

RAISE Up Actions to Support Family Caregivers

August 30, 2023

2023 HCBS Conference



The
John A. Hartford
Foundation



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Agenda

- **Introduction:** Salom Teshale, Senior Policy Associate, Aging and Disability, The National Academy for State Health Policy
- **Washington State:** Bea Rector, Assistant Secretary, Aging and Long-Term Support Administration, Washington State Department of Social and Health Services
- **North Dakota:** Nancy Nikolas-Maier, Director, Adult and Aging Services Section, North Dakota Department of Human Services
- **Philanthropic Perspective:** Scott Bane, Program Officer, The John A. Hartford Foundation
- **Q&A**
- **Wrap-Up**

RAISE Up Actions to Support Family Caregivers: Introduction

*Salom Teshale (steshale@nashp.org)
Senior Policy Associate, Aging and Disability
August 30, 2023*



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About NASHP

The National Academy for State Health Policy (NASHP) is a nonpartisan organization committed to developing and advancing state health policy innovations and solutions.

NASHP provides a unique forum for the productive exchange of strategies across state government, including the executive and legislative branches.

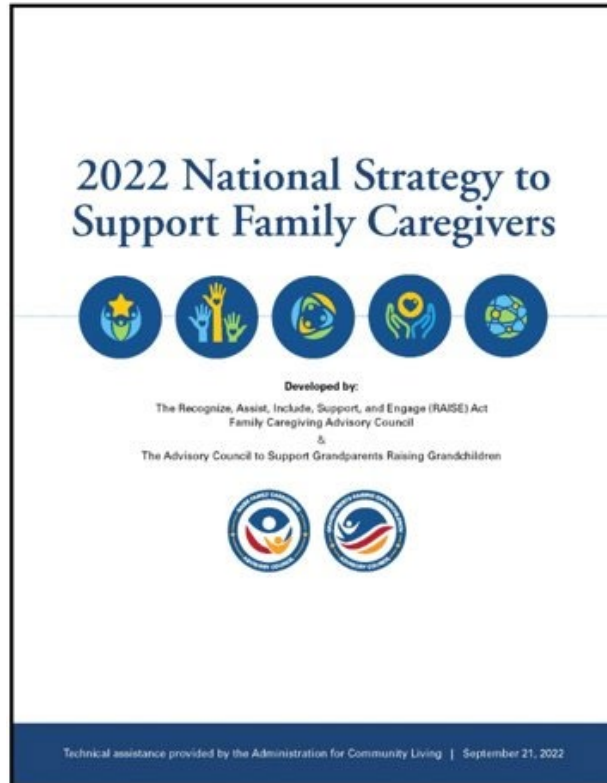


The Recognize, Assist, Include, Support & Engage (RAISE) Family Caregivers Act – An Overview

- Became law: Jan 22, 2018
- Three core elements
 - Family Caregiving Advisory Council
 - Initial Report to Congress
 - National Strategy to Support Family Caregivers

2022 National Strategy to Support Family Caregivers

acl.gov/CaregiverStrategy



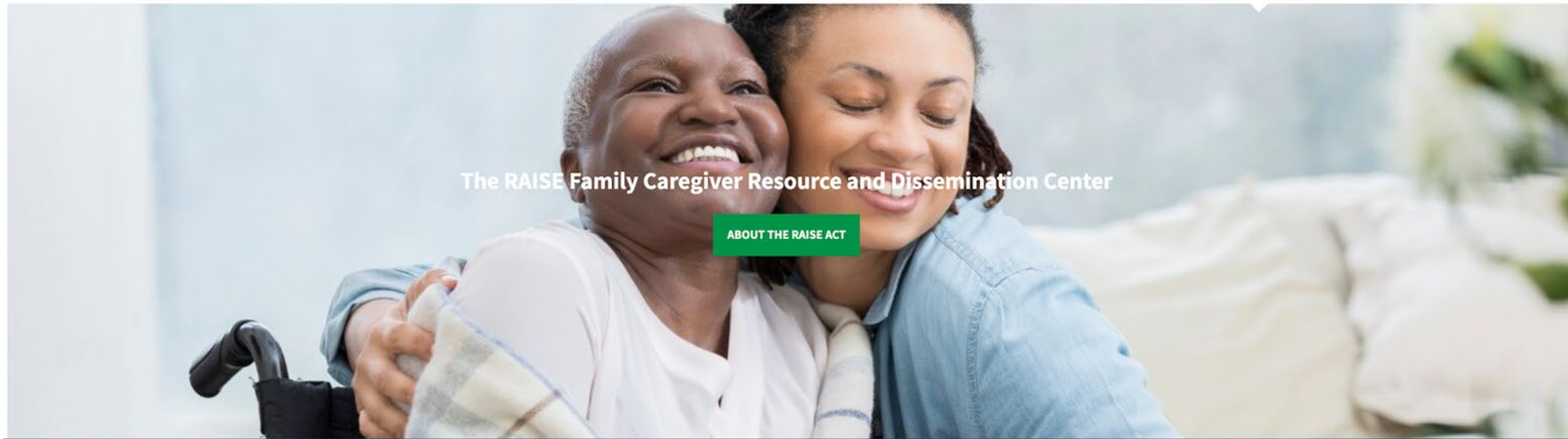
- Includes ~350 federal actions and 150+ state, community, and other partner actions
- Strategy Framework:
 - Goal 1: Increase awareness of and outreach to family caregivers
 - Goal 2: Advance partnership and engagement with family caregivers
 - Goal 3: Strengthen family caregiver services and supports
 - Goal 4: Ensure family caregiver financial and workplace security
 - Goal 5: Expand data, research, and evidence-based practices to support family caregivers

