The Joint Legislative Executive Committee on Aging and Disability

May 19, 2014
Meeting Materials

- Agenda
- The Older American's Act and Area Agencies on Aging: Overview of Financing, Services, and Access, Dan Murphy, Northwest Regional Council
- Healthy Communities and Healthy Aging, Patti Migliore Santiago, Andrea Valdez, Office of Healthy Communities, Department of Health
- Age-Friendly Livable Communities, Gary Beagle, Clark County Commission; Jacqui Kamp, Colete Anderson, Clark County Community Planning
- Family Caregiver Support Program Update, David Mancuso, Research & Data Analysis Division, Department of Social & Health Services; Bea Rector, Aging & Long-Term Support Administration, Department of Social & Health Services
- Expanding Eligibility for the Family Caregiver Support Program in SFY 2012: Updated Findings, Bridget Lavelle, David Mancuso, Alice Huber, Barbara E.M. Felver, Department of Social & Health Services
- Has the use of Tailored Caregiver Assessment and Referral System Impacted the Well-being of Caregivers in Washington: Report to the Washington Aging & Long-Term Support Administration, Rhonda J.V. Montgomery, University of Wisconsin-Milwaukee
- Developing a State Alzheimer's Plan Update, Bill Moss, Aging & Long-Term Services & Supports, Department of Social & Health Services

1889

Washington State Legislature

John A. Cherberg Building
PO Box 40466
Olympia, WA 98504-0466
(360) 786-7407

Aging & Disability
Joint Legislative Executive Committee

John L. O’Brien Building
PO Box 40600
Olympia, WA 98504-0600
(360) 786-7160

Monday
May 19, 2014
1:00 to 4:00 p.m.

House Hearing Rm B
John L. O'Brien Building
Olympia, WA

AGENDA

1. Introductions and Opening Comments.
2. Older Americans Act.
   Dan Murphy, Northwest Regional Council
3. Area Agencies on Aging outreach activities.
   Dan Murphy, Northwest Regional Council
4. Healthy Communities and Transportation Issues.
   a. Patti Migliore-Santiago, Department of Health
      Andrea Valdez, Department of Health
   b. Gary Beagle, Clark County Commission
      Jacqui Kamp, Clark County Community Planning
      Colete Anderson, Clark County Community Planning
   c. Jim Curtain, Seattle Department of Transportation
5. Family Caregiver Support Program.
   David Mancuso, Department of Social and Health Services
   Bea Rector, Department of Social and Health Services
6. State Alzheimer's Plan update.
   Bill Moss, Department of Social and Health Services

Committee information and meeting materials can be found at the Committee's webpage:
http://www.leg.wa.gov/jointcommittees/ADJLEC/Pages/default.aspx

The Older American's Act and Area Agencies on Aging

Overview of financing, services and access

Presented to the Joint Legislative and Executive Committee on Aging and Disability

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Dan Murphy, Executive Director
Northwest Regional Council
May 19, 2014

What this presentation will cover

1. The Older American's Act and the roots of Area Agencies on Aging

2. The non-Medicaid funding that Area Agencies on Aging administer

3. The services those funds purchase

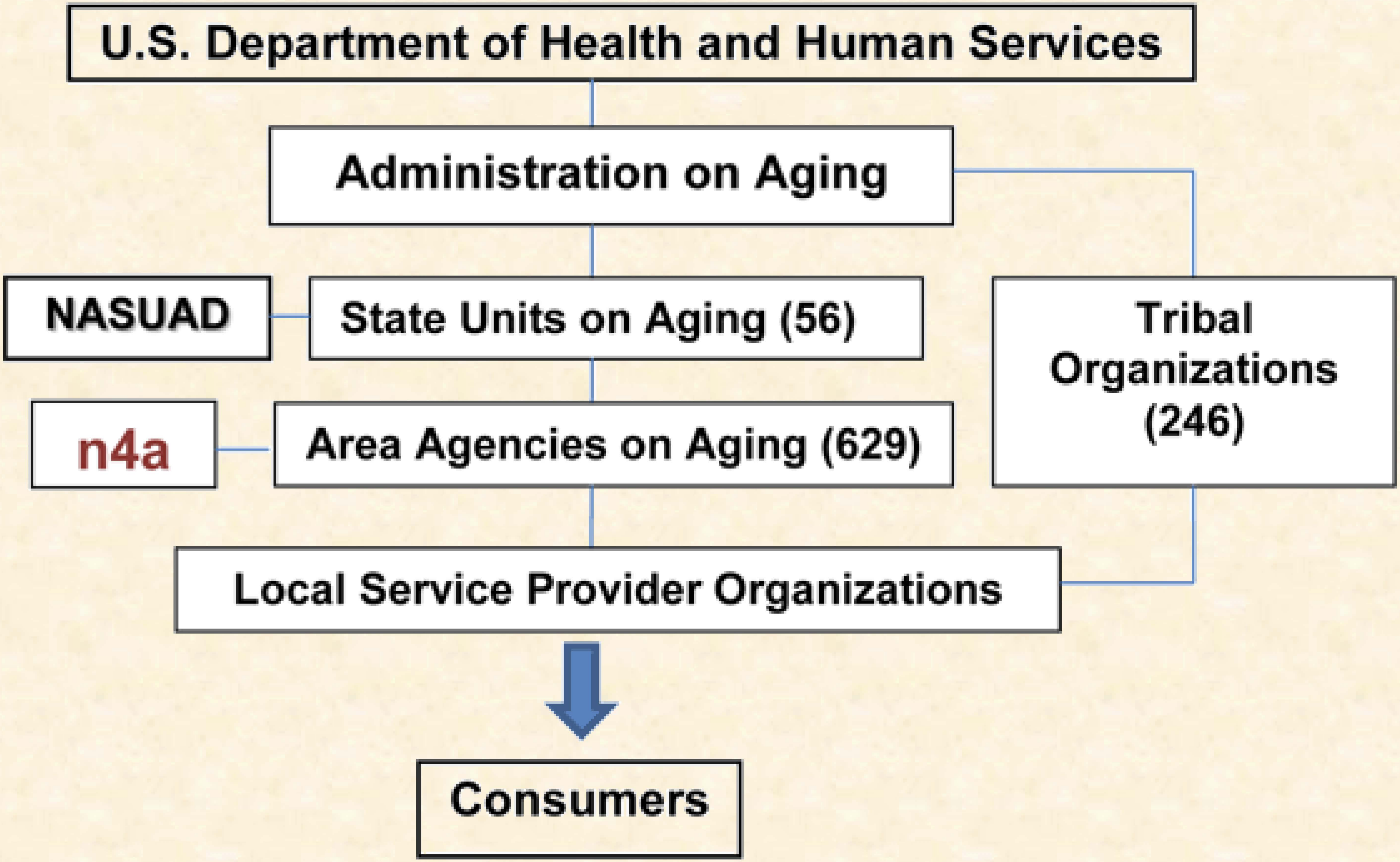
4. Areas of priority for the future:
   a. Aging in place
   b. Health
   c. Outreach, information, and assistance
   d. Support for unpaid caregivers

5. The impact of being rural

The Older American's Act lists ten broad goals for older people

1. An adequate retirement income
2. The best possible physical and mental health
3. Suitable housing, independently selected
4. Full restorative services for those who require institutional care
5. Employment with no age-based discrimination
6. Retirement in health, honor, dignity
7. Pursuit of meaningful activity
8. Efficient community services which provide social assistance in a coordinated manner
9. Immediate benefit from proven research
10. Freedom, independence, and free exercise of individual initiative in planning and managing their own lives

National Aging Services Network



U.S. Department of Health and Human Services

Administration on Aging

NASUAD

State Units on Aging (56)

Tribal Organizations (246)

n4a

Area Agencies on Aging (629)

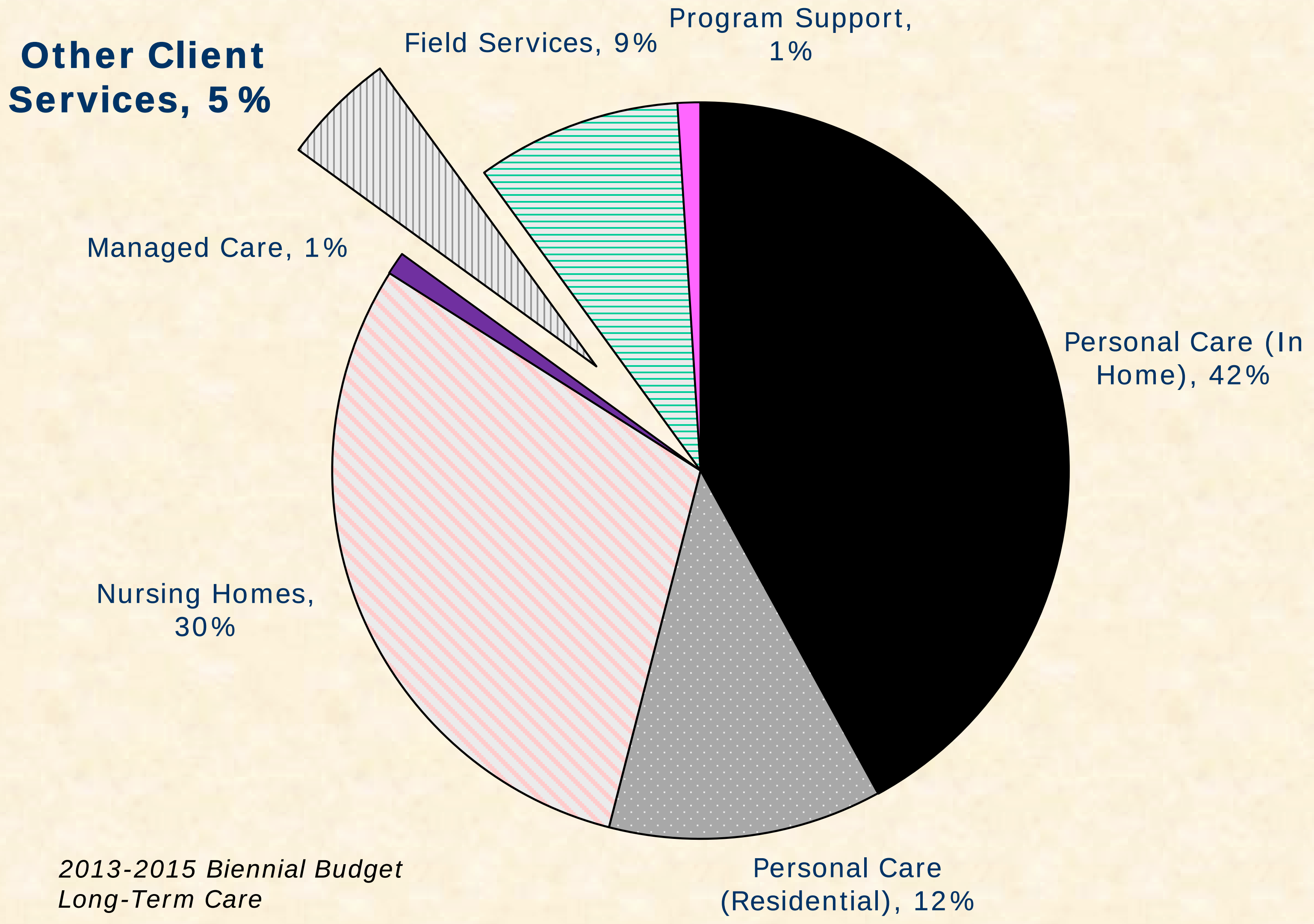
Local Service Provider Organizations

Consumers

Key Dates

1965	Older Americans Act (OAA) signed into law as part of federal Great Society along with Medicare and Medicaid
1973	Older Americans Act establishes Area Agencies on Aging
1977	Washington enacts the Senior Citizen Services Act (SCSA)
1984	Washington state becomes a “first mover” in using Medicaid home and community-based services
1988	Washington state establishes the respite program to support unpaid family caregivers
2001	The Older American’s Act is expanded to include caregiver supports
2011	Washington state further expands the family caregiver support program

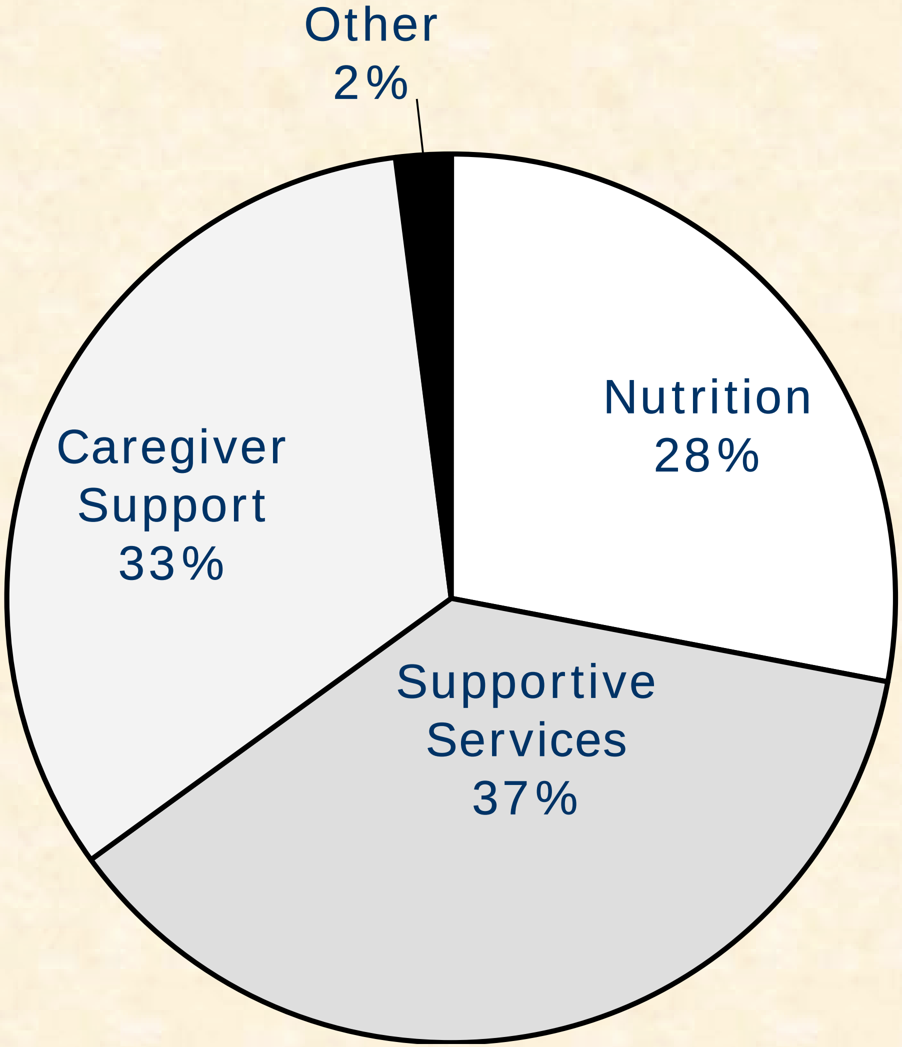
OAA, SCSA, and Family Caregiver Support combine to less than 5% of the LTC budget



2013-2015 Biennial Budget
Long-Term Care

OAA, SCSA, and related state/federal funding provides nutrition, caregiver support, and supportive services

$46 Million Annual Funding



Nutrition and supportive services

Nutrition

- Group meals
- Home delivered meals
- Access to fresh farmer's market produce

Supportive Services

Access

- Information and assistance
- Senior transportation
- Case management/nursing services
- Legal services

In-Home

- Chore/personal care/bath assistance
- Minor home repairs
- Visiting and telephone reassurance

Social and Health Services

- Adult day care/day health
- Abuse prevention
- Health screening/health promotion
- Mental Health

Family Caregiver Support Program and “Other” activities

Caregiver Supports

Family Caregiver Support Program
Kinship Support and Kinship Navigator

Other Activities

Senior employment
Long-term care ombudsman
Foot care
Senior Newsletters

Age-related issues tend to cluster in predictable areas

Aging in Place

Elder Abuse

Ageism

Maintaining Income

Staying Active & Connected

Health Care

Care Giving

Population growth that outpaces funding requires difficult choices

- When the Older American's Act was signed one in eight Americans was age sixty or older. It is now about one in six. By 2030 it will be one in four

- Area Agencies on Aging will continue to educate, advocate, and partner to make improvements on all key issue areas, but funding has not kept up and ability to fund "gap filling" supportive services has diminished

- Priority for limited funding is on:
  - Aging in place
  - Health
  - Outreach, information and assistance
  - Support for unpaid family caregivers

