

The Participant-Driven Memory Café

JF&CS Memory Café Percolator

Exhale Collaborative Workshop 2, February 26, 2024



For more than 150 years, Jewish Family & Children's Service has been helping individuals and families build a strong foundation for resilience and well-being across the lifespan.

Workshop 2: The Participant-Driven Memory Café

- Who attends a café and what they need
- How to encourage participation and feedback
- Leadership and other active roles for participants



Any burning questions?



Who attends a Memory Café?

- People living with mild, moderate, or advanced dementia
- People with undiagnosed cognitive changes
- Family members, friends
- Professional caregivers
- Volunteers




Do you require a care partner to attend?

- Exhale is grounded in supporting the needs of family caregivers.
- Cafés are not meant to be drop-off respite programs.
- Let family members know that the café is for them, too!



Benefits to family caregivers

- A rare opportunity to ENJOY together
- Accepting, normalizing environment
- Breaks through the tendency to become isolated
- Encourages new friendships
- Sparks warmth, sense of connection between care partners
- Helps with symptoms



“Gives me an anchor to my week. An excuse to get out of my place!”

“We’ve made new friends and learned of other resources for families coping with dementia.”

“Starting the day at the Memory Café puts my husband in good spirits that carry through the day!”

Reasons that some may wish to attend solo

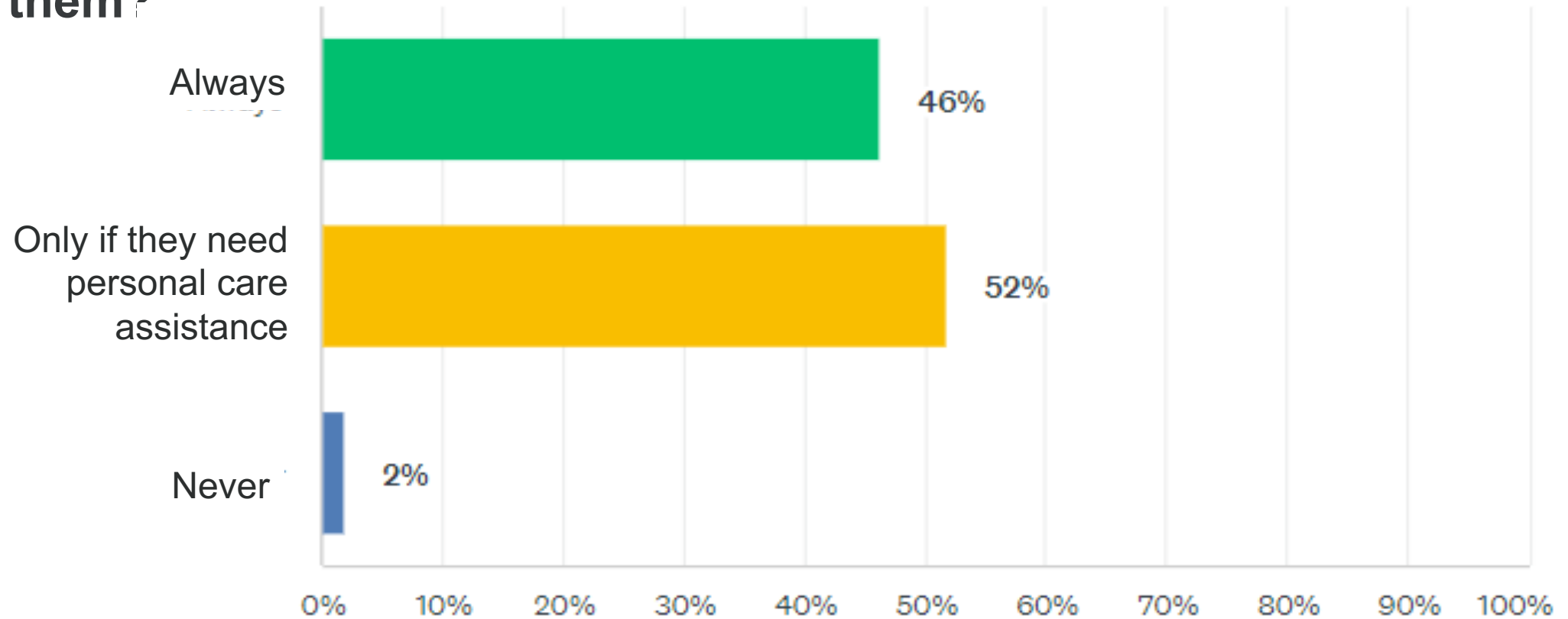
- Some participants living with cognitive changes or dementia are able to interact, participate, and manage their own personal care
- Some do not have a care partner
- Some care partners may ask if they may drop off their relative
 - Solo time is precious
 - Life intrudes (scheduling conflict, urgent errand, etc)
 - Make sure they understand that the café is designed for them, too
 - Offer to explain the benefits of attending the café for them



