

Welcome to

**Let's Talk**  
**About Dementia**  
**And Culture 2022**

*November 15, 2022*

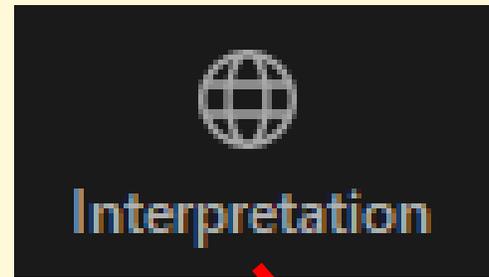
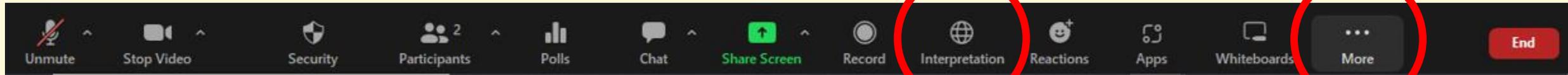
同聲即時翻譯

Traducción instantánea simultánea

Tradução instantânea simultânea

Dịch nhanh đồng thời

## Language Interpretation

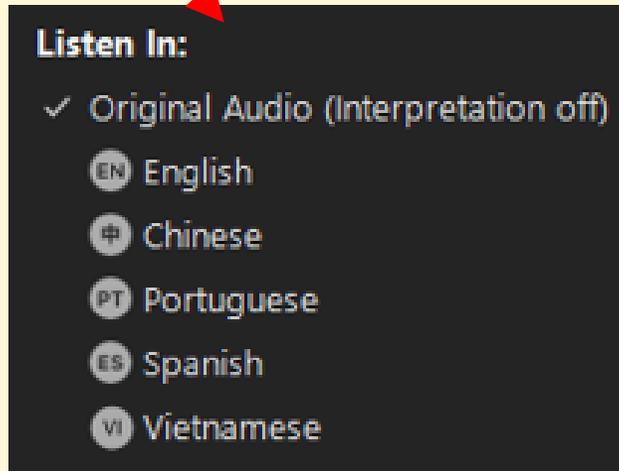


點擊地球符號

Haga clic en el símbolo del globo

Clique no símbolo do globo

Bấm vào biểu tượng quả địa cầu



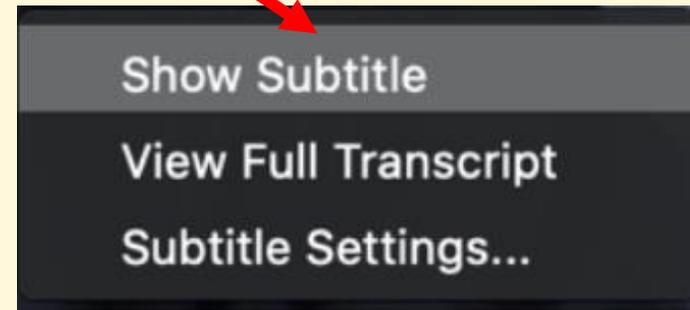
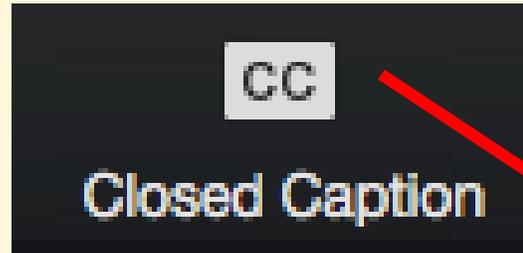
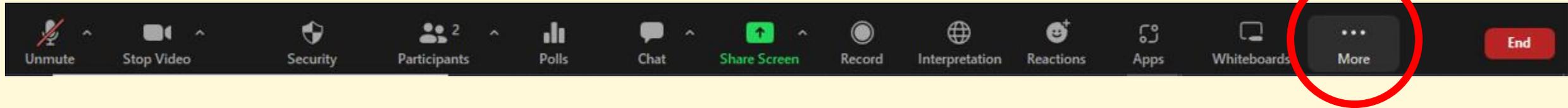
選擇你的語言

Elige tu idioma

Escolha seu idioma

Chọn ngôn ngữ của bạn

# Captions in English



# THANK YOU TO OUR MAJOR SUPPORTERS

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Jewish Family & Children's Service



Point32 Health Plan Foundation



Lebovitz Family Charitable Trust

# THANK YOU TO OUR SILVER SPONSORS

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Embrace Home Care



Massachusetts Councils on Aging



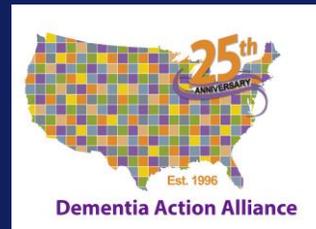
# THANK YOU TO OUR PROMOTIONAL PARTNERS

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Alzheimer's Association Massachusetts/New Hampshire Chapter



Dementia Action Alliance



National Council of Dementia Minds



# THANK YOU TO OUR SPEAKERS, INTERPRETERS AND MANY HELPERS

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Arnetta E. Baty  
Carl Byron Baty  
Bonnie Burman  
Kun Chang  
Alana Dundon  
Anitra (Nia) Mostacero  
Tirsa Ramirez  
Saw Reh  
Kathy Service  
Judith Thermidor

Andrew Katz  
Anne Muskopf  
Jessica Roque  
Marjie Sokoll  
Rachel Barglow  
Feng Gao  
Denise Gracia  
Stefany Sanchez Molina  
Lina Nguyen  
Rosane Rose  
Rosemarie Thornton

# THANK YOU TO COLLABORATING ORGANIZATIONS

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Dementia Friends USA and Global  
Inaya Dia and Ayah Rodah  
Asian Women for Health

Greater Boston Chinese Golden Age Center

Latino Health Insurance Program

Ohio Council for Cognitive Health

Rounding the Bases, Inc.