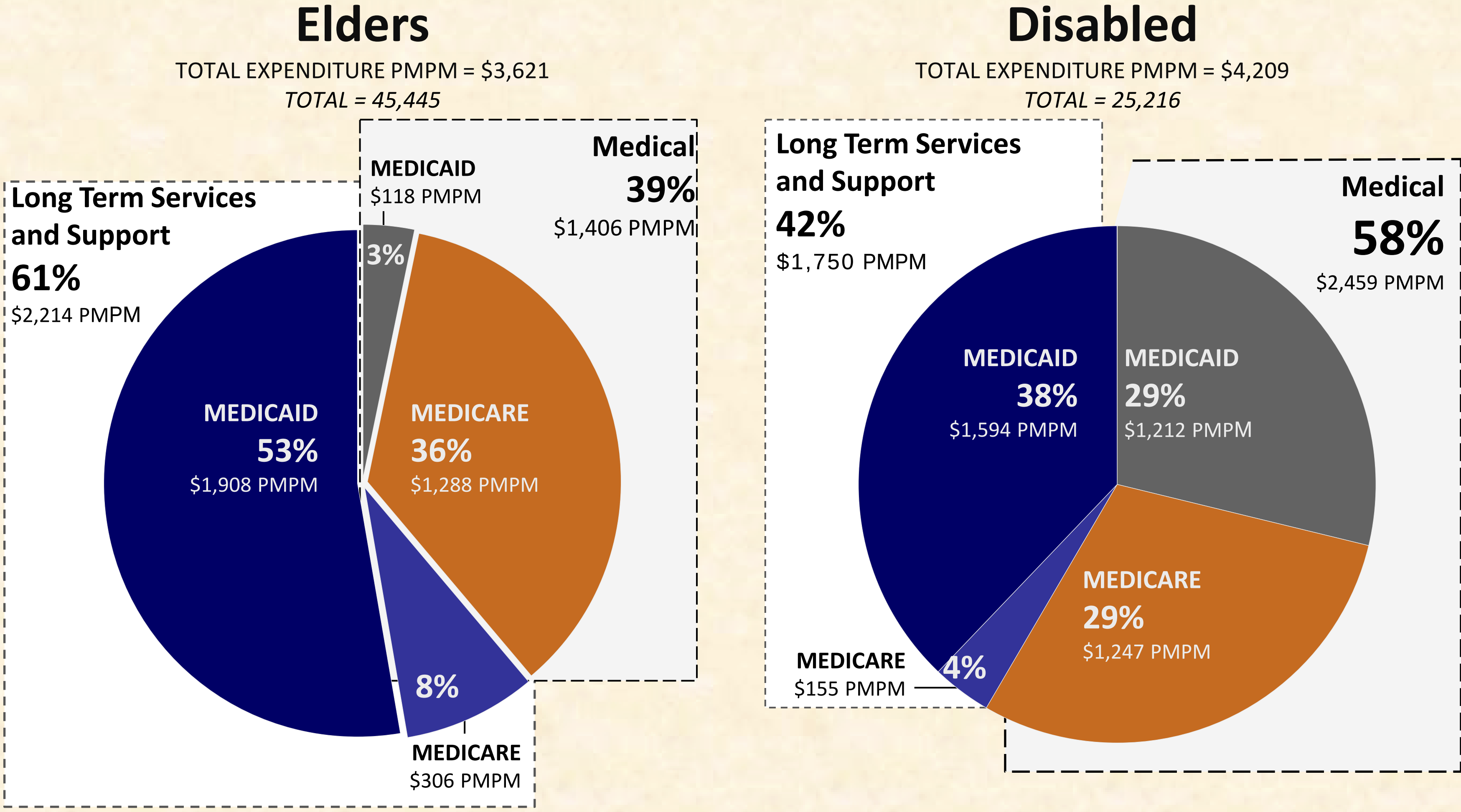
Successful aging in place means more people with long-term needs must be supported at home

- Of the 40,000 people who receive Medicaid in-home care managed by AAA's, we want to be sure:

  - Those who need mental health treatment get it
  - Those who need substance abuse treatment get it
  - Those who are at risk for diabetes are screened
  - Hospitalizations only happen when necessary
  - Emergency room visits only happen when necessary
  - People who are discharged from hospitals are rehospitalized less frequently
  - Those whose body weight threatens their health have support to improve their condition

Medicaid and Medicare Medical and LTSS Expenditures

Persons receiving LTSS services in SFY 2011



SOURCE: RDA Integrated Client Database

Achieving better outcomes requires working the “demand side”

Health Homes: Care Coordinators help high risk clients keep the varied services many clients utilize coordinated (behavioral health, long term care, chemical dependency, primary care, etc). The Coordinators motivate clients take control of their health, and coordinate community resource referrals toward client goals

Care Transitions: A transition coach performs a home visit and follow-up after discharge from the hospital

Chronic Disease Self Management: Classes for individuals to assist them in managing their chronic illness using the Stanford University evidence-based program,

Chronic Pain Self Management: Classes for individuals to assist them in managing their chronic pain using the Stanford University evidence-based program

Providing information and sustaining family caregivers is critical

- 70% of people age 65+ will need long-term care
- 65% of people age 40+ report little or no planning for their LTC needs
- Private LTC insurance is out of reach for many
- 37% of people 40+ believe Medicare covers on-going in-home care. 44% believe long-term nursing home stays are covered. They are wrong.
- The result can be a too familiar path to Medicaid

1. Someone has a need for care
2. Family Caregivers become exhausted
3. Out of pocket spending exhausts resources
4. Medicaid

Aging and Disability Resource Centers are a “help desk” for those who don’t know where else to turn

Information and Referral:

Walk-in, dial-in, or log-in accessibility
Home visits
Information on services and supports.
Help understanding benefits and eligibilities
Linkage to local resources
Assistance with bewildering paperwork

Options Counseling:

Person-centered counseling and decision support for those who face aging or disability related issues

Community Outreach and Education:

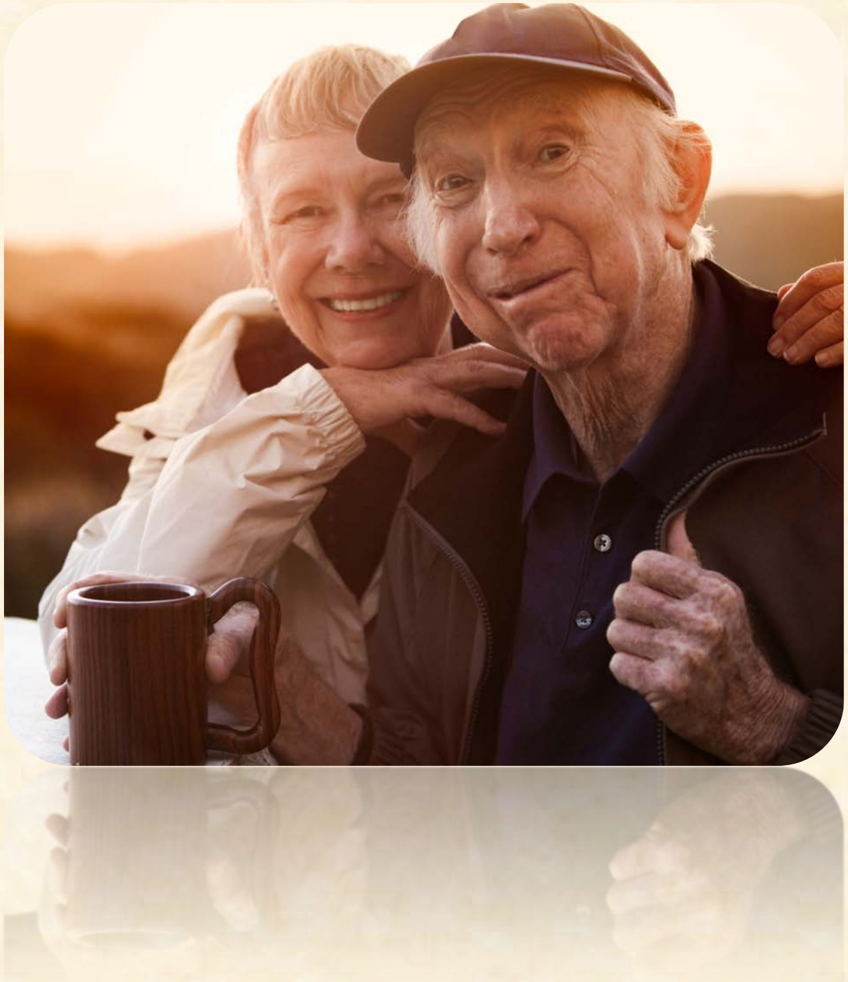
Continual public engagement, resource fairs, publicity, flyers, brochures, community trainings

Each day 850,000 unpaid family caregivers in Washington:

- Provide emotional support
- Help with daily activities and household tasks
- Handle finances
- Help with personal care
- Provide necessary nursing care
- Manage healthcare
- Advocate

What Do Caregivers Need?

- Information about services and coping with caregiving issues
- Training for providing important care
- Someone to call when they feel overwhelmed
- A break…



2014 Family Caregiver Support Program Services

- Information, Education, and Service Coordination
- Crisis Prevention and Intervention
- Flexible Options for Respite
- Financial Eligibility Assistance
- Mental Health Counseling and Support
- Outreach to “Hidden Caregivers”
- In-home Training
- Respite
- Evidence-based supports:
  - Memory care and wellness
  - “Star-C” training to provide skill in managing difficult behaviors
  - “Powerful tools for caregivers” training
  - Chronic Disease Management

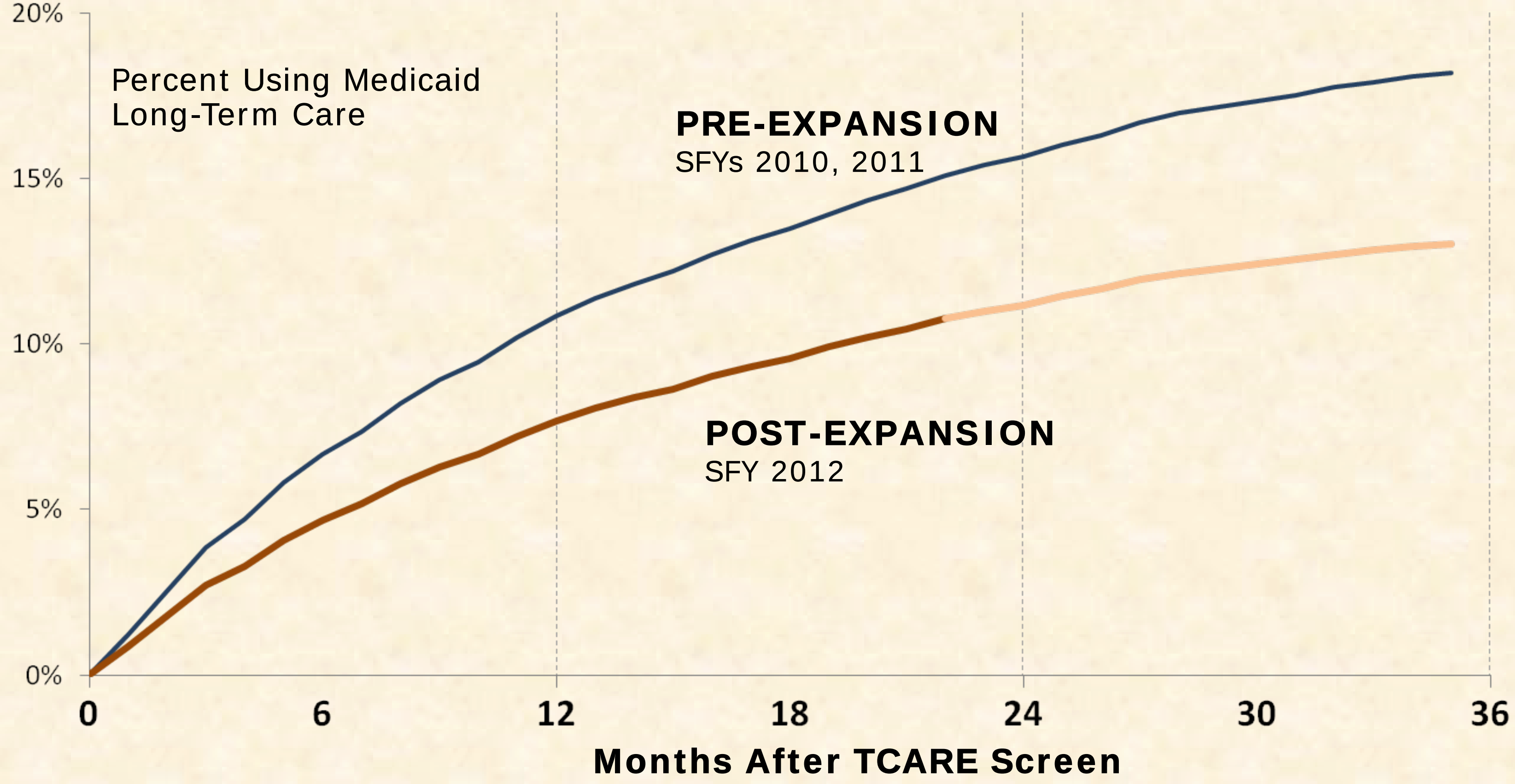
The Family Caregiver Support Program makes a difference

- 84% of caregivers reached show significant improvement in key outcomes
- Over half of the people receiving care had been diagnosed or had a probable diagnosis of Alzheimer's
- Another 30% had evidence of a memory problem
- The average cost to support a family caregiver is $3,900 per year compared to the average for Medicaid in-home care of $18,000 to $20,000

Recent expansion has delayed enrollments in Medicaid

- ***Time from TCARE® Screen until First Use of Medicaid Long-Term Care***

Pre- and Post-Expansion, Controlling for Baseline Differences



Source: DSHS Research and Data Analysis

The impact of being rural

- The challenge in urban areas is volume
- In rural areas, the challenge is supporting infrastructure:
  - ✓ To have administrative capacity
  - ✓ To provide specialized programs
  - ✓ To provide site-based programs
  - ✓ To communicate
  - ✓ To transport
- Achieving “critical mass” is a challenge for pilots, and where the “trickle down” distribution of statewide funding is small
- Rural areas are particularly challenged by the multiple effects of the recession on state and local funding, fund raising, and the apparent reluctance of Boomers to volunteer

Questions?

Dan Murphy, Executive Director
Northwest Regional Council
dan.murphy@dshs.wa.gov
(360) 676-6749

PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND
HEALTHIER WASHINGTON

Healthy Communities and Healthy Aging

Aging and Disability, Joint Legislative Executive Committee
May 19, 2014

Patti Migliore Santiago, MAOM, Partnership, Planning and Policy Program Manager
Andrea Valdez, MPA, Policy Analyst
Office of Healthy Communities

Washington State Department of Health

What is a Healthy Community?

- Where we work, learn, live, play, and worship
- People can be as healthy as possible in a safe and nurturing environment

PUBLIC HEALTH
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HEALTHIER WASHINGTON

Washington State Department of Health

Building a Comprehensive System

2000

Funded each county for tobacco prevention

2003

Healthy Communities projects in 14 counties

2009

Launched statewide Healthy Communities program

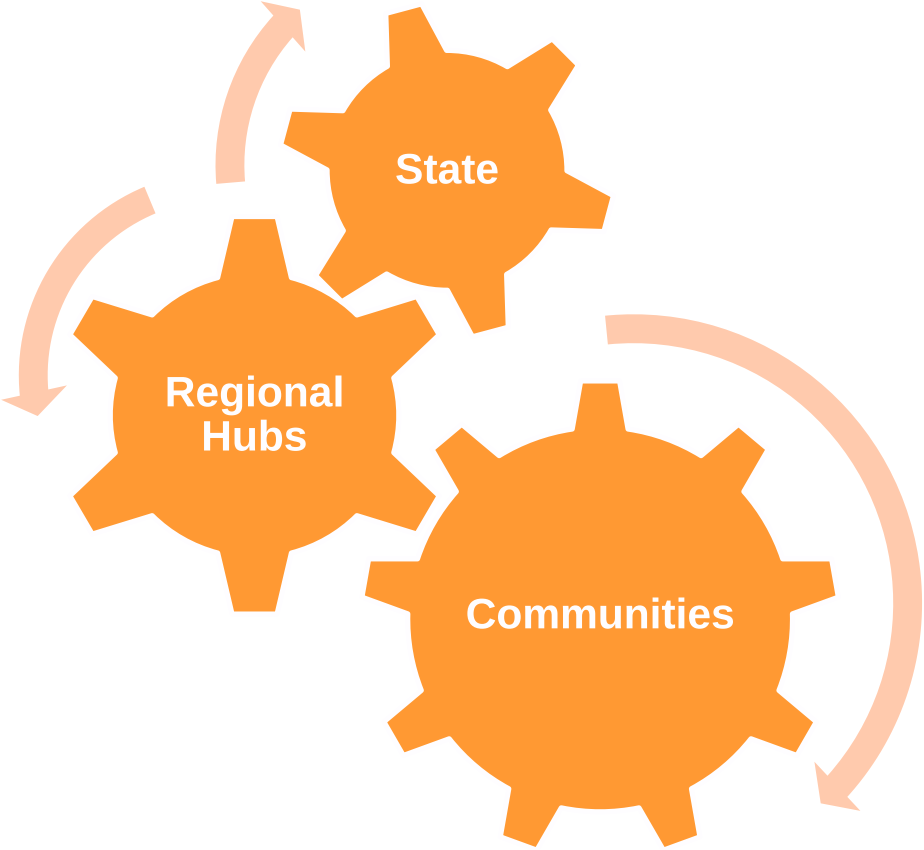
2011

Community Transformation Grant

PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND
HEALTHIER WASHINGTON

Washington State Department of Health

The Future of Healthy Communities



2014 and beyond:
Continue to serve regions and communities as the system changes

PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND HEALTHIER WASHINGTON

What is the Washington State Plan for Healthy Communities?

- A statewide plan that supports a comprehensive approach to life long health
- Plan will be used to coordinate prevention and wellness efforts in our communities
- Challenge strategies and objectives – no one entity can do this alone

How Was the Plan Developed?