What is common practice?

Percolator survey, August 2018.
54 respondents

Do you require a participant living with dementia to bring a care partner with them?



A must

FEBRUARY 23rd

MARCH 22nd

APRIL 19th

It is a time you can leave behind worries and focus on having fun and knowing that you are not alone.

PLACE: WESTWOOD SENIOR CENTER

210 Nahatan St, Westwood

TIME: 2:15 to 3:30 pm

**For more information and upcoming dates, please visit:
<http://whiteoakcottages.com/services/memory-cafe/>**

We ask caregivers to be present with any guests that need personal care assistance.

WHITE OAK
COTTAGES

Memory café is brought to you by White Oak Cottages at Fox Hill Village as part of the "Dementia Friendly Community" initiative - providing resources to families facing memory loss as well as local community training. For more information, please contact guide@whiteoakcottages.com.

6 Longwood Drive, Westwood MA. (781) 320-1999



Personal care assistance can include

- Assistance ambulating
- Assistance eating
- Assistance in the bathroom
- Assistance meeting transportation



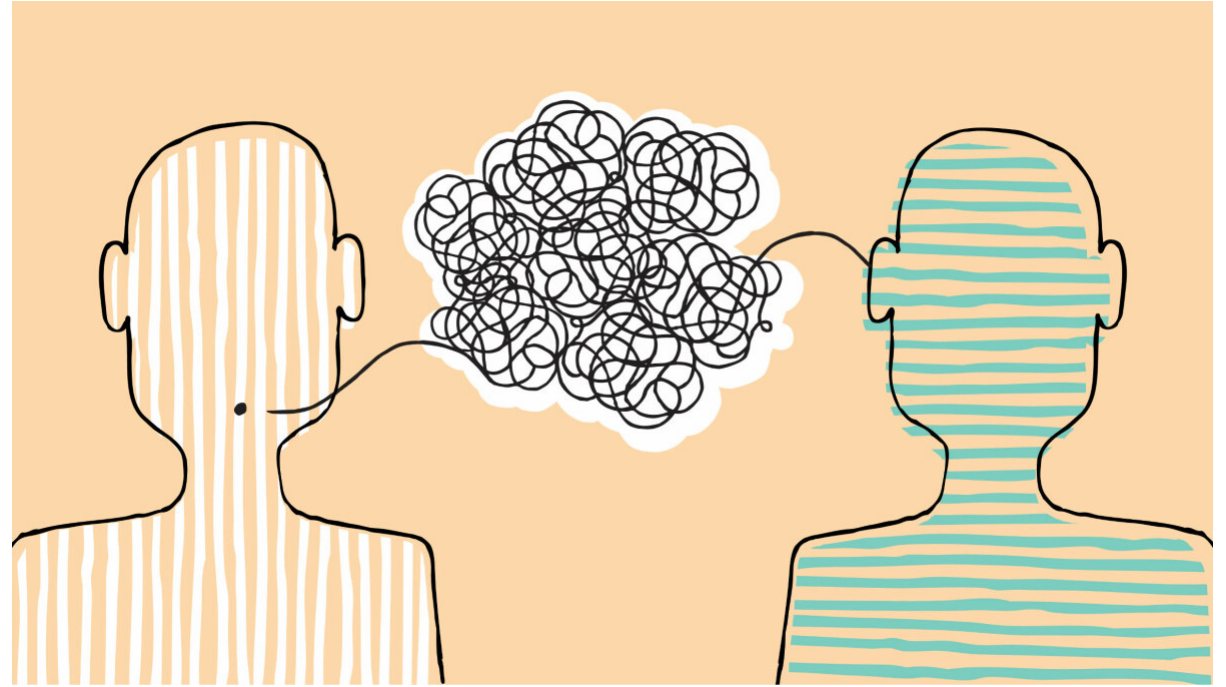
Another must

- Require **groups** to reach out in advance and coordinate with you
- Can you accommodate the number of people they want to bring?
- Make sure they understand the purpose of the program
- Make sure they bring enough staff to support personal care needs of participants they bring



How to communicate these guidelines?

- On your flyer
- In your messages to your mailing list
- In a “FAQ” section on your website



We are Family

- An open door for additional family members
- An enjoyable day + learning about dementia friendly activities and communication
- Be careful of toddlers



Professional caregivers

- One of the hardest, most underpaid jobs
- A vital connection for participants
- An enjoyable day + learning about dementia friendly activities and communication
- Include professional caregivers in discussions and activities



Volunteers

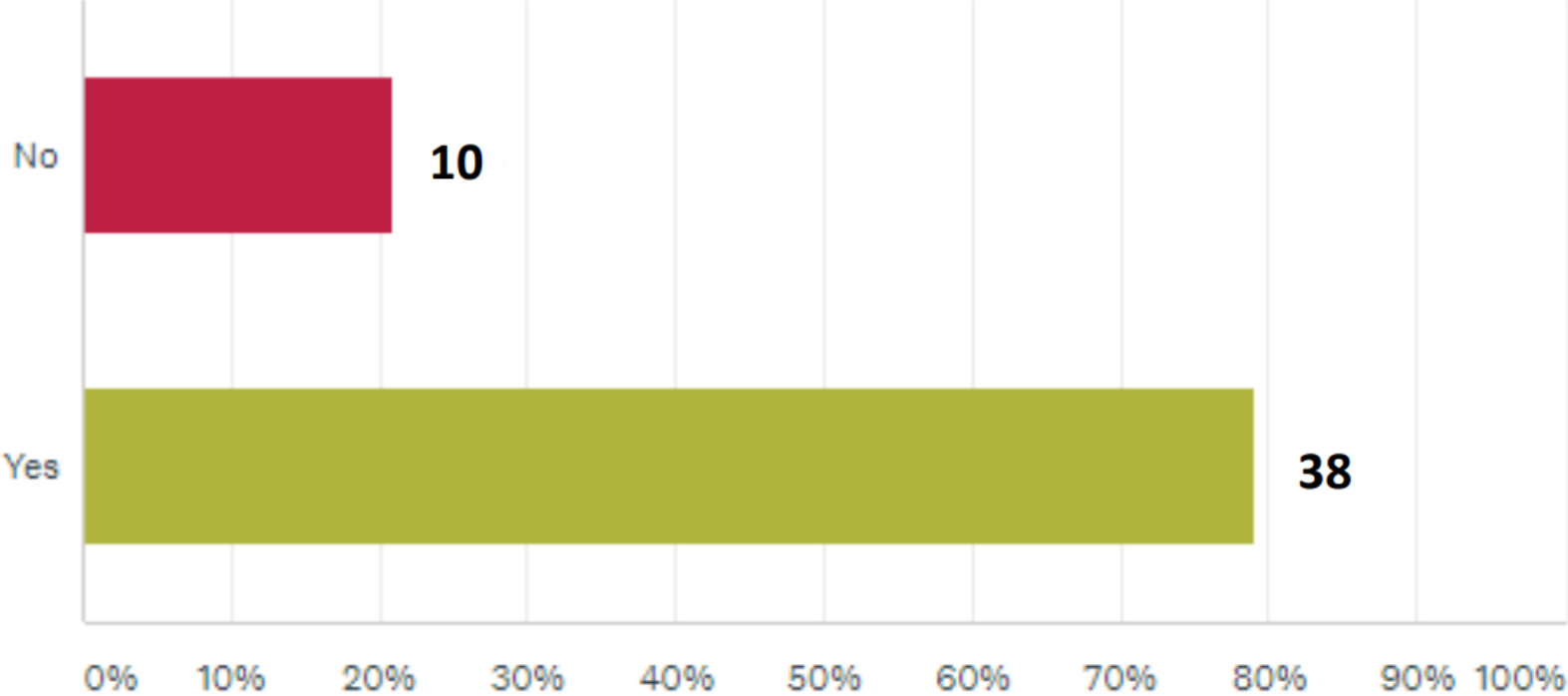
- Extra hands on deck
- Can bring in another generation, culture, experience
- Volunteers see a strength-based view of dementia



