

# Alzheimer's Disease Working Group

## *Session 5 – The Caregiver's Journey*

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### **Vision**

*People with Alzheimer's disease and their families will receive the support and care they need through early detection and diagnosis, high quality health and long term supports and services, and communities that are prepared to meet their needs.*

**Bill Moss, Chair**

Aging and Long Term Services Administration

May 14, 2015



# Welcome

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# Today's Meeting Goals

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- Receive input from caregivers about support priorities and recommendations.
- Review draft goals, strategies and recommendations. Prioritize and identify short- and longer-term recommendations.
- Provide advice on implementation plan.



# Agenda Overview

<b>10:00 – 10:15 a.m.</b>	<b>Welcome</b>
<b>10:15 – 11:30 a.m.</b>	<b>The Caregiver’s Journey</b>
<b>11:30 – 2:00 p.m.</b>	<b>Review Goals, Strategies and Recommendations</b>
<b>12:00 – 12:30 p.m.</b>	<b>Working Lunch – An Effective Plan</b>
<b>12:30 – 2:00 p.m.</b>	<b>Continue work on Goals, Strategies and Recommendations</b>
<b>2:00 – 2:15 p.m.</b>	<b>Break</b>
<b>2:15 – 3:00 p.m.</b>	<b>Implementation Planning</b>
<b>3:00 – 3:15 p.m.</b>	<b>Public Comment Period</b>
<b>3:15 – 3:30 p.m.</b>	<b>Wrap Up and Next Steps</b>



# The Caregiver's Journey

***Hilarie Hauptman, Facilitator***

***Arlene Johnson***

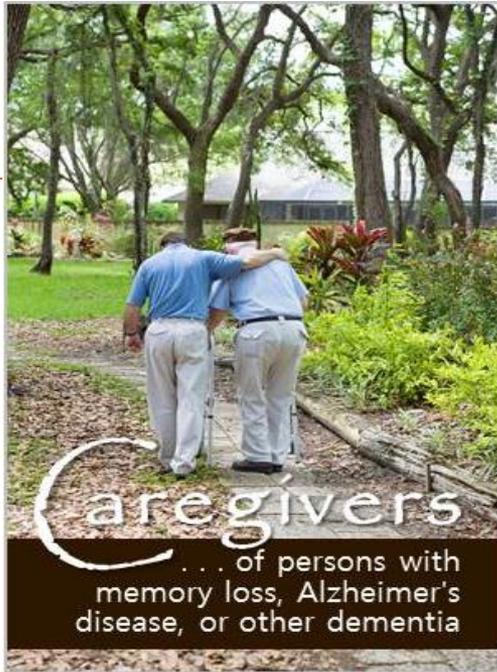
***Bill Baker***

***Peggy Quan***

***Debbie Hunter***

***Todd Larson***





## How many family caregivers in Washington? How many are caring for people with memory loss or dementia?

- Estimated 900,000 family caregivers<sup>1</sup>
- Estimated 270,000 caring for someone with memory loss, including Alzheimer's or other dementia<sup>2</sup> (30% of CG, BRFSS 2007)
- Providing care for person with memory loss or dementia **DOUBLES** the odds that caregiver experiences serious mental health condition (as compared to other caregivers)