- Vision of a single statewide plan for chronic disease prevention *(Rolled 14 former strategic state plans into one)*
- Development of priorities working with internal focus groups and using data, best practices research, and logic modeling
- External stakeholder input from key partners at state agencies, state-level coalitions, and local public health

Why is the Plan Important?

- Approach that brings together diverse sectors and organizations to achieve a common set of results
- The plan is our common agenda
  - ✓ Frames a shared understanding of the issues we face and the actions to address them

Builds on Collective Impact Approach

Common Agenda	• Shared understanding of a community problem with a joint approach to addressing it.
Shared Measurement	• Consistent data collecting and reporting with mutual accountability for results.
Mutually Reinforcing Activities	• Participant activities are coordinated to support the plan of action.
Continuous Communication	• Consistent and open communication which builds trust across sectors and reinforces the work toward shared objectives.
Initiative Support	• Efforts are unified to bring partners together, line up resources, and support infrastructure.

Washington State Department of Health

Healthy Living Collaborative of Southwest Washington

- Cross-sector collaboration to build a healthier community
- Collective impact in action

HEALTHY NEIGHBORHOODS and FAMILIES

NEIGHBORHOODS
Natural Leaders

LOCAL
Health Coalitions

REGION
S.W. Healthy
Living Collaborative

STATE
Prevention Alliance

Collective Infrastructure

Basic Needs ◆ Environmental Safety
Food Systems ◆ Criminal Justice
Arts and Culture ◆ Healthy Infrastructure
Health Care ◆ Community Development
Economic Development ◆ Faith-Based
Health and Human Services ◆ Education

Physical - Social - Economic - Service Collaborations

Washington State Department of Health

Life Course Approach

GOALS

Increase the number of Washingtonians who are healthy at every stage of life.

Achieve health equity by eliminating health disparities.

EPIDEMIOLOGY & SURVEILLANCE

ENVIRONMENTAL APPROACHES

HEALTH SYSTEMS

CLINICAL & COMMUNITY PREVENTIVE SERVICES

Healthy Starts | Sexual and Reproductive Health | Tobacco and Substance Abuse Prevention | Active and Safe Environments | Healthy Eating | Screening, Referral, and Follow-up | Social and Emotional Wellness | Quality Clinical and Preventive Treatment Services | Health Equity

Epidemiology and Surveillance

- Gathering, analyzing, and sharing data
- **State Plan Strategy**: Use data to monitor population health, including information about disparately affected populations
- Use data to identify regions with 65+ population without a primary care provider

Environmental Approaches

- Involves physical or material changes to the economic, social or physical environment
- Strategies address a wide range of topics
  - ready access to nutritious, high-quality affordable foods and beverages
  - falls prevention
  - sexual health of older adults

Washington State Department of Health

Transportation

- Personal mobility is a crucial need for aging adults and those with disabilities in Washington
- Important that these individuals have access to safe, affordable transportation options
- We envision a Washington where healthy and safe behaviors are easier and more convenient to have in physical environments

PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND HEALTHIER WASHINGTON

Washington State Department of Health

Working Together for Improved Transportation

- **State Plan Strategy**: Increase access to safe and affordable physical activity where people work, learn, live, play, and worship
  - ✓ Complete Streets reduce speeds on roadways, add bike lanes and street lights, and provide ADA compliant sidewalks
  - ✓ Streets are safe for everyone, no matter who they are and how they travel

Health Systems

- Improve the effective delivery and use of clinical and other preventive services to prevent disease and mitigate or manage complications

Health Systems

- **State Plan Strategy**: Improve the knowledge and ability of health care professionals to deliver comprehensive evidence based services, including integrated mental health and chemical dependency screening and interventions
  - ✓ Integrated screening by clinicians to address social connectedness and depression during well-checkups

Clinical and Community Preventive Services

- Partnerships between clinical service providers and community based organizations

Clinical and Community Preventive Services

- **State Plan Strategy**: Enhance capacity, infrastructure, and leadership of community-based organizations to provide the support necessary to maintain positive mental and physical well-being
  - ✓ Community partners can promote the use of services as well as assist patients in overcoming barriers to access, such as transportation. This makes it easier for people to “follow the doctor’s orders” and take charge of their own health.

Moving Forward

- Align with existing efforts to support aging adults and those with disabilities in Washington
- Collectively address prevention and wellness to reduce health care costs
- Consider budget and policy options to effectively implement these evidence-based strategies

PUBLIC HEALTH
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HEALTHIER WASHINGTON

Age-Friendly
Livable Communities

Clark County Commission on Aging

May 19, 2014
Joint Legislative Executive Committee on Aging and Disability

What is community?


A NATION? A STATE?


A CITY?


A NEIGHBORHOOD?

A POLITICAL VIEW?


A RELIGION?


A CULTURE?

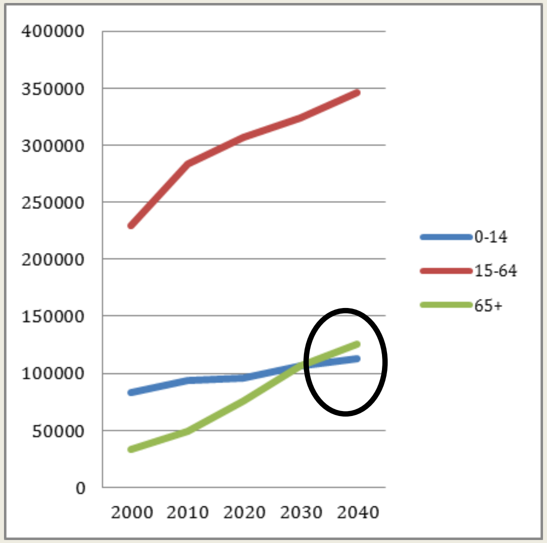
Commission on Aging's definition

"A livable community is one that has affordable and appropriate housing, supportive community features and services, and adequate mobility options, which together facilitate personal independence and the engagement of residents in civic and social life."

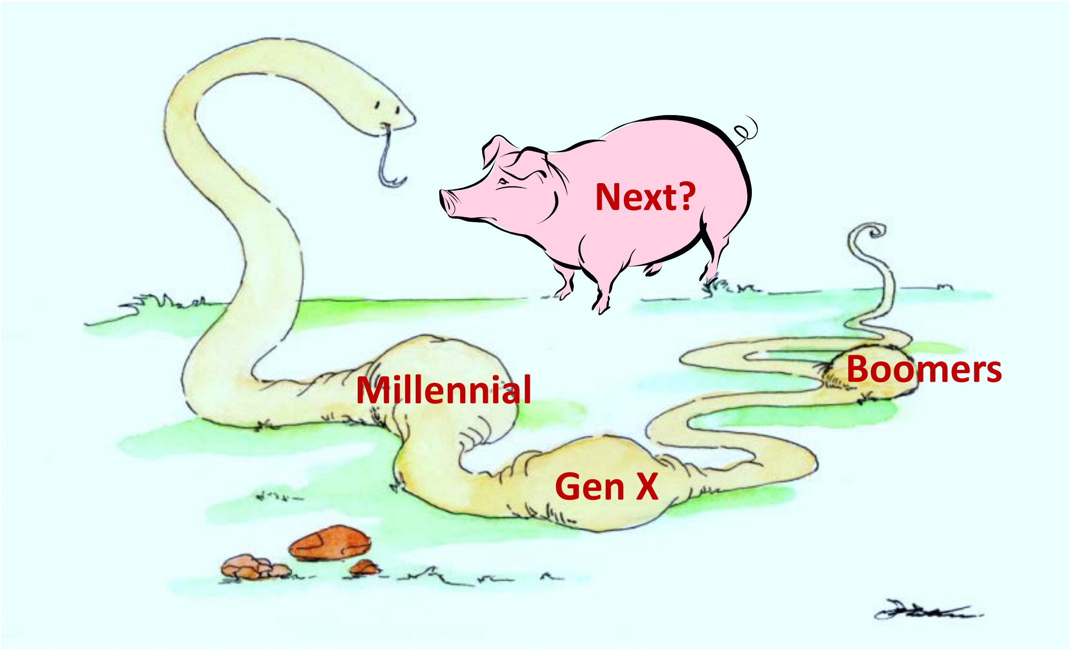
THE COMING AGE WAVES

How will this effect our community?

By 2040, there will be more people in Clark County 65 and older than children under 15.



Source: State of Washington Office of Financial Management 2013

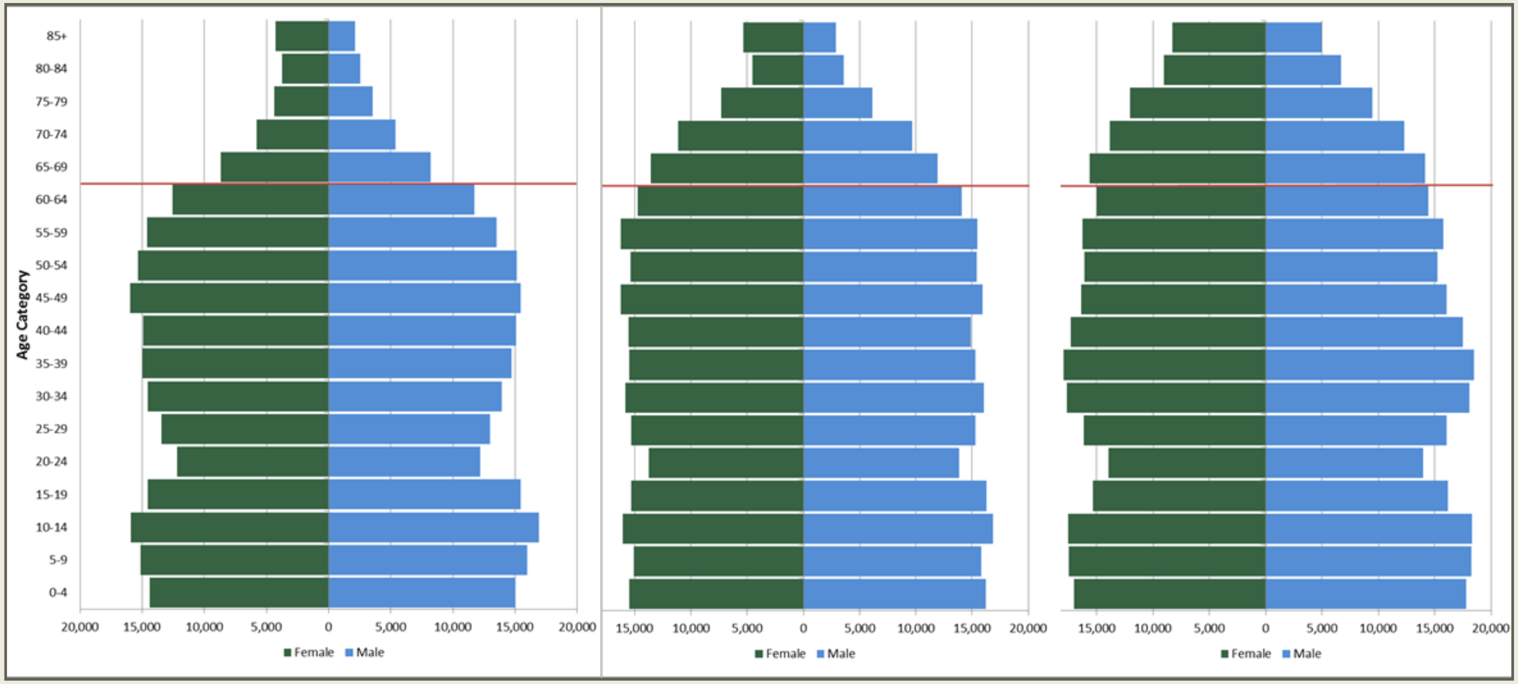


THE COMING AGE WAVES

How will this effect our community?

Clark County, Washington

Population Forecast by Age Category and Gender



2010
425,363

2020
477,884

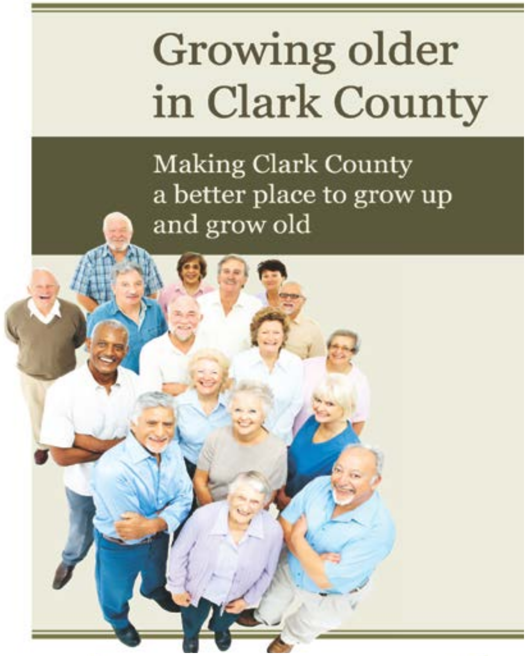
2030
536,717

Source: U.S. Census Bureau

THE COMING AGE WAVES

How do we prepare for the waves?

- Aging Readiness Task Force
- Aging Readiness Plan
    - 91 strategies
    - Appoint a Commission on Aging
    - Retain county leadership
    - Recognize this effort is for all ages



Growing older in Clark County

Making Clark County
a better place to grow up
and grow old

CLARK COUNTY
COMMISSION
on
AGING

Commission on Aging

Focus Areas

Communication

Advocacy

Awareness

Housing

Community
Engagement

Supportive
Services

Healthy Communities

Transportation

Benchmarks

Housing

Provide a variety of housing that is affordable and adaptable to changing needs.

Project: Shared Housing

"The idea: Independent, physically capable seniors share housing in order to divide the costs, split up the chores, and enjoy some companionship… It's just like the "Golden Girls," only without Bea Arthur."
– The Columbian Newspaper (Editorial board) 3/13/14

What is it?

- Two or more unrelated people share a home
- Homeowner renting out a vacant bedroom
- Two or more people renting a home together

Benefits:

- Financial support
- Companionship
- Sense of security
- Aging-in-community

Housing

*Provide a variety of housing that is affordable and **adaptable** to changing needs.*

Project: Universal Green Design

What is it?

Ways to make a home more comfortable for a wide range of people.

- No step entrances
- Open floor plans
- No step showers
- Wider hallways and doorways

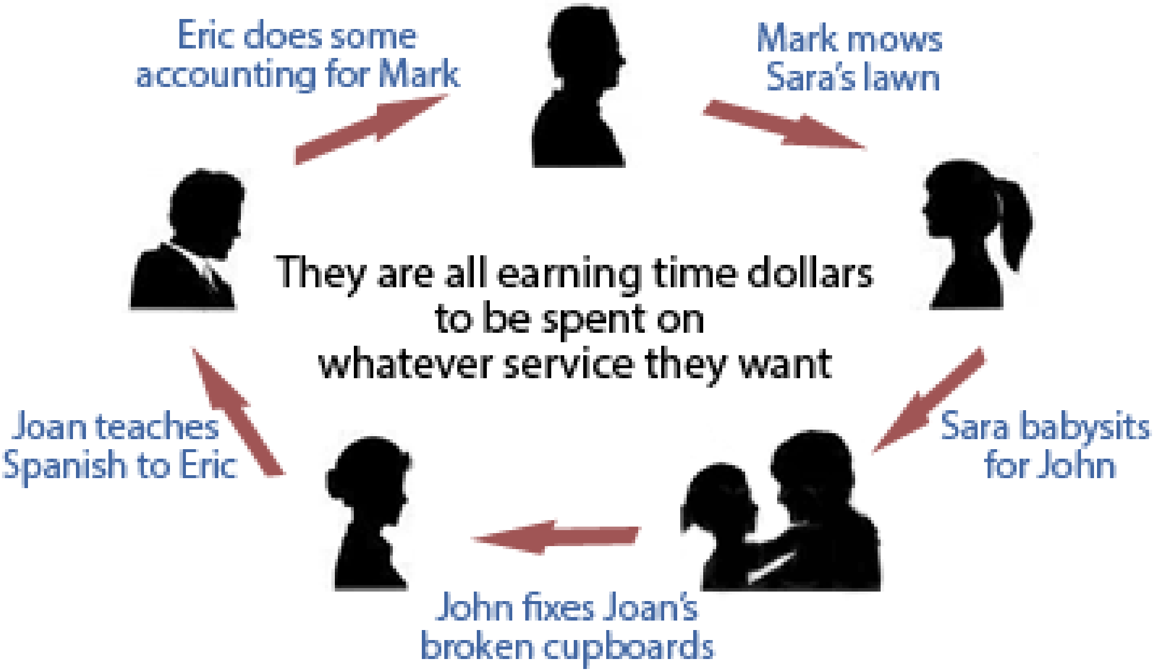
Benefits:

- Enables people to "age-in-place"
- Eliminates challenges for visitors with mobility impairments
- Simplifies housekeeping
- Cost-efficient because it is energy-efficient

Community Engagement

Promote volunteer opportunities for people who need help and for those looking to help.

Project: Timebanking



What is it?

