Advisory Council on Alzheimer's Disease and All Other Dementias

Executive Office of Elder Affairs
Elizabeth Chen, Secretary

August 16, 2022
3:00-5:00 pm
Video Conference

Agenda

1. **Welcome, Logistics, Introductions** *(15 min)*

2. **Developing Approach for Building Diversity, Equity, and Inclusion (DEI) into the Council's Work: Presentation & Discussion** *(35 min)*

3. **Younger-Onset Dementia and Equity Analysis Workgroup: Presentation & Discussion** *(30 min)*

4. **Council Member Roundtable Discussion** *(30 min)*

5. **Next Steps and Vote to Adjourn** *(10 min)*

Workstream: Equitable Access and Care
Workstream Lead: Jatin Dave, MD

Diversity - Any dimension that can be used to differentiate groups and people from one another.[i]

Equality vs. Equity - *Equality* has to do with giving everyone the exact same resources, whereas *equity* involves distributing resources based on the needs of the recipients.[ii]

Equality - Equality aims to ensure that everyone gets the same things in order to enjoy full, healthy lives.[iii]

Equity - Equity is defined as "the state, quality or ideal of being just, impartial and fair." The concept of equity is synonymous with fairness and justice. To be achieved and sustained, equity needs to be thought of as a structural and systemic concept [iv]

Heterogeneous - Consisting of dissimilar or diverse ingredients or constituents [v]

Inclusion - The action or state of including or of being included within a group or structure. More than simply diversity and numerical representation, inclusion involves authentic and empowered participation and a true sense of belonging.[vi]

i. **US Department of Housing and Urban Development**
ii. Ellen Gutoskse, **What's the Difference Between Equity and Equality?**
iii and iv. Annie E. Casey Foundation. **Race Equity and Inclusion Action Guide.**
v. **https://www.merriam-webster.com/dictionary/heterogeneous**
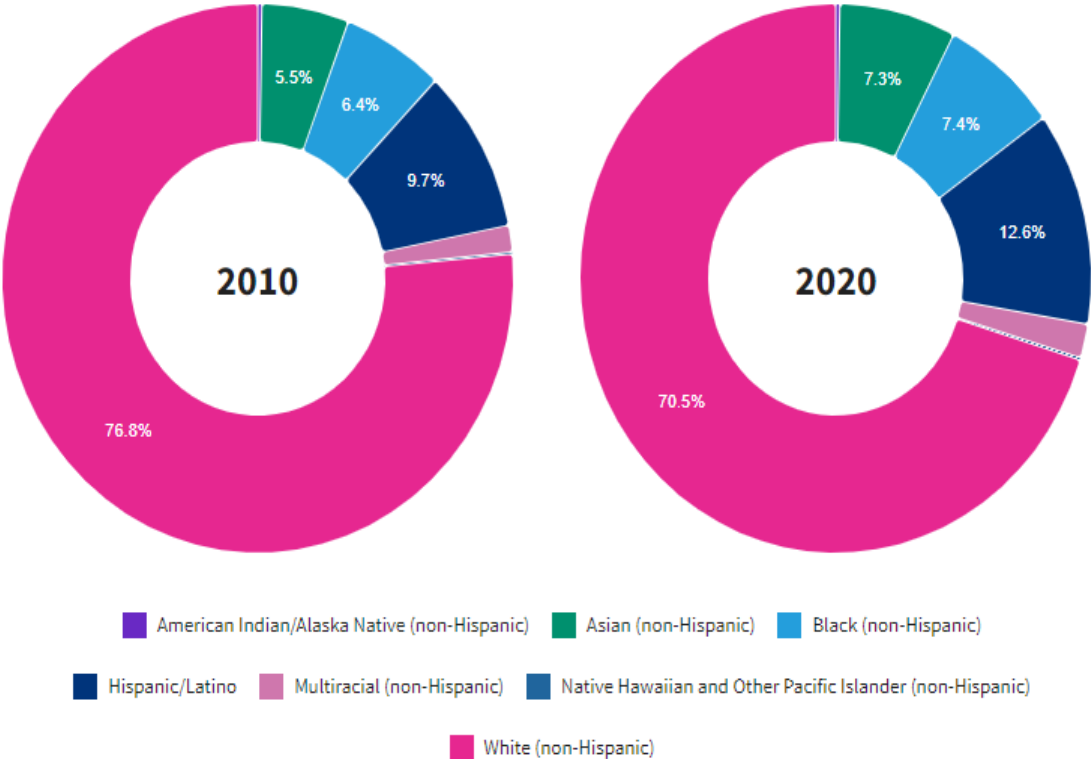vi. Annie E. Casey Foundation. **Race Equity and Inclusion Action Guide.**

