

Alzheimer's Advisory Council



**Executive Office of Elder Affairs
Elizabeth Chen, Secretary**

**May 5, 2021
3:00-5:00 pm
Video Conference**



Agenda



- 1. Welcome, Logistics, Introductions (10 min)**
- 2. Quality of Care Workstream (50 min)**
 - Care Planning Presentation (10 min) and Discussion (15 min)
 - Staffing & Training Presentation (10 min) and Discussion (15 min)
- 3. Caregiver Support and Public Awareness Workstream (50 min)**
 - (a) Four 5-minute presentations:
 - Video production
 - Website development
 - Cross-referrals
 - Caregiver experience
 - (b) Discussion (30 min)
- 4. Closing Remarks and Final Roll Call (10 min)**

Alzheimer's Advisory Council Moving from Planning to Action, 2021



Workstream: Quality of Care Implementation of Recommendations Status and Discussion

May 5, 2021

Workstream Leads

Maura Brennan, MD

Linda Pellegrini, MS, GNP-BC



Quality of Care Workstream Recommendations



As described by the Council in the Alzheimer's State Plan:



Recommendation #1

**Develop a person-directed
care plan framework and template**



Recommendation #2

**Develop a plan that ensures staff receive
training and support needed to build and
retain interprofessional teams with
expertise in dementia**



Recommendation #1: Care Planning



Recommendation #1

Develop a person-directed care plan framework and template





Care Planning Implementation Team



Linda Pellegrini, MS, GNP-BC

Council Member & Workstream Co-lead
Care Planning Implementation Team Co-lead
Geriatric Nurse Practitioner
UMass Memorial Medical Center

Susan Antkowiak

Council Member
Care Planning Implementation Team Co-lead
Vice President of Programs & Services
Alzheimer's Association

Mike Belleville

Council Member
Dementia Advocate

Deb Dowd-Foley

Caregiver Specialist
Elder Services of Worcester Area, Inc.

Laurie Herndon, MSN, GNP, BC

Project Director
Hinda and Arthur Marcus Institute for Aging
Research, Hebrew SeniorLife

Judy Johanson

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

Gad A. Marshall, MD

Medical Director of Clinical Trials at Center for
Alzheimer Research and Treatment,
Brigham and Women's Hospital (BWH); Associate
Neurologist at BWH; Assistant in Neurology at
Massachusetts General Hospital; Associate
Professor of Neurology at Harvard Medical School

Victoria Martischnig

Graduate Student (MPH candidate)
Southern New Hampshire University



Care Planning Implementation Status



Updates and Accomplishments

- Gathering resources (e.g., Workbook: What Matters to Me; My Health Matters, Stanford Letter Project, etc.)
- Convening preliminary meetings with potential collaborators
- Intern acquired - Victoria Martischnig, Public Health Graduate Student, Southern New Hampshire University
- Collaboration with Diagnosis & Services Navigation Workstream Leads

Next Steps

- Convene two focus groups, one comprised of people living with dementia, the other comprised of caregivers
- Make decision if using an existing tool or create a new template



Care Planning Challenges and Solutions

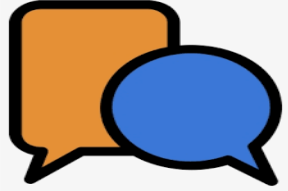


Challenges

- Avoid redundancy, template should be value-added
- Due to underdiagnosis, it will be challenging to engage people living with dementia early enough for them to fully participate
 - when will it be appropriate to engage caregivers
 - how do we engage caregivers and maintain the voice of the person living with dementia
- Engaging unsupported individuals
- Funding a third-party convener of stakeholders to develop the template

Solutions

- Convene focus group of people living with dementia and caregivers to explore usefulness of template, ensuring voice of person living with dementia is incorporated



CARE PLANNG DISCUSSION (15 min)



Discussion

1. Is the person-driven care plan template an effective tool for developing care plans based on the values and priorities of the person living with dementia?
 - Can the tool effectively engage the voice of the person living with dementia regardless of stage of disease?
 - Do we have the opportunity to market this to healthcare professionals and the public?
 - Will we have the necessary resources and funding?
2. How do we promote the partnership between practitioners and their patients to utilize the person-driven model of care planning?