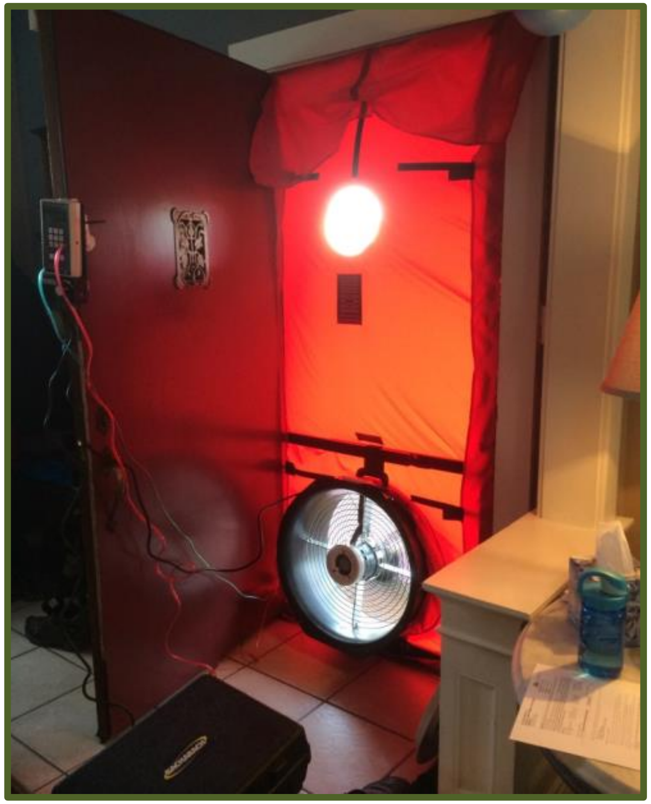
- Similar to bartering
- Every hour of service = one hour of credit for service you need
- All services valued equally
- Online database allows members to indicate services they can provide and see what others offer

Benefits:

- Financial benefit
- Builds community
- Donation of time to others
- Allows flexibility in volunteering

Healthy Communities

Create healthier places in the built environment.



Project: 60+ Weatherization Project

Boundaries of pilot neighborhood

What is it?

- Grant program for 60+ to reduce energy costs through weatherization improvements
- 10% participant buy-in, not to exceed $500
- Pilot neighborhood

Benefits:

- Enables aging-in-place through affordability of home costs
- Makes homes more comfortable

Housing and Healthy Communities

Provide a variety of housing that is affordable and adaptable to changing needs.
Create healthier places in the built environment.

Project: Land use and zoning changes

What is it?

- Changes zoning codes to allow development of complete neighborhoods
  - Mix of housing
  - Services (jobs, stores, restaurants)
  - Schools and open/public spaces
- Changes codes to allow easier development of accessory dwelling units and duplexes
- Changes codes to allow assisted living facilities and co-housing developments in single-family residential zones

Benefits

- Allows more opportunity to “age-in-community”
- Encourages walking, promotes small business development, reduce reliance on automobiles, and increase social interaction and safety

Transportation and Mobility

Promote independence through a variety of mobility options.

Project: Volunteer Sidewalk Program

What is it?

- Allows volunteers to build sidewalks and walking paths using alternative materials other than concrete

Benefits:

- Opportunity to build safe walkways in a timely and cost-effective manner
- Increases health and safety of area residents and visitors

Transportation and Mobility

Promote independence through a variety of mobility options.

Project: Accessible Transportation Coalition Initiative (ATCI)

What is it?

- Bringing together all transportation providers in Southwest Washington to work on a plan to better coordinate transportation services

Benefits:

- Innovative mechanisms to stretch dollars
  - Creation of a mobility and resource management solutions program

Supportive Services

Promote well-being, safety and independence through a variety of services.

Project: Telehealth/Telemedicine

What is it?

- The delivery of health related services using telecommunication technology

Benefits:

- Improves access to care
  - Minimize travel from home to doctor for rural residents
- Financial benefit
  - Families have decreased travel & out of pocket expenses, lost work, childcare needs
- Reduces cost of healthcare
  - Avoids risky, unnecessary and expensive transports

There is no cost to attend this event but an RSVP is requested. Register at: www.clark.wa.gov/aging

Telehealth: Fact or Fantasy?

October 2nd, 2013

CLARK COUNTY COMMISSION on AGING

Conference Agenda

7:30a.m.—8:00a.m.
Registration / Continental Breakfast

8:00a.m.—8:15a.m.
Welcome & Introductions
Randy Scheel, MS

8:15a.m.—9:15a.m.
Keynote
Miles Ellenby, MD

Break 9:15a.m.—9:30a.m.

9:30a.m.—10:15a.m.
Nancy Vorhees, RN

10:15a.m.—11:00a.m.
Vanessa Leigh-McLaughlin

11:00a.m.—11:45a.m.
David Kelly
Tracy Zitzelberger, MPH

11:45a.m.—12 Noon
Closing Comments
Randy Scheel, MS

For More Information & RSVP

Clark County Commission on Aging
www.clark.wa.gov/aging
360-397-2280 ext. 4913
comm-aging@clark.wa.gov

Randy Scheel
360-449-1477
Randy.coa.usa@gmail.com

Special thanks to. . .

- A Caring Heart, Senior Housing Referral
- At Your Place Senior Care
- Beagle Burke & Associates
- Elfin Services
- Fort Vancouver Convalescent Center
- Prestige Care
- ProPac Pharmacy
- The Messenger

Conference Location

PeaceHealth Southwest Medical Center—Education Center
400 NE Mother Joseph Place
Vancouver, WA 98664

Miles Ellenby, MD
Associate Professor,
Pediatric Critical Care
Medical Director,
Telehealth Program
OHSU

Nancy Vorhees, RN
Chief Operating Officer—
Inland Northwest Health
System / Northwest TeleHealth

Vanessa Leigh-McLaughlin
Founder/CEO
Edithforge
WelcomeHome Health

David Kelly
Executive Director
Area Agency on Aging and
Disabilities of Southwest
Washington

Tracy Zitzelberger, MPH
Administrative Director &
Research Associate,
Oregon Center for Aging
&Technology—OHSU

Randy Scheel, MS
Fort Vancouver
Convalescent Center
Caretique
The Park Lido

Communication

Promote a communication network that informs, Involves and empowers people and communities.

Project: Speakers Bureau

What is it?

- Group of volunteers who raise community awareness about the Aging Readiness Plan, initiatives underway to combat challenges identified in it, and the Commission on Aging and its projects

Benefits:

- Inform county citizens about available services
- Raise awareness on issues affecting the community
- Garner support to implement projects identified in Aging Readiness Plan

A FREE SEMINAR FOR AGES 55+

CASCADE INN *Proudly Presents*

"Aging with Confidence"

- Aging Readiness
- Recognizing Financial Exploitation
- Important Resources Provided

KOELSCH SENIOR COMMUNITIES CARING FOR SENIORS FOR OVER 55 YEARS

Featuring Gary Beagle

Senior Managing Fiduciary with Beagle, Burke & Associates, Certified National Master Guardian, and the current Chairperson of Clark County's Commission on Aging

- Wednesday, March 26th, 2014
- From 6:30 - 8:00 p.m.
- Cascade Inn - 11613 SE 7th Street, Vancouver

(360) 254-3555

Please register by March 19th

REGISTER NOW!

CASCADE INN
SERVING SENIORS SINCE 1958
A Koelsch Senior Community
www.cascadeinnwashington.com

In Partnership With
BEAGLE BURKE & ASSOCIATES

Opportunities for help

What can happen at the state level to assist local efforts?

- **Universal Design**: Encourage the International Code Council to develop a regulatory framework for a *Universal Design Code, similar to efforts made toward Green Building code* – ask the WA Building Code Council to create interim standards.
- **Leadership/Coordination/Grant funding**: Start up costs for age-friendly community initiatives (i.e. Timebanking and Shared Housing programs)
- **Telehealth/Telemedicine**: Senate Bill 5708 and House Bill 1448 – providers need reimbursement for services
- **60+ Weatherization**: Continue funding the Community Energy Efficiency Program

Planning for Age-Friendly Communities

For more information

Clark County Commission on Aging

Website: *www.clark.wa.gov/aging*

QUESTIONS & ANSWERS

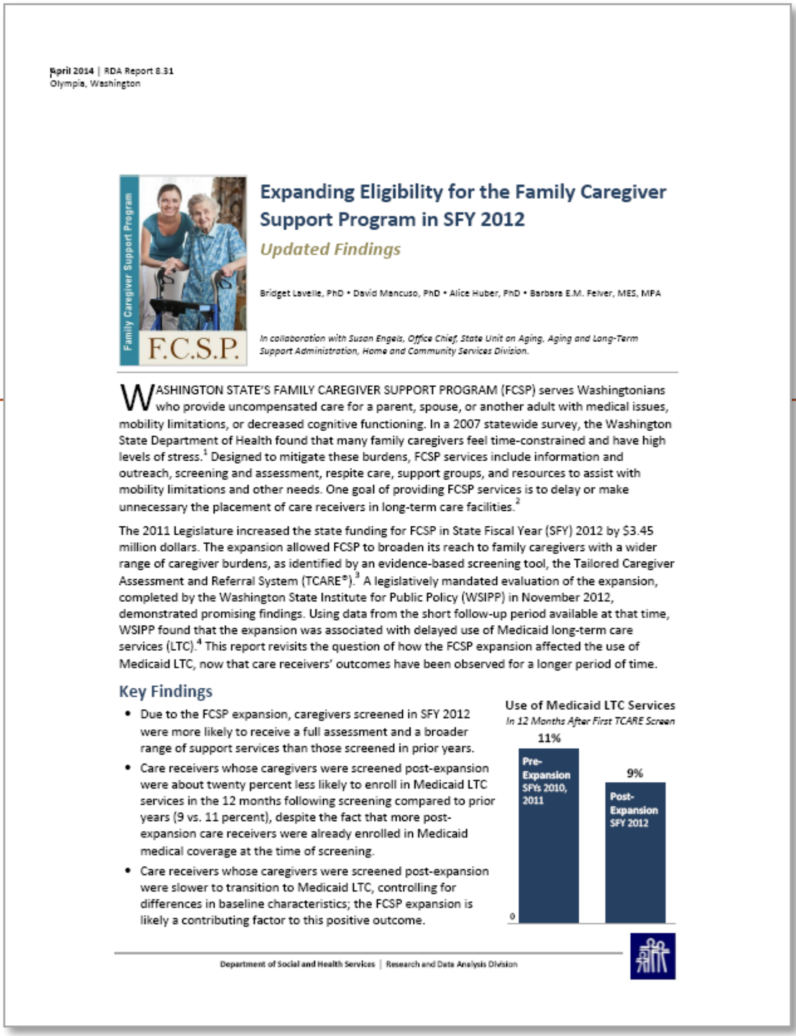
Family Caregiver Support Program Update

Joint Legislative Executive Committee on Aging and Disability

David Mancuso, PhD
DSHS Research and Data Analysis Division

Bea Rector
DSHS Aging and Long-Term Support Administration

May 19, 2014



April 2014 | RDA Report 8.31
Olympia, Washington

Expanding Eligibility for the Family Caregiver Support Program in SFY 2012

Updated Findings

Bridget Lavelle, PhD • David Mancuso, PhD • Alice Huber, PhD • Barbara E.M. Felver, MES, MPA

In collaboration with Susan Engels, Office Chief, State Unit on Aging, Aging and Long-Term Support Administration, Home and Community Services Division.

WASHINGTON STATE'S FAMILY CAREGIVER SUPPORT PROGRAM (FCSP) serves Washingtonians who provide uncompensated care for a parent, spouse, or another adult with medical issues, mobility limitations, or decreased cognitive functioning. In a 2007 statewide survey, the Washington State Department of Health found that many family caregivers feel time-constrained and have high levels of stress.[1] Designed to mitigate these burdens, FCSP services include information and outreach, screening and assessment, respite care, support groups, and resources to assist with mobility limitations and other needs. One goal of providing FCSP services is to delay or make unnecessary the placement of care receivers in long-term care facilities.[2]

The 2011 Legislature increased the state funding for FCSP in State Fiscal Year (SFY) 2012 by $3.45 million dollars. The expansion allowed FCSP to broaden its reach to family caregivers with a wider range of caregiver burdens, as identified by an evidence-based screening tool, the Tailored Caregiver Assessment and Referral System (TCARE®).[3] A legislatively mandated evaluation of the expansion, completed by the Washington State Institute for Public Policy (WSIPP) in November 2012, demonstrated promising findings. Using data from the short follow-up period available at that time, WSIPP found that the expansion was associated with delayed use of Medicaid long-term care services (LTC).[4] This report revisits the question of how the FCSP expansion affected the use of Medicaid LTC, now that care receivers' outcomes have been observed for a longer period of time.

Key Findings

- Due to the FCSP expansion, caregivers screened in SFY 2012 were more likely to receive a full assessment and a broader range of support services than those screened in prior years.
- Care receivers whose caregivers were screened post-expansion were about twenty percent less likely to enroll in Medicaid LTC services in the 12 months following screening compared to prior years (9 vs. 11 percent), despite the fact that more post-expansion care receivers were already enrolled in Medicaid medical coverage at the time of screening.
- Care receivers whose caregivers were screened post-expansion were slower to transition to Medicaid LTC, controlling for differences in baseline characteristics; the FCSP expansion is likely a contributing factor to this positive outcome.

Use of Medicaid LTC Services
In 12 Months After First TCARE Screen

Department of Social and Health Services | Research and Data Analysis Division

DSHS Research and Data Analysis Division, April 2014: http://publications.rda.dshs.wa.gov/1502

Support for Family Caregivers: Interrupting the path to Medicaid is Critical

Each year the 850,000 informal caregivers in Washington provide **$10.6 billion** of unpaid assistance to individuals needing assistance to stay in their homes

Contrast this with the **$1.5 billion** spent on Medicaid Long Term Services and Supports (LTSS) each year which covers:

- Nursing homes
- Personal care and supportive services in licensed residential settings
- Personal care in the client's own home

Without these unpaid caregivers the amount needed for Medicaid LTSS would be much higher

*AARP Public Policy Institute, Valuing the Invaluable, 2011 Update

Family Caregiver Support Program Expanded in FY 2012

- **Family Caregiver Support Program**
    - Provides supportive services for unpaid family caregivers in Washington
    - Services include information and assistance, screening and assessment, consultation, respite care, support groups, and training and other resources to assist with caregiving tasks and experiences
- **Program expanded in SFY 2012**
    - Initial funding was \$6.3 million. Program expanded by \$3.4 million, a 55% ↑
    - Allowed program to provide a higher level of services to a greater number of caregivers screened for the program, and to serve caregivers with somewhat lower levels (but still high) of caregiving stress/burden

Family Caregivers are a vulnerable population

The **Family Caregiver Support Program (FCSP)** provides critical services for 8,600 unpaid family caregivers, only **1**% of family caregivers in Washington State.

The participating FCSP family caregivers:

- 55% are over age 60
- 31% work full or part time, and
- 50% scored high on depression scale

*WA State TCARE® Data

Family Caregivers are a vulnerable population

45% of FCSP caregivers report their own health status to be:

- Fair,
- Poor, or
- Very Poor

Statewide health data indicate that caregivers as compared to non-caregivers have:

- Have more physical and other limitations, and
- Are less likely to see a doctor when they need to because of cost*

Research confirms clear relationship between untreated depression and impacted physical health.

*WA State 2011 Department of Health BRFSS Data

FCSP Improves Outcomes for Family Caregivers

Majority of caregivers (84%) show significant improvements on key outcomes

Over a 6-month period, caregivers who receive ongoing support show statistically significant improvements in:

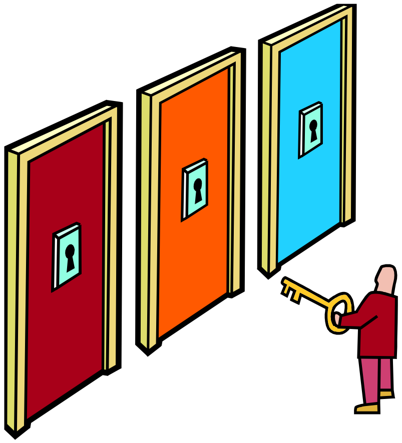
- Stress burden
- Relationship burden
- Objective burden
- Depression
- Comfort with caregiving role

Spousal caregivers also show a decreased “intention to place”

Family Caregiver Support Program
Outcomes for both Caregivers and Care Receivers

When caregivers access support earlier in their caregiver journey, before they are experiencing the highest levels of stress and 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 health and well-being is improved
- The likelihood of the caregiver needing Medicaid LTSS is reduced

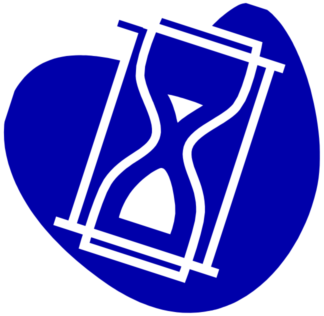


Family Caregiver Support Program
WA State TCARE® Data Demonstrates

Caregivers who did not continue in the FCSP (for variety of reasons) had come to the program too late to make a significant difference. They showed up with:

- The highest level of depression levels, and
- Were struggling with problem behaviors of their care receivers
- Their care receiver was more likely to enter Medicaid LTSS

Too little, too late!