RAISE Family Caregiver Resource and Dissemination Center

<https://www.nashp.org/the-raise-family-caregiver-resource-and-dissemination-center/>



HOME ABOUT US PUBLICATIONS **POLICY** EVENTS CAREERS CONTACT 



The RAISE Family Caregiver Resource and Dissemination Center

[ABOUT THE RAISE ACT](#)

THE FAMILY CAREGIVING ADVISORY
COUNCIL AND FACULTY

COUNCIL MEETING MATERIALS AND
RESOURCES

STATE RESOURCES

RESPITE CARE



[nashp.org](https://www.nashp.org)

RAISE Act State Policy Roadmap

- State strategies and promising practices
- <https://www.nashp.org/roadmap-for-family-caregivers/>



Public Awareness and Outreach



The Direct Care Workforce



Financial and Workplace Security



Family Caregiver Services and Supports



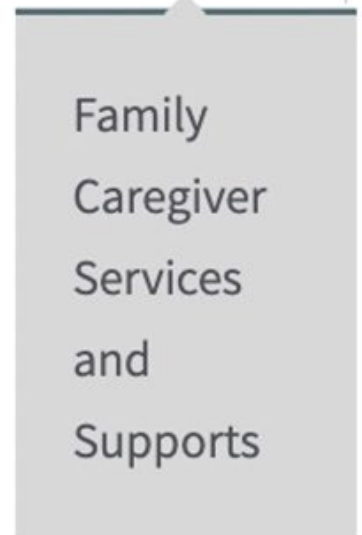
Using Research, Data, and Evidence-Informed Practices to Support Family Caregivers



Engagement of Family Caregivers in Health Care Systems

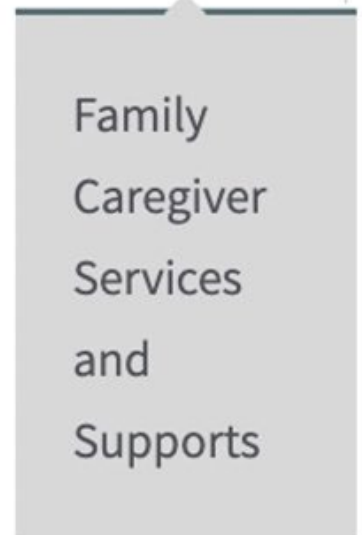
Family Caregiver Services and Supports

- To help caregivers receive services that enable them to provide care in their homes, states can address funding by:
 - Blending and braiding federal and state funding for services like respite care
 - Leveraging new Medicaid funding and flexibilities
 - Rebalancing toward more home and community-based services
 - Paying family caregivers through Medicaid self-direction options



Family Caregiver Services and Supports

- State examples:
 - Connecticut: plans to incorporate caregiver assessment, training, respite, care coordination, and the Care of Persons with Dementia in their Environments (COPE) evidence-based support model into permanent initiatives for caregivers of those with Alzheimer's and related dementias
 - Georgia: Structured Family Caregiving through its 1915(c) Elderly and Disabled Waiver, with caregiver supports for unpaid caregivers living with the Medicaid beneficiary



Using Research, Data, and Evidence-Informed Practices

- To support data, research, and evidence-informed practices for family caregivers, states can:
 - Use broader definitions of family caregiver that go beyond blood relatives
 - Collect family caregiver data and outcomes
 - Compile state inventories of family caregiver services
 - Develop state evaluations of family caregiver programs
 - Implement evidence-supported programs for family caregivers



Using Research, Data, and Evidence-Informed Practices

- State Examples:
 - California: evaluation of caregiver services including data from Caregiver Resource Centers, funded primarily by California's Department for Health Care Services. The evaluation included comparison data on a national (Caregiving in the U.S. Survey) and a state level (California Health Interview Survey); CRC-reported outreach and education data; and qualitative data
 - Massachusetts: access to evidence-based programs, including the Savvy Caregiver (English and Spanish) and Powerful Tools for Caregivers through the Home Care Program, the Family Caregiver Support Program, and the Medicaid 1915(c) Frail Elder waiver



Next Steps

- Learn more about the National Strategy at acl.gov/CaregiverStrategy
- New RAISE Advisory Council convened July 2023; will focus on an update and implementation
- Full Council meetings are livestreamed and open to the public at acl.gov/raise
- The plan: update the National Strategy every two years

Thank you!

