



**Family Caregiving  
Advisory Council Meeting**

**July 16, 2020**

# Welcome and Roll Call

Greg Link, Director  
Officer of Supportive and Caregiver Services  
Administration for Community Living





# Opening and Convening Remarks

Lance Robertson  
Administrator/Assistant Secretary for Aging  
Administration for Community Living



# Agenda Overview and Updates

- 1:00 – 1:45 **Medicare and Family Caregivers**
- 1:45 – 2:30 **Medicaid and State Programs**
- 2:30 – 2:45 **Short Break**
- 2:45 – 3:30 **Listening Sessions (Feedback)**
- 3:30 – 4:10 **Initial Report to Congress**
- 4:10 – 4:30 **Wrap Up & Next Steps**

# Medicare and Family Caregivers

Judy Stein, JD  
Executive Director  
Center for Medicare Advocacy



David A. Lipschutz, JD  
Associate Director/Senior Policy Attorney  
Center for Medicare Advocacy





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# **Medicare and Family Caregivers**

## **July 16, 2020**

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Judith Stein, Executive Director, Attorney

David Lipschutz, Associate Director, Attorney



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The Center for Medicare Advocacy is a national, non-profit law organization founded in 1986 that works to advance access to comprehensive Medicare and quality health care. Based in Washington, DC and CT, with additional attorneys in CA, MA, NJ.

- Staffed by attorneys, advocates, communication and technical experts
- Education, legal analysis, writing, assistance, and advocacy
- Systemic change – Policy and Litigation
  - Based on our experience with the problems of real people
- Medicare coverage and appeals expertise
- Medicare/Medicaid Third Party Liability Projects



## **Discussion Questions**

1. How does Medicare impact family caregivers?
2. What home health and home care does Medicare cover?
3. What are the biggest barriers and challenges?
4. What options should the Council consider to expand support for family caregivers through Medicare?



## **Medicare Snapshot**

- Medicare = insurance program enacted 1965, changed over time
- Pays a portion of the cost of some health care
  - Premiums, deductibles, cost-sharing are required of beneficiaries
- 62 million+ beneficiaries in 2020
- Half of all Medicare beneficiaries live on annual incomes less than \$29,650; 25% live on annual incomes below \$17,000
- 50% have savings less than \$73,800; 10% have no saving or are in debt
- Beneficiaries of advanced age and younger beneficiaries with disabilities have yet lower incomes
- Medicare does not provide coverage for family caregivers



## **Medicare Home Health Coverage – The Law**

- Individual is “homebound” and requires skilled care:
  - Nursing or physical or speech therapy
  - Occupational therapy to continue coverage
- Home health aides (personal hands-on care) only covered if individual also receives skilled care
  - 28 to 35 hours/week of home health aide and nursing services combined
- No duration of time limitation
  - Not just an acute care benefit
- Coverage w/o regard to presence of family/caregiver





## **Medicare Home Health Coverage – In Practice**

- Often those who qualify are unable to obtain coverage/care or not all that's needed and coverable under the law
- Access to home health aides is shrinking
- Inappropriate application of an “improvement standard” (in violation of *Jimmo v. Sebelius*)
  - Care to maintain condition or slow decline is coverable
- Changes in access due to changed payment incentives



## **Medicare Advantage – Limited Aide Coverage for Some**

- Medicare Advantage (MA) = private insurance plans that must cover at least what traditional Medicare covers
- MA plans are allowed to provide extra benefits with rebate dollars
- Congress and CMS have recently expanded scope of what MA plans can cover, including care in the home (without homebound or skilled care requirements)
- When included in plan benefits, such services are limited
- MA is not the solution for caregivers



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## **Recommendations/Possible Next Steps**

- Absent a comprehensive LTSS benefit, there are steps that can be taken ...

## **Recommendation #1:**

- Ensure the scope of current Medicare home health benefits, generally, and home health aides, specifically, are actually provided. Simply put, ensure that current law is followed.

## **Recommendation #2:**

- Create a new stand-alone home health aide benefit that would provide coverage without the current homebound or skilled care requirements, using Medicare's existing infrastructure as the vehicle for coverage.



## **Recommendation #3:**

- Identify other opportunities for further exploration within and without the Medicare program, including additional Medicare revisions, demonstrations, and initiatives overseen by the Center for Medicare and Medicaid Innovation (CMMI).



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## **Medicare and Family Caregivers**

### **Questions?**

For further information, to receive the Center's free weekly electronic newsletter, *CMA Alert*, update emails and webinar announcements, contact:

**Communications@MedicareAdvocacy.org**

Or visit

**MedicareAdvocacy.org**

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# Medicare and Family Caregivers Council Discussion

1. What options should the Council consider to expand support for family caregivers through Medicare?
2. Based on CMA's presentation, what recommendations should the council consider putting forward in the Report to Congress?
3. Based on these suggested recommendations, are there specific actions to consider including in the National Strategy?

# Medicaid and State Programs

Bea Rector M.P.A.