How has the racial and ethnic makeup of Massachusetts changed?

In **2020**, Massachusetts was more diverse than it was in 2010. In **2020**, the **white (non-Hispanic)** group made up **70.5%** of the population compared with **76.8%** in **2010**.

Between **2010** and **2020**, the share of the population that is **Hispanic/Latino** grew the most, increasing **2.9** percentage points to **12.6%**. The **white (non-Hispanic)** population had the largest decrease dropping **6.2** percentage points to **70.5%**.

Source: Census Bureau

Racial makeup of Massachusetts   Hide Hispanic ethnicity

2010
- 5.5%
- 6.4%
- 9.7%
- 76.8%

2020
- 7.3%
- 7.4%
- 12.6%
- 70.5%

Legend:
- American Indian/Alaska Native (non-Hispanic)
- Asian (non-Hispanic)
- Black (non-Hispanic)
- Hispanic/Latino
- Multiracial (non-Hispanic)
- Native Hawaiian and Other Pacific Islander (non-Hispanic)
- White (non-Hispanic)

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Non-English Speakers

MOST COMMON LANGUAGES

1. Spanish
   632,230 speakers (9.67%)

2. Portuguese
   206,232 speakers (3.15%)

3. Chinese (Incl. Mandarin, Cantonese)
   148,270 speakers (2.27%)

24.7% of Massachusetts citizens are speakers of a non-English language, which is higher than the national average of 22%.

In 2019, the most common non-English language spoken in Massachusetts was Spanish. 9.67% of the overall population of Massachusetts are native Spanish speakers. 3.15% speak Portuguese and 2.27% speak Chinese (Incl. Mandarin, Cantonese), the next two most common languages.
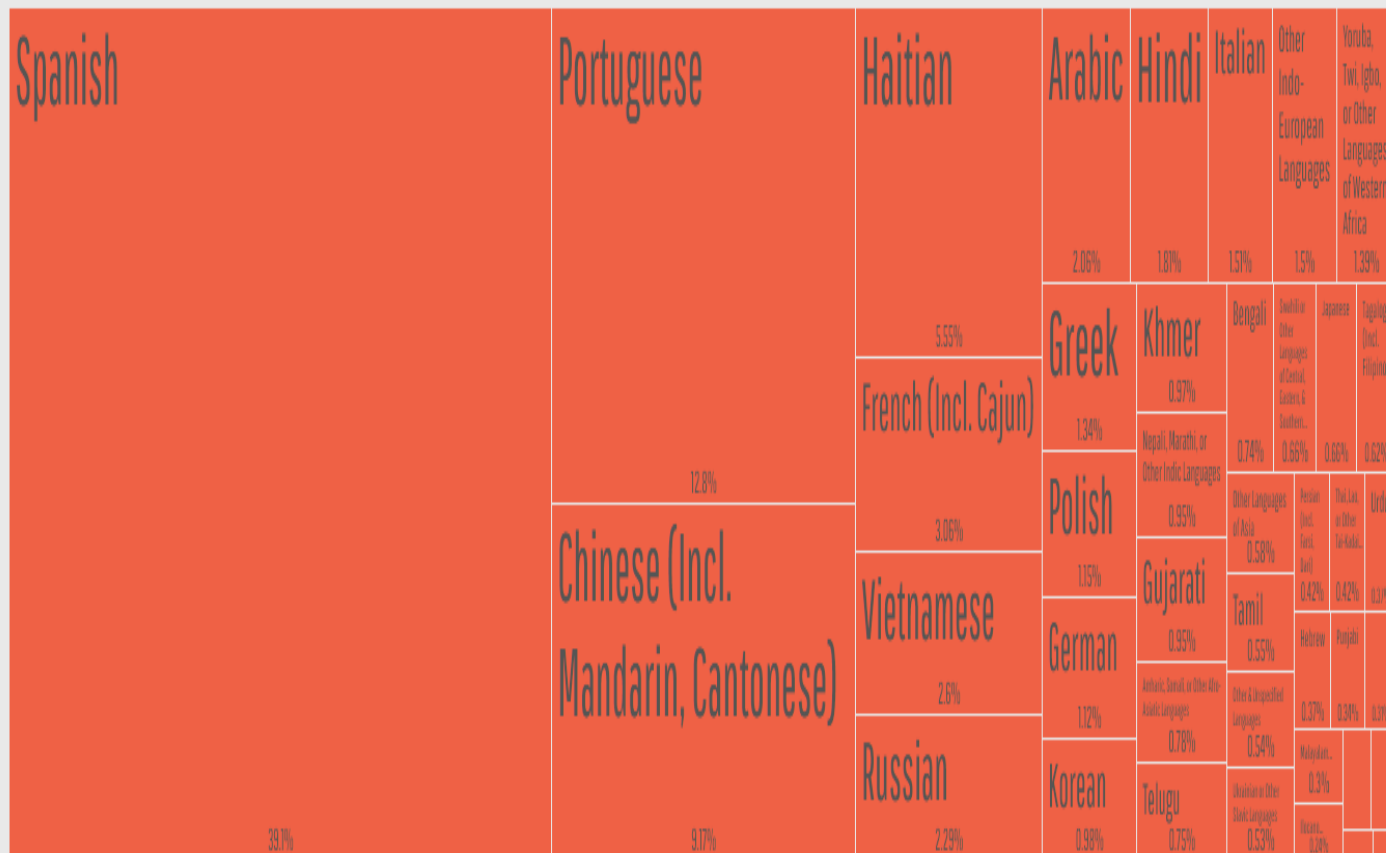
Data from the Census Bureau ACS 1-year Estimate.