Recommendation #2: Staffing & Training



Recommendation #2

Develop a plan that ensures staff receive training and support needed to build and retain interprofessional teams with expertise in dementia





Staffing & Training Implementation Teams



Interprofessional Training Implementation Team

Maura J. Brennan, MD

**Council Member & Training
Implementation Team Co-lead**

Program Director

Baystate Health Geriatrics Workforce
Enhancement Program

Robert Schreiber, MD

Training Implementation Team Co-lead

Vice President and Medical Director
Program of All-inclusive Care for the
Elderly (PACE)
Fallon Health

Pam Mirick, RN

Former Caregiver and nurse

Nina M. Silverstein, PhD

Professor of Gerontology
University of Massachusetts Boston

Direct Care Worker Recruitment & Retention Implementation Team

Tara Gregorio

**Recruitment & Retention Implementation
Team Co-lead**

President, Massachusetts Senior Care
Association

Lisa Gurgone, MS

**Recruitment & Retention Implementation
Team Co-lead**

Executive Director
Mass Home Care



Interprofessional Training Implementation Status



Updates and Accomplishments

- Two ECHO programs up/forthcoming: Baystate Geriatrics Workforce Enhancement Program (GWEP) (an age-friendly/QI focus), UCLA/Alzheimer's Assoc. ECHO focused exclusively on dementia care
- Completing list of existing resources to identify gaps and opportunities for rapid initial spread of current tools and resources including those available at Centers of Excellence, GWEPs, CBOs/ Alzheimer's Assoc., Health Resources and Services Administration (HRSA), etc.

Next Steps

- Broaden group to wider range of professional caregivers: APs, social workers, community health workers, direct care workers, etc.
- Compile and post an annotated online list of resources/tools for interprofessional teams with URL links
- Connect to other workgroups so training can be designed/adapted as necessary to achieve all Advisory Council goals
- Meet with Institute for Healthcare Improvement (IHI) leadership and Alzheimer's Assoc. to leverage collaboration with Age-Friendly Health System (AFHS) movement and ongoing Alzheimer's Assoc. initiatives



Interprofessional Training Challenges and Solutions



Challenges

- Multiple stressors and competing demands of frontline clinicians and concomitant difficulty in securing time/team support for training
- Gaps in perceived value of geriatrics & dementia care by clinicians, systems, patients and families

Solutions/Potential Strategies

- Make trainings/ongoing coaching as practical and valuable as feasible—synchronous and asynchronous times, professional development (CME, project support, etc.), support for individual patient care, linked to AFHS recognition, incorporate into training/planning for Annual Wellness Visits, adapt to individual circumstances and resources
- Consider a phased-in mandate for an interprofessional team (> 4 professions) with expertise in dementia and ongoing training/support for care of older adults?
- Leverage AFHS movement for public relations campaign as feasible



Direct Care Worker Recruitment & Retention Implementation Status



Updates and Accomplishments

- Launched the Direct Care Worker Recruitment & Retention Implementation Team in April as part of the Council's Quality of Care Workstream
- Began to develop a list of existing Direct Care Workforce initiatives and trainings

Retention and Recruitment Initiatives	Research and Analysis
Extended Care Career Ladder Initiative (ECCLI), Personal and Home Care Aide Training Initiative, Commonwealth's Long term Care Staffing Portal	State Auditor Reports on Home Care, Research by Home Care Aide Foundation, "Who Will Care for Us?" by Dr. Paul Osterman, MIT, Cliff Effect Research, UMASS Boston
Wage and Benefit Initiatives	Policy and Strategy Groups
Nursing Home Quality Initiatives, Salary Reserve/Enough Pay to Stay Initiatives, COVID19 Temporary Rate Increases	MA Healthcare Workforce Development Collaborative, Reinventing Work Initiative (Federal Reserve Bank), MA Legislative Commission for Nursing Homes Quality
Career Ladders and Curriculum Development	
Extended Career Ladder Initiative (ECCLI), Alzheimer's Supportive Home Care Aides, PHCAST Training, Community Colleges/Vocational Schools, Training Providers	

Next Steps

- Gather Feedback from stakeholders on additional resources
- Review existing Direct Care Worker initiatives and trainings for best practice recommendations, with a focus on ADRD Training and Support



Direct Care Worker Recruitment & Retention Challenges and Solutions



Challenges

- Interprofessional Staff – Recognizing and valuing the Direct Care Worker (DCW)
- Financial
- Education/Training
- Availability of Workers