Director

Washington State Department of Social and Health Services



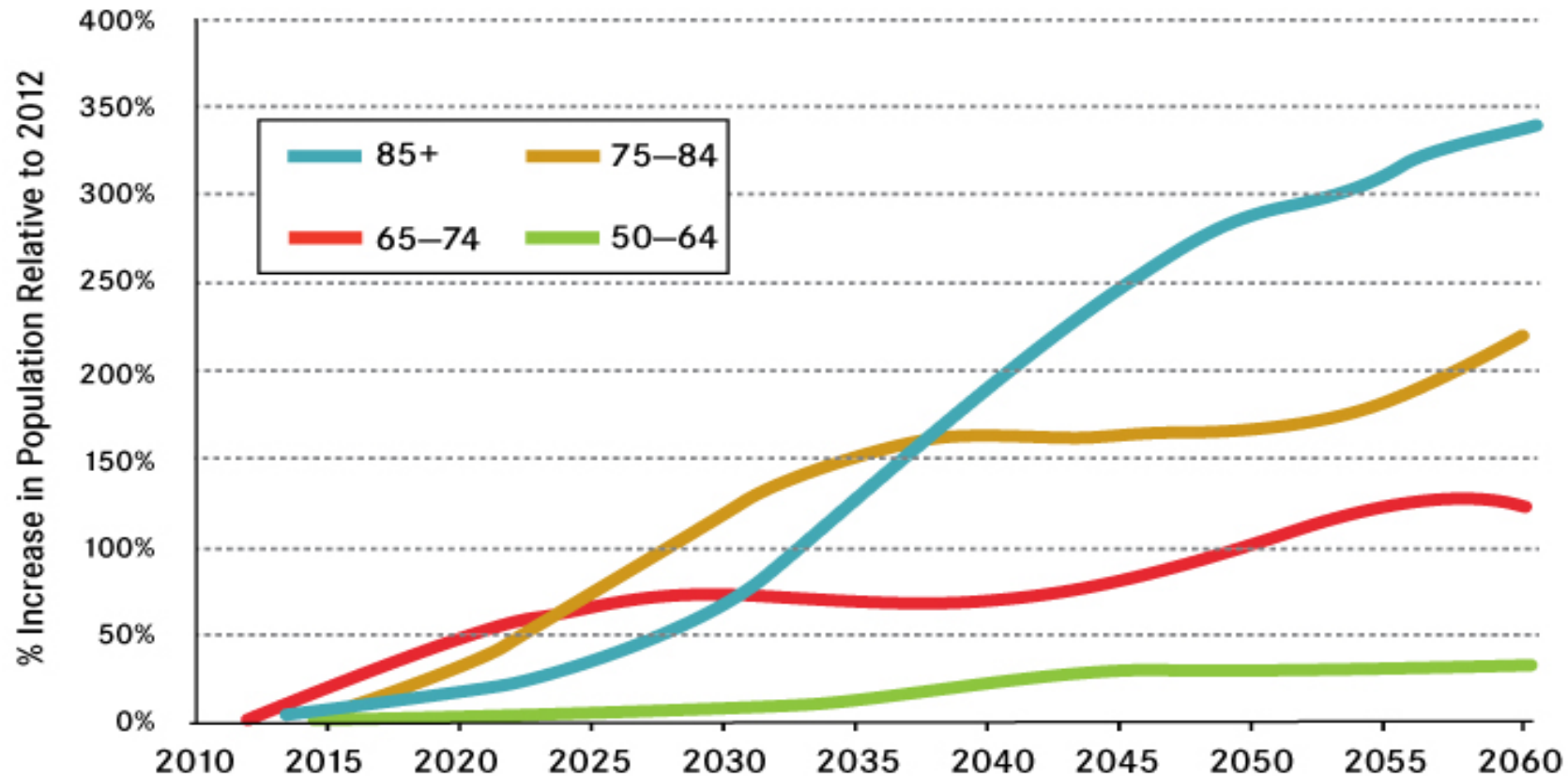
Transforming  
Lives

# Family Caregiver Policies & Innovations: Washington State

**Bea Rector, Director, Home and Community Services  
Aging and Long-Term Support Administration  
Washington State Department of Social and Health Services**



# Aging Demographics Force Continued Innovations in Long Term Services & Supports



# Path to Medicaid Long-Term Services and Supports

**\$148,000**

Average senior  
retirement savings

**\$260,000**

Average life cost of  
long-term services and  
supports

You have a need for care



Your family caregivers become exhausted



Your out-of-pocket expenses diminish  
your financial resources



You turn to Medicaid for long-term  
services and supports

# Washington Supports Family Caregivers



Providing supports  
to unpaid caregivers



Paying caregivers  
through Medicaid

# Strategies for Supporting Caregivers

## Older Americans Act, State and VA

- Caregiver Assessment & Services for Unpaid Caregivers
- Kinship Caregiver Navigators and Services
- Use of evidence-based models
- Veteran's Directed Care program

## Medicaid Services

- Allow family caregivers to be paid in Medicaid programs
- Allow family caregivers to administer medications and provide skilled services
- Allow nurse delegation
- Paid training
- Provide care coordination and transition supports

## Statutes Supporting Caregivers

- CARE Act & Family Care Act
- Paid Family Medical Leave Act
- Long-Term Care Trust Act



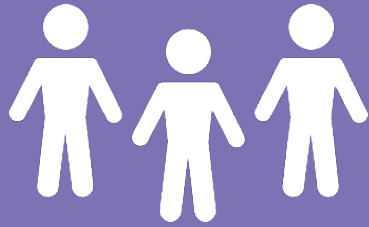
# Paid Family Caregivers Supporting Client Autonomy

- Family members have been providing paid personal care in Washington since 1981
- Required and optional trainings and certification are offered in 11 languages
- Paid family members are entitled to the same pay and benefits as other workers





# Unpaid Caregivers Shoulder the Burden



There are over 850,000 unpaid caregivers in Washington State.



The work of these unpaid caregivers is valued at \$10.6 billion per year.