Source: **https://datausa.io/profile/geo/massachusetts#demographics**

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Examples of Underrepresented Groups

- Black/African American (not Latinx)

- Latinx, including Brazilian/Portuguese speaking

- Cape Verdean

- Immigrants and refugees

- Asian immigrants (in order of number of people in MA: Chinese, Vietnamese, Khmer/Cambodian, Korean, Burmese)

- Individuals living in rural areas

- Individuals who are incarcerated

- Individuals with housing insecurity

- LGBTQ+ communities

- Native Americans

- People living alone with dementia

- Individuals with intellectual and developmental disabilities (I/DD)

- Blind or vision impaired

- People with hearing loss/late deafened

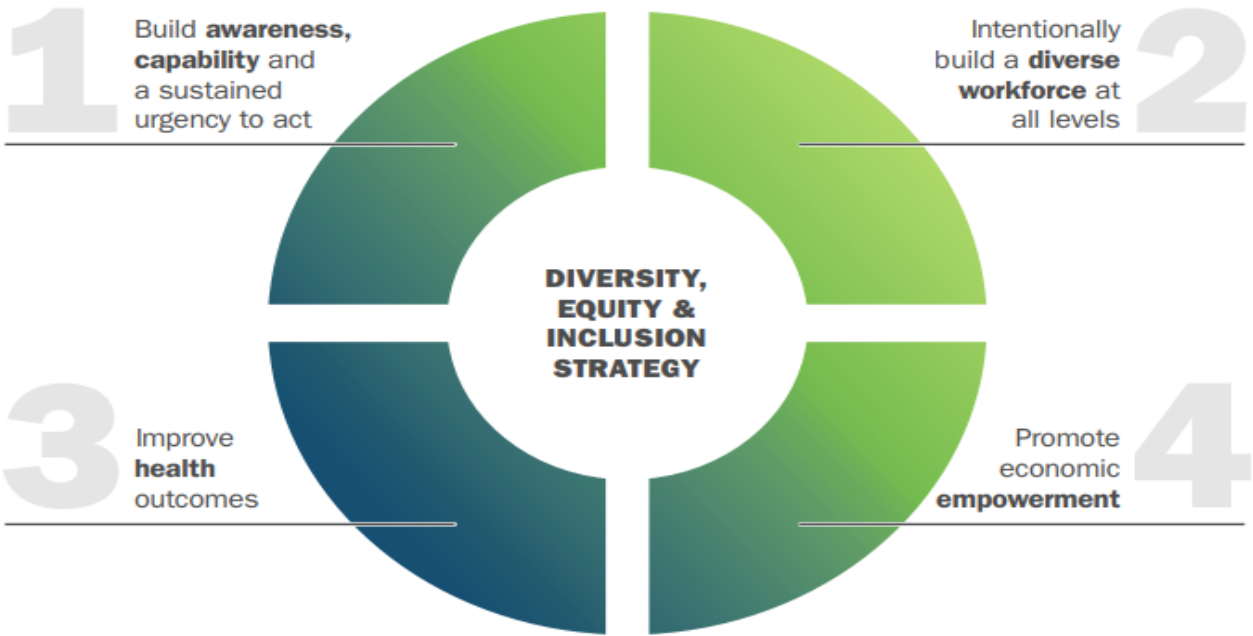- Veterans

OUR COMMITMENT

Championing inclusion within and outside our organization to amplify the power of diversity

As a company that pioneers science for the betterment of humanity, Biogen believes that any form of prejudice, racism or intolerance is unacceptable and has no place at our company. To advance our mission, we seek to engage the world's brightest minds, and have long prioritized diversity, equity and inclusion (DE&I) not only as a moral imperative, but as a competitive strength.

In 2020, after the murder of George Floyd, it became clear that we needed to do more to promote our values both within our company and globally. We held dozens of listening sessions across all levels of the organization, engaged with outside experts and consulted community organizations. What we heard compelled us to recognize Juneteenth as an official U.S. holiday beginning in 2021 and helped shape our enhanced four-part DE&I strategy.

Successful implementation will require and enable us to build an inclusive organization of diverse, talented employees who reflect the patients we serve and the communities where we operate. It also involves collaborating with external organizations, peers and others to address the health inequities in care for the disease areas we treat. As part of our commitment, we have