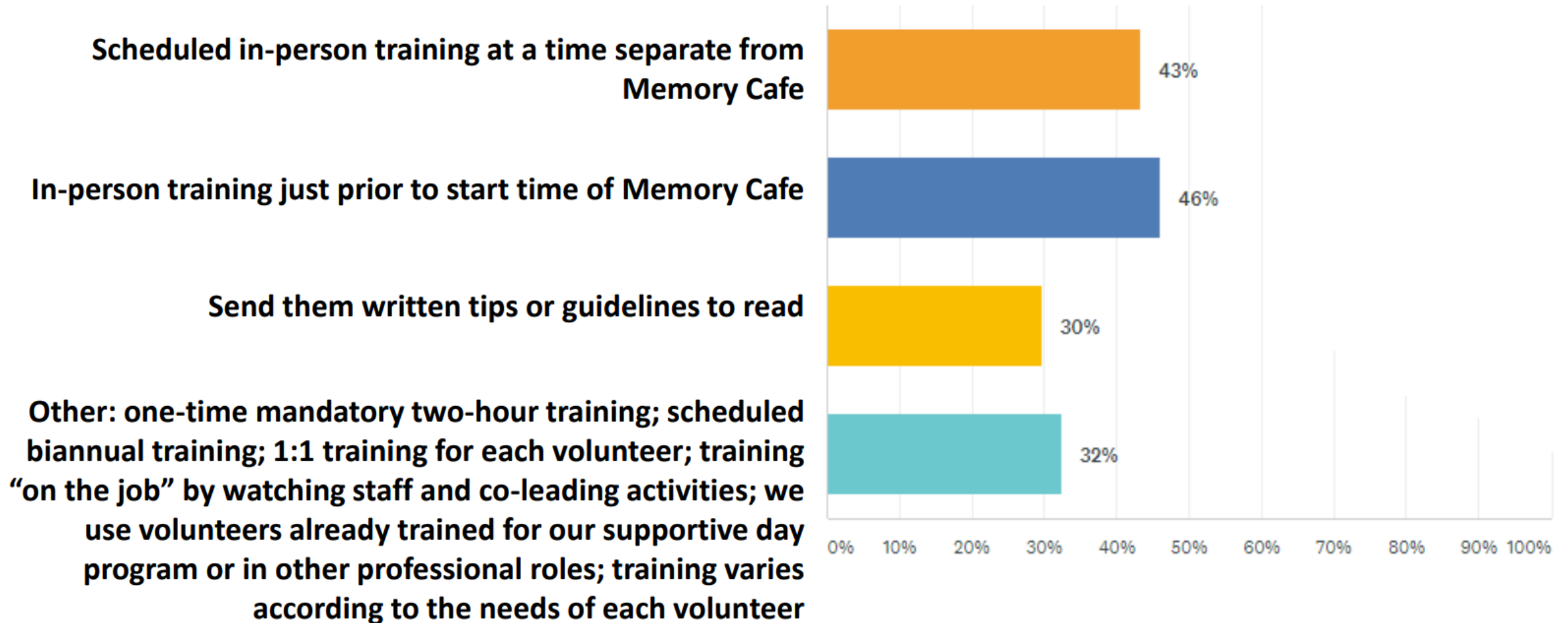
What is common practice?