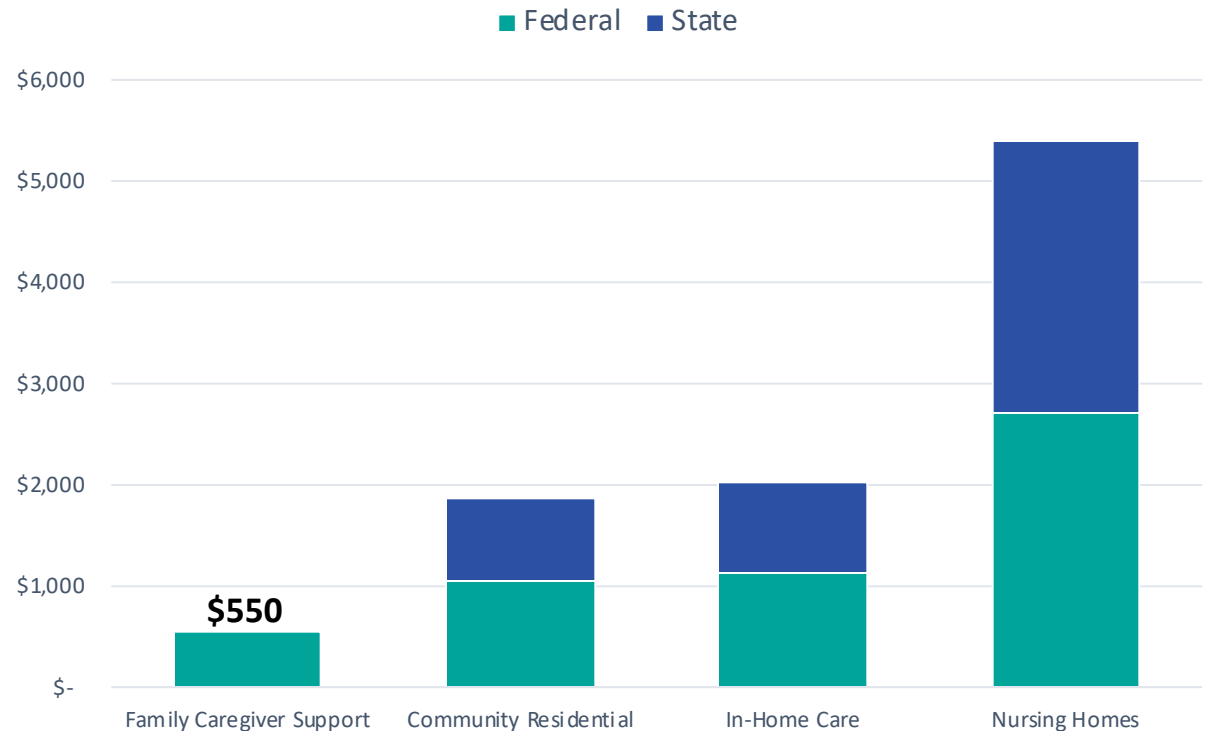


If 1/5 stopped providing care, it would double the cost of LTSS.

# Family Caregiver Support Services

Family caregiver support services are a low-cost option compared to traditional Medicaid long-term services and supports.

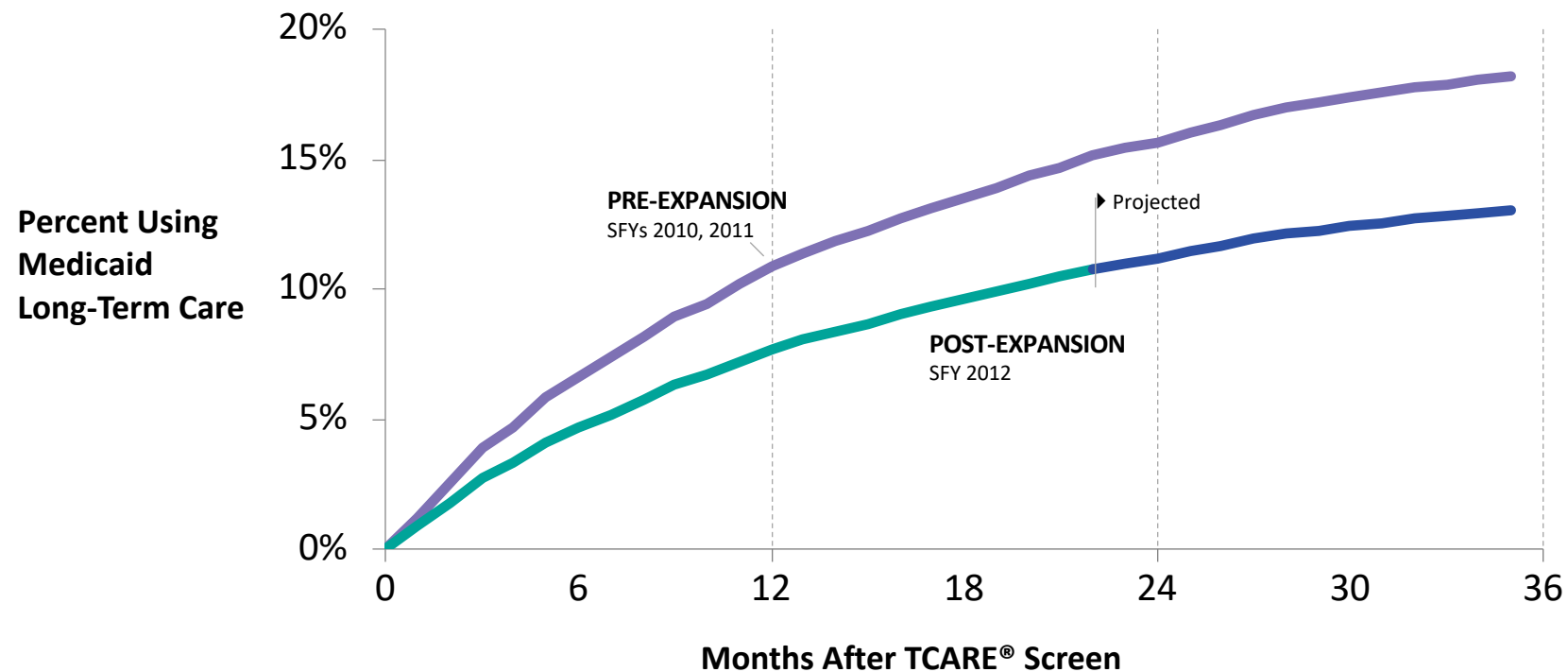
Monthly Per Capita Costs – Medicaid LTSS  
Projected SFY 2018