Southeast Asian Coalition of Central Massachusetts

# Housekeeping

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- This meeting is being recorded.
- A link to recordings, slides and resources will be shared.
- Please keep yourself on mute.
- Please submit any questions or comments for the speakers into the chat box.
- Having problems connecting to the meeting? Chat “Ask Tech Help” directly.

# Continuing Education Units (CEUs)

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Requirements: You must attend the whole event and complete the evaluation survey (to be emailed after the event).

- Social Work: This program has been approved for 3.0 Social Work Continuing Education hours for relicensure, in accordance with 258 CMR. NASW-MA Chapter CE Approving Program, Authorization Number D 91323.
- Nursing, and Other Professions: A certificate of attendance is available.

# Let's See Who Is Here Today!

An nou  
pale

讓我們談談

စကားပြောကြရအောင်

Vamos  
conversar

Hablemos

Hãy nói chuyện

Let's  
Talk

# Our Plan For Today - times are approximate

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- 1:10 p.m. Welcome: Nora Moreno Cargie, Point32 Health Foundation
- 1:15 p.m. Disparities, Differences, and the Case for Community Partnerships: Beth Soltzberg
- 1:40 p.m. Introduction of Community Partners. Personal story: Anitra (Nia) Mostacero
- 1:50 p.m. Roundtable Discussion with Community Partners
- 3:20 p.m. Break; photo montages and personal messages
- 3:35 p.m. Road to Representation: Beth Soltzberg
- 4:00 p.m. Let's hear from you! Q&A, discussion
- 4:25 p.m. Closing

See Program Book  
for details



Welcome: Nora Moreno Cargie  
President, Point32Health Foundation  
Vice President, Corporate Citizenship,  
Point32 Health Foundation



Point32Health Foundation

# Framing Today's Conversation: Disparities, Differences, and the Case for Community Partnerships

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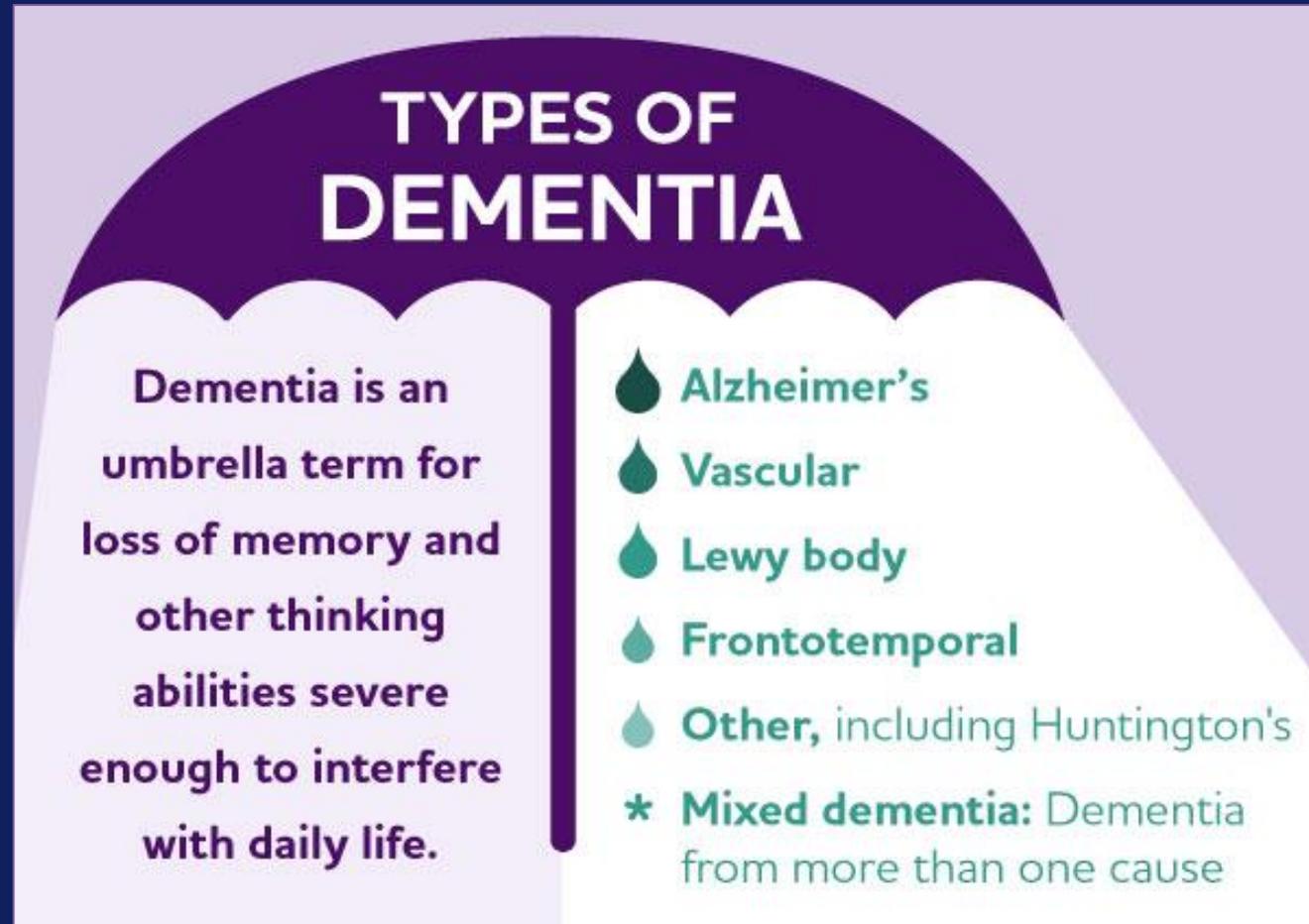
# Beth Soltzberg, LICSW, MBA