# The Caregiver's Journey – Table Discussions

**Looking at all the feedback we've received so far:**

- **Public Survey**
- **Listening Sessions**
- **Caregiver's Presentation**

**Do our draft recommendations cover the bulk of the aggregate feedback related to caregivers?**



# Providing Care for People with Memory Loss and Dementia



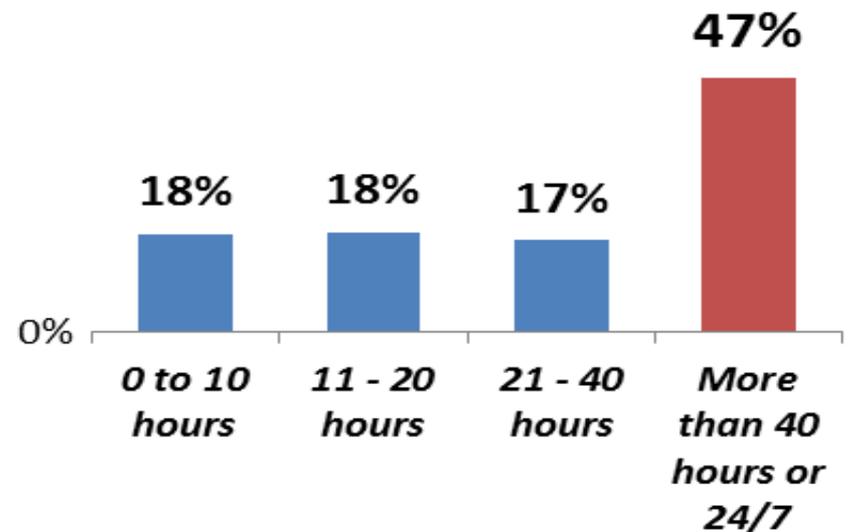
- **Caregiving intensity grows as memory loss becomes more progressed**
  - Caring for persons with memory loss increases the odds that the caregiver provides high-intensity care by 56 percent
  - Caring for persons with diagnosed Alzheimer's disease or other dementia increases the odds of high-intensity care by 75 percent
- **Providing high-intensity care is associated with:**
  - A five-fold increase in the odds that the caregiver experiences a serious mental health condition
  - 45 percent lower odds of the caregiver being in good or better health.



# Online Survey of Family Caregivers 2014 (WA)

- **Almost half** of responding caregivers care for someone with memory loss, Alzheimer's or dementia
- **83% of those caregivers** report they care for someone who often or sometimes acts in ways that are challenging or upsetting to the caregiver

**Intensity of Care  
Provided by  
Unpaid Caregivers**  
*hours per week*



# Impacts on Employment & Health



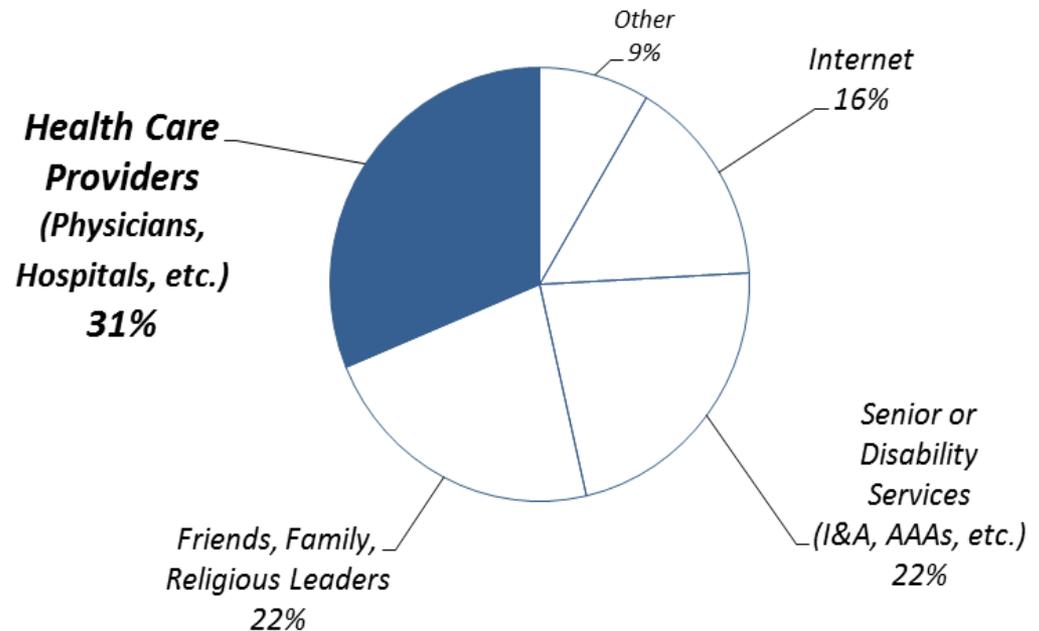
- **40%** of previously employed caregivers had stopped work due to caregiving
- **71%** of caregivers employed part-time cut back on their work hours to do caregiving.
- **65%** say that caregiving creates/aggravates their health problems.
- **38%** rate their current health as poor, very poor, or only fair.