# Family Caregiver Support Outcomes

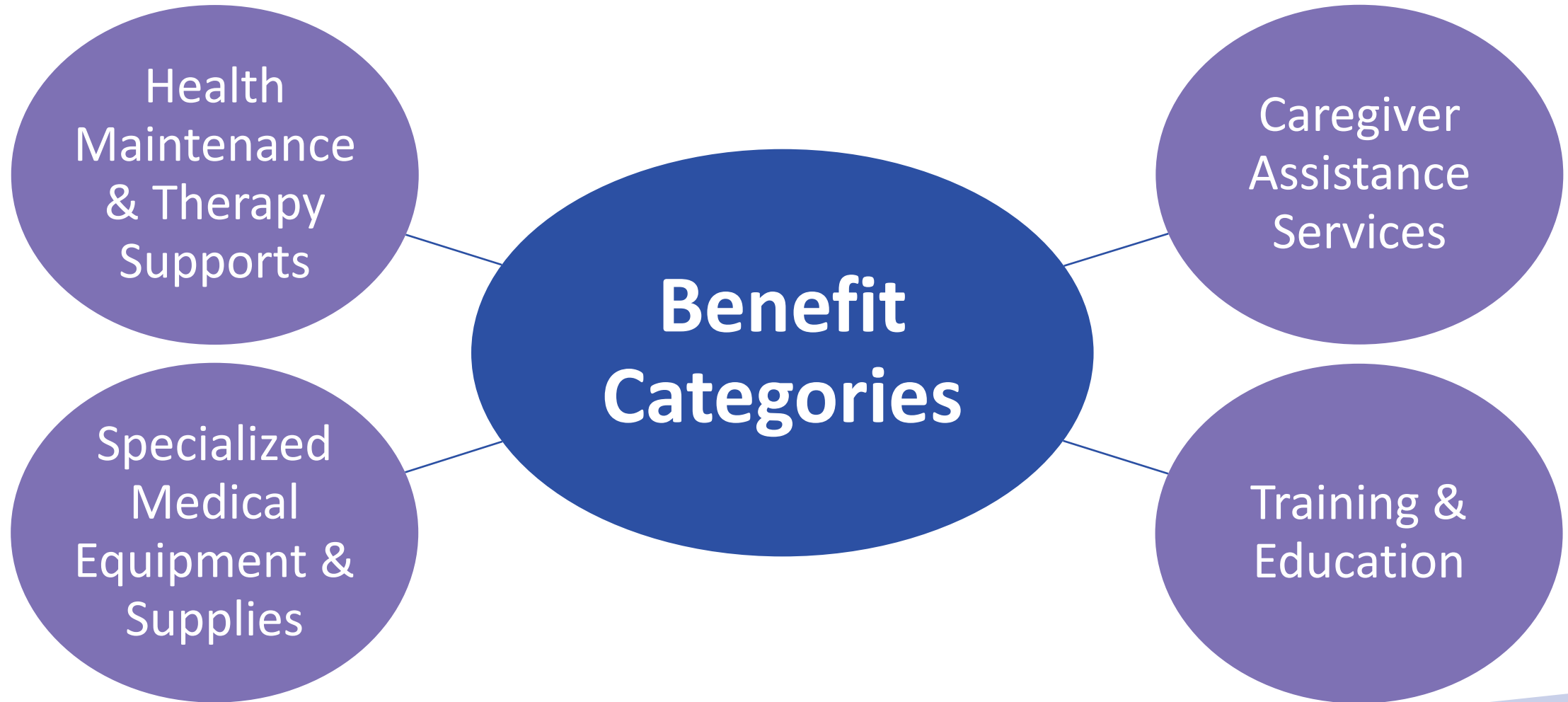
## Time from TCARE® Screen until First Use of Medicaid Long-Term Care