- Director, JF&CS Alzheimer's/Related Disorders Family Support Program
- JF&CS Memory Café Percolator
- Dementia Friends Massachusetts
  - *Lead/Master Trainer*
  - *Community Partner Initiatives*
  - *Synagogue Initiative*



*Waltham, Massachusetts*

# What is dementia?



Source: Alzheimer's Association

It's normal to have a harder time remembering things as we get older



There are treatable causes of memory loss and confusion

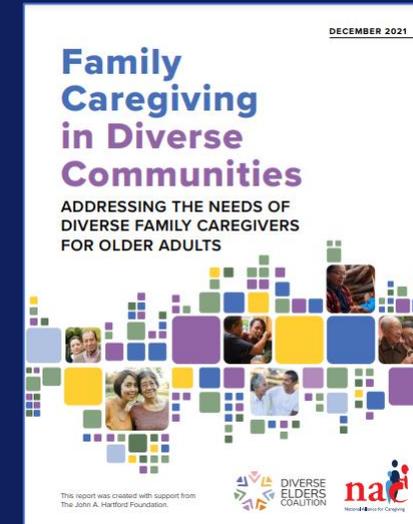
- Depression
- Grief
- B12 deficiency
- Infection, such as urinary tract infection
- Dehydration
- Thyroid imbalance
- Side effects of medications, especially in combination

*Talk with a health care provider if you are concerned.*

# Dementia affects the whole circle of people who care



- Family and friends need support and information also
- Many resources are available including education, support groups, social activities, and assistance with many types of needs





# 2022 Alzheimer's Disease Facts and Figures



**1 in 3**

seniors dies with Alzheimer's or another dementia

Over **11 million** Americans

provide unpaid care for people with Alzheimer's or other dementias



These caregivers provided more than 16 billion hours valued at nearly

**\$272 billion**

Source: Alzheimer's Association, 2022

# People can live well with dementia

Kate Swaffer

Emily Ong



Dementia Alliance International,  
[www.dementiaallianceinternational.org](http://www.dementiaallianceinternational.org)



# Now let's focus the lens at different levels...



# Global Perspective

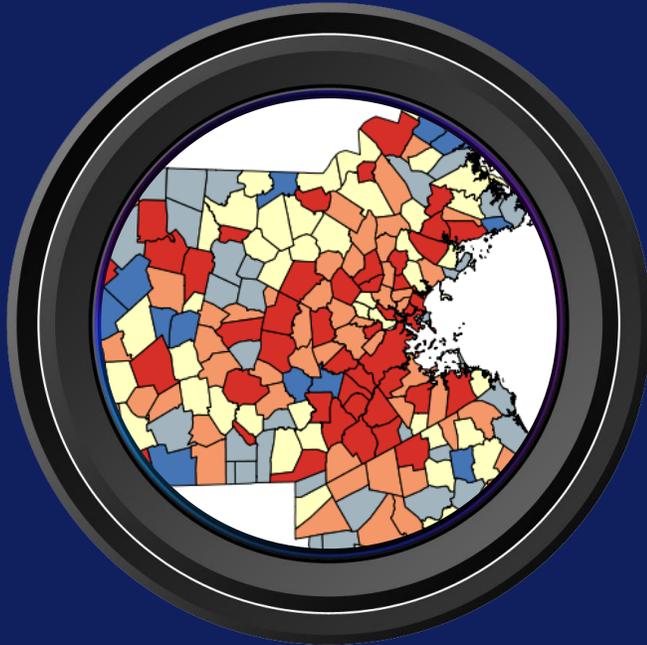
The global population is rapidly aging = more people in the US and worldwide are living with dementia.



31% of home care workers are immigrants.  
– PHI.org, 2022

Our US communities are multicultural.

# Linguistic/Cultural/Geographic Community Perspective



“Disparities are differences in health and health care between groups that stem from broader inequalities.” – Kaiser Family Foundation

There are disparities in:

Risk of dementia

Access to getting a diagnosis

Access to research participation

Access to information and services

# Disparities in the risk of developing dementia

In a 2016 study of 274,283 people over 14 years in Northern California by Dr. Mayeda and team, these population groups had the highest risk of developing dementia:

1. African-American
2. American Indian and Alaska Native
3. Latino
4. Pacific Islander
5. White
6. Asian-American

# Disparities in the risk of developing dementia

- 2019 study found that LGBTQ+ people were 29% more likely to report changes in their memory and thinking (subjective cognitive decline), which may be an early sign of dementia.
- Women are more likely than men to develop dementia, AND to care for someone who is living with dementia.