OUR ENHANCED DE&I STRATEGY INCLUDES A STRONG COMMITMENT TO TRANSPARENCY

1 Build **awareness, capability** and a sustained urgency to act

2 Intentionally build a **diverse workforce** at all levels

DIVERSITY, EQUITY & INCLUSION STRATEGY

3 Improve **health** outcomes

4 Promote economic **empowerment**

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Source: 2021 Diversity, Equity & Inclusion Report, Biogen

- As you know, we are in the process of building an "Equity & Inclusion (EI) team" and working on making it more heterogeneous.

- An EI Team kick-off meeting will be convened as soon as possible.

- The EI team will be asked to review and edit a draft of the Council's "vision" and "pledge" to promote DEI in our work.

DRAFT

VISION

The *Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias* envisions a Commonwealth that reflects the communities we serve and values and benefits all people affected by dementia equally — one that addresses cultural, economic, environmental, and other societal barriers. We recognize and value the lived experience of all Massachusetts residents affected by dementia and strive for equitable outcomes for all.

PLEDGE

As we work to achieve our goals, we pledge to:

- Build and cultivate a culture of diversity, equity, and inclusion among all individuals working to advance the Council's goals including the Council, its workgroups, focus groups, and other partners.

- Listen to, learn from, respect, and value diverse life experiences and perspectives including the experiences of those disproportionally affected by societal barriers to dementia research, care, services, support, and decision-making.

- Highlight and address inequities as we develop policy recommendations, programs, and resources for individuals and families affected by dementia and hold ourselves accountable for successes and failures.

- Commit to residents affected by dementia that they will receive the support, services, and care needed to live healthy and meaningful lives.

