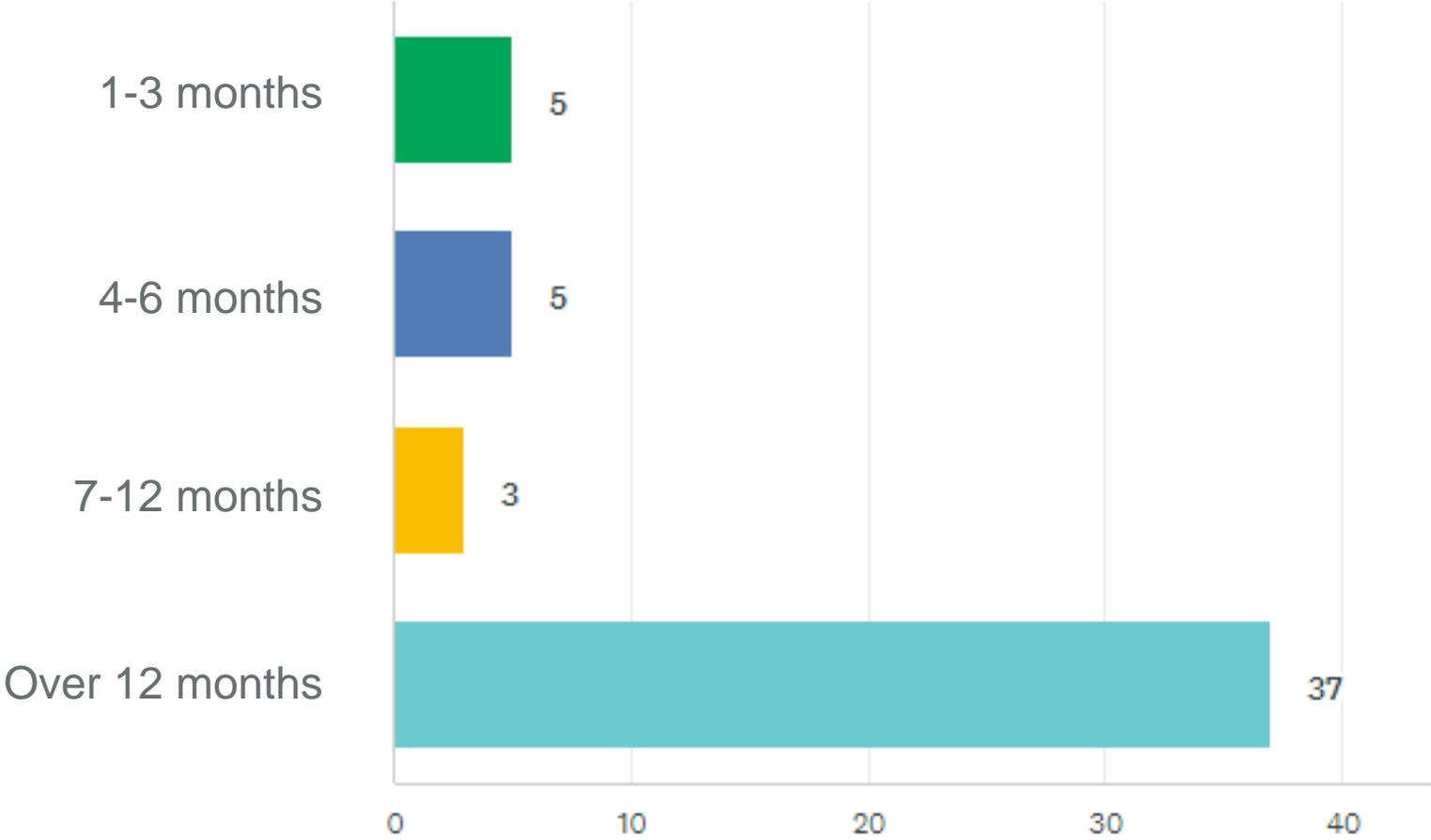
Let's look at the survey results...