# Disparities in access to diagnosis

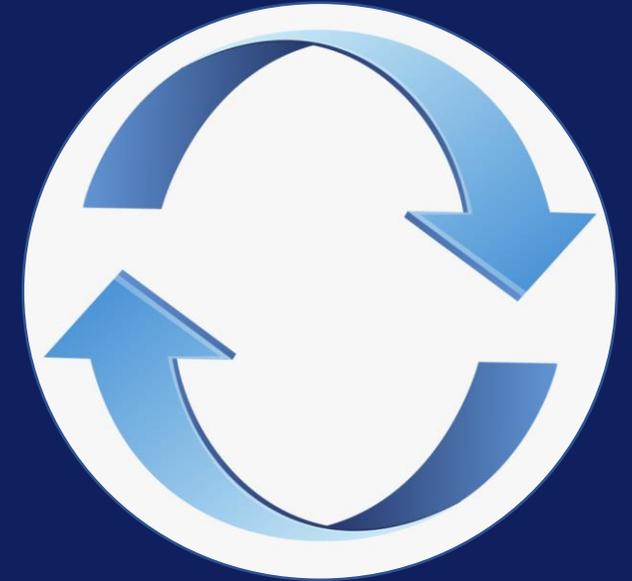
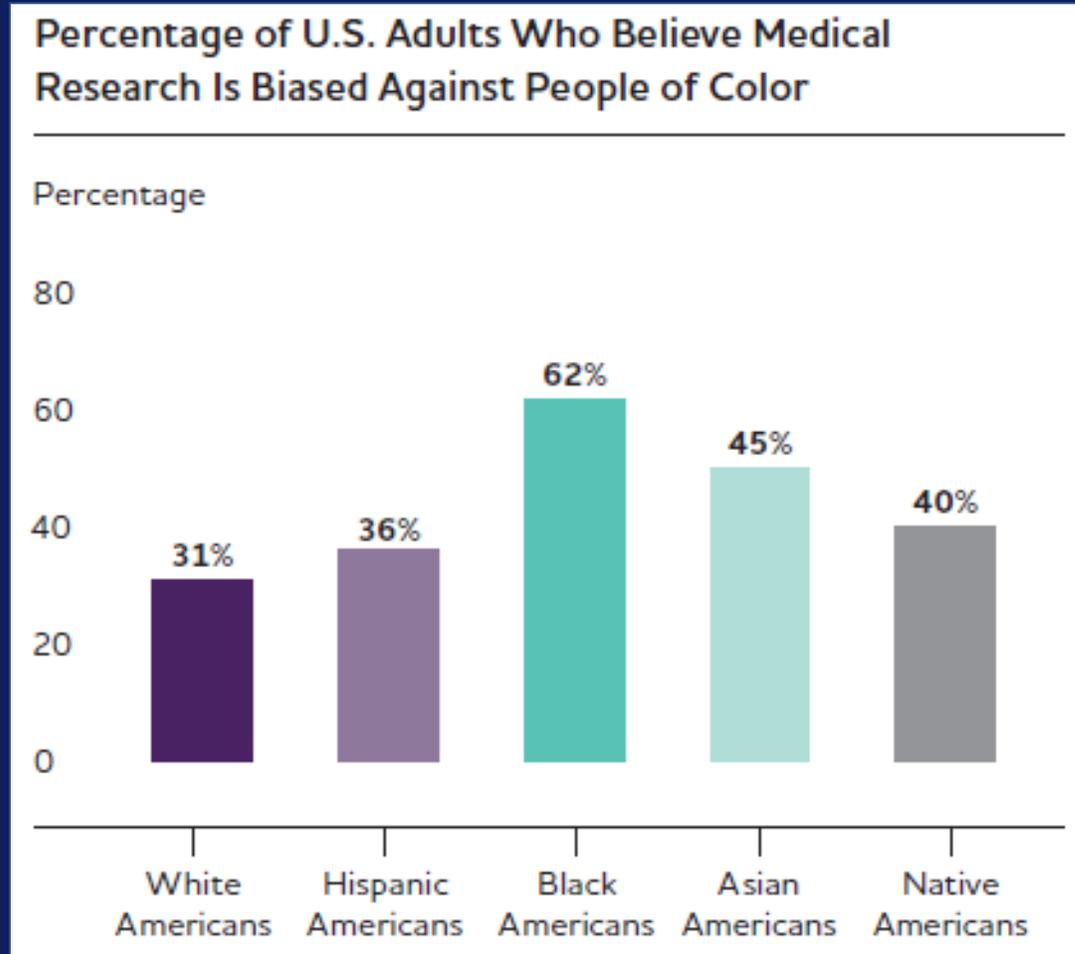
“Black participants in Alzheimer’s disease research studies were 35% less likely to be diagnosed with Alzheimer’s and related dementias than white participants, despite national statistics that indicate that Black Americans are overall about twice as likely to develop dementias than whites.”