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Why Diversity, Equity, and Inclusion (DEI) Matter

- Some populations experience greater societal barriers than others to quality dementia care, support, and risk reduction

- Some barriers are specific to dementia; some apply to all healthcare

- Barriers exist for individuals before a diagnosis, after a diagnosis, and at every stage of the disease

- People who are disproportionately affected by these barriers struggle at the beginning of their dementia journey and at each additional stage

- As a potential reference for workgroups, we listed some examples of barriers and groups disproportionately affected by them (Appendix A)

Goal - Build a solid foundation of DEI into our work

Objectives

1. *Engage diverse Equity & Inclusion (EI) Team to:*

   a) Identify barriers that may prevent certain groups from benefiting from the Council's work

   b) Determine reasons for the barriers; identify approaches to eliminate them, weaken them, or mitigate their impact

2. *Refine recommended policies, implementation plans, activities, programs, or deliverables to achieve our DEI goal*

1. Deploy members of the EI Team to work collaboratively with the workgroups to achieve our DEI goal

2. Prior to deploying the team's members to advise workgroups, convene them to learn from each other by responding to the following:

   a) What challenges have you encountered associated with dementia that are specifically due a lack of cultural understanding?

   b) What benefits have you experienced when interacting with people who had a solid understanding of your cultural community?

Proposed Approach

1. **Review & Provide Feedback**

   a) Volunteers ("advisors") from EI Team review the workgroup's relevant materials or activities.

   b) Provide feedback to the workgroup at one of its meetings.

2. **Allow for Shared Leadership and Accountability**

   a) The workgroup leader/ Council member informs the Council of the status and next steps around addressing the advice provided.

   b) If the workgroup and advisors did not reach consensus at the workgroup's meeting, the recommendation(s) and issues are discussed and voted upon by the Council.

1. How can we ensure that the Council's membership reflects the diversity of the people we serve?

2. If you are a member of (or work with people within) an underrepresented group, is there anything you would like to share from your personal experiences before we convene the EI Team?

3. What challenges have you encountered or expect as we build DEI into our work?

4. If you lead a workgroup, can you explain how this approach would be implemented within your workgroup in terms of your specific activities or work products?

5. Other ideas or concerns about how to incorporate DEI into our work?

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APPENDIX A

Societal Barriers to Quality Dementia Care, Services, Support, and Risk Reduction

Some Examples of Societal Barriers and Groups Disproportionately Affected

Examples of Barriers	Examples of Groups Disproportionately Affected
Lack access to screening and diagnosis	People lacking financial resources (Black/African Americans, Hispanic Individuals, Native Americans) Rural dwellers People ages 30-64 living with undiagnosed younger onset Alzheimer's Disease (AD) People ages 45-64 living with undiagnosed non-AD dementia (Frontotemporal dementia and Lewy Body dementia)
Sensitive to stigma and fear of talking with doctor about cognitive impairment	There may be specific groups disproportionately affected by this barrier
Lack understanding of difference between dementia and normal aging	There may be specific groups disproportionately affected by this barrier
No informal/family caregiver options	Individuals living alone; LGBTQ+ individuals; People estranged from family
Lack financial resources	Black/African Americans; Hispanic Individuals; Native Americans
Unable to navigate the bureaucracies	People lacking financial resources (see above)
Lower educational attainment	People lacking financial resources (see above)
Lack reliable transportation	People lacking financial resources (Black/African Americans, Hispanic Individuals, Native Americans); Rural dwellers; People unable to drive and without access to public transportation
Under age 65 and experiencing dementia symptoms	People ages 30-64 living with undiagnosed younger onset Alzheimer's Disease (AD); People ages 45-64 living with undiagnosed non-AD dementia (Frontotemporal dementia, Lewy Body dementia)
Lack access to healthcare	Black/African Americans and other minority populations
Work in low-paying jobs without health insurance benefits	Black/African Americans and other minority populations
Unemployed	Black/African Americans and other minority populations

Disclaimer - This list is for illustrative purposes and is not the result of a thorough or robust review of studies or data and should not be interpreted as such.