Family Caregiver Support Program

To address Washington's age wave, we need additional investments to FCSP:

- Serve another 1% of state's unpaid family caregivers
- Increase dementia-capable practices and services
- Provide greater outreach and service to underserved populations
- Embed more evidence-based and effective practices statewide
- Improve TCARE® online capability to meet evolving needs
- Expand caregiver information, assistance and one on one consultation and care planning

WSIPP & RDA Reports on FCSP Expansion

WSIPP Report	RDA Report
Published November 2012	Published April 2014
Follow-up data available through FY 2012; median follow-up time for post-expansion group 5 months	Follow-up data available through FY 2013; all post-expansion group members have at least 12 months follow-up
The expansion resulted in a statistically significant delay in the use of Medicaid-paid LTSS, but due to short follow-up period, “this favorable result should be regarded as a tentative finding”	Using sufficient follow-up period, confirmed statistically significant delay in the use of Medicaid-paid LTSS

Higher screening rate, greater access to services post-expansion

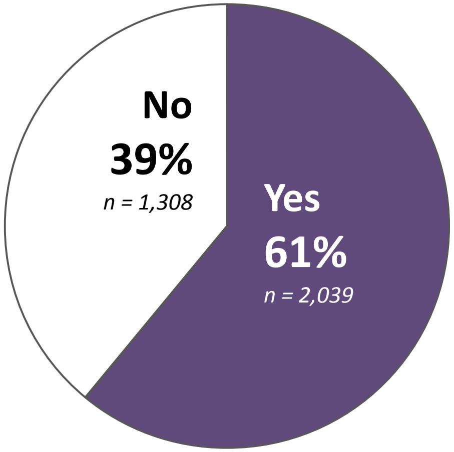
- The post-expansion period was half as long, but about the same number were screened
- Of those screened, a higher percentage went on to receive the higher level of services (for example, respite care, help with housework and errands)

Pre-Expansion

TWO YEARS: SFY 2010, 2011

TOTAL = 3,347

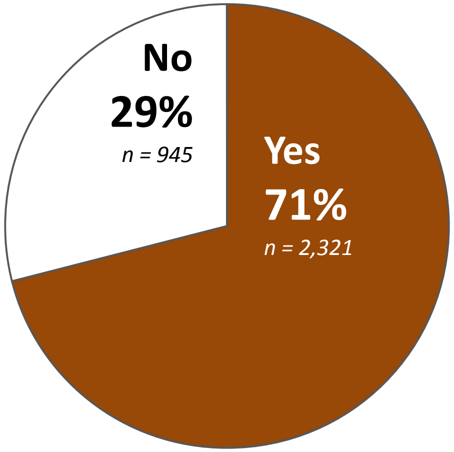
▸ ***Received higher level of services?***



Post-Expansion

ONE YEAR: SFY 2012

TOTAL = 3,266



Family Caregiver Support Program Changes: Pre- versus Post-Expansion Differences

- Expansion met goal of serving caregivers “further upstream”
- Caregivers served at the higher level of care post-expansion had somewhat lower levels of stress and burden than those served pre-expansion…
    - TCARE® screen identified slightly fewer areas of significant caregiver burden
    - Care recipients slightly younger, less likely to have dementia
- …but majority were still “high-intensity” caregivers.
    - Average post-expansion caregiver provided about 40 hours per week of care
    - 75 percent provided care for more than 1 year
    - About half of caregivers served post-expansion scored “high” on “stress burden” and on “depression”, respectively
    - Average age of care recipients 78 years
    - More than a third of care recipients had diagnosed dementia, and just over half had either diagnosed or suspected dementia

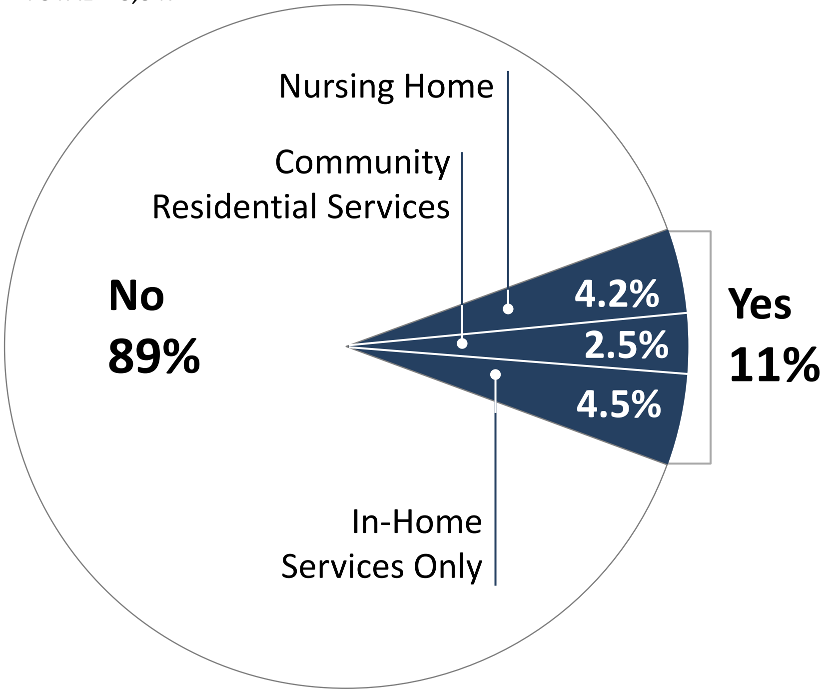
Family Caregiver Support Program Changes: Pre- versus Post-Expansion Differences

- Other notable differences:
  - Post-expansion FCSP caregivers provided care for more aging parents, fewer spouses
  - Post-expansion FCSP care receivers more likely to be enrolled in Medicaid medical coverage at time of TCARE® screen

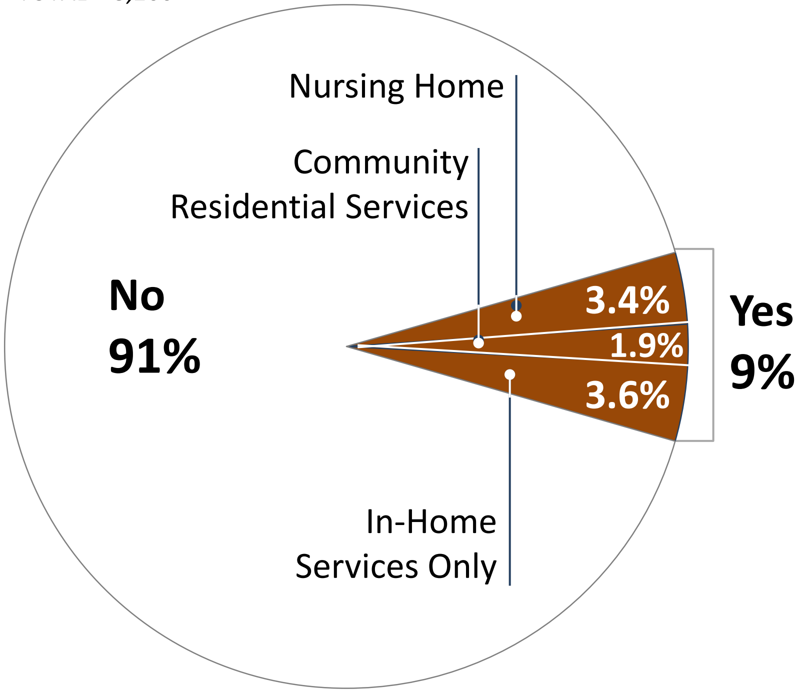
Use of Medicaid Long-Term Care in Year after Screening: Pre- versus Post-Expansion Comparison

- ***Used Medicaid Long-Term Care services in 12 months following TCARE® screen?***

PRE-EXPANSION
SFYs 2010, 2011
TOTAL = 3,347



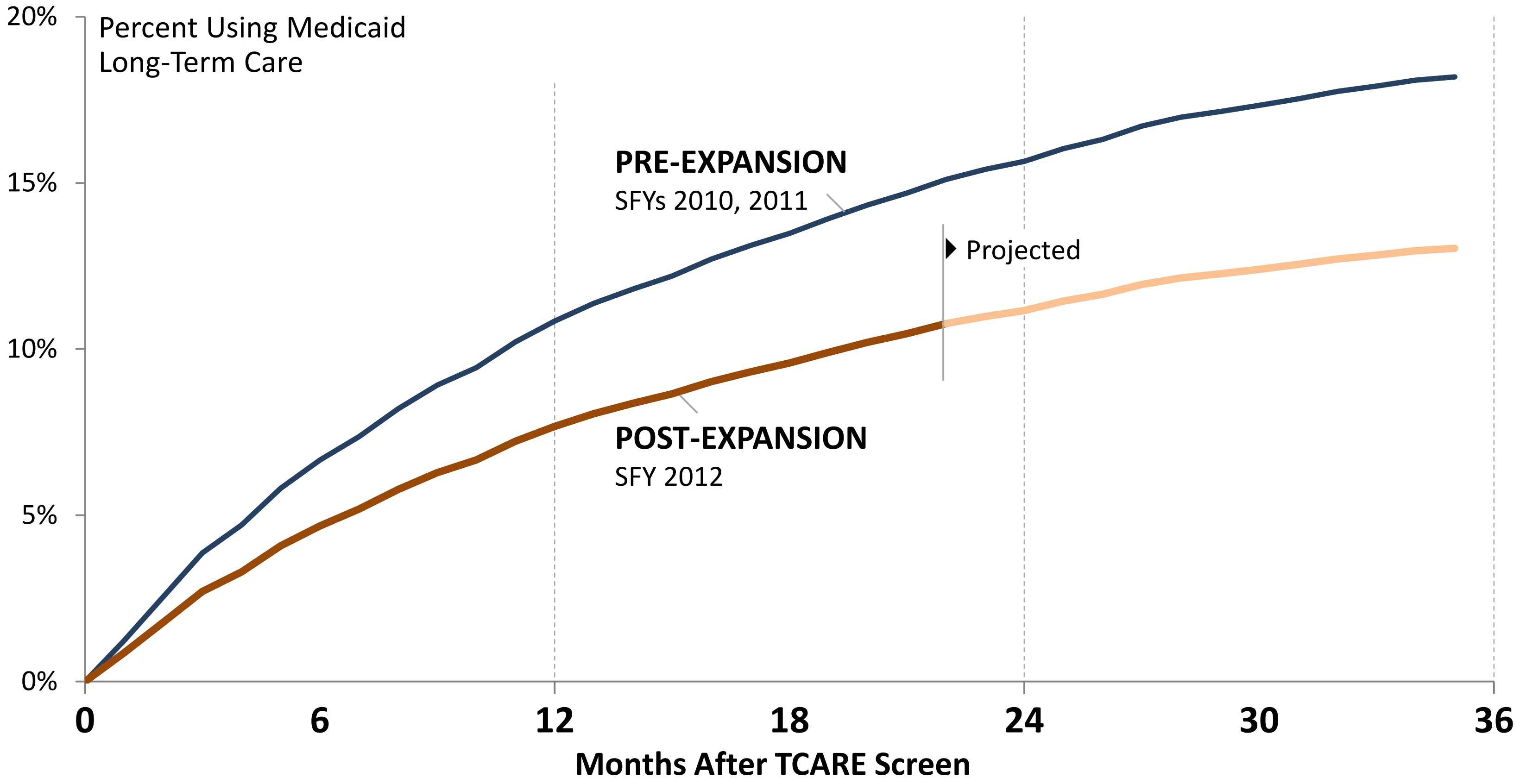
POST-EXPANSION
SFY 2012
TOTAL = 3,266



Time until Use of Medicaid Long-Term Care: Controlling for Baseline Differences

- ***Time from TCARE® Screen until First Use of Medicaid Long-Term Care***

Pre- and Post-Expansion, Controlling for Baseline Differences



Summary of findings

- **Expansion increased access to FCSP services**
  - The volume of FCSP screening activity increased, and caregivers screened post-expansion were more likely to receive a full assessment and a broader range of support services than those screened in prior years
- **Expansion delayed transition to Medicaid long-term care services**
  - When access to FCSP services increased, utilization of Medicaid LTC decreased
  - This occurred despite the fact that more post-expansion care receivers were already enrolled in Medicaid medical coverage at time of screening

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Family Caregiver Support Program
F.C.S.P.

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Use of Medicaid LTC Services
In 12 Months After First TCARE Screen

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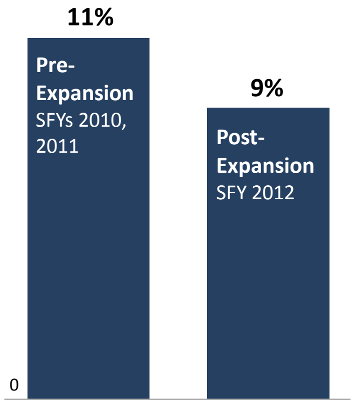
Use of Medicaid LTC Services

In 12 Months After First TCARE Screen



Family Caregiver Support Program Changes

Pre- versus Post-Expansion Differences

In SFY 2010, FCSP began using an evidence-based screening tool, the Tailored Caregiver Assessment and Referral System (TCARE®), to assess the caregiving situations of family caregivers in Washington State and to help determine what levels and types of services are needed.[3] The TCARE® screening tool identifies and categorizes caregivers' levels of burden (High, Medium, Low) in five domains: 1) relationship burden; 2) objective burden; 3) stress burden; 4) depression; and 5) caregiver identity discrepancy. Caregivers who complete the screening are eligible for the standard level of FCSP services. Those whose screening results indicate a higher level of caregiver burdens become eligible to additionally receive a full TCARE® assessment from a Family Caregiver Specialist, followed by consultation, the development of a care plan, and a higher tier of FCSP services.

The 2011 Legislature increased the state funding for the FCSP in SFY 2012 by $3.45 million dollars. Washington's Aging and Long-Term Support Administration used most of this funding to lower eligibility thresholds for the higher tier of services, and to provide that tier of services to a greater number of family caregivers. Prior to the expansion (up through the end of SFY 2011), caregivers were eligible if they scored "High" in at least four out of five burden domains on the TCARE® screen. Starting in SFY 2012, caregivers were eligible if they scored "High" in at least one domain or "Medium" in at least three domains. [5] For additional background on the Family Caregiver Support Program and its expansion, please refer to WSIPP's November 2012 report[4] or the website of Washington's Aging and Long-Term Support Administration.[6]

Table 1 (adjacent page) presents the number and characteristics of caregivers who first received a TCARE® screen in the two pre-FCSP-expansion years (SFY 2010, SFY 2011) and in the first post-expansion year (SFY 2012), as well as the number and characteristics of caregivers in both periods who screened into the higher tier of FCSP services. The caregivers who met eligibility criteria to receive the higher level of services including first assessments were a subset of those screened. In the post-expansion year, not only were caregivers screened at a higher rate (nearly the same number in SFY 2012 than in the previous two fiscal years combined) but a greater proportion of them were screened into the higher tier of services (71 percent vs. 61 percent).

Public awareness of the expansion was expected to yield a post-expansion screening population with somewhat lower needs than the pre-expansion screening population; that is indeed reflected in the data. Of caregiver-receiver dyads screened in SFY 2012, caregivers reported fewer burdens and receivers were less likely to have dementia. Care receivers were also more likely to be enrolled in Medicaid medical coverage.[7] The analyses in this report use statistical models to control for these and other compositional differences between caregivers screened in the two time periods.

The eligibility changes instituted under the expansion also resulted in different characteristics for caregiver-receiver dyads who screened into the higher tier of FCSP services before and after the expansion. Consistent with the lowered eligibility thresholds, caregivers who screened into the higher tier of services in SFY 2012 reported lower levels of burden on the TCARE® screening, cared for their care receivers for fewer hours per week, and had been caring for care receivers for a shorter period of time. Care receivers were also slightly younger, less likely to be the spouse of the caregiver, less likely to have a dementia diagnosis, and more likely to be enrolled in Medicaid medical coverage.

Despite these differences, it is important to note that caregivers served in both time periods had high levels of burdens and needs. The average number of caregiving hours per week was lower for those screened into the highest service tier after the expansion (52 versus 43), but post-expansion caregivers still provided care at a level of hours equivalent to a full-time job. A recent analysis of 2007 statewide survey data found that "high-intensity caregivers"— those who provide more than 20 hours per week of care for a period of one year or longer—were five times more likely than non-caregivers to have severely poor mental health and also had significantly worse physical health compared to non-caregivers, controlling for age, gender, and income. Although those findings derive from survey data with a different wording of the hours of caregiving question, a parallel measure constructed from the TCARE® assessment data shows that nearly three-quarters (73 percent) of caregivers screened into the higher tier of FCSP services in the pre-expansion period could be considered "high-intensity" caregivers, as well as the majority of caregivers (61 percent) screened into the higher tier of FCSP services in the post-expansion period.[8]

TABLE 1.