- Lennon, et al. Black and white individuals differ in dementia prevalence, risk factors, and symptomatic presentation. *Alzheimer’s and Dementia*.2021; <https://doi.org/10.1002/alz.12509>

# Disparities in research participation

- Research is how tools for diagnosis and treatment are developed
- Research is how we know what we know
- Latino and Black Americans make up less than 10% of all clinical trial participants in active Alzheimer's/Related Dementia research. - National Institute on Aging, 2021.
- **We do not have any information about many demographic groups**

# Lack of Trust – a vicious cycle



Source: Alzheimer's Association, 2021



# Long recognition that change is needed

Bipartisan action from Congress:

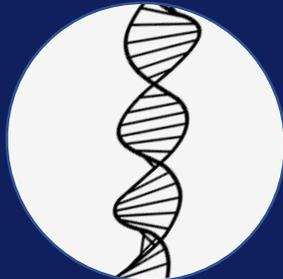
- 1985 – Groundbreaking report (“Heckler Report”)
- 1986 – Office of Minority Health established
- 1993 – Office of Research on Minority Health established
- 2000 – National Center on Minority Health and Health Disparities
- 2021 – John Lewis National Institute on Minority Health and Health Disparities (NIMHD) Research Endowment Revitalization Act

# A different way to look at risk factors and how to reduce risk

# Risk Factors for developing dementia that we cannot change – “non-modifiable”



Aging



Genetics

# “Modifiable” Risk Factors

What we can change

- As an individual
- As a society



# Modifiable Risk Factors

Ask: Where are there barriers to access?

More research underway

Treat sensory impairments

## 10 WAYS TO LOVE YOUR BRAIN



# Societal Change is Needed



# Individual Person Perspective

Your individual risk is not necessarily the same as your group's risk.



Each person is unique. Individuals may not follow group “norms.”

Each person has many facets.

Effective support focuses on the individual.

# Keep in mind: people can live well with dementia



Dementia Action Alliance, [www.daanow.org](http://www.daanow.org)

**Talking about dementia is the gateway  
to knowledge and support.**

# Talking about dementia is the gateway

What else?

Trauma

Legacy of Discrimination

Financial Barriers

An nou pale

Vamos conversar

Belief systems

Lack of cultural services

Few providers from the community

Community providers not trained in dementia

ကားပြောကြရ

Language Barrier

Late/No Diagnosis

Geographic Barrier

讓我們談談

Hãy nói chuyện

Fear

Silence/ Stigma

Hablemos

# Our Goal

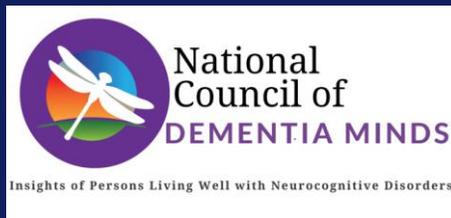
“I am eager to see all those living with dementia and their care partners **break through the barrier wall of stigma** to live the most fulfilling and productive lives.”

– **Sandy Halperin, living with dementia**

# Breaking through the wall means getting what YOU need

Self advocacy can be empowering and greatly reduce stigma

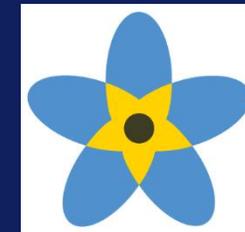
Everyone needs to communicate in order to seek information and support