Some Examples of Societal Barriers and Groups Disproportionately Affected

Examples of Barriers to Risk Reduction (12 Modifiable risk factors)	Examples of Groups Disproportionately Affected
Less education	People lacking financial resources (Black/African Americans, Hispanic Individuals, Native Americans)
Social isolation	Individuals living alone; People isolated from family; People estranged from family; Individuals with mental health or behavioral health conditions
Untreated hearing loss	Non-Hispanic white adults ages 60 and over
Depression	Racial/ethnic, gender, and sexual minorities (due to lack of access to high-quality mental health care, stigma surrounding mental health care; and lack of awareness about mental health)
Obesity	Black/African Americans, Hispanic Individuals, Native Americans
Excessive alcohol consumption	Minority populations (e.g., racial/ethnic, gender, sexual identity); Military veterans
Physical inactivity	Hispanic, Black/African Americans, Native Americans; Adults ages 25 and older with less than a high school education; Adults ages 25 and older living in poverty
Smoking	Adults that live in rural areas; Military veterans; Lesbian/gay/bisexual adults (LGB); Adults that did not graduate high school; Americans living in poverty; Uninsured Americans; Indigenous peoples; Americans with mental or behavioral health conditions; Adults in public housing
High blood pressure	Black/African Americans; Asian Americans; Hispanic Americans
Diabetes	Native Americans; Hispanic Americans; Black/African Americans
Traumatic brain injury (TBI) (including concussion)	TBI: people between the ages of 15 - 24 years; persons under the age of 5 or over the age of 75 also at a significantly higher risk Concussions: older adults and children ages 4 and under (due to fall risk); Adolescents (due to bike accidents and sports-related head injuries); Military personnel (due to exposure to explosive devices)
Air pollution	Black/African Americans, Asian and Hispanic Americans; Low-income populations; People with occupational exposure to air pollution

Disclaimer - This list of examples is for illustrative purposes and is not the result of a thorough or robust review of studies or data and should not be interpreted as such.

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APPENDIX B

Links to Helpful Resources

Links to Helpful Resources

- *Diversity, Equity, and Inclusion in Alzheimer's and Dementia - PowerPoint Presentation,* Alzheimer's Association

- *Special report on Race, Ethnicity and Alzheimer's in America, 2021 Alzheimer's Disease Facts and Figures* (Section 7), Alzheimer's Association

- *Diversity, Equity & Inclusion,* Alzheimer's San Diego

- *Diversity, Equity, Inclusion & Access,* Minnesota Board on Aging

- *Better Brain Health through Equity: Addressing Health and Economic Disparities in Dementia for African Americans and Latinos*, Milken Institute

- *LGBT and Dementia*, Sage and Alzheimer's Association

- *Connecting with Asian and Pacific Islanders (AAPIs) About Dementia,* National Asian Pacific Center on Aging

- *Dementia and IDD*, Eunice Kennedy Shriver Center, UMass Chan Medical School

- *The Most Costly Chronic Medical Condition in America: Experts Talk About the Rural Aspects of Alzheimer's Disease and Related Dementias,* Kay Miller Temple, MD

- *Supporting Native American elders living with dementia,* Jennifer Tinkelberg

- *Attacking cultural trauma and dementia among Vietnamese immigrants*, UC Davis Health

- *Serving Hispanic Families, Home and Community Based Services for People with Dementia and their Caregivers: A Toolkit for the Aging Network,* Alzheimer's Association

- *Perspectives in Brief: Planning for the Next Phase in Alzheimer's Disease: Partnering with Communities of Color*, Biogen

Caregiver Factsheets from the Diverse Elders Coalition - DiverseElders.org

- *[What Providers Should Know About African American Family Caregivers]*
- *[What Providers Should Know About American Indian Family Caregivers]*
- *[What Providers Should Know About AAPI Family Caregivers]*
- *[What Providers Should Know About Hispanic Family Caregivers]*
- *[What Providers Should Know About LGBT Family Caregiver]*
- *[What Providers Should Know About Southeast Asian American Family Caregivers]*

Younger-Onset & Equity Analysis Update & Next Steps

Workstream: **Equitable Access and Care**
Workgroup: **Younger-Onset & Equity Analysis**
Workgroup Lead: **Rhiana Kohl, PhD**
Presenter: **Joe Montminy, Dementia Advocate and Workgroup member**