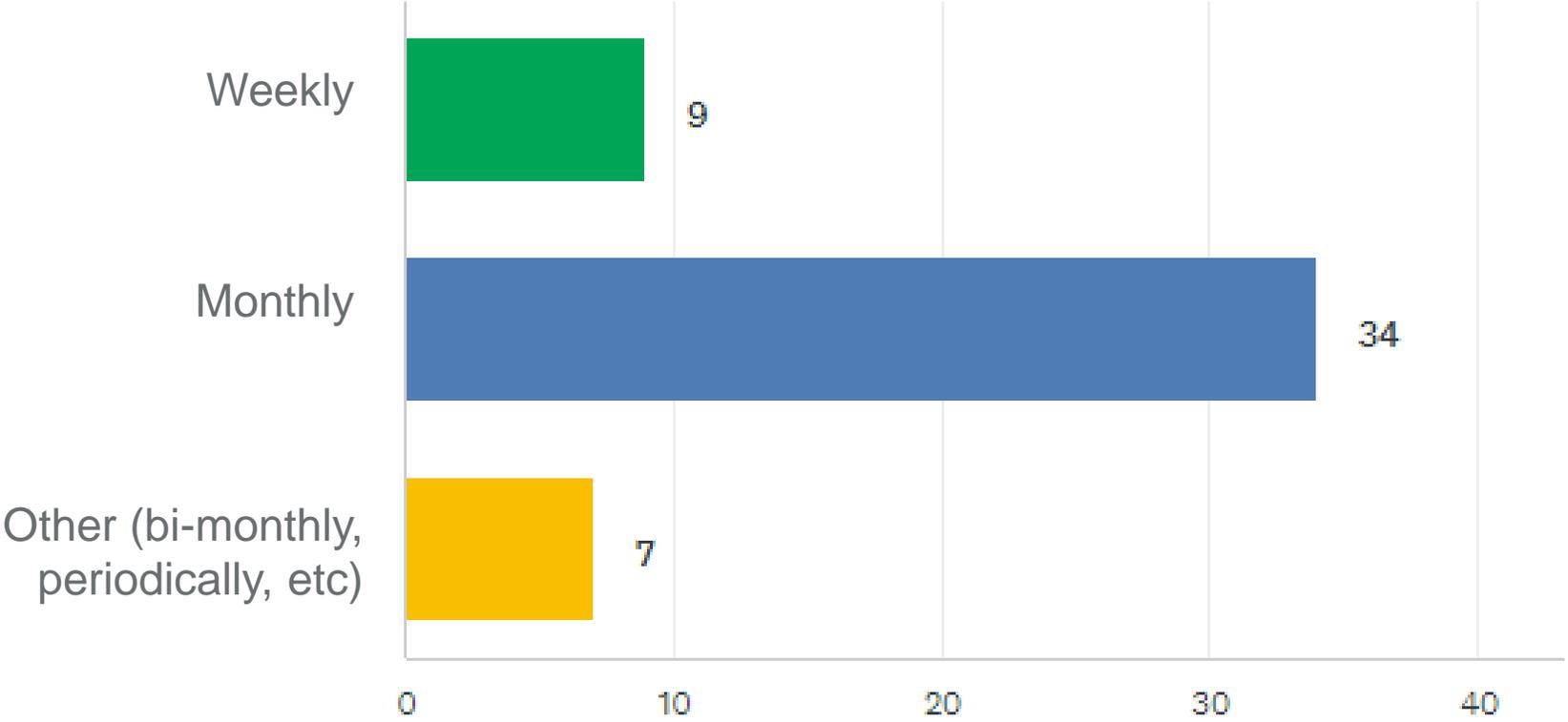
Thank you to all who responded! n = 50



How long has your café been open?



How frequently does your café meet?



Does your café have any of the following attributes?

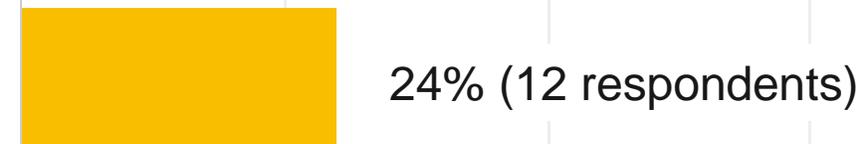
Guests who have been recently diagnosed or whose dementia is early in its progression regularly attend and participate in your café.



Some or all of your café guests play a role in choosing the activities and/ or deciding how the café runs.



Some or all of your café guests act as volunteers at your café.



Café guests have a structured way to support each other, such as encouraging each other to attend café gatherings and offering each other support in between café gatherings.



0 10 20 30 40

Great ideas and practices already underway!



Have you found any other ways to get guests involved as creators, facilitators, and/or providers of mutual support?