# A trusted community member is the best messenger.



# Dementia Friends is a global public awareness initiative.



**Step 1: We train community members to be  
“Champions.”**

**Step 2: Champions lead one-hour interactive  
workshops about dementia in their community.**



**JF&CS/ Dementia Friends Massachusetts has contracted with community partners since 2019.**

**Community Champions are the key!**

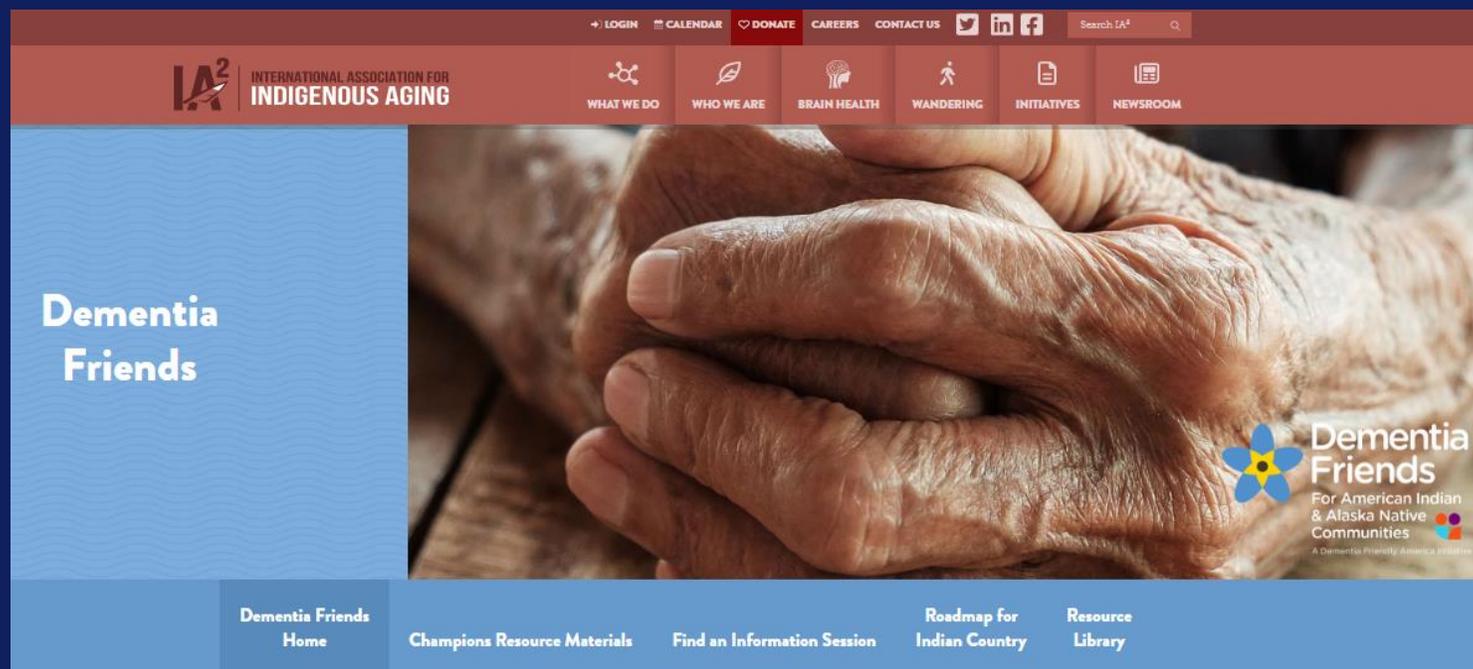


# How did we choose which communities to focus on?

- **Communities with demonstrated high risk of dementia (Black/African American, Latino/Hispanic, Down Syndrome)**
- **Massachusetts Limited English Proficient populations**
- **Interested individuals and organizations**

*Combination of outreach and building on existing relationships. This is a work in progress!*

# Dementia Friends for American Indian and Alaska Native Communities



<https://iasquared.org/dementia-friends/>

# Introduce Community Partners

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# Community Partners



**Carl Byron Baty**



**Arnetta E. Baty**



**Kun Chang**



**Alana Dundon**



**Tirsa Ramirez**



**Saw Reh**



**Judith Thermidor**



**Kathy Service**



**Bonnie Burman**



**Anitra (Nia) Mostacero**



**Anitra (Nia) Mostacero, Advocate**

# Community Partners Roundtable

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# Discussion Questions:

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1. When people in your community hear the word “dementia,” what does this mean to them?
2. In your Dementia Friends sessions, what information or ideas about dementia have been surprising or useful to your participants?
3. What does your community need most, when it comes to dementia? What barriers get in the way of meeting these needs?
4. What would help people in your community who are living with dementia, and their family members, to feel comfortable communicating about dementia?

~ Break ~

*Enjoy this video montage to get to know  
our Community Partners*

---

*Put your questions, comments and  
resources in the Chat box*



A photograph of a forest path during autumn. The path is covered in fallen orange and red leaves. Tall trees with vibrant yellow and orange foliage line both sides of the path, creating a canopy overhead. In the center of the image, there is a dark blue rectangular overlay containing white text. The text reads "COUNTDOWN TIMER" in all caps, followed by "15:00" in a large, light blue font.

COUNTDOWN TIMER

15:00

**Road to Representation:  
How Dementia Friends Massachusetts  
has followed the “Four R’s” to engage  
and serve more cultural and linguistic  
communities**

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# Dementia Friends Massachusetts' Four R's:

- Realization
- Resources
- Relationships
- Road

We share this model as an example – not as an ideal!

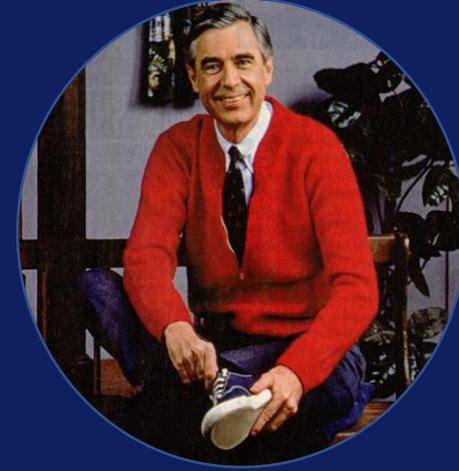
**“We make the road by walking.”  
- Antonio Machado**

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# 1. Realization

How does Dementia Friends Massachusetts' performance compare with our mandate?

# Ask : Who are the people in your neighborhood?



- 29.1% of Massachusetts residents are non-white or are white/Hispanic.
- 23.9 % of Massachusetts residents speak a language other than English at home.
- The most common languages other than English spoken in Massachusetts are Spanish, Portuguese, Chinese (including Mandarin and Cantonese) and Haitian.

Source: 2020 Census and American Community Survey

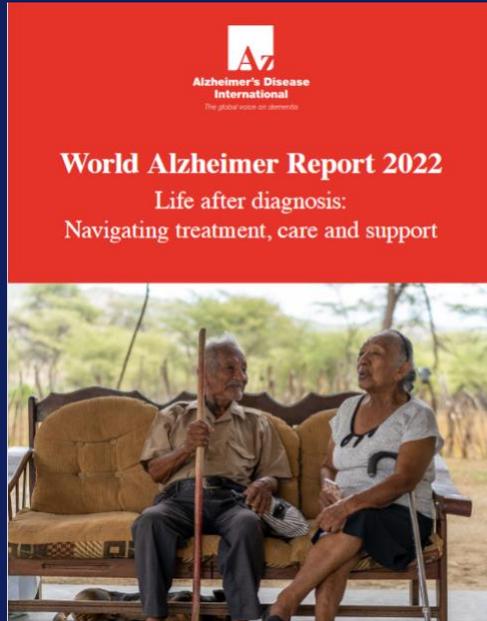
# Ask : Who are the people in your neighborhood?