Younger-Onset & Equity Analysis Workgroup of the Council's Equitable Access & Care Workstream:

Rhiana Kohl, PhD, Council Member (Workgroup Lead)

Mike Belleville, Council Member & Dementia Advocate

Kathy Devine, Prescription Advantage Program Manager - EOEA

Liz Gross, Caregiver

Chelsea Gordon, Director of Public Policy & Advocacy, Alzheimer's Association, MA/NH Chapter

Judy Johanson, Dementia Advocate - Mass. Alzheimer's Disease Research Center, MGH

Tracy Lungelow, Caregiver

Joe Montminy, Dementia Advocate

Paul Mathew, MD, Caregiver

Barbara Meehan, Council Member & Dementia Advocate/Former Caregiver

Workgroup's Charge

Conduct an analysis of the needs of people affected by younger-onset dementia and provide guidance for other teams on how to apply an equity and inclusion lens by using this population as a case study

Source: The Council's Annual Reports, April 2020 and April 2021

Our Goal

Address unmet needs and close gaps in equality, equity, and inclusion for people living with younger-onset dementia and
the people who care for them

1. Identified challenges or unmet needs associated with younger-onset dementia

2. Examined each need through an equality and equity lens by identifying why they remain unmet:

Barriers to Equality	*Barriers to Equity*
Individuals living with dementia under age 60 do not qualify for some state-supported essential services and supports available to older adults living with dementia and their caregivers.	*Individuals living with younger-onset dementia and their caregivers have unmet needs due to the differing nature of their needs compared with older adults living with dementia.*

3. Developed a list of state supported services & supports available for older adults living with dementia

4. Examined eligibility and age restrictions around each service and support

   ➢ Identified those unavailable or not easily accessible to younger adults

5. Determined if the unmet needs resulted from barriers to equality or equity and categorized them within six themes:

Public Awareness, Education, and Stigma	Diagnosis	Services & Supports
Caregivers	Finances	Clinical Trials

1. Prioritize unmet needs and develop recommendations to address them

2. While preparing our recommendations, we will likely focus on developing approaches to address:

   - Building awareness of and expanding access to services and supports for those living with younger-onset dementia and the people who care for them

3. Provide Council with recommendations around unmet needs falling within the purview of the Council's other workstreams
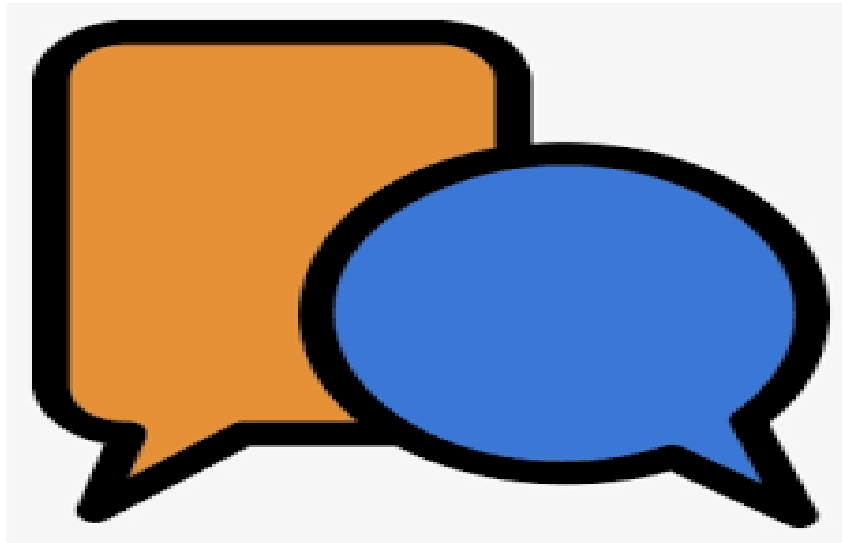
4. At a future Council meeting, we will provide:

    a) Our recommendation(s) and justification in terms of challenges, unmet needs, and feasibility

    b) Proposed implementation plan(s)

Questions or Comments?

Next Meeting:

November 1
3:00 to 5:00 pm

Location: Video Conference

Vote to Adjourn