**48%** feel that the person they care for cannot be left at home alone at all, or for only one hour



# Where (or to whom) do CGs look for assistance?

- Family caregiver supports are not well known
- Just 26% of these online respondents had heard of the FCSP
- Health care providers are the most common place for caregivers seeking information



**Physicians also named as #1 choice for information in both the FCSP Evaluation, and in the ADWG Public Survey!**



# Family Caregivers Served in FCSP

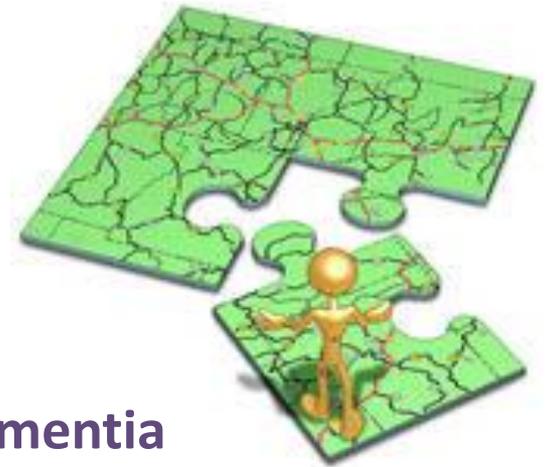
*FCSP serves a significant number of families living with memory loss/dementia*

- **53%** are caring for individuals with Alzheimer's Disease or dementia
- Another **32%** caring for individuals with memory/cognitive problems
- **82%** are coping with challenging behaviors of care receivers
- **75%** spend at least 40 hours a week caregiving



# Family Caregiver Support Program

- Respite Care
- Specialized caregiver information
- Emotional supports (counseling, support groups)
- Training & education
- Supplies & equipment
- Mental Health/Wellness Referrals
- Evidence-based screening and assessment (TCARE®)
- Consultation & care planning



## Building Dementia Capability:

- Memory Care & Wellness Services (dementia day program)
- STAR-C dementia consultation
- Reducing Disability in Alzheimer's Disease/RDAD (NIH grant, ends 2015)
- Dementia Capable Systems Grant (2014-2017) – strengthening links between project partners/early stage



# FCSP Outcomes of Recent FCSP Expansion

When caregivers access support **earlier** in the caregiver journey, before they experience highest levels of stress, depression and/or burden:

- There is a statistically significant delay in the use of Medicaid long term services and support (LTSS) for the care receiver
- The caregiver's well-being is improved



# Goals, Strategies and Recommendations

A **Goal** is a big idea or visionary statement. It should be broad, memorable, and framed as an action.

Ensure access to comprehensive supports for family caregivers

A **Strategy** is a high level plan to achieve a goal. It is not too specific, however.

Increase access to respite

Provide guidance and support for dementia caregivers in navigating the system

**Recommendations** are specific, measurable and time-bound steps that support a particular strategy.

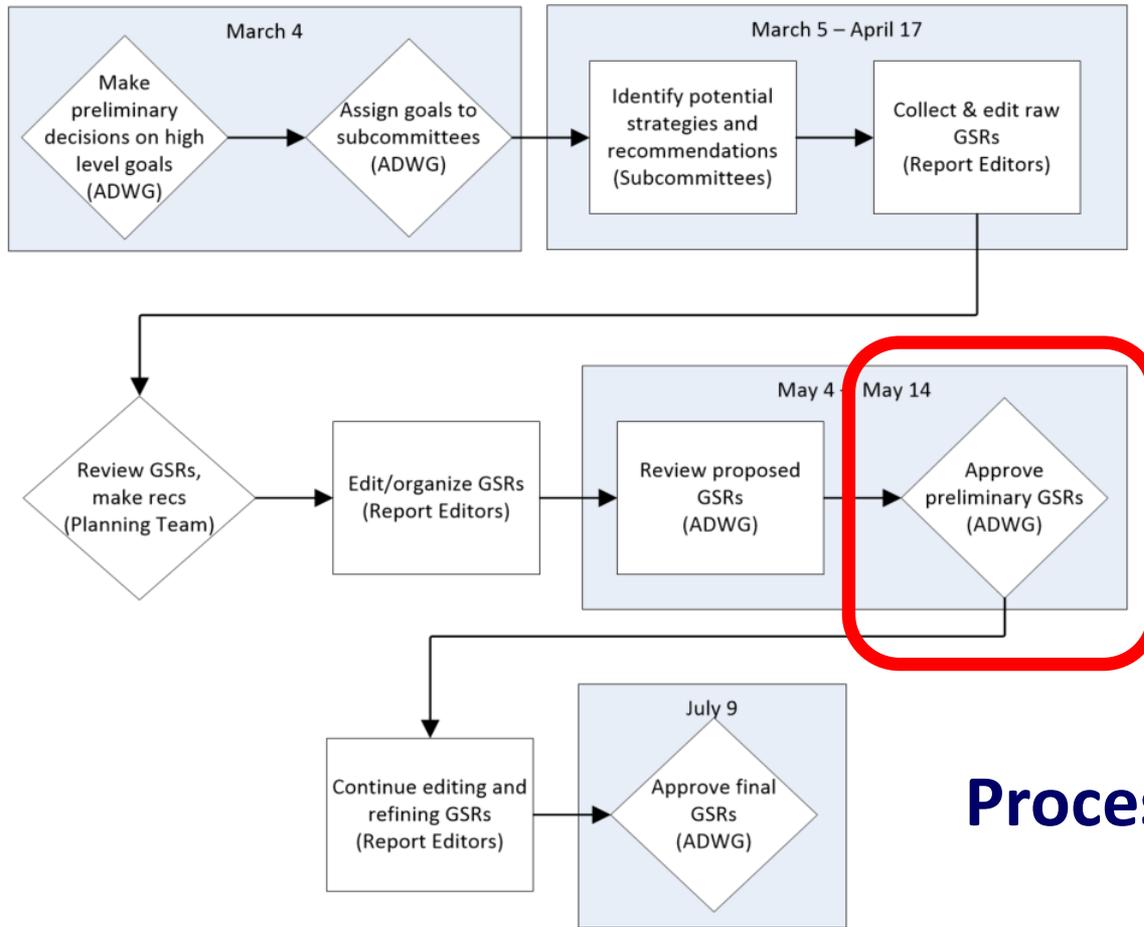
DSHS and partners should promote education and coaching around utilizing natural support networks and care teams to support the person with dementia and the family caregiver.