1. Involve guests in planning and design
2. Create individualized roles for specific guests
3. Encourage interaction
4. Get feedback
5. Support advocacy beyond the cafe

Have you found any other ways to get guests involved as creators, facilitators, and/or providers of mutual support?

1. Involve guests in planning and design

- Engage members as seed members for new Virtual Café groups
- People living with dementia are on our Board
- Ask guests to help bring in new participants

Have you found any other ways to get guests involved as creators, facilitators, and/or providers of mutual support?

2. Create individualized roles for specific guests

- Song leaders, joke tellers; one guest shops for decorations and decorates the café
- We have a guest who attends and likes to share poetry. Currently encouraging him to consider leading a creative writing project where all cafe participants could share their thoughts to create a piece of their own or a group piece.
- We knew that a former caregiver whose wife died with dementia was a master gardener. He presented a program at one of our memory cafés.
- I strive to appoint each participant based on their strengths to shine for others in a leadership capacity by learning as much of their history and subject matter expertise as possible (in a residential setting)

Have you found any other ways to get guests involved as creators, facilitators, and/or providers of mutual support?

3. Encourage interaction

- Encourage conversation among participants
- “Match make” guests who might want to connect outside the café, by introducing them
- Take advantage of Zoom format by having guests bring “show and tell” items
- Pair guests living with dementia to work on a craft together
- At our café, we discuss strategies to address the challenges of dementia
- Allow time after the café for guests to sit and chat, exchange contact info, etc.

Have you found any other ways to get guests involved as creators, facilitators, and/or providers of mutual support?

4. Get feedback

- Formal surveys, e.g. SurveyMonkey
- Informal feedback opportunity at the end of every café; e.g., ask weekly for discussion topics
- Observe guests' response to different activities

Have you found any other ways to get guests involved as creators, facilitators, and/or providers of mutual support?

5. Support advocacy beyond the café

- We involve guests in planning and contributing to our Age/Dementia Friendly City. We address important issues in our city and hold City Hall meetings with our city officials. We also cross generations with our local University on events happening in our city. For example, we just celebrated our "Senior Homecoming". Our participants were in a parade and a Sock Hop to follow.
- Our memory café is for residents of our retirement community (500+ people), and it is billed as for people with memory challenges and all allies (spouses, friends, family, paid caregivers, etc.) to build a dementia-friendly community.
- Engaging members as Dementia Friends presenter partners
- We have had guests create poems and crafts that are shared outside of the Cafe

6 quick presentations of effective practices

1. Beverley Cassidy – including people living with dementia on the memory café board of directors
2. Emily Williams – memory café kickoff event featuring a person living with dementia
3. Brian Connolly – group decision-making process about how to handle COVID-related changes to the café and other programming choices
4. Rob Griesel (cannot attend, Beth will present for him) – providing a phone list with photos, to encourage interaction between café meetings, and identifying guests to lead specific activities each time
5. Erika Campbell – in a residential community, identifying individual leadership strengths and using the café as part of a dementia-friendly community process
6. Shelly Roy - involving guests in planning and contributing to a Age/Dementia Friendly City initiative, meeting with city officials, and intergenerational activities with the local university

Discussion



What is difficult or gets in your way?



Challenges

General challenges –

- Pandemic – meeting virtually reduces interaction; guests vary in comfort with Zoom.
- Transportation
- Engaging and meeting the needs of underserved communities in our town
- Getting the word out/attendance
- Lack of staff time – it's quicker and easier to do it yourself, unfortunately

Challenges

Newly diagnosed guests –

- People newly diagnosed are reluctant to attend anything that has to do with dementia care. We call our cafe Harmony Cafe and invite them to "volunteer." A different model may be better for people who have just been diagnosed.

Guests with advanced dementia –

- Most of our guests have advanced dementia
- Some of our guests do not know they have dementia

Challenges

Stigma, progression and variability of dementia –

- Some of our guests reacted negatively to the words “memory,” “dementia” or “Alzheimer’s.” We had to adapt our café’s name, omitting the word memory and removing the logo and name of our organization
- As dementia progresses, it is hard to limit roles for safety reasons
- As dementia progresses, planning and complex social interaction is difficult. Café coordinators must focus on strengths and not place a burden on lost abilities
- People living with dementia helped to establish our café, but it’s hard to get ongoing participation in leadership roles
- Changes in mood or energy level of guests requires staff to be flexible in implementing the program
- Our guests come and go – there is not a lot of consistency over time.