Solutions

- Quality Jobs Initiatives/Career Ladders/Upskilling Existing Staff
- Align Work with Existing Initiatives Working to Re-Envision the DCW System
 - Massachusetts Health Care Collaborative Direct Care Initiatives Recommendations - Harvard Project on Workforce research to update our understanding of direct care training and career pathway models
 - American Rescue Plan Act Investments
 - Federal and State Efforts to Support DCWs and Caregivers
 - President Biden's American Jobs Plan
 - Senator Spilka's Caregiver Initiative
- Gather a list of core competencies for ADRD training for DCWs



DISCUSSION (15 min)



Interprofessional Training and Direct Care Worker Recruitment & Retention

1. How can we motivate universal training and track consistent participation?
2. Are we more likely to achieve our goals by focusing exclusively on the problem of dementia care or can we secure more traction by linking to broader movements, notably AFHS or perhaps Patient Priorities Care, which include a focus on care for those with dementia or can be readily adapted/expanded to do so?
3. How can we improve the lives of direct care workers through training, professional development, better wages? What is the role for state legislation?

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Workstream: Caregiver Support & Public Awareness

Implementation of Recommendations

Status and Discussion

May 5, 2021

Workstream Leads

Barbara Meehan

Hector R. Montesino



Caregiver Support & Public Awareness



As described by the Council in the Alzheimer's State Plan:



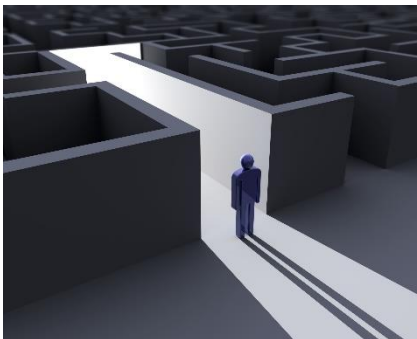
Recommendation #1

Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it



Recommendation #2

Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers



Recommendation #3

Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner



Implementation Team Presentations



Caregiver Support & Public Awareness Workstream

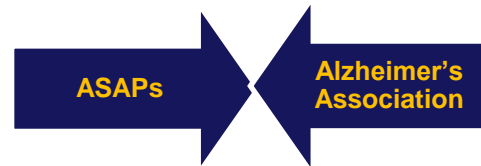
- Today, each of this workstream's four implementation teams will provide a brief presentation:



Video
Production
(5 min)



Website
Development
(5 min)



Cross-
Referrals
(5 min)



Caregiver
Experience
(5 min)

- To make the most of our time, **please make note of your questions during the presentations and we will convene a 30-min Q/A session after all four have been presented**



Recommendation #1: Video Production



Recommendation #1

Make and distribute three videos (English, Portuguese, Spanish) of caregivers talking about the help they got, and how they got it





Video Production Implementation Team



Barbara Meehan

**Council Member & Workstream Co-lead
Implementation Team Co-lead**

Alzheimer's Advocate/Former Caregiver

Hector R. Montesino

**Council Member & Workstream Co-lead
Implementation Team Co-lead**

President

Embrace Home Care Services

Milagros Abreu, MD, MPH

President/ CEO and Founder

The Latino Health Insurance Program, Inc.

Jennifer Hoadley, CDP

Regional Manager Southeastern MA

Alzheimer's Association, MA and NH Chapter

Patty Sullivan

Program Director

Dementia Friendly Massachusetts



Video Production Status



Updates & Accomplishments

- Established contact with MassAccess who will work with us to film and format videos and provide them to all MassAccess cable channel members. The videos will be available to download and available for viewing on YouTube
- Identified interviewers
- Solidified material to cover in videos
- Determined that the video needs to be 30 minutes

Next Steps

- Identify caregivers for videos by end of May 2021
- Work with caregivers to establish comfort
- Contact non-MassAccess cable TV stations; distribute videos widely



Video Production Challenges & Solutions



Challenges

- Providing video access in multiple venues
- Finding caregivers comfortable with being in video

Solutions

- Dr. Abreu will help identify appropriate caregivers who speak Spanish and Portuguese
- Other team members will identify appropriate English-speaking caregiver

We will have time for your questions soon. In the meantime, Barb Meehan will present the work of the Website Development Team.