Fund DSHS to expand funding for respite care, and explore flexible service models, such as overnight care, drop-in day care, volunteer-based programs, crisis/emergency respite, and models that promote wellness, e.g., Memory Care & Wellness Services.

Create a state-specific “road map” for family caregivers, providing information about what to expect over time to help plan for the future.



# Goals, Strategies and Recommendations

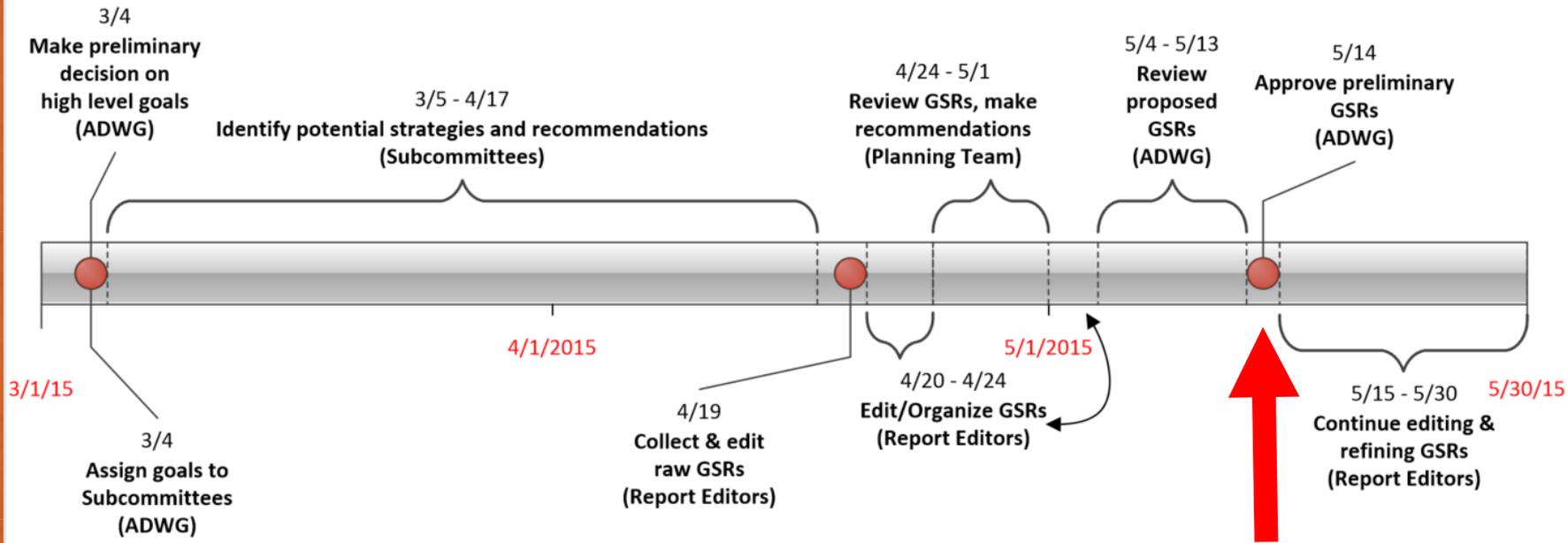


Today's Task

Process Flowchart



# Goals, Strategies and Recommendations



You are here

## Process Timeline



# Prioritizing the Strategies

## Goal 1

## Strategies

Increase  
Public

Facilitate increased diagnosis and accessing of services

Awareness,  
Engagement  
and

**4<sup>th</sup>** Reverse/reduce stigma surrounding dementia

Education  
about  
Dementia

**1<sup>st</sup>** Create a sense of hope and empowerment for people with dementia

Ensure statewide coordination of information and referral

A single portal (website) entry system for access to services

**3<sup>rd</sup>** Identify and utilize reliable and evidence-based information on Alzheimer's disease and other dementias