Number and Characteristics of Caregiver-Receiver Dyads

	Caregivers Receiving First TCARE® Screen			**Caregivers Screened into Higher Tier of FCSP Services**		
EXPANSION PRE vs. POST ▸	**PRE**	**POST**	*Diff.*	**PRE**	**POST**	*Diff.*
STATE FISCAL YEAR ▸	**2010, 2011**	**2012**		**2010, 2011**	**2012**	
Number of caregiver-receiver dyads	3,347	3,266		2,039	2,321	
Characteristics of caregiver-receiver dyads						
Total number of "High" burdens	2.7	2.4	*	3.2	2.8	*
High burden scores on individual items:						
Relationship burden	39%	33%	*	47%	38%	*
Objective burden	58%	46%	*	72%	55%	*
Stress burden	51%	44%	*	62%	53%	*
Depression	51%	43%	*	61%	51%	*
Identity discrepancy	72%	70%		82%	79%	
Caregiver is caring for:						
Spouse	52%	45%	*	57%	48%	*
Parent	37%	41%	*	34%	40%	*
Child	2%	2%		2%	3%	
Other	9%	11%		7%	9%	
Caregiver age	65.8	63.1	*	66.5	63.8	*
Care receiver age	77.9	77.0	*	78.5	77.7	*
Care receiver is male	48%	47%		50%	49%	
Caregiver would definitely consider placing receiver out-of-home	7%	7%		6%	7%	
Care receiver has diagnosed dementia	39%	35%	*	42%	38%	*
Care receiver enrolled in Medicaid medical coverage at screen	10%	14%	*	7%	11%	*
Hours of caregiving per week	*Not available*			52	43	*
Caregiver has been providing care:						
Less than 6 months	*Not available*			10%	13%	*
6 to 12 months	*Not available*			9%	12%	*
13 to 24 months	*Not available*			13%	15%	
24 months to 5 years	*Not available*			30%	29%	
Over 5 years	*Not available*			39%	31%	*
"High-Intensity" caregiver *More than 20 hours per week for more than 1 year*	*Not available*			73%	61%	*

NOTE: All variables come from the TCARE® screen with the exception of hours of caregiving, length of time caregiver has been providing care, and "high-intensity" caregiver. These three, from TCARE® assessment data, are not available for the larger population of caregivers receiving the first TCARE® screen. Significant differences shown: *p<0.01.

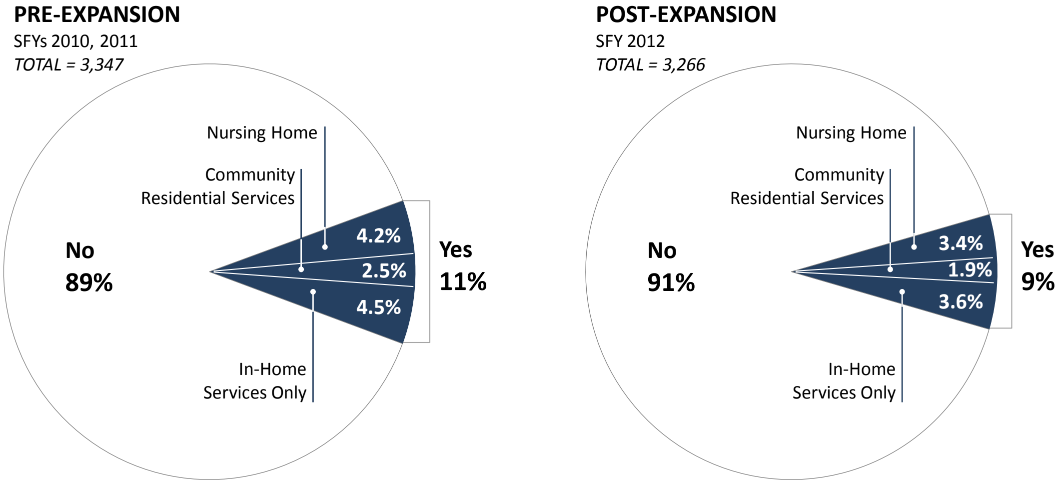
Use of Medicaid Long-Term Care in Year after TCARE® Screen

Pre- versus Post-Expansion Comparison

Because caregivers screened in SFY 2012 were more likely to receive the higher level of FCSP services, they may also have been able to continue providing care for a longer period of time, delaying the need for their care receivers to enroll in Medicaid long-term care services.

The data shows that the great majority of care receivers whose caregivers are served by FCSP (roughly 9 in 10) do not utilize Medicaid long-term care services within a one-year period. But those whose caregivers completed TCARE® screens in the post-expansion period (SFY 2012) were about 20 percent less likely to use Medicaid LTC services in the year following the screen compared to care receivers whose caregivers were screened in the pre-expansion period (SFY 2010, SFY 2011): 9 percent of care receivers of dyads screened in the post-expansion period enrolled in Medicaid LTC within 12 months, compared to 11 percent of care receivers of dyads screened in the pre-expansion period. Among those who did go on to receive Medicaid LTC in the follow-up year, the proportion in nursing home services, community residential services, and in-home services only was roughly equal for care receivers whose caregivers were screened in the two time periods.

Used Medicaid Long-Term Care services in 12 months following TCARE® screen?



Time until Use of Medicaid Long-Term Care

Controlling for Baseline Differences

The lower overall use of Medicaid LTC for care receivers whose caregivers were screened in the post-expansion period could be due to the expansion itself—more caregivers screened in SFY 2012 received services that enabled them to keep caring for their care receivers in the home—or could be attributable to differences in characteristics of the caregiver-receiver dyads screened in the two time periods. We use statistical models to control for those compositional differences between caregivers served in the two time periods that were captured by the TCARE® screening.

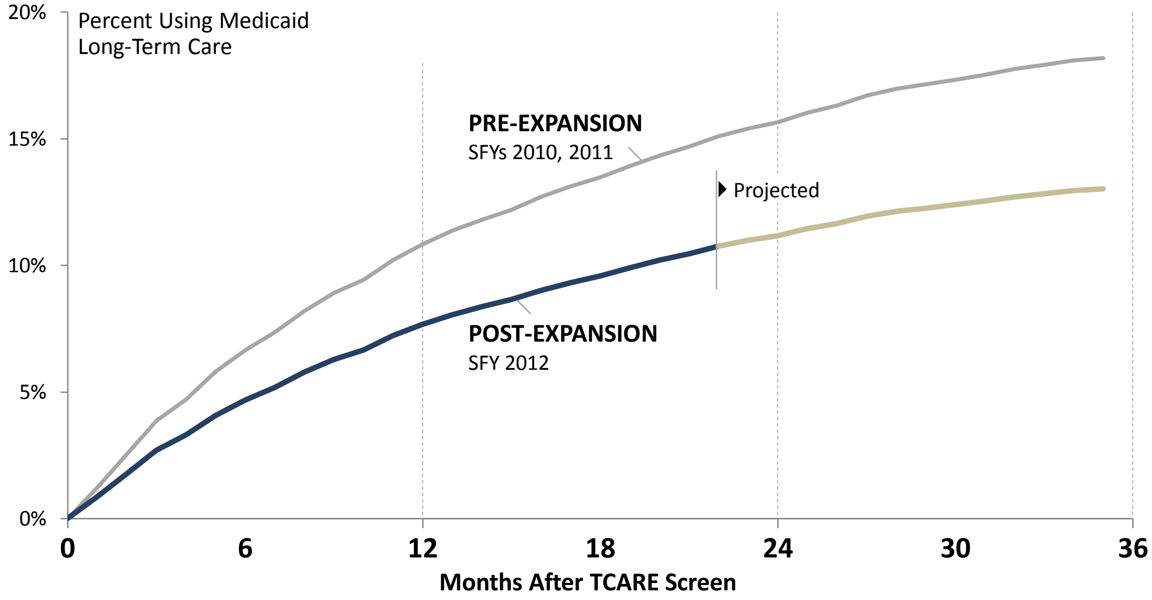
Using statistical survival models, we compare the time elapsed between a caregiver's first TCARE® screening and his or her care receiver's first use of Medicaid LTC services, for pre- and post-expansion FCSP family caregivers. The many FCSP care receivers who never use Medicaid LTC are accounted for in these models, as are care receivers with varying lengths of follow-up time.

Results indicate that the expansion of FCSP was associated with a statistically significant delay in the use of Medicaid LTC services, controlling for baseline differences (differences at screening) between pre- and post-expansion caregiver-receiver dyads. The full model can be found in the technical notes. Although results suggest that the expansion successfully helped more family caregivers better manage their caregiving and decreased the rate at which their care receivers move onto Medicaid LTC services, it remains a possibility that other differences between pre- and post-expansion caregiver-receiver dyads, that were not possible to identify and control using existing data, also influenced study findings.

The figure below shows the estimated time from TCARE® screen until first use of Medicaid long-term care services, by the time period in which the caregiver was screened, if they were to share the same set of baseline characteristics (measured at the time of the TCARE® screen).[9] As shown, care receivers whose caregivers were screened in the pre-expansion period transitioned onto Medicaid LTC services more quickly than those screened in the post-expansion period—who were more likely to be eligible for a full TCARE® assessment and a higher level of TCARE® services. The difference in the percent using Medicaid LTC was minimal in the first months after the TCARE® screen, but grew over time.

Time from TCARE® Screen until First Use of Medicaid Long-Term Care

Pre- and Post-Expansion, Controlling for Baseline Differences



The full survival analysis results indicate, as one might expect, that care receivers enrolled in Medicaid medical coverage at the time their caregivers completed a TCARE® screening are much quicker than their peers to transition onto Medicaid long-term care services – their estimated hazard of transitioning onto Medicaid LTC is more than five times that of care receivers not already enrolled in Medicaid medical.[10] It is worth noting that fewer care receivers transitioned onto Medicaid LTC services in the post-expansion period, despite the fact that more care receivers in the post-expansion period were already enrolled in Medicaid medical coverage at the time of TCARE® screening (14 vs. 10 percent).

This report evaluates the effects of the Family Caregiver Support Program expansion on care receivers' time to enrollment in Medicaid long-term care services. We compared Medicaid long-term care (LTC) utilization in the months following a TCARE® screen for those caregivers screened during the pre-expansion period (SFY 2010, 2011) with those screened during the post-expansion period (SFY 2012). To compile data for this evaluation, TCARE® screening and assessment records were linked with Medicaid enrollment and payment records as well as death records.

IDENTIFYING FIRST SCREENS

Because the FCSP expansion targeted caregivers new to the program, we identified caregiver-receiver dyads receiving their first TCARE® screens. (Only 2 percent of caregivers care for more than one receiver; these caregiver-receiver dyads were treated separately in the FCSP program and in this evaluation.) From a comprehensive file of TCARE® screens and assessments over the relevant period, we combined records from all valid screens with non-missing dates and care receiver DOBs, with similar records from initial assessments not preceded by screens (these were treated as screens for the purposes of the analysis). When caregiver-receiver dyads were associated with multiple screens, we identified the earliest screen based on the date administered.

IDENTIFYING FIRST ASSESSMENTS

Caregiver-receiver dyads who met the applicable eligibility threshold went on to get a full TCARE® assessment and a higher level of FCSP services. To identify dyads which did so, we determined whether those with a first screen during the study period (SFY 2010 through SFY 2012) received an assessment in a short window of time following their screening date. FCSP guidelines specify that an assessment should occur within 30 days of the screen. To be inclusive of exceptions to the policy and assessments with possible data entry errors, we include assessments administered up to 3 days before and up to 45 days after the screening date.

SELECTION CRITERIA FOR CAREGIVER-RECEIVER DYADS INCLUDED IN ANALYSIS

The caregiver-receiver dyads in this analysis included all those with a first TCARE® screen from FCSP during the study period (SFY 2010 through SFY 2012) who: 1) Were not being served by two other ALTSA programs, Nursing Home Diversion and the Dementia Partnerships Program; 2) Were receiving no Medicaid LTC services at the time screened; 3) Were not in public or private residential care at screening; and 4) Did not present administrative data linkage errors. Dyads in the "pre-expansion" group were those first screened in SFY 2010 and SFY 2011 (n = 3,347); dyads in the "post-expansion" group were those first screened in SFY 2012 (n = 3,266).

SURVIVAL ANALYSIS WITH STATISTICAL CONTROLS

Because the central evaluation question concerns the timing of an event—transition to Medicaid LTC services—the evaluation utilizes survival analysis, a type of regression analysis designed to examine outcomes across persons with varying lengths of follow-up time. In this evaluation, dyads first receiving TCARE® screens have more or less follow-up time depending on the date the screening was administered and the death date of the care receiver, if applicable. We used Cox regression, the standard approach for survival analysis. Survival analysis is a regression-based statistical model of longitudinal outcomes that can control for baseline characteristics. In this evaluation, we controlled for characteristics of the individual caregiver-receiver dyads identified on the TCARE® screening instrument. (Because the more extensive information gathered using the full TCARE® assessments was only available for the subset of dyads which screened into this higher level of services, it was not used among the controls for the survival analyses.)

SURVIVAL ANALYSIS RESULTS: *Predicting Hazard of Transitioning to Medicaid LTC*

Characteristic of Caregiver-Receiver Dyad at TCARE® Screening	Parameter Estimate	Standard Error	Chi-Square	p-value	Hazard Ratio
Screened post-expansion (SFY 2012)	-0.3630	0.0718	25.5509	<.0001	0.6960
Caregiver's total number of "high" burdens	0.1163	0.0196	35.1806	<.0001	1.1230
Caregiver is spouse of receiver	0.0863	0.0756	1.3033	0.2536	1.0900
Care receiver age	0.0088	0.0026	11.8401	0.0006	1.0090
Care receiver is male	-0.2914	0.0746	15.2397	<.0001	0.7470
Caregiver would definitely consider placing receiver out-of-home	0.5845	0.1063	30.2453	<.0001	1.7940
Care receiver enrolled in Medicaid medical coverage at screen	1.7035	0.0809	443.9300	<.0001	5.4930
Care receiver has diagnosed dementia	0.1528	0.0726	4.4302	0.0353	1.1650
TOTAL = 6,613					

NOTES

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[1] Washington State Department of Health 2007 Behavioral Risk Factor Surveillance System (BRFSS).

[2] According to Washington State law, (RCW 74.41.020) it is intended that FCSP program shall, "Encourage family and other nonpaid individuals to provide care for adults with functional disabilities at home, and thus offer a viable alternative to placement in a long-term care facility."

[3] Montgomery, R. & Kwak, J. (2008). Tailored Caregiver Assessment and Referral (TCARE): An evidence-based model to target services for caregivers. *American Journal of Nursing,* 108, 54-57; and Montgomery, R. et al. (2011). Effects of TCARE® intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66, 640-647.

[4] Miller, M. (2012). *Did expanding eligibility for the Family Caregiver Support Program pay for itself by reducing the use of Medicaid-paid long-term care?* (Document No. 12-11-3901). Olympia, WA: Washington State Institute for Public Policy. Note: Minor differences in sample definitions between WSIPP's 2012 report and the current report yield differences in sample characteristics.

[5] Some area agencies on aging (AAAs) lowered the eligibility criteria for a TCARE® assessment and consultation to three high burdens prior to the SFY 2012 expansion.

[6] Washington State Department of Social and Health Services, Aging and Long-Term Support Administration, Caregiver Assessment and Planning (http://www.altsa.dshs.wa.gov/Professional/TCARE/).

[7] Enrollment in Medicaid coverage is distinguished from receipt of Medicaid-paid long-term services and supports. Only the subset of persons enrolled in Medicaid coverage who apply and are determined functionally eligible receive Medicaid-paid long-term services and supports.

[8] To gauge weekly hours of caregiving, the Washington State Department of Health's 2007 Behavioral Risk Factor Surveillance System (BRFSS) survey asks caregivers, "In an average week, how many hours do you provide for [care receiver] because of his/her long-term illness or disability?" In FCSP, the weekly hours of caregiving is the sum of responses to four separate questions in the TCARE® assessment: "During the past week, about how many hours total did you help the care receiver with the following activities: (a) Eating, bathing, dressing, or helping with toilet functions? (b) Meal preparations, laundry, or light housework? (c) Providing transportation to appointments and/or shopping? (d) Legal matters, banking, or money matters?" In the analysis of "high-intensity" caregivers in the 2007 BRFSS conducted by Mary LeMier, Washington State Department of Health, "high-intensity" caregivers are defined as those providing more than 20 hours per week of care for a period of one year or longer. In available TCARE® assessment data, "high-intensity caregivers" are defined as those providing more than 20 hours per week of care for a period of longer than one year.

[9] In particular, the plotted numbers reflect the estimated time to Medicaid LTC for pre- and post-expansion caregivers who both have baseline characteristics reflecting the overall average from both groups.

[10] Hazard is the instantaneous risk that an individual who has not yet experienced the event in question will do so. For additional detail, see Singer, J. & J. Willett. (2003). *Applied Longitudinal Data Analysis: Modeling Change and Event Occurrence.* New York: Oxford Press.

RDA CONTACT

David Mancuso, PhD • 360.902.7557• david.mancuso@dshs.wa.gov

Copies of this paper may be obtained at www.dshs.wa.gov/rda/ or by calling DSHS' Research and Data Analysis Division at 360.902.0701.
Please request REPORT NUMBER 8.31

Has the use of Tailored Caregiver Assessment and Referral® System Impacted the Well-being of Caregivers in Washington?

Report to the Washington Aging and Long-Term Support Administration

May 2014

Rhonda J.V. Montgomery, PH.D
Helen Bader School of Social Welfare
University of Wisconsin-Milwaukee

SUMMARY

Data Source:

Data used for this report were obtained from the Washington State Department of Social and Health Services (DSHS) Aging and Long-Term Support Administration (ALTSA) were taken from records for caregivers participating in the Family Caregiver Support Program (FCSP). The data were collected via the use of the Tailored Caregiver Assessment and Referral® (TCARE®) system assessment tool between March 2010 and December 2013.