Pre- and Post-Expansion, Controlling for Baseline Differences

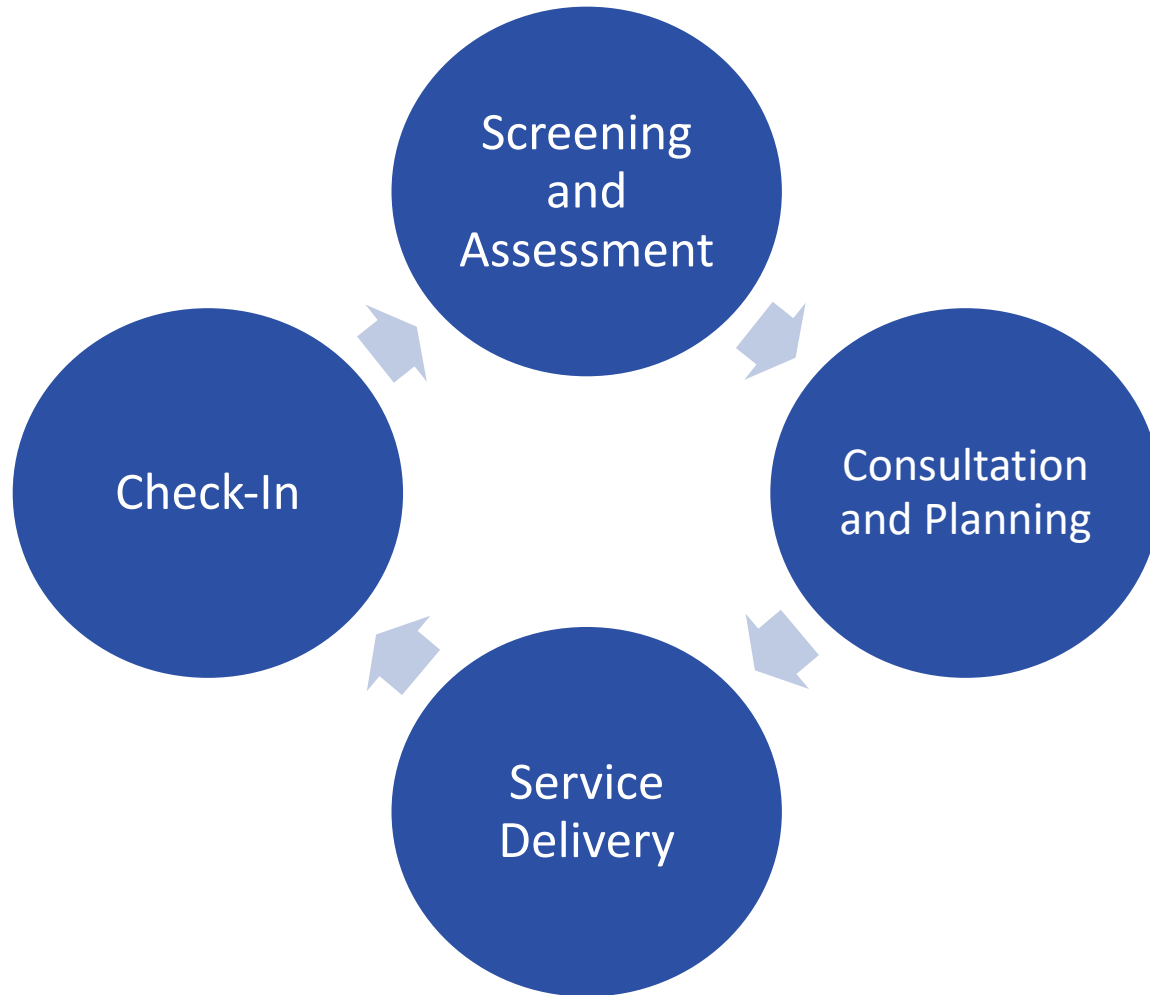


Source: Bridge Lavelle, PhD; David Mancuso, PhD; Alice Huber, PhD, Barbara E.M. Felver, MES, MPA; DSHS Research and Data Analysis, April 2014.

# Medicaid Alternative Care Benefits



# Evidence-Based Assessment



The model for TCARE is to provide the right service at the right time.

# Outcomes for Family Caregivers

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.”

84%

of caregivers show  
a significant  
improvements on  
key outcomes

# Attention to Caregivers Makes a Difference



4 in 5

Caregivers reported that the FCSP helped them understand the importance of taking care of themselves.

“It was so helpful to have someone say ‘you need to take care of yourself and here are services you can use’.”

“I was amazed in the first interview that a lot of the questions were about me and how I was doing...I wasn't expecting that.”

# Assisting Caregiver Also Helps Care Receiver

Tom cares for his wife, Janet who lives with dementia. Tom takes care of meals, does the shopping and cleaning and makes sure Janet takes her medications. For Tom, the housework isn't that tough. It's Janet's behavior – she follows him around when she is anxious, she repeats questions, and is often mean to him.

**MAC provides meal prep, shopping, cleaning and medication reminders. MAC provides memory care and wellness services** for Janet twice a week. Not only does Janet benefit from being around her peer group, but Tom gets respite while Janet is at the center. Janet comes home tired and happy, and the rest of their day together is smooth.



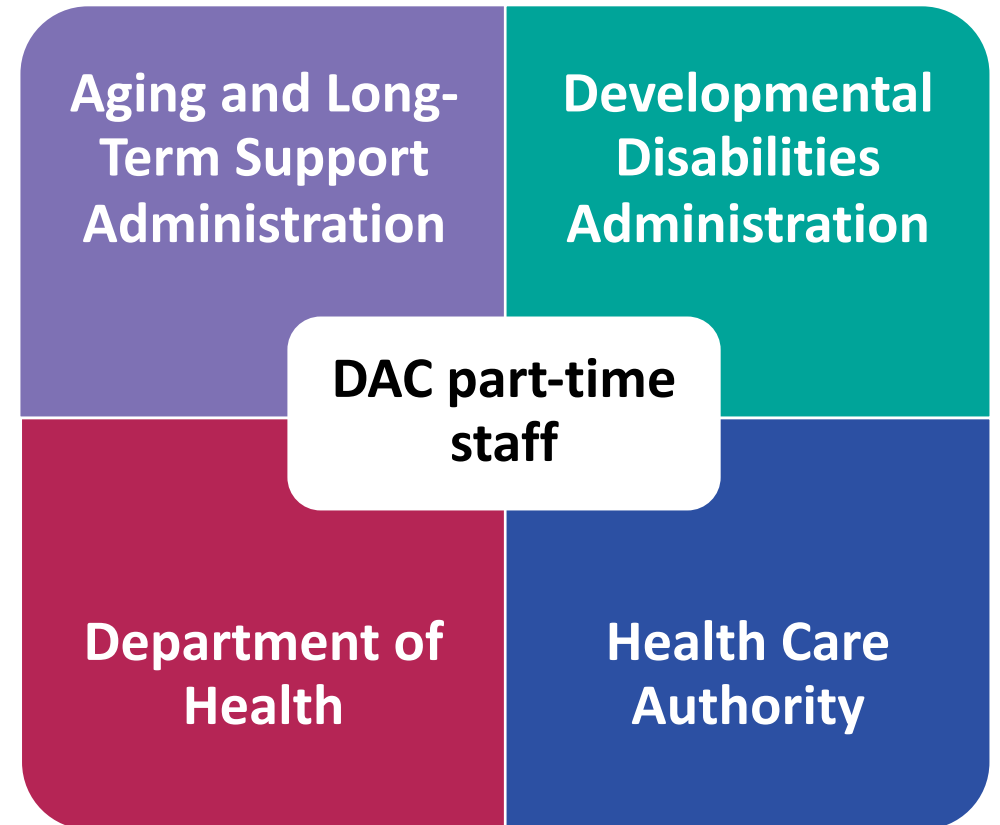


# Dementia Action Collaborative

- Alzheimers Disease Working Group (ADWG) developed Washington State Plan to Address Alzheimer's Disease and Other Dementias
- In 2016, the ADWG established the Dementia Action Collaborative (DAC) to implement the 7 goals and 134 recommendations of the Plan.
- The DAC consists of 60+ organizations and individuals representing many sectors and perspectives.

## Goal #4:

Ensure access to family caregiver supports.