**2<sup>nd</sup>** Promote advance care planning and advance financial planning in the early stages of dementia before function declines

Promote collaboration and coordination among the private and public sector to increase awareness



# Working Lunch – An Effective Plan

*Let's hear from legislators and policy leaders about what an effective state plan would look like from their perspective....*

- 1. Do you have advice about the number of strategies and recommendations that should be included?**
- 2. Do you want to see recommendations identified as short and long term?**
- 3. What other advice do you have as we complete the draft plan?**



# Working Lunch – An Effective Plan

*At your tables, discuss the following:*

- 1. What are some characteristics of the most effective plans you have seen?**
- 2. Look at the hopes and fears you identified early in the process. Is the report coming together in a way that meets your expectations?**
- 3. What advice if any do you have as we complete the draft report?**

*Be prepared to report out to the larger group.*



# Recommendations Exercise

Promote research and innovation into the causes and effective interventions for dementia

Strategy	Recommendations (needed policies or responses)	Priority – H/M/L	Short/Long Term	Legislation – Y/N/DK	Funding – Y/N/DK
A. Increase support for basic, clinical and translational research around cognitive health, dementia and effective dementia care.	1. Explore ways to improve the research infrastructure for supporting basic, translational, and clinical research in the state and region.				
	2. Leverage the metrics from health information exchanges as they become available, to support research efforts at the clinic level.				
	3. UW, DSHS, DOH, HCA will explore funding opportunities and collaborations for Washington to participate in dementia care service innovation programs.				
B. Develop relationships with key community stakeholders to assess and pilot culturally specific/ relevant services.	1. Identify all organizations and institutions in WA involved in AD research to promote research awareness and strategic alliances.				
C. Increase number of research participants.	1. Engage community physicians to encourage patient referral to and participation in clinical trials and provide examples of 'how to have the conversation'.				



# Common Questions and Concerns

1. All of the strategies are important. It is hard to prioritize them.
2. I saw feedback in the survey or listening session notes that wasn't included in our recommendations. Should we add it?
3. I'm not comfortable prioritizing any of the recommendations. Why do we need to do that?
4. Some of the recommendations are still pretty similar, can we consolidate them?
5. Other \_\_\_\_\_?



**Break**

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# Implementation Planning

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**Bea Rector (for Bill Moss)**



# Implementation Planning

- Establish an Advisory Group to monitor the plan
  - May include many members of the ADWG
  - Meet semi-annually
  - Advisory group would hear progress reports
- Establish a Steering Committee to coordinate the plan
  - Comprised of key staff from DSHS, DOH, HCA, Alzheimer's Association/Society
  - Meet quarterly
  - Establish and execute specific actions to advance plan



## Implementation Planning, continued

- Incorporate Implementation Recommendations into the Plan
- Refresh plan every 3-5 years
- Communicate progress to Advisory Group and Legislature annually via an annual report
- Monitor approaches used by other states (ex: Act on Alzheimer's – MN/ND)
- Administratively housed at DSHS
- Use ADWG Planning Team (comprised of subcommittee chairs) to refine the implementation plan
- Will report back in July



# Implementation Planning, continued

1. Questions for Bea about the initial recommendations.
2. What do you think about the Advisory Group idea?
3. Do you have any concerns about any of the initial ideas?
4. What did you really like about the proposed implementation structure?
5. Would you be willing to be considered for a position on the Advisory Group, if that is what we use going forward?



# Public Comment Period

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# Wrap-Up

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# Staff Support

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# Action Items

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- **Next ADWG Meeting:**
  - **Thursday, July 9, 2015**
  - **10:00 am - 3:30 pm**
  - **Tukwila Community Center**



**Thank you**

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# Session Evaluation

1  
★

2  
★★

3  
★★★

4  
★★★★

Content	Process
Outcomes	Facilities

Comments:

Are there other topics you would like to hear about?