Percolator survey, December 2018. 48 respondents

Do you have volunteers at your Memory Café?



How do you train your volunteers?



Pearls of wisdom about volunteers

- Make sure volunteers understand the philosophy and goals of the café.
- It's better to have a few volunteers you can count on than many volunteers.
- Family members or friends of a participant living with dementia who has died or can no longer attend may become committed volunteers.



Top tips for volunteers

- Be warm and friendly! Think of yourself as hosting a party.
- Participate actively and enthusiastically!
- You may not know who is living with dementia and who is not – and that's fine!
- Don't raise the topic of dementia unless the participant does.
- Do not provide hands-on assistance. Tell a staff person if someone needs help.
- Tell a staff person if anything is making you uncomfortable.



Top tips for volunteers

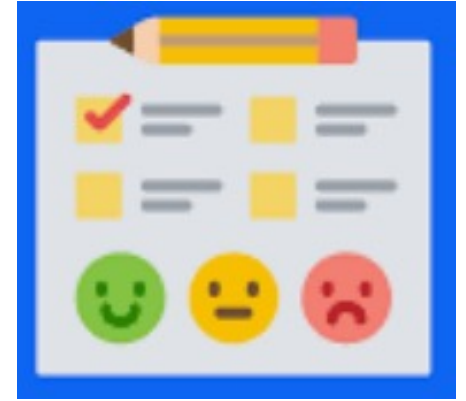
When having a conversation:

- Allow some extra time and quiet for the person to respond.
- Avoid questions that require short-term memory. Try sharing your own memories or using imagination.