- 1 - 3% of the population has an intellectual/developmental disability (I/DD)
- About 1 person in 700 has Down Syndrome
- People with I/DD are living longer and more likely to develop dementia

# Dementia Friends Massachusetts' Performance

- End of 2018: Less than 5% of new Dementia Friends were in a primarily non-English speaking community or community of color; none were people with I/DD
- **What were the reasons for this disparity?**

# Ask: Is Dementia Friends something that people need? Is it appropriate for many communities?



“National awareness campaigns must tackle stigma and lack of education on dementia, as this continues to be a barrier to accessing diagnosis and post-diagnosis support.”

“Stigma remains pervasive...as a consistent barrier to accessing diagnosis and care, contributing to misinformation, isolation, shame, and even abuse and neglect.”

- World Alzheimer’s Report, “Life after diagnosis: Navigating treatment, care and support,” Alzheimer’s Disease International, 2022

# Dementia Friends is a global program



# Pilots and Feedback

June 2018:  
Multicultural Coalition  
on Aging



# Pilot: Greater Boston Chinese Golden Age Center

July 2018: Kun Chang and Xing Li trained as Champions

They tested the Dementia Friends curriculum with community members

Results: the framing of “becoming a friend” worked well!



# Root of the disparity: Champion participation



Volunteers need:

- Time
- Awareness of the issue
- Commitment to the issue (note competing priorities)
- Comfort with the volunteer activity
- Accessible materials and training
- Relationships help!

## 2. Resources

How do we address the barriers that make it hard for people from all communities to become Champions?

## Resources are needed for:

- **Materials (translation, modification)**
  - **Community partners**
  - **Interpretation services**

# Where do the resources come from?

- Build into your grant proposal: resources to compensate partners fairly; enough time to recruit, build relationships, tailor and change the approach based on feedback and individual community needs
- Critical role of funder
  - Tufts Health Plan Foundation/Point32 Health Foundation
  - JF&CS



# Materials

1. Define a core set of materials to translate professionally.
2. Community partner Champions then “road test” the materials.
3. Make necessary changes.

جلسة إعلامية  
دفتر العمل

أهلاً بك!

أصدقاء الأرفف: حارة من حركة عالمية نشأت من جمعية الإعياء في المملكة المتحدة والتي ترجع أصولها إلى برنامج دعم الأرفف في اليابان. وهي الآن متواجدة في الولايات المتحدة.

والهدف من ذلك هو مساعدة كل فرد على فهم معنى ما على فهم رسائل رئيسية عن الأرفف وكيف يؤثر على الناس وكيف يمكننا أن نحدث فرقاً في حياة الأشخاص المتعاملين مع الأرفف.

أولاً من أن يحصل الأشخاص المتعاملين بالأرفف على فهم أرحمهم والمساعدة في مجتمعهم المحلية فضلاً عن تلك التي الأرفف والأصدقاء والمبتعثون إلى الأرفف.

والهدف أيضاً أن تستطيع المساعدة عندما تصبح من مجتمعنا متعلق الأرفف. فضلاً عن أن تكونك هذا.

من المهم جداً أن نتحدث عن هذا الأمر وإن كنت تعتقد أن مرض الأرفف غير ذي أهمية أو غير ذي صلة.

أستعدون لطرح أسئلة وأفكارهم ورحمهم الطويل المتصلة لتشارلز أرفف الذي يلعب من الأرفف.

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歡迎!

關愛失智症之友是由英國阿滋海默症協會擴展的一項全球性運動，起源於日本的失智症支持者計劃。現正在美國推行。

Men Kâk fê sou demans

Konédy sou sante sêvo. Memm jan ak lòt pati nan lòt a, sêvo nou devlope epi chanje pandan tout lavi nou. Moun ki fè rechèch yo te jwenn ke nou ka rekonstrwi demans nou nan fè egèsis, manje pou sante, pase tan ak lòt moun, dèmi ase, jere estrès, evajye bagay li nouvo pou "agaje sêvo nou", ak evite bliki egrete nan sêvo tankou chèk nan sêvo. Konédy sa yo trè bon pou nou tout, a nempòt ki laj.

Prevalans demans. Apre yo nan nif adilt 65 an ogèl, ou byen ke yo n' ka konte moun ki gen mwens pase 65 lane, devlope demans. Moun ka devlope demans memm li yo memm yo estè de ki la tan. Koulye a, pa gen okenn faktè pou prevni ouwa gen demans, memm ke moun ki fè rechèch yo ap travay di pou atenn li sa a.

Etap nan demans. Senòtm demans yo gen tandans ogmante ouk le tan. Pafwa moun pale de diferan "etap yo" nan demans. Seyon enfòmasyon Zanmi Demans lan gen tandans pou konsantre sou premye ak etap mitan yo. Pa egzanp, wèdyo Senk Menaj fè yo montre sèman moun ki kapab pale pou konman demans afekte yo. Li pa gen ladann okenn moun ki gen demans nan yon nivo trè avanse. Pou kilè moun k ap viv avèk demans, senòtm yo pral evajyèlman nan nan yo etap avanse, epi yo pral bezwen swen ak asistans ak tout pati nan lavi detouche yo.

Eksperyans fami yo Demans gen yo trè gwo enpak sou manm fami ak zanmi yo. Anpl "patnè swen" ap goumen pou yo bay sipò chak yo pandan ke yo soufri pat relasyon an kouman li te konte ye avan. Pran swen yo moun ki soufri demans ka trè difisil, enkonpòman, fèkman ak fwayman. Li kapab tou gen enplòyifikasyon ak rekòmans. Zanmi demans yo pwajite pou soule konsyèyasyon sou nesansite patnè swen ou byen ke moun ki gen maldè demans.