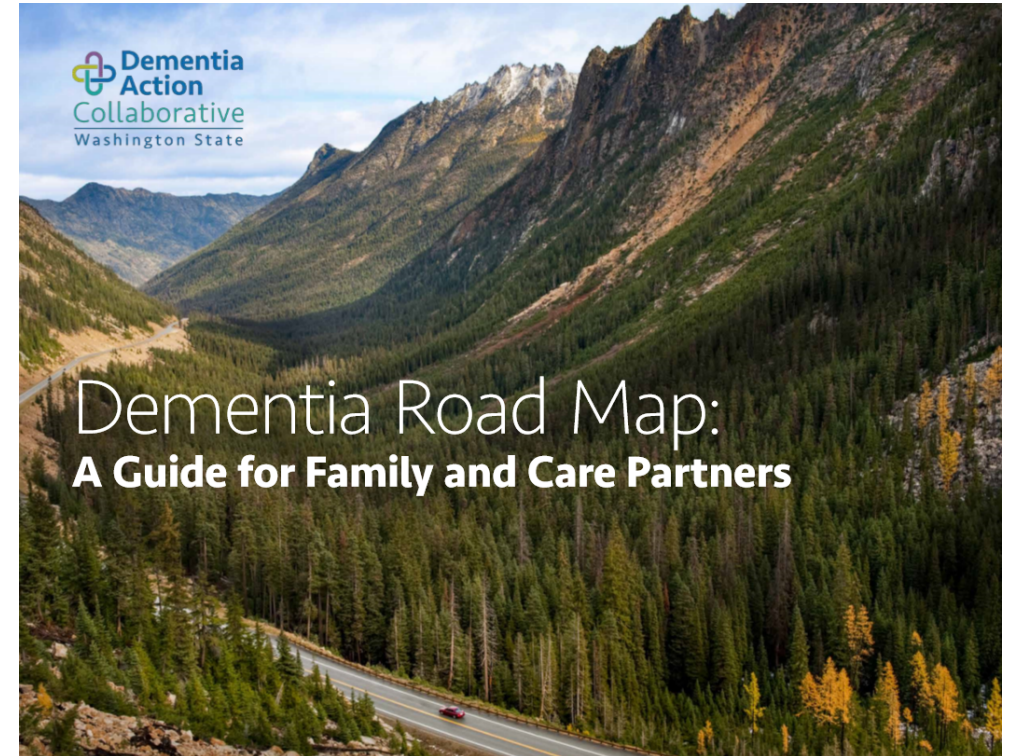


# Dementia Support for Caregivers

## The Dementia Road Map: A Guide for Family and Care Partners

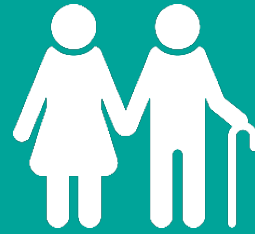
Support through the stages of dementia:

- Wondering and Worried
- Mild Cognitive Impairment
- Early-Stage Dementia
- Mid-Stage Dementia
- Late-Stage Dementia



Link: [Dementia Road Map: A Guide for Family and Care Partners](#)

# Paid Family & Medical Leave



Provides up to 12 weeks of paid leave per year to care for family member with serious health condition.



May care for spouses, partners, grandparents, parents, siblings, children and grandchildren.

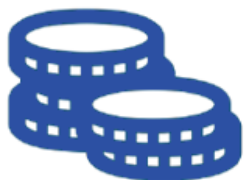


Receive up to 90% of weekly pay, maximum of \$1,000 per week.

# Long-Term Care Trust Act



All W-2 workers  
contribute.



They pay 58 cents per  
\$100 of income.



The trust fund invests  
the money.

- Each person who is eligible to receive the benefit can access services and supports costing up to **\$36,500**.
- The value of this benefit will increase over time.

# Long-Term Care Trust Act

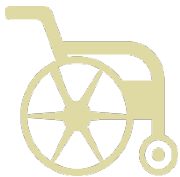
The benefit can be used for a range of services and supports, including:



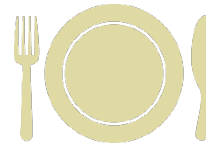
Professional care in your home, a licensed residential facility or a nursing facility



Special training, consultation, pay and other supports for family caregivers



Adaptive equipment and technology like wheelchair ramps and medication reminder devices



Home-delivered meals



Home safety evaluations



Rides to the doctor



# Kinship Caregivers



## Kinship Caregivers Support Program

- Addresses the urgent needs of the children living with low-income grandparents and relatives **without the involvement of the child welfare system.**
- Provides an average of \$300/child to meet sudden necessities.

## Kinship Navigator Program

- Navigators promote awareness of available resources for health, financial, legal, and other support services.
- Funded in 30 of 39 counties and 8 tribes.

# Recommended Actions

Make policies to support paid family caregivers:

- Allow family to be paid as caregivers in Medicaid programs
- Allow family to administer medications and provide skilled services even when paid
- Increase access to nurse delegation programs by paid family caregivers

Expand services and supports to unpaid family caregivers:

- Offer care coordination and transition support
- State or Medicaid funding to support family caregivers
- Evidence-based models



# Recommended Actions



Support statewide legislation and policies:

- Family Medical Leave Act
- CARE Act
- Workplace caregiver-friendly policies
- Surveillance of Family Caregivers (e.g., BRFSS)
- LTSS Trust

Support federal legislation and policies that provide:

- Funding of Aging and Disability Resource Centers (ADRCs)
- Additional funding for Title 3E of the Older Americans Act
- Specific programs that would provide enhanced federal match for caregiver-centric programs
- Ways to support states in implementing and sustaining evidence-based programs for caregivers



# Questions?

**Bea Rector**

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# Medicaid and State Programs Council Discussion

1. How can states better finance long-term services and supports in ways that acknowledge the role of family caregivers?
2. What can states do to support people who are not yet eligible for Medicaid but are at risk?
3. Based on this discussion, what recommendations should the council consider including in the Report to Congress?
4. Based on these suggested recommendations, are there specific actions to consider including in the National Strategy?

# Short Break

# Listening Sessions Feedback

Eileen J. Tell

Principal and CEO

ET Consulting, LLC

Fellow with the LeadingAge LTSS Center @UMass Boston



Pamela Nadash, Ph.D.