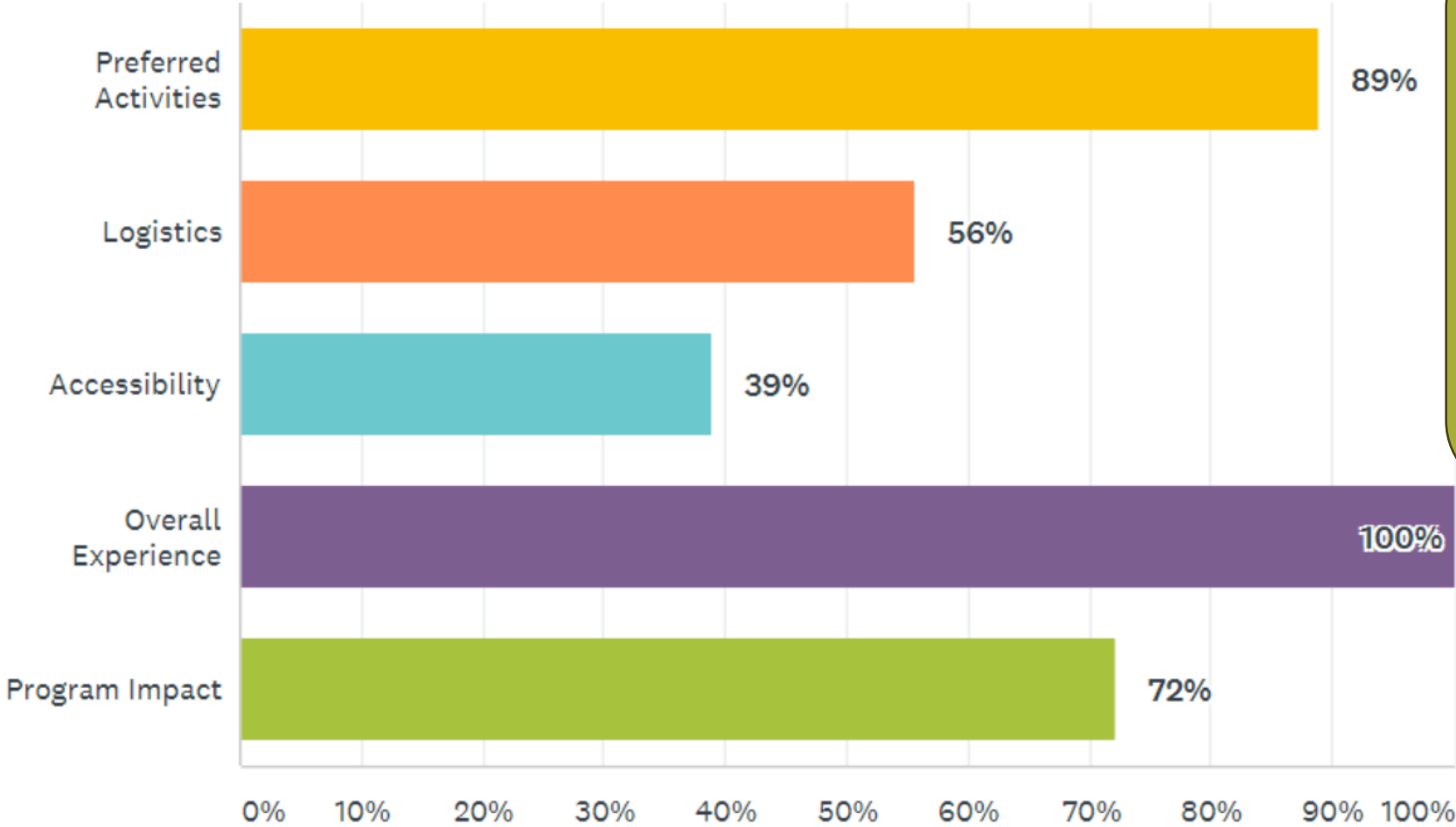
Encouraging participation and feedback

- Most cafés have a formal system to get feedback for program improvement
- Examples:
 - Participants complete an 8-face mood scale before and after each session
 - One-on-one feedback requested during a monthly reminder call
 - Group discussion after each session, or quarterly
 - Paper survey and/or electronic survey after each session, quarterly, every six months, or annually



What are you surveying participants about?

Percolator survey, September 2017. 38 respondents



It's a great idea to survey volunteers regularly, too (separately from participants)

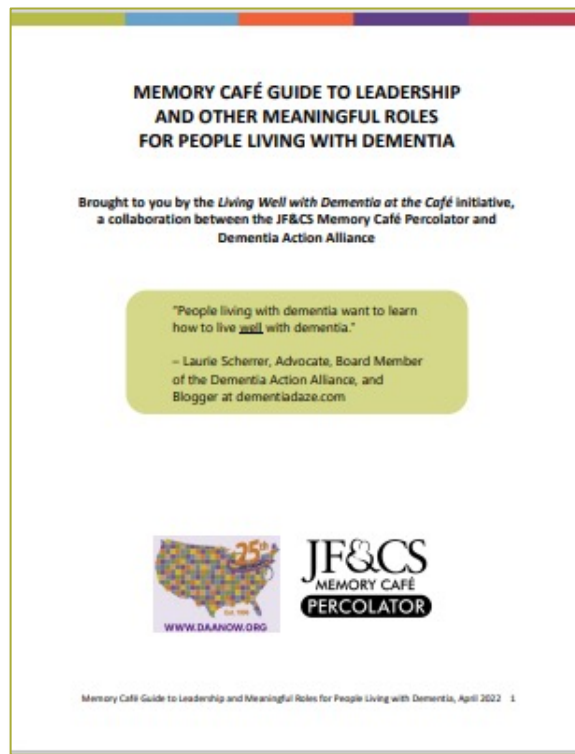
“We don’t feel so alone”