Recommendation #2: Website Development



Recommendation #2

Place on the Massachusetts Executive Office of Elder Affairs (EOEA) website, an overview of statewide pathways, services, and supports for people living with dementia and their caregivers





Website Development Implementation Team



Pam MacLeod, MBA, PMP

Implementation Team Lead

Senior Project Director

MA Executive Office of Elder Affairs and
UMass Medical School

Molly Evans

Senior Policy Manager

MA Executive Office of Elder Affairs

Anagha Kumar

Student Intern, Harvard College

MA Executive Office of Elder Affairs

Annette Peele, MSW

Director of Community Programs

MA Executive Office of Elder Affairs



Website Development Status



Updates & Accomplishments

- Developed a “website mock-up”
- Described available services, supports and resources
- Presented information in a topic-by-topic format
- Began recruiting caregivers to test a draft version of the website
- Developed a guide with questions to help facilitate a discussion with the website’s evaluators (caregivers)

Next Steps

- Will build and have caregivers use and test the website in May and June 2021



Website Development Challenges & Solutions



Challenges

- Including enough information to be helpful, but not so much that it becomes overwhelming
- Avoiding government jargon when describing programs/services

Solutions

- Categorize information and include Tables of Contents for easy navigation
- Ensure that each webpage contains a short list of information with headings for easy scanning
- Have caregivers test a draft version of the site and incorporate their feedback before going live



Website Development Question for Council



The website's resources are organized by the following topics. **Did we miss any important topics?**

Table of Contents in the "About" webpage

1. **Services** (*When users select this topic, they will be directed to the service categories on the next slide*)
2. **Caregiver Support**
3. **Social Engagement**
4. **Resources on Alzheimer's Disease and Related Dementia**
5. **Clinical Trial Participation**
6. **Advocacy and Volunteering**



Website Development Question for Council



Did we miss any important service categories?

Table of Contents in the “Services” webpage

1. Service Navigation and Referral
2. Support Groups and Peer-to-Peer Companion Programs
3. Elder Abuse Prevention
4. Insurance Navigation and Support
5. In-Home Programs, Services, and Meals
6. Community-Based Supports for MassHealth Members
7. Locating a Nursing Home or Assisted Living Residence

Next up: Pam MacLeod will introduce work designed to address the third recommendation of the caregiver support & public awareness workstream