Key Findings:

- 84% of caregivers who remained in the program for six months reported improved levels of stress and depression.
- The 16% of caregivers who did not show improvement were providing more assistance of all types and were caring for family members who engaged in more problem behaviors. There was also a decline in the functional level of the persons for whom they provide care.
- After 12 months of participation in the program, caregivers continued to have statistically significant lower levels of stress and depression than they did at the time of initial enrollment.
- As a group, caregivers who placed the care recipient in a long term care facility prior to the six-month follow-up had the highest levels of stress and depression at the time of the of the initial assessment. Their scores on all measures of stress and depression were higher than those of caregivers who continued in the program and those of caregivers whose care recipient died prior to the six-month follow up.
- The group of caregivers whose care recipient died prior to the six-month follow-up was providing the most assistance for care recipients with the greatest functional impairment, but did not have higher levels of stress. They had the lowest scores of relationship burden and the highest levels of uplifts or positive feelings about caregiving.

A. Background

This report provides a summary of findings from analyses of records for 11,101 informal caregivers who participated in the Family Caregiver Support Program (FCSP) administered by the Aging and Long-Term Support Administration (ALTSA) in the Washington State Department of Social and Health Services. The Tailored Caregiver Assessment and Referral® (TCARE®) system was adopted by ALTSA in 2009 in response to a directive from the Washington State Legislature to identify and use an evidence based assessment and referral tool for use within the Family Caregiver Support Program (FCSP).

As part of TCARE® implementation, the DSHS developed a three tiered eligibility and authorization process. Level 1 provides unpaid caregivers with information and referrals to community resources and, if needed, services up to $250. Caregivers who choose to participate in level 2 of the program complete the short TCARE® screen which includes: three measures of caregiver burden (i.e. objective burden, relationship burden, stress burden), a measure of the caregivers' positive feelings about caregiving (uplifts), a measure of the caregivers' acceptance of the caregiving role (identity discrepancy) and measures of the caregivers' depression and their intention to place the care recipient in a long term care facility. Caregivers who score low or medium on most of the measures may receive up to $500 in services. Caregivers who have scores that are in the medium and high range are invited to complete the full TCARE® in-depth assessment. Caregivers' responses to the assessment questions are processed by a computer software that uses a decision algorithm to provide a profile of the caregiver and suggestions for a service plan that are used by the care managers to tailor a care plan to the caregivers' current needs.

B. Caregivers Served With TCARE® Protocol (March 2010 through December 2013)

Between March 2010 and December 2013, 11,101 family caregivers completed the TCARE® screening process. Half (49.5%) of the caregivers were husbands (15.8%), wives (31.9%), or partners (1.7%) of the care recipient; 40.8% were sons (8.7%) or daughters (32.1%); and distant relatives and friends accounted for the remaining 9.7%. The mean age of caregivers was 64 and the mean age of care recipients was 77. The majority (85%) of caregivers were white, but the sample did include small numbers of Asians, Blacks, Latinos, Pacific Islanders, and Native Americans. Scores for 25% of these caregivers on the five measures of caregiver stress and depression did not meet the threshold to be eligible for level 3 services. The remaining 8,314 caregivers completed the full-in-depth structured TCARE® interview. A greater proportion of spouse caregivers (79%) completed the full assessment than did adult children (72%) or more distant relatives (65%). This report provides detailed information about the 5,592[1] spouse and adult children caregivers who completed the full TCARE® assessment between March 15, 2010 and December 15, 2013 and would be eligible for a six-month follow up assessment.

C. Outcomes for Caregivers Who Completed a Six-Month Follow-Up

Current policy of the FCSP requires follow-up with a TCARE® screening to be conducted with caregivers after six months of enrollment. If a caregiver's scores on the measures of stress and depression have improved over the course of six months, only minor adjustments are made to the care plan, if needed. If a caregiver's scores on key measures have not improved, the full TCARE® assessment is completed with the caregiver. A six-month follow-up assessment was conducted with 57.4% of the caregivers who were eligible for the follow-up assessment. Data from these assessments provide strong evidence for the benefits of the TCARE® process. Most important, the levels of stress and burden for 84% of these caregivers had diminished over the six month period. The mean scores for this group decreased by 13% for stress burden, 10% for objective burden, 8% for relationship burden, 7% for identity discrepancy (i.e. comfort with caregiving role), and 9% for depression. Equally important, scores for uplifts, or caregivers' positive feelings, increased by 4%.

A full follow-up assessment was deemed appropriate for the 16% of caregivers whose scores on the key outcomes had not improved at the time of follow-up. Although there are potentially numerous idiosyncratic reasons for this lack of improvement, two possible explanations should be considered as they have implications for practice and policy decisions. It is possible that the care plans created for these caregivers did not effectively meet their needs. It is also possible that the care plan was initially effective, but the care plan became obsolete due to changes in the condition of the care recipient or the resources of the caregiver.

Findings from two analyses provide support for the latter explanation. First, it is useful to look at differences between the two groups of caregivers (those who improved and those who did not) at the time of enrollment. At the time of the initial assessment, there were no differences between the two groups in the functional levels of the care recipients nor in the level any of the three types of caregiver burden or and depression reported. However, caregivers in the group that failed to improve were caring for persons who engaged in more problem behaviors and were providing more assistance with ADLs (eating, bathing, dressing and toileting functions), transportation and money and legal matters. Moreover, there was a statistically significant decline over the six month period in the functional level of the person for whom they were providing care. In short, the 16% of caregivers whose stress and depression levels were not improved, were providing the most care for care recipients whose condition continued to decline. Given that these caregivers were already providing the greatest number of hours of care, it is highly likely that the increase in functional disability of the care receiver translated to a need for more or different support services. Consequently, the initial care plans were no longer meeting the needs of the caregiver. Together these findings underscore the importance and the efficiency of conducting follow-ups to identify the small group of caregivers in need of the more in-depth follow-up.

D. Outcomes for Caregivers Who Completed a 12-Month Follow-Up Assessment

Current policy for the FCSP requires a full assessment to be conducted with caregivers on an annual basis regardless of the caregiver's scores on the key measures of stress or burden. Data for 1,381 caregivers who completed the full TCARE® assessment 12 months after enrollment in the program provide evidence that the positive impact of the TCARE® protocol persists over time. Over a one year period, the condition of the care recipients deteriorated as indicated by increased need for assistance with all types of daily activities including help with personal care. In response, caregivers increased the number of hours they spent providing help with eating, bathing and dressing. Yet, despite these statistically significant increases in disability of the care recipient and in the hours providing care, the mean scores for the caregivers on all measures of caregiver burden and depression decreased. **In short, with the support of TCARE®, caregivers served by the FCSP over a one year period were able to maintain their health and improve their emotional and mental health while providing more assistance to care recipients who experienced a decline in functional abilities.**

E. Caregivers Who Left the Program Prior to Six-Month Follow–Up

Reasons for leaving

To gain a full understanding of the benefits and limitations of the FCSP program, a detailed analysis was conducted that focused on characteristics of 1,665 caregivers who dropped out of the program prior to the six-month follow-up. The majority (66%) of these caregivers left the program because the care recipient was placed in a long term care facility (24%), the care receiver died (34.7%) or the caregiver was no longer available due to death, moving, or illness (5.7%). The remaining 34% of caregivers who did not complete a follow-up chose not to participate in the program or the care managers were unable to contact them.

Differences in characteristics between caregivers who continued and caregivers who left the program

Given the emphasis of the FCSP on promoting continued community living, an important question to ask is: *Did the caregivers who made the decision to place the care recipient in a long term care facility* *differ in any significant way from those who continued to be served in the program?* The answer is yes, they did differ in several important ways. Caregivers whose family members moved to a long term care facility were more likely to be caring for an individual who had memory problems, the majority (60.5%) of whom had a medical diagnosis of Alzheimer's disease or other dementia. These care recipients engaged in more problem behaviors and required more assistance with everyday activities such as meal preparation, laundry and household tasks, than did the care recipients of caregivers who continued in the program to the 6-month follow-up. However, their caregivers did not spend more time providing assistance with these tasks, but they did spend more time providing assistance with ADLs (bathing, dressing, eating, and toileting). The biggest difference between the group of caregivers who continued to provide care and those whose care recipient moved to a care facility was their level of stress and depression. The mean scores for all measures of caregiver burden, depression and intentions to place the care recipient in a care facility were highest for caregivers who ultimately did place the care recipients in a long term care facility.

Two observations that have policy implications can be made about these differences between the two groups. First, it is highly likely that the caregivers who placed their care recipient in a long term care facility were seeking and receiving help too late in the caregiving process. The levels of caregiver burden and depression that these caregivers were experiencing was so high that they were already considering or seeking placement of the care recipient in a facility when they first made contact. This is the group of caregivers that is often in crisis and unable or unwilling to consider other options. In short, the services offered by the FCSP were too little, too late. This pattern suggests that the FCSP is most effective when services are offered to caregivers before their stress levels become very high.

The second observation concerns the challenge of caring for individuals with memory problems and problem behaviors. Although these individuals are often physically able to perform daily tasks and chores, their memory and behavior problems create a situation that requires constant vigilance on the part of caregivers. The difficulty of maintaining constant vigilance is not captured by measures of functional ability or the number of hours that a caregiver spends performing tasks. They must be constantly vigilant and in many ways they are "on call" 24 hours a day, 7 days a week. It is, therefore, not surprising that the caregivers who ultimately moved the care recipient to a care facility were more likely to be caring for someone with memory and/or problem behaviors.

The final analysis that was conducted focused on caregivers whose family members died prior to a scheduled six-month follow-up assessment. The analysis provides two findings that are informative. Family members caring for an adult at the end of life were providing the most care for individuals who were the most physically impaired. Yet, despite this greater workload, their mean scores for relationship burden, stress burden, and identity discrepancy did not differ from those of caregivers who continued in the program to the six-month follow up. They also expressed no greater intention to place the care recipient in a long term care facility than did caregivers who continued in the program and reported experiencing the most positive feelings about caregiving. Clearly these findings underscore the fact that the physical work of caregiving is not the most important factor that influences caregiver's ability and willingness to continue to provide care. Rather, it is the emotional well-being of the caregiver that is the driving force.

End Note

[1] 25% (1,910) of the 7,502 spouse and adult-children caregivers in had not been enrolled in the TCARE® program long enough to be eligible for a six-month follow-up assessment.

F. Technical Appendix

Table 1. Frequencies of Characteristics of Washington TCARE® Caregivers (Mar 2010-Dec 2013) *(n=11,101)*

	Full Sample (N=11,101)	Full Assessment Completed (N=8,314)	Screen Only Completed (N= 2,787)
	N (%)	**N (%)**	**N (%)**
Gender			
Male	3020 (27.2)	2215 (26.6)	805 (28.9)
Female	8079 (72.8)	6097 (73.3)	1982 (71.1)
Other	2 (.0)	2 (.0)	0 (0.0)
Race			
White	9407 (84.7)	7184 (86.4)	2223 (79.8)
Black or African American	364 (3.3)	285 (3.4)	79 (2.8)
Native Hawaiian/Other Pacific Islander	50 (0.5)	34 (0.4)	16 (0.6)
American/Alaskan Native	248 (2.2)	113 (1.4)	135 (4.8)
Asian	471 (4.2)	375 (4.5)	96 (3.4)
Unreported	195 (1.8)	96 (1.2)	99 (3.6)
Other	322 (2.9)	210 (2.5)	112 (4.0)
Hispanic/Latino	468 (4.2)	325 (3.9)	143 (5.1)
Two or More Races Indicated	488 (4.4)	342 (4.1)	146 (5.2)
Employment Status **			
Employed	-	2125 (25.6)	-
Not Employed	-	5630 (67.7)	-
Relationship to the care recipient			
Spouse/Partner	5498 (49.5)	4357 (52.4)	1141 (40.9)
--Husband	*1759 (15.8)*	*1340 (16.1)*	*419 (15.0)*
--Wife	*3545 (31.9)*	*2877 (34.6)*	*668 (24.0)*
--Partner	*194 (1.7)*	*140 (1.7)*	*54 (1.9)*
Adult Child	4525 (40.8)	3259 (39.2)	1266 (45.4)
--Son	*966 (8.7)*	*682 (8.2)*	*284 (10.2)*
--Daughter	*3559 (32.1)*	*2577 (31.0)*	*982 (35.2)*
Other	1078 (9.7)	698 (8.4)	380 (13.6)
Live with Care Receiver**			
Yes	-	6855 (82.5)	-
No	-	989 (11.9)	-
Self-reported health **			
Very Poor	-	158 (1.9)	-
Poor	-	841 (10.1)	-
Fair	-	2767 (33.3)	-
Good	-	3544 (42.6)	-
Very Good	-	1004 (12.1)	-
Care recipient memory loss			
No memory problem	1952 (17.6)	1298 (15.6)	624 (22.4)
Memory or cognitive problem suspected	3351 (30.2)	2440 (29.3)	908 (32.6)
Probable Alzheimer's, not medically diagnosed	1729 (15.6)	1292 (15.5)	427 (15.3)
Yes, Alzheimer's, medically diagnosed	4069 (36.7)	3284 (39.5)	828 (29.7)

** indicates variable only found in assessment

Table 2. Descriptive Statistics of Characteristics of Washington TCARE® Caregivers (Mar 2010-Dec 2013) *(n=11,101)*

	Full Sample (N=11,101)	Full Assessment Completed (N=8,314)	Screen Only Completed (N= 2,787)
	Mean (SD)	**Mean (SD)**	**Mean (SD)**
Caregiver Age (in years)	63.81 (14.15)	64.51 (13.79)	61.87 (15.07)
Care recipient Age (in years)	77.57(12.41)	78.02 (12.10)	76.39 (13.26)
Caregiver annual income**	-	1990.36 (1613.35)	-
Missing Data - N(%)	-	*2299 (27.7)*	-
Caregiver assistance (hours per week) **			
Eating, bathing, dressing or toilet functions	-	14.17 (15.46)	-
Meal preparation, laundry or light housework	-	20.82 (12.99)	-
Provide transportation to/from appointments	-	6.49 (5.99)	-
Legal matters, banking, money matters	-	3.40 (4.88)	-
Care recipient ADLs (0-44)**	-	8.55 (7.17)	-
Care Recipient IADLs (0-24)**	-	18.51 (4.73)	-
Care Recipient Problem Behaviors (0-45)**	-	11.90 (7.28)	-
Intention to Place (1-4)	1.79 (.94)	1.82 (.94)	1.77 (.98)
Relationship Burden (5-25)	11.13 (5.15)	11.81 (5.16)	9.66 (4.87)
Objective Burden (6-30)	21.73 (6.47)	23.21 (5.64)	18.09 (7.02)
Stress Burden (5-25)	15.52 (5.45)	16.57 (5.06)	12.99 (5.53)
Depression (10-40)	24.24 (7.09)	25.55 (6.63)	21.18 (7.21)
Identity Discrepancy (6-36)	24.61 (7.11)	26.10 (6.26)	21.13 (7.88)
Uplifts (6-30)	15.03 (6.18)	14.48 (5.94)	16.38 (6.57)

** indicates variable only found in assessment

Table 3. Paired T-test for Follow-Up Screen Key Outcomes- Time 1 and Time 2 *(n=2702)*

Outcome	**Time 1**	**Time 2**	**t**	**df**	**% Change**
Relationship Burden	11.54	10.59	11.157***	2701	8.0%
Objective Burden	23.03	20.79	20.347***	2701	10.0%
Stress Burden	16.21	14.16	22.652***	2701	13.0%
Uplifts	14.41	14.92	-5.438***	2701	4.0%
Depression	25.29	22.92	19.441***	2701	9.0%
Discrepancy	25.79	24.05	13.466***	2701	7.0%

Note; Asterisks denote significant differences between times at the levels specified below

* = p<.05, **=p<.01, ***p<.001

Table 4. Time 1 With Assessment & Screen Follow-Up- Chi Square *(n=3212)*

	Time 1 With Screen Follow-Up (N=2702)	Time 1 With Assessment Follow-Up (N=510)
	N (%)	**N (%)**
Gender		
Male	763(28.2)	136 (26.7)
Female	1938 (71.7)	374 (73.3)
Other	1 (.0)	0 (.0)
Race		
White	2353 (87.1)	450 (88.2)
Black or African American**	115 (4.3)	9 (1.8)
Native Hawaiian/Other Pacific Islander	10 (0.4)	0 (.0)
American/Alaskan Native	26 (1.0)	6 (1.2)
Asian	127 (4.7)	25 (4.9)
Unreported	14 (0.5)	6 (1.2)
Other	66 (2.4)	15 (2.9)
Hispanic/Latino	104 (3.8)	23 (4.5)
Two or More Races Indicated	113 (4.2)	24 (4.7)
Employment Status		
Employed	617 (22.8)	119 (23.3)
Not Employed	1940 (71.8)	358 (70.2)
Relationship to the care recipient		
Spouse/Partner	1674 (62.0)	312 (61.2)
Adult Child	1028 (38.0)	198 (38.8)
Live with Care Receiver		
Yes	2373 (87.8)	439 (86.1)
No	201 (7.4)	46 (9.0)
Self-reported health **		
Very Poor	45 (1.7)	11 (2.2)
Poor	248 (9.2)	69 (13.5)
Fair	916 (33.9)	161 (31.6)
Good	1179 (43.6)	199 (39.0)
Very Good	314 (11.6)	70 (13.7)
Care recipient memory loss		
No memory problem	415 (15.4)	88 (17.3)
Memory or cognitive problem suspected	708 (26.2)	137 (26.9)
Probable Alzheimer's, not medically diagnosed	396 (14.7)	86 (16.9)
Yes, Alzheimer's, medically diagnosed	1183 (43.8)	199 (39.0)

Note; Asterisks denote significant differences between categories at the levels specified below.
* = p<.05, **=p<.01, ***p<.001