Challenges

Some guests may not want a larger role –

- Guests seem to like having staff set up and manage the café. “Most who attend just want to be entertained.”
- Guests are busy at home managing life’s challenges – I don’t want to burden them
- The care partners look forward to a break, and don’t want to have to plan and lead activities

Your questions and DAA Board members' responses



Questions about...

1. Café leadership
2. Promoting interaction
3. Getting feedback
4. Café programming
5. Promoting learning and advocacy beyond the café

Your questions about café leadership

- **What steps are needed to recruit people living with dementia in a planning or advisory role?**
 - You have to ask – don't assume that people realize that there is an opportunity to be more involved!
 - Treat each person as an individual. Do not assume that a person living with dementia needs a care partner to participate with them.
 - Keep in mind the value of feeling a sense of purpose. Even a small task (e.g., handing out pencils) gives the person a sense of importance and belonging.
 - Try to identify individual passions, and be willing to “roll with them”!
 - Each café will be different – let local interests flourish!
- **How do you support these individuals in this role?**
 - Provide clear information about your café's goals, values, and the tasks that are expected
 - Consider piloting this process with one or two people to start, to make sure that you have time to fully support them

(continued)

Your questions about café leadership

- How do we make sure that these roles are meaningful and not “token” roles?
 - Provide clarity, support, and a substantive role
 - For example, maybe some café guests could take turns being a “host” or “welcome committee,” and sit with newcomers to the café. This makes a meaningful contribution to creating a welcoming environment.

Your questions about promoting interaction

Interaction -

- What kind of seating helps people mix and interact? Do round tables work better than rectangular? People tend to sit with those whom they already know.
 - Seating does matter!
 - Different seating may work for different parts of the café. Round tables are great for socializing in small groups. A circle of chairs could work for a facilitated activity.
 - There is benefit to people sitting with the people they know, and also benefit to meeting new people. Just look for opportunities to welcome new people as well as encourage friendships.

Your questions about getting feedback

Feedback -

- What are the best ways to get feedback from guests about the programming they want?
 - A mix of approaches will enable you to hear more voices
 - It's good to offer a formal survey, in combination with many informal ways to get regular feedback

Your questions about programming

- **Some guests expect high-quality, polished programming, which makes it hard to have other guests volunteer to lead activities. How to balance this?**
 - Every café is different. Some will truly love “do-it-yourself” activities, and others will prefer programs by professionals.
 - Set your guests’ expectations! Don’t bill it as “Broadway” if it’s going to be “Off-Broadway!”
 - Work with your guest who is offering a program, to make sure that they understand the café’s goals and that they have the support to do it successfully
 - Offer short segments, where guests read a poem, tell a joke, share a talent, etc – without asking them to lead an hour-long program if they are not experienced at this.

Your questions about advocacy and learning beyond the cafe

Reducing the stigma of dementia

- Cafe coordinators generally don't raise the topic of dementia, so that the café is a comfortable place for people who have not been diagnosed or are not comfortable with their diagnosis.
- However, many guests can benefit from the opportunity to talk or learn about dementia.
- Breaking the silence can help to reduce stigma.
- Consider: conversation starters that may open up conversation about dementia, such as “What are some of the challenges of life these days?”
- Consider: inviting a person living with dementia to talk for 10 minutes about living fully with dementia. **Poll Question – would you request a Zoom presentation from an advocate living with dementia, if Dementia Action Alliance made it available?**

Your questions about advocacy and learning beyond the cafe

Advocacy beyond the café -

- We would like to have a functional, short survey form that is easy for café guests to fill out in regards to their needs in our city.
- Look at Dementia Friendly America's dementia friendly community toolkit for survey examples

Other questions??



Resources

- Dementia Action Alliance
 - Words Matter guide: <https://daanow.org/wp-content/uploads/2020/05/WORDS-MATTER-Revisions.pdf>
 - Many other resources: visit www.daanow.org
- National Council of Dementia Minds: <https://dementiaminds.org/>
- Dementia Alliance International: <https://www.dementiaallianceinternational.org/resources/>
- Dementia Friendly America – toolkit for dementia-friendly communities, inclusion and leadership of people living with dementia:
<https://www.dfamerica.org/inclusion-and-leadership-of-people-living-with-dementia>
- Others?

Open Discussion



Save the date!

**Next Percolator Idea Exchange is
Thursday, March 10, 1:30 – 3:30
EDT**

Please let Beth know if you would
like to present your hybrid café!



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