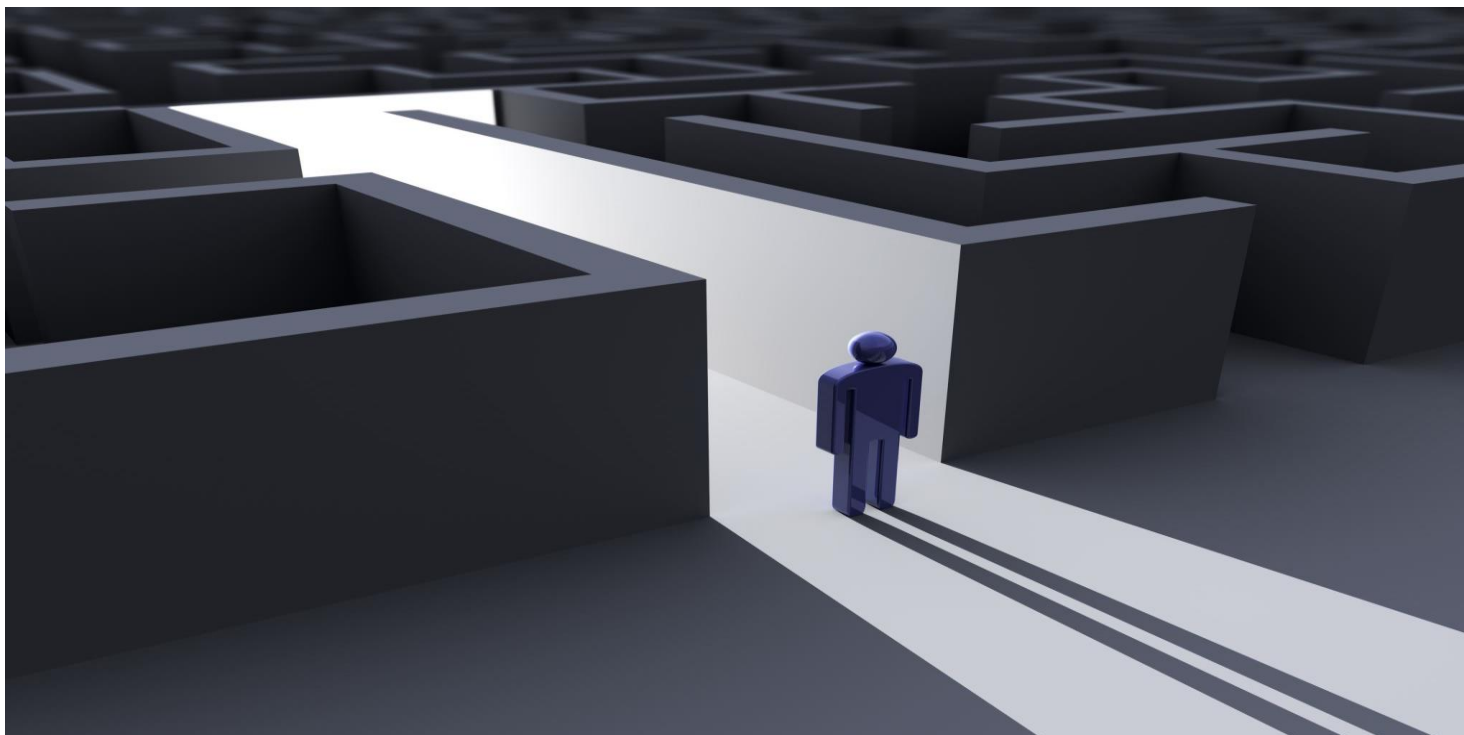
Recommendation #3: Caregiver Experience



Recommendation #3

Implement changes at the Aging Services Access Points (ASAPs) to ensure that stressed caregivers get what they need in an effective and consistent manner

(all caregivers including dementia caregivers)

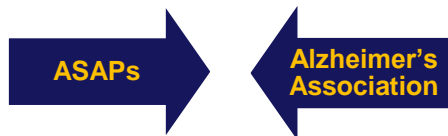




Caregiver Experience Implementation Teams



Cross Referrals Implementation Team



Pam MacLeod, MBA, PMP

Implementation Team Lead

Senior Project Director, MA Executive Office of Elder Affairs (EOEA) and UMass Medical School

Referrals from ASAPs

Kathy Devine

Director, Prescription Advantage Operations, EOEA

Carole Malone

Assistant Secretary, EOEA

Annette Peele, MSW

Director of Community Program Services, EOEA

Referrals from Alzheimer's Association

Nicole McGurin

Programs & Services Director

Alzheimer's Association, MA/NH Chapter

Julia Perriello

Manager, Helpline and Community Referrals

Alzheimer's Association, MA/NH Chapter

Caregiver Experience Implementation Team



Amanda Bernardo

Implementation Team Lead

Director of Communications and Strategic Initiatives
MA Executive Office of Elder Affairs (EOEA)

Kathy Devine

Director, Prescription Advantage Operations, EOEA

Molly Evans

Senior Policy Manager, EOEA

Pam MacLeod, MBA, PMP

Senior Project Director, MA Executive Office of Elder Affairs (EOEA) and UMass Medical School