Associate Professor

Department of Gerontology

McCormack Graduate School

University of Massachusetts



# Listening Session Feedback: Part I

Presentation to the ACL RAISE Family Caregiver Advisory  
Council Meeting

July 16, 2020



# Presentation Outline

- Listening session research design
- Major take-aways so far
- The solutions that resonate most with family caregivers
- Differences observed by different types of caregiver situations
- Unexpected results
- Planning for future listening sessions

# Design of Initial Four Groups

	Caregiver Situation	Education and/or Income
Group 1, May 28	Parents caring for children with special needs	Higher levels
Group 2, June 1	Parents caring for children with special needs	Lower levels
Group 3, June 2	Any other type of family caregiver situation	Higher levels
Group 4, June 3	Any other type of family caregiver situation	Lower levels



# Discussion Guide

- Priority Concerns – Used items from the RFI closed-category list
  - Asked participants to vote on and discuss priorities
- Discussed two domains of the solutions that resonated most:
  - Caregiver Services and Supports
  - Financial and Workplace Solutions



# Which of the following is THE SINGLE MOST IMPORTANT for improving the lives of family caregivers such as yourselves?



Caregiver training



Care coordination/care transitions



Day services & programs



Direct pay to family caregivers



Information, education, referral



Respite care



Technology in the home to assist families

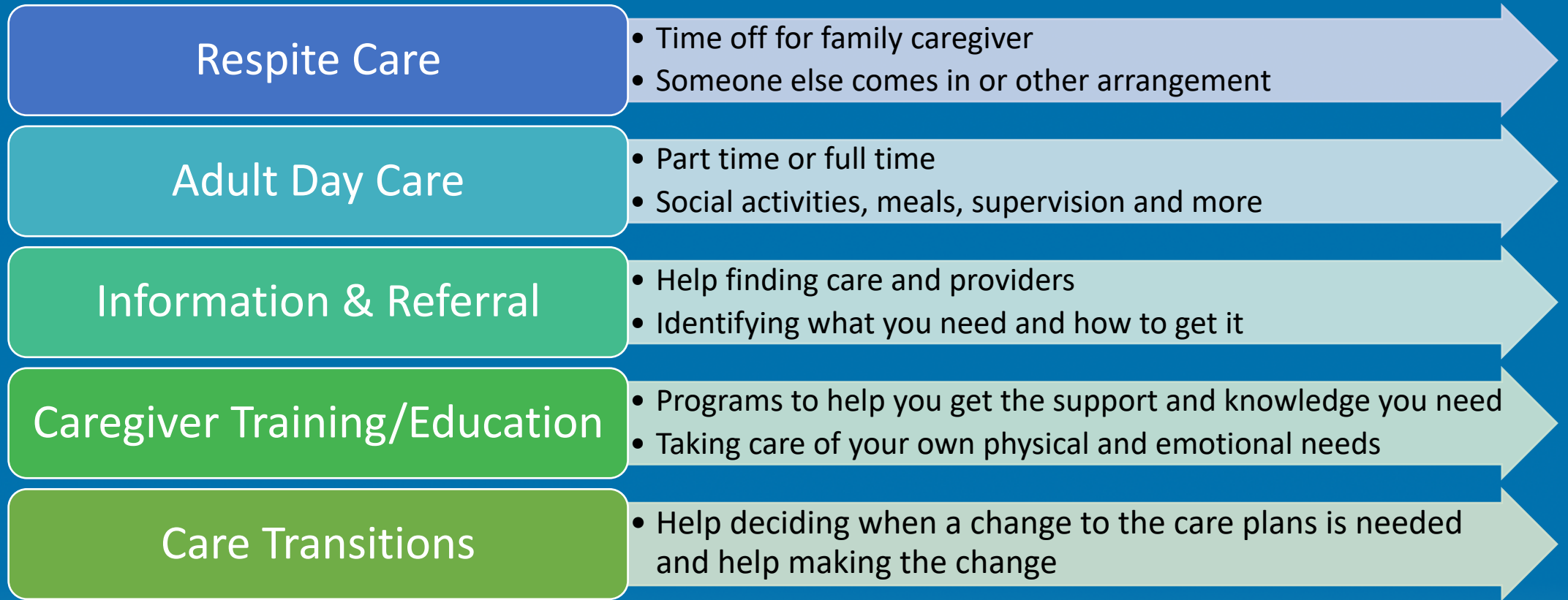


Tax Incentives – credits/deductions for family caregivers



Workplace Protections

# Caregiver Services And Supports



# Financial & Workplace Help

## Workplace Protections

- Family Medical Leave: more of it; more of it paid; more flexibility. Better workplace policies (flextime, part-time, etc.)

## Tax Incentives

- Deductions, credits,
- Family caregiver as a “self-employed” business expense

## Retirement Support

- Count caregiving hours toward Social Security

## Direct Pay Support

- Pay at-home caregivers
- Pay caregivers who stay in the workforce so they can hire help

## Technology

- Pay for/discounts on telehealth, assistive devices, in-home sensors, home modification

# Participant Characteristics

- Ages 28 to 71
- Demographically diverse
  - Age, gender, race/ethnicity, education, income
- Varied life situations
  - Marital status, employment status
- Varied caregiver situations
  - Parents caring for children with a wide range of conditions
  - Individuals caring for parents, grandparents, others



# Priority Concerns

- Caregiver training and education
- Respite care
- Workplace accommodations
- Direct pay for caregiving
- Tax incentives
- Information and referral
- Care coordination

# Caregiver Training

Worry about being inadequately trained for the medical aspects of caregiving, everyday support, and managing anxiety and stress

*“My son is autistic...I didn’t even know what it meant when he was diagnosed...if someone could have explained to me how I would have been able to help him in the beginning.”*

*“Nobody ever taught me how to do the medical portion of taking care of my son...It can be scary. I wish someone like a nurse...could have spent more time teaching me how to use his medical equipment.”*

*“I need training on how to emotionally deal with my work...some skills to psychologically work with her.”*

# Caregiver Training

## Ideas about how to get that training

*“...maybe a class once or twice a week...a ‘one stop shop’ place you could go.”*

*“somebody..could come into the house and show us what we should be doing.”*

*“online training where we could watch videos.”*

# Information and Referral

- Participants wanted more transparency and confidence in I&R services
- Potential referral agency conflict of interest:
  - Are they referring out of convenience or self-interest?
- Wanted assurance that referrals are person-centered