Table 5. Time 1 With Assessment & Screen Follow-Up- T-Tests *(n=3212)*

	Time 1 With Screen Follow-Up (N=2702)	Time 1 With Assessment Follow-Up (N=510)
	Mean (SD)	**Mean (SD)**
Caregiver Age (in years)	66.24 (12.86)	65.93 (12.54)
Care Recipient Age (in years)	78.79 (10.40)	78.60 (10.14)
Caregiver annual income***	1986.76 (1550.67)	1676.32 (1457.99)
Missing Data - N(%)	*695 (25.7)*	*142 (27.8)*
Caregiver assistance (hours per week)		
Eating, bathing, dressing or toilet functions*	13.96 (15.02)	15.46 (15.96)
Meal preparation, laundry or light housework	21.82(12.59)	23.05 (13.91)
Provide transportation to/from appointments***	6.21 (5.74)	7.70 (6.38)
Legal matters, banking, money matters**	3.17 (4.42)	3.80 (4.57)
Care recipient ADLs (0-44)	8.26 (6.81)	8.57 (7.45)
Care Recipient IADLs (0-24)	18.52 (4.54)	18.75 (4.62)
Care Recipient Problem Behaviors (0-45)*	11.46 (6.91)	12.20 (7.43)
Intention to Place (1-4)	1.68(.85)	1.66 (.87)
Relationship Burden (5-25)	11.54 (4.97)	11.61 (5.38)
Objective Burden (6-30)	23.03 (5.59)	22.89 (5.78)
Stress Burden (5-25)	16.21 (4.96)	16.28 (5.30)
Depression (10-40)	25.29 (6.44)	25.02 (6.94)
Identity Discrepancy (6-36)	25.79 (6.31)	25.77 (6.68)
Uplifts (6-30)	14.41 (5.89)	14.43 (5.91)

Note; Asterisks denote significant differences between categories at the levels specified below.
* = p<.05, **=p<.01, ***p<.001

Table 6. Paired T-test Comparing Initial Assessment (T1) and Second Assessment Follow-Up (T3) Outcomes (*n=1,381)*

Outcome	**Time 1**	**Time 3**	**t**	**df**	**% Change**
Relationship Burden	11.75	11.51	1.929*	1380	2.1%
Objective Burden	23.22	22.03	7.650***	1380	5.1%
Stress Burden	16.53	15.34	8.940***	1380	7.2%
Uplifts	14.34	14.58	-1.797	1380	-
Depression	25.75	24.19	8.848***	1380	6.1%
Discrepancy	26.04	25.60	2.471*	1380	1.7%

Note; Asterisks denote significant differences between times at the levels specified below
* = p<.05, **=p<.01, ***p<.001

Table 7. Paired T-test Comparing Initial Assessment (T1) and Second Assessment Follow-Up (T3) Key Characteristics (*n=1,381)*

	Time 1	Time 3	t	df	% Change
ADLs	8.23	9.38	-9.282***	1380	-14.0%
IADLs	18.67	19.16	-5.579***	1380	-3.0%
Problem Behaviors	11.75	11.30	2.831**	1380	4.0%
Hours spent assisting eating, bathing, dressing, or helping with toilet functions	13.85	15.14	-3.405**	1380	-9.0%
Hours spent assisting meal preparation, laundry, or light housework	21.75	21.69	.177	1380	-
Hours spent assisting providing transportation to appointments and/or shopping	6.32	5.86	2.636**	1380	7.0%
Hours spent assisting legal matters, banking or money matters	3.14	3.06	.613	1380	-
Self-rated Health	3.52	3.50	.875	1379	-
Memory Problems	1.51	1.47	1.291	1380	-

Note; Asterisks denote significant differences between times at the levels specified below
* = p<.05, **=p<.01, ***p<.001

Table 8. Paired T-test Comparing Initial Assessment (T1) and Assessment Follow-Up (T2) Outcomes (*n=510)*

Outcome	Time 1	Time 2	t	df	% Change
Relationship Burden	11.61	11.83	-1.035	509	-
Objective Burden	22.89	22.55	1.198	509	-
Stress Burden	16.28	15.84	1.856	509	-
Uplifts	14.43	14.59	-.703	509	-
Depression	25.02	24.73	.952	509	-
Discrepancy	25.77	25.94	-.577	509	-

Note; Asterisks denote significant differences between times at the levels specified below
* = p<.05, **=p<.01, ***p<.001

Table 9. Paired T-test Comparing Initial Assessment (T1) and Assessment Follow-Up (T2) Key Characteristics (*n=510)*

	Time 1	Time 2	t	df	% Change
ADLs	8.57	10.04	-6.134***	509	-17.1%
IADLs	18.75	19.35	-3.617***	509	-3.3
Problem Behaviors	12.20	12.32	-.421	509	-
Hours spent assisting eating, bathing, dressing, or helping with toilet functions	15.46	16.47	-1.329	509	-
Hours spent assisting meal preparation, laundry, or light housework	23.05	21.99	1.590	509	-
Hours spent assisting providing transportation to appointments and/or shopping	7.70	7.26	1.285	509	-
Hours spent assisting legal matters, banking or money matters	3.80	3.86	-.235	509	-
Self-rated Health	3.49	3.47	.527	504	-
Memory Problems	1.53	1.58	-.932	509	-

Note; Asterisks denote significant differences between times at the levels specified below
* = p<.05, **=p<.01, ***p<.001

Table 10: Comparison of Caregiver and Care Receiver Characteristics by Follow-Up Completion Type

	Time 1 With Screen Follow-Up (N=2702)	Time 1 With Assessment Follow-Up (N=510)	Time 1 With No Follow-Up CR Death (N=577)	Time 1 With No Follow-Up CR Placement (N=397)
	N (%)	**N (%)**	**N (%)**	**N (%)**
Gender + ∞				
Male	763(28.2)	136 (26.7)	128 (22.2)	122 (30.7)
Female	1938 (71.7)	374 (73.3)	449 (77.8)	275 (69.3)
Other	1 (.0)	0 (.0)	0 (.0)	0 (.0)
Race				
White +*✧□	2353 (87.1)	450 (88.2)	534 (92.5)	371 (93.5)
Black or African American ^ +*	115 (4.3)	9 (1.8)	5 (0.9)	6 (1.5)
Native Hawaiian/Other Pacific Islander	10 (0.4)	0 (.0)	3 (0.5)	1 (0.3)
American/Alaskan Native	26 (1.0)	6 (1.2)	6 (1.0)	2 (0.5)
Asian +*✧□	127 (4.7)	25 (4.9)	14 (2.4)	8 (2.0)
Unreported	14 (0.5)	6 (1.2)	7 (1.2)	1 (0.3)
Other✧	66 (2.4)	15 (2.9)	7 (1.2)	9 (2.3)
Hispanic/Latino +✧	104 (3.8)	23 (4.5)	10 (1.7)	9 (2.3)
Two or More Races Indicated	113 (4.2)	24 (4.7)	15 (2.6)	10 (2.5)
Employment Status				
Employed	617 (22.8)	119 (23.3)	116(20.1)	85 (21.4)
Not Employed	1940 (71.8)	358 (70.2)	416(72.1)	295 (74.3)
Relationship to the Care Recipient				
Spouse/Partner	1674 (62.0)	312 (61.2)	358 (62.0)	241 (60.7)
Adult Child	1028 (38.0)	198 (38.8)	219(38.0)	156 (39.3)
Live with Care Recipient				
Yes	2373 (87.8)	439 (86.1)	519 (89.9)	348 (87.7)
No	201 (7.4)	46 (9.0)	44 (7.6)	39 (9.8)
Self-Reported Health ^✧				
Very Poor	45 (1.7)	11 (2.2)	7 (1.2)	6 (1.5)
Poor	248 (9.2)	69 (13.5)	50 (8.7)	49 (12.3)
Fair	916 (33.9)	161 (31.6)	210(36.4)	120 (30.2)
Good	1179 (43.6)	199 (39.0)	242(41.9)	172 (43.3)
Very Good	314 (11.6)	70 (13.7)	68(11.8)	50 (12.6)
Care Recipient Memory Loss +*□∞				
No memory problem	415 (15.4)	88 (17.3)	94 (16.3)	22 (5.5)
Memory or cognitive problem suspected	708 (26.2)	137 (26.9)	188 (32.6)	67 (16.9)
Probable Alzheimer's, not medically diagnosed	396 (14.7)	86 (16.9)	75 (13.0)	68 (17.1)
Yes, Alzheimer's, medically diagnosed	1183 (43.8)	199 (39.0)	220 (38.1)	240 (60.5)
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**
Caregiver Age (in years) +*✧□	66.24 (12.86)	65.93 (12.54)	67.45 (12.42)	68.09 (13.12)
Care Recipient Age (in years) +*✧□	78.79 (10.40)	78.60 (10.14)	80.43(9.97)	80.81 (8.28)
Caregiver Annual Income ^✧□∞	1986.76 (1550.67)	1676.32 (1457.99)	1882.45 (1495.13)	2121.72 (1589.68)
Missing Data - N(%)	*695 (25.7)*	*142 (27.8)*	*151 (26.2)*	*104 (26.2)*
Caregiver Assistance (hours per week)				
Eating, bathing, dressing or toilet functions ^+*✧∞	13.96 (15.02)	15.46 (15.96)	21.40 (17.01)	17.52 (16.40)
Meal preparation, laundry or light housework +	21.82(12.59)	23.05 (13.91)	23.52 (12.59)	22.90 (11.97)
Provide transportation to/from appointments ^✧□	6.21 (5.74)	7.70 (6.38)	5.99 (5.66)	6.58 (5.32)
Legal matters, banking, money matters ^+*	3.17 (4.42)	3.80 (4.57)	3.37 (4.32)	3.87 (5.83)
Care Recipient ADLs (0-44) +*✧∞	8.26 (6.81)	8.57 (7.45)	13.23 (7.66)	9.02 (6.42)
Care Recipient IADLs (0-24) *✧□	18.52 (4.54)	18.75 (4.62)	20.49 (3.61)	20.24 (3.67)
Care Recipient Problem Behaviors (0-45) ^*□∞	11.46 (6.91)	12.20 (7.43)	11.86 (7.19)	14.74 (8.13)
Intention to Place (1-4) *□∞	1.68(.85)	1.66 (.87)	1.73(.85)	2.42 (1.05)
Relationship Burden (5-25) *□∞	11.54 (4.97)	11.61 (5.38)	11.20 (5.18)	12.55 (5.26)
Objective Burden (6-30) +*✧□∞	23.03 (5.59)	22.89 (5.78)	23.90(5.16)	24.83 (4.92)
Stress Burden (5-25) *□∞	16.21 (4.96)	16.28 (5.30)	16.48 (5.02)	17.78 (4.83)
Depression (10-40) +*✧□∞	25.29 (6.44)	25.02 (6.94)	25.88 (6.54)	26.92 (6.68)
Identity Discrepancy (6-36) *✧□∞	25.79 (6.31)	25.77 (6.68)	25.84 (6.20)	27.91 (5.32)
Uplifts (6-30) +*□∞	14.41 (5.89)	14.43 (5.91)	15.08 (6.08)	12.75 (5.32)

^ Denotes a significant difference between T1 With Screen Follow-Up and T1 With Assessment Follow-Up.
+ Denotes a significant difference between T1 With Screen Follow-Up and T1 With No Follow-Up CR Death.
*** Denotes a significant difference between T1 With Screen Follow-Up and T1 With No Follow-Up CR Placement.**
✧ Denotes a significant difference between T1 With Assessment Follow-Up and T1 With No Follow-Up CR Death.
□ Denotes a significant difference between T1 With Assessment Follow-Up and T1 With No Follow-Up CR Placement.
∞ Denotes a significant difference between T1 With No Follow-Up CR Death and T1 With No Follow-Up CR Placement.

Developing a State Alzheimer's Plan Update

Joint Legislative Executive Committee on Aging and Disability

Bill Moss
DSHS Aging and Long-Term Services and Supports

May 19, 2014

Developing a State Alzheimer's Plan

- In Washington State, an estimated 110,000 individuals have AD or a related dementia
- By 2025, this is projected to be 150,000
- Unless an approach to prevent or effectively treat AD is found, the number of people with the disease will increase significantly in the next twenty years

Developing a State Alzheimer’s Plan

- A National Plan to Address Alzheimer’s Disease was released in 2012 (Update 2014: http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf)
- State Alzheimer’s Plans have been enacted in a large majority of states (http://act.alz.org/site/PageNavigator/state_plans.html)
- SSB 6124 provides legislative authorization to develop an Alzheimer’s Plan for Washington State
- DSHS is to convene an Alzheimer’s disease working group

Alzheimer’s Disease (AD) Touches all Sectors of the Economy

- The majority of care for people with Alzheimer’s disease or other dementias falls to family
- Significant care & support needs of people living with dementia impacts state and federal governments, health and long-term care systems and business
- This act is an opportunity to develop a comprehensive, coordinated effort to promote cognitive health and increase the dementia capability of our many intersecting systems of support and services for people with dementia and their family caregivers

Deliverables

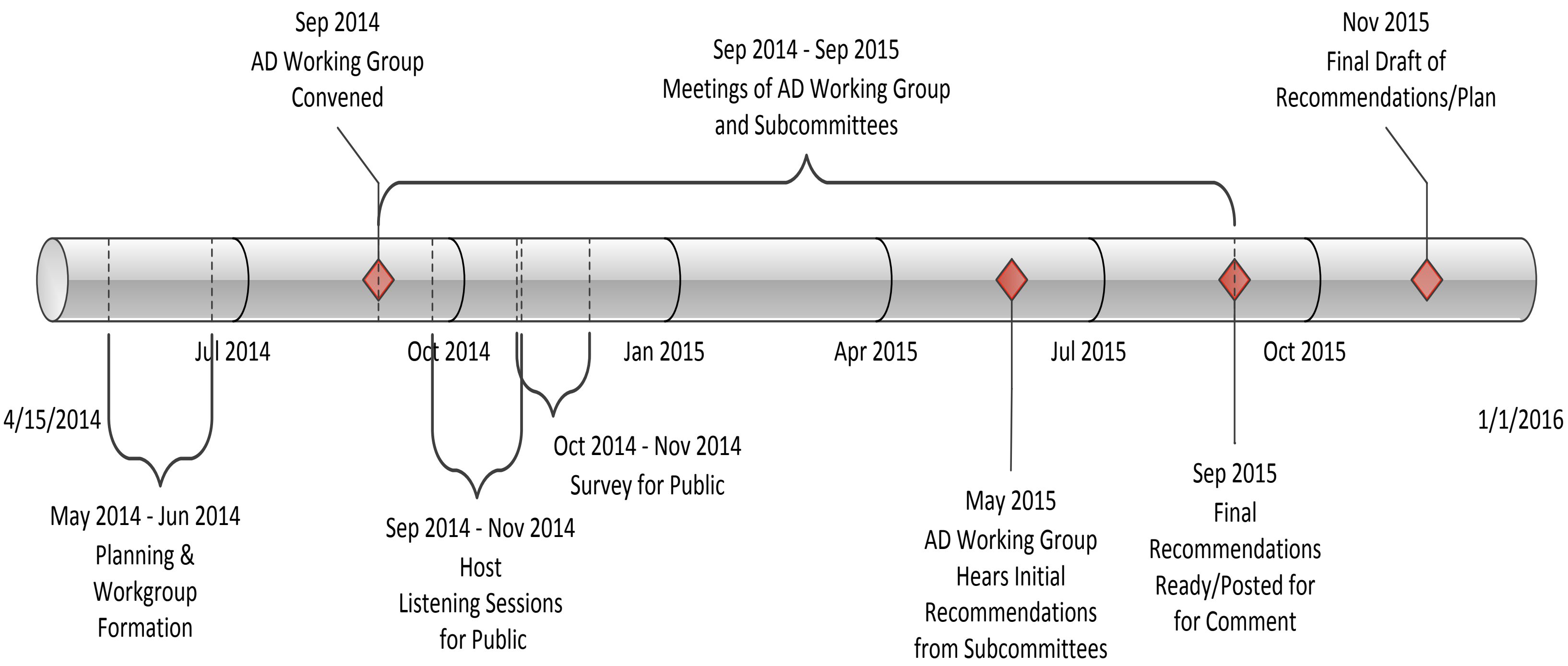
- DSHS must submit a report providing findings and recommendations of the AD working group, including any draft legislation necessary to implement the recommendations

- Due to the governor and the health care committees of the senate and house of representatives January 1, 2016

Establishing the AD Working Group

- In process of identifying membership of working group
- Goal is to have membership roster complete on or around June 30, 2014
- Membership is outlined in SSB 6124 and includes people with dementia, family caregivers of people with dementia, state agency leadership, members of the legislature, health care providers, home and residential care providers, health policy advocates and researchers

Proposed Project Timeline



Sep 2014
AD Working Group
Convened

Sep 2014 - Sep 2015
Meetings of AD Working Group
and Subcommittees

Nov 2015
Final Draft of
Recommendations/Plan

May 2014 - Jun 2014
Planning &
Workgroup
Formation

Sep 2014 - Nov 2014
Host
Listening Sessions
for Public

Oct 2014 - Nov 2014
Survey for Public

May 2015
AD Working Group
Hears Initial
Recommendations
from Subcommittees

Sep 2015
Final
Recommendations
Ready/Posted for
for Comment

Anticipate first meeting of full AD Working Group in early September 2014