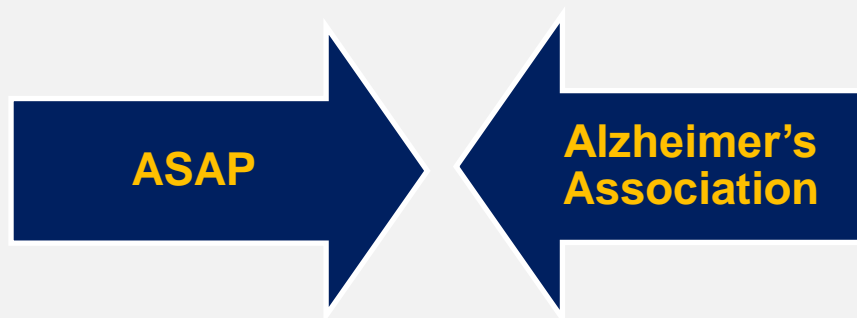
Annette Peele, MSW

Director of Community Program Services, EOEA

Lynn C. Vidler, BSW, MBA

Director of Home and Community Programs

**Make cross-referrals a standard practice
between the ASAPs and Alzheimer's Association**





(1) Cross-Referrals Team Status



Updates and Accomplishments

- Reviewed current practices around cross-referrals between MA elder service agencies (ASAPs) and the Alzheimer's Association Helpline (aka "24/7 Helpline")
- Checked the resource database on the 24/7 Helpline website used by the public to ensure accuracy of its ASAP information
- Made improvements to the internal resource database used by 24/7 Helpline staff to highlight the role of ASAPs
- Determined that referrals from the ASAPs' Information & Referral staff to the 24/7 Helpline and vice versa are already considered a standard practice (when practical and appropriate) and part of staff training



(1) Cross-Referrals Team

Next Steps



Next Steps

Will reinforce cross-referrals as a best practice:

- Alzheimer's Assoc. will place this topic on the agenda of an upcoming meeting of its MA/NH Chapter staff
 - Will showcase ASAP offerings and provide example of how a referral made a positive difference for an individual or family
- EOEA will distribute brief talking points about the 24/7 Helpline (provided by Alzheimer's Assoc.) to all supervisors of ASAP call-takers
- EOEA has placed this topic on the agenda of all three regional Aging & Disability Resource Consortia (ADRC) meetings to be convened in May 2021
 - Attendees will include I&R staff, options councilors, and family caregiver support specialists



(1) Cross-Referrals Team Challenges & Solutions



Challenges

- As its primary focus, the 24/7 Helpline provides brief counseling to address an “in-the-moment” crisis or emergency, often making an ASAP referral impractical
- ASAP call-takers, however, are more likely to receive comprehensive information from callers, so it almost always makes sense to refer callers affected by dementia to the 24/7 Helpline along with referrals to local programs and services
- Although cross-referrals are considered standard practice (when practical), caregivers that participated in the caregiver support workgroup’s quick and very limited test were not referred in either direction although doing so would have benefited their situations

Solutions

- EOEa and the Alzheimer's Assoc. will reinforce cross-referrals as a standard practice (applying the approach described in the previous slide)
- The Caregiver Experience Team will conduct a robust review and evaluation of caregiver experience and cross-referrals will be part of that review

Next up: Amanda Bernardo will present progress made on our Caregiver Experience Project



(2) Caregiver Experience



- 1. Conduct a robust evaluation of the caregiver experience when contacting ASAPs, identify areas for improvement at ASAPs, and implement improvements where needed**
- 2. Require that ASAP staff refer caregivers to the Massachusetts Family Caregiver Support Program when appropriate**
- 3. Assess all ASAPs' automated phone messages and make changes to ensure these are clear and make it easy for caregivers to connect to individuals for help**





(2) Caregiver Experience Team Status



Updates & Accomplishments

- The Caregiver Experience Team had a successful kick-off meeting to design project scope, which included an exercise to discuss the ideal caregiver experience
- The team defined project scope and agreed to recruit a diverse set of caregivers to assist with caregiver experience project
- The team discussed the general concepts of the project with select members of aging network and will bring in stakeholders, as applicable

Next Steps

- Due to the COVID-19 vaccine distribution, the team has had to briefly pause the caregiver experience project; it will resume work and begin recruiting caregivers this spring
- The team expects to complete the project in fall 2021



(2) Caregiver Experience Team Challenges & Solutions



Challenges

- There may be challenges in recruiting caregivers that are not already directly connected with the aging services network
- There are challenges designing a project that balances both understanding what the caregiver experience is when they contact the aging network, while also acknowledging that finding the aging network may present its own set of difficulties for a caregiver

Solutions

- The team has identified a variety of partners that may be able to assist in the recruitment of caregivers
- The team agreed to define the project scope as reviewing the experience once a caregiver has connected with the aging services network

Next up: Hector Montesino and Barb Meehan will facilitate a Q/A session



CAREGIVER SUPPORT & PUBLIC AWARENESS DISCUSSION (30 min)



I. Your Questions and Comments?

- Video Production
- Website Development
- Cross-Referrals
- Caregiver Experience



Next Steps



Next Council Meeting - September 1, 2021, 3:00 to 5:00 pm

Presentations/Discussions on:

1. Equitable Access & Care
2. Diagnosis & Services Navigation