- A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19 by Masoud et al. 2021
- Semi-structured interviews in Spanish and English were conducted with individuals living with dementia and family care partners who regularly attend Memory Cafés hosted by partners in a Texas Memory Café Network. (n = 17)
- <https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2021.660144/full>



Meaningful involvement: “Nothing about us without us!”

Percolator and Dementia Action Alliance collaboration



- The two goals: inclusion and empowerment
- Sharing the voice of people living with dementia
- Involving café participants in planning and design
- Creating individualized roles
- Encouraging interaction among participants
- Supporting advocacy beyond the café
- Resources
- Download at www.jfcsboston.org/Percolator

Ideas to involve participants in planning and design

- Establish an advisory board or planning committee and continuously invite participants to join. Meetings can be short and informal.
- Have a sharing time when you invite participants to bring poems, quotes, stories, artwork, memorabilia, etc.
- Ask participants to be your ambassadors and help spread the word about your café. Designate “bring a friend” month.
- Ask for help and participation during the café – handing items out, sharing a story, sitting with a new participant to welcome them.

“Even a small task, like handing out pencils, gives the person a sense of importance and belonging.”
– Laurie Scherrer, Advocate

Create individualized roles

- A friendly, caring or sociable participant can volunteer as a greeter.
- One café has a participant who shops for decorations and decorates the café.
- The JF&CS Memory Café has a “poet in residence,” who reads an original poem at the end of each café gathering.

“One of our care partners has taught yoga before. I finally got around to asking if she would lead a session for the café, and she was delighted! I’d been worried that she would see this as a burden. I offered her the same honorarium I usually give our teaching artists. I think that our participants will be excited and supportive of ‘one of their own’ leading the session.”
-Café coordinator

Tips for successful “DIY” sharing

- Offer short segments, where participants 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!
- “Set your participants’ expectations! Don’t bill it as ‘Broadway’ if it’s going to be ‘Off-Broadway!’” – Mike Belleville, Advocate





Encourage interaction among participants

- Begin the café gathering each time with a welcome and simple introduction, so that everyone knows the purpose of group and any ground rules.
- Some cafés start with a welcome song or other ritual



Encourage interaction among participants

- Pair participants to work on an activity or project together.
- Allow time after the café for participants to sit and chat, exchange contact info, etcetera.
- One café has established an “opt in” process for those who would like to share their contact information. They include a photo of each person on the contact sheet.



Room arrangements

- Small tables promotes small group interaction.
- Tables are needed for food or handwork such as making art, but can be a barrier to large group interaction.
- A circle of chairs helps people interact with the facilitator and each other during a large group activity.



Room arrangements

- Be aware of acoustics. Minimize background noise.
- Make sure there's enough space between small tables.
- Avoid music with lyrics or turn off background music when you want the group to focus on an activity or conversation.



Room arrangements – general tips

- Physically accessible (expect a range of mobility needs)
- Clear signage
- Good lighting
- Avoid shiny floors if possible
- Enclosed or well-demarcated space
- Family bathroom if possible



Nothin' fancy



“We’ve relied on the file cards more than anything else! We leave the cards and markers on tables, and ask if they’d like to volunteer, be on our board, present something, or what topics or themes they be interested in. We’ve gotten a lot of really interesting suggestions.”

– Beverley Cassidy, Memory Café
Nova Scotia

Above all, people want to feel they belong



“It creates a feeling of home.”



Percolator section of next workshops

- Workshop #3: What to do at a Café and who does it
- Workshop #4: Understanding (and reducing) stigma