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Dementia Friends Massachusetts  
Gid Chanpyon

Byenveni nan Zanmi Demans (Dementia Friends)! Ou ap vin kole tèt ak 48 milye de Chanpyon atravè lemond, k ap ede konnètse nou yo vin pi favorab ak demans. Gid Chanpyon a pa rakonte w tout bagay ke w chwè konnen yo fason pou w kapab ede lòt sèyon enfòmasyon sou Zanmi Demans (Dementia Friends).

Men Kâk fê sou demans

Konédy sou sante sêvo. Memm jan ak lòt pati nan lòt a, sêvo nou devlope epi chanje pandan tout lavi nou. Moun ki fè rechèch yo te jwenn ke nou ka rekonstrwi demans nou nan fè egèsis, manje pou sante, pase tan ak lòt moun, dèmi ase, jere estrès, evajye bagay li nouvo pou "agaje sêvo nou", ak evite bliki egrete nan sêvo tankou chèk nan sêvo. Konédy sa yo trè bon pou nou tout, a nempòt ki laj.

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• My name is \_\_\_\_\_

• As a Dementia Friend I will: (check which actions you will take)

Show that I'm a Dementia Friend

Talk to someone with dementia

Help someone with dementia

THANK YOU FOR \_\_\_\_\_

Dementia Friends Massachusetts

Hãy cùng tham gia vào một hoạt động toàn cầu nhằm thay đổi cách mọi người nghĩ, hành động và nói về sa sút trí tuệ!

Làm thế nào để trở thành một Dementia Friend? Người bạn đồng hành hỗ trợ người sa sút trí tuệ! Bạn sẽ trở thành một Dementia Friend sau khi tham dự một buổi thông tin kéo dài 1 tiếng, để học nắm vững hiểu biết chính về sa sút trí tuệ, và những điều đơn giản bạn có thể làm để tạo ra sự khác biệt trong cộng đồng của mình.

Có gì ở Buổi Thông tin? Đây là một buổi thảo luận được dẫn dắt bởi một tình nguyện viên Quản lý của Dementia Friends. Bạn sẽ học về sa sút trí tuệ là gì, sống với nó sẽ như thế nào, và một số gợi ý giúp bạn giao tiếp với người bị sa sút trí tuệ.

Người tham dự nói gì:  
"Tôi đã được khai sáng."  
"Ước gì tôi được biết thêm nhiều từ 5 năm trước, khi gia đình tôi phải trải qua những điều này."  
"Tôi sẽ nhận biết thêm rất nhiều ở cả chỗ làm lẫn cộng đồng"

Trình bày Công đồng Massachusetts cũng như trên toàn Hoa Kỳ, Soltzberg tại JF&CS

Somos Dementia Friends

Note: websites can be auto-translated.

# Materials are necessary but not sufficient!

- Trusted community members are **essential**.
- **Fair compensation** is necessary.
- **Key qualifications** for community partners:
  - A trusted role in the community
  - Ability to engage community members and facilitate sessions
  - An interest in spreading awareness about dementia
  - **Not necessary:** prior extensive knowledge about dementia, degrees, certifications

# Interpretation

Think through a sustainable pathway for participation.

- One English-speaking Master Trainer in Massachusetts so far means:
  - Champions must either speak English or
  - Have the support of a bilingual Community Partner Champion
- Identify funds for interpretation as needed (plan for double the time!)
- Do not ask partners to provide interpretation free of charge

# 3. Relationships

Build trust through time and respect

# Relationships

- Do your homework: learn about the community's priorities and barriers to trust
- Avoid the “last-minute ask” - allow time to find partners who are truly interested
- Support community partners' own initiatives
- Provide structures for open communication
- Take advice, respond to requests
- Expect each community to have unique needs; be flexible

# Relationships



Group meetings on Zoom every other month to get to know each other and learn from each other

# Relationships allow learning

## Examples:

- Different perspectives on self-advocacy
- Perspective and needs of service providers must be considered to reach participants with intellectual/developmental disabilities (I/DD)
- Trust and trauma, based on experiences within the US and in country of origin

# 4. Road

How are we doing, and where do we go from here?



- In the past 14 months, community partners have led 65 information sessions, yielding 1,204 new Dementia Friends
- Now: 23-24% of new Dementia Friends participants are in one of the focal communities, better matching Massachusetts demographics



# Nope! This process is ongoing

- We will always be learning and trying to become more inclusive.
- We are adapting based on what community partners and JF&CS each have to offer.
- This is a lot of work. There are no shortcuts.
- **There is nothing better than mutual learning and knowing that the right people are at the table to make real progress!**

# Last word: Comments from partners and participants

“I really liked sharing my new knowledge with my community...I know a lot of people were scared so it makes me feel good that I can help give more information and guide them.” - Community Partner



“I will spend more time to communicate patiently with someone who has dementia, and understand their feelings.” – Chinese participant

“I feel inspired to continue sharing these experiences with other people to reduce the stigma.” – Portuguese-speaking participant



# Let's Talk!

Put your questions and comments into  
the Chat box!

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- Evaluation survey
- CEU certificates
- Webpage with recordings and updated Resource List

شكرًا لك

Mèsi

Obrigada

謝謝

благодарю вас

Cảm ơn bạn

Thank you

Gracias

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