*“I don’t really have full confidence with the resources that are offered -- that is not really much alternative to pick from.”*

*“A lot of the referrals you get are to their own affiliated places. You really want someone who’s unbiased caring about the person.”*



# Respite Care

- Participants strongly desired respite, but:
  - Expressed concern about the quality of services and the safety of the care recipient
- Reported guilt and worry
- Reported challenges in finding adequate respite care
- Worried about care recipients' resistance to help from outsiders
- Cost also a major concern

# Respite Care

*“For me, it’s truly just the break from everything....resources that could come in to take some of the burden off.*

*“Right now I need a break. ...Someone to come in where the government would basically offset the cost...that would be a big plus.”*

*“We don’t have family here...I’m 99.9% of the time taking care of his needs...so it’s not really possible to ask for too much help. So it’d be nice to have respite once in a while.”*

*“I love the concept of respite care but ....I get afraid of the notion just because we don’t really know what’s happening when we’re not there.”*

# Care Coordination

Care coordination was a concern -- especially as care needs change and for families who move often

*“The programs are out there, but you have to know how to get them.”*

*“ One of the biggest obstacles I had was probably the care coordination and care transitions. You tend to be in a round robin situation where you’re calling and leaving a message...they call you, you miss their call...and then you don’t hear back from them.”*

*“Instead of trying to do this all by myself, there are probably awesome programs that I have no clue exist but I don’t have time to research them.”*

*“There were times we weren’t sure where or who to communicate with to try to get some assistance with some of the things he needed.”*

# The Financial Impact of Caregiving

Participants highlighted the importance of workplace accommodations, tax incentives, and direct pay for caregiving work

*“Something needs to happen to recognize that, as a full-time caregiver to my son, I am working...in fact...harder than I’ve ever worked in my life.”*

*“Financial is one of our..biggest issues with all of this.”*

*“The financial responsibility that comes with having a child with needs for us has been very large.”*

*“I’m not making enough to sustain taking care of two people, especially... having to pay for outside help because I have to work so much just to make as much money as I can to take care of both of us.”*



# Workplace Accommodations

- FMLA and PTO are not enough
- Without help, caregivers have difficulty maintaining a full-time job

*“Even something similar to what they just put out for COVID [would help.] Being in a job that doesn’t count having a kid sick as PTO or sick leave; it has to be taken as vacation days.”*

*“They don’t give FMLA for a grandmother...You won’t get any pay unless you have vacation time or PTO.”*

*“Being in a job that doesn’t count having a sick kid as personal time off or as sick leave...it has to be taken as vacation days.”*

# Direct Pay for Caregiving

- Significant interest in direct pay to caregivers
- Also financial help with home modifications, medical expenses, medication, etc
- Feelings about direct pay associated with the financial burdens and career impacts of caregiving

*“Something needs to happen to recognize that as a full time caregiver to my son, I am working... harder than I’ve ever worked in my life. What financial compensation can be matched to that, I don’t know.*”

*“In California...there’s a program called IHSS...and you actually fill out a timecard and you are compensated. I think it’s a good thing.”*

*“I think direct pay support probably would be most helpful for me.”*

# Tax Incentives and Social Security Credit

- Strong support for
  - Tax credits and/or ability to deduct caregiver expenses
  - Ability to count any care recipient as dependent for tax purposes
- Support for getting extra credit toward Social Security for caregiving hours

*“If your family member has a diagnosis and you’re taking care of them, definitely, it would be great to have a tax incentive.”*

*“It would be nice if I could actually put her on my taxes...and be able to take off all of her medical bills and the drugs and paying for somebody to ...come in and watch her.”*

*“...it would be a good idea to count the caregiving hours because I’m out of work 15 years now...if those hours would’ve counted [toward Social Security], I’d probably be fully vested and would be able to get all that I have coming to me.”*

# Differences Between Caregiver Groups

- Parents caring for children with disabilities
  - Caregiving training needs were more pressing and crossed a broader spectrum of medical, behavioral, and other needs
  - Higher priority on direct pay for caregiving and workplace accommodations
  - Need for respite care but greater reluctance to use it
- Other family caregivers
  - More open to using respite care
  - Tax incentives and Social Security credits were of interest



# Unexpected Results

- Extent of agreement on interest in pay for direct care and other types of financial solutions
- Desire for respite care but concerns about using it (financial, emotional and logistical)
- Lack of awareness and understanding of services generally
  - Understanding of hospice care was particularly poor
  - Little awareness and use of day care programs
  - Frequent mentions of inability to identify and access relevant services
- Sense of isolation experienced by family caregivers

# Plans for Additional Listening Sessions

- Four (4) additional groups with family caregivers of adults
- Two (2) additional groups of parents caring for children
- One (1) Spanish-speaking group (in collaboration with Baker Ripley)
- Two (2) larger virtual Listening Sessions with stakeholders:
  - Provider/Service Organization
  - Advocacy organizations
- Two (2) special-focus population groups:
  - Teen caregivers (in collaboration with American Association of Caregiving Youth)
  - Grandparents caring for Grandchildren (in collaboration with Generations United)

We welcome your comments, questions and discussion!



COMMUNITY CATALYST

Because we all should have a say  
in decisions that affect **our health**



LeadingAge  
**LTSS CENTER**  
**@UMass Boston**

*Research bridging policy and practice*

# Listening Sessions (Feedback) With Council Discussion

1. What have been the big take-aways from the listening sessions so far?
2. What types of family caregiver solutions seem to resonate most with family caregivers; and does it differ by the different types of caregivers and their situations?
4. Any surprises?
5. What other types of participants should be in future focus groups?

# Initial Report to Congress

Sarah Markel, PMP  
Aging Services Program Specialist, AoA  
Administration for Community Living



# Initial Report to Congress Council Discussion

1. Given that the report to Congress follows the requirements of the RAISE Act and Council feedback, are there any changes that should be made to the outline?
2. Are there missing elements we need to consider adding?

# Wrap Up & Next Steps

Greg Link, Director  
Officer of Supportive and Caregiver Services  
Administration for Community Living





Thank You