- steshale@nashp.org

Transforming
Lives

RAISE Up Actions to Support Family Caregivers

HCBS Conference 2023

Co Presenter:

Bea Rector, *Assistant Secretary*
Aging and Long-Term Support Administration



RAISE Act National Strategies for State/Local Entities

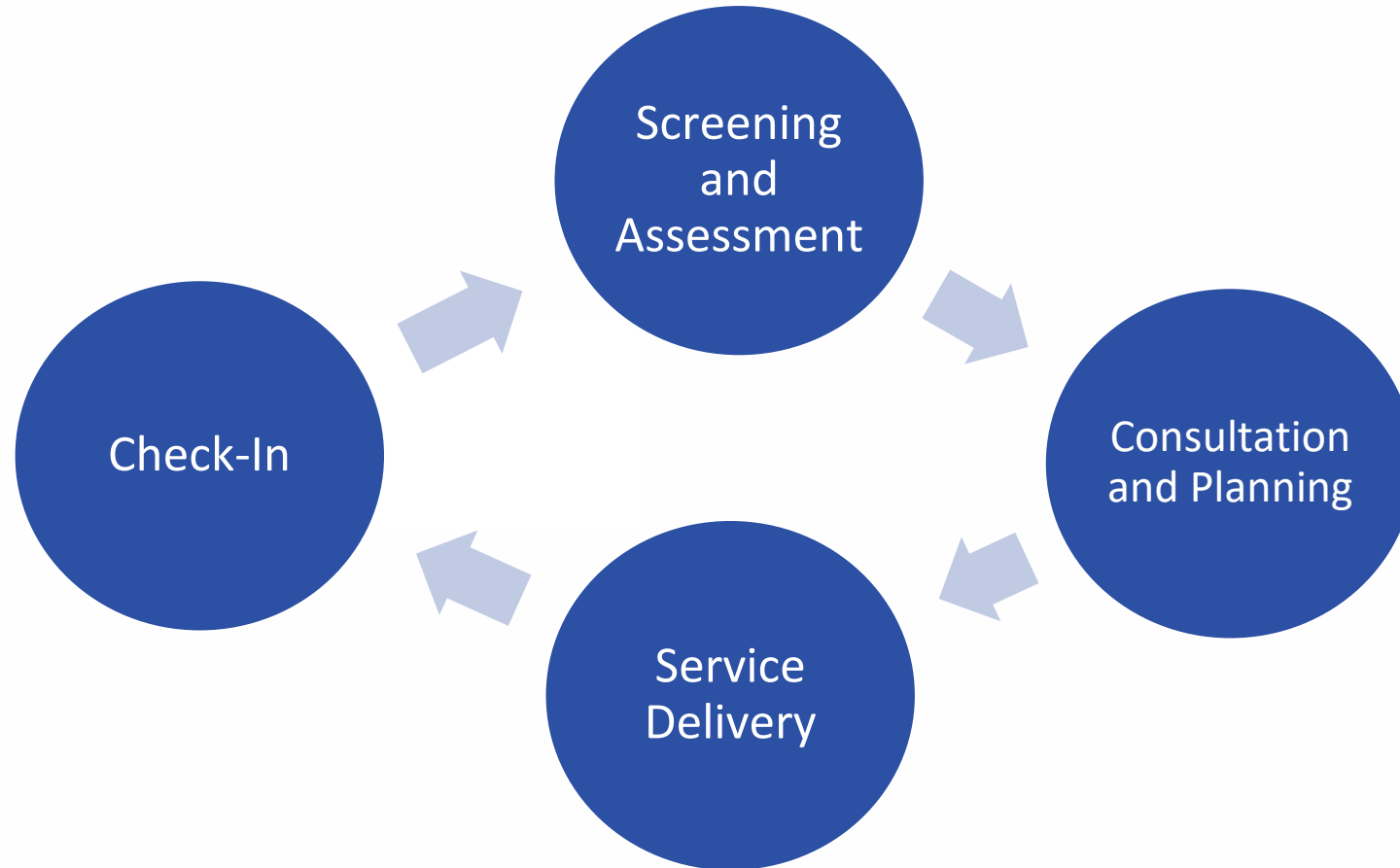
- The National Strategy suggests additional focus areas to work on next. Every state can find new opportunities. WA plans to:
 - Develop Employer Toolkit for supporting employed family caregivers
 - Explore remote support development in the family caregiver space
 - Continue to address workforce shortages for respite providers
 - Focus on EDAI across initiatives



In the U.S. today, **one in six employees** is a caregiver for a relative or friend¹, and spends on average **more than 20 hours a week**² providing some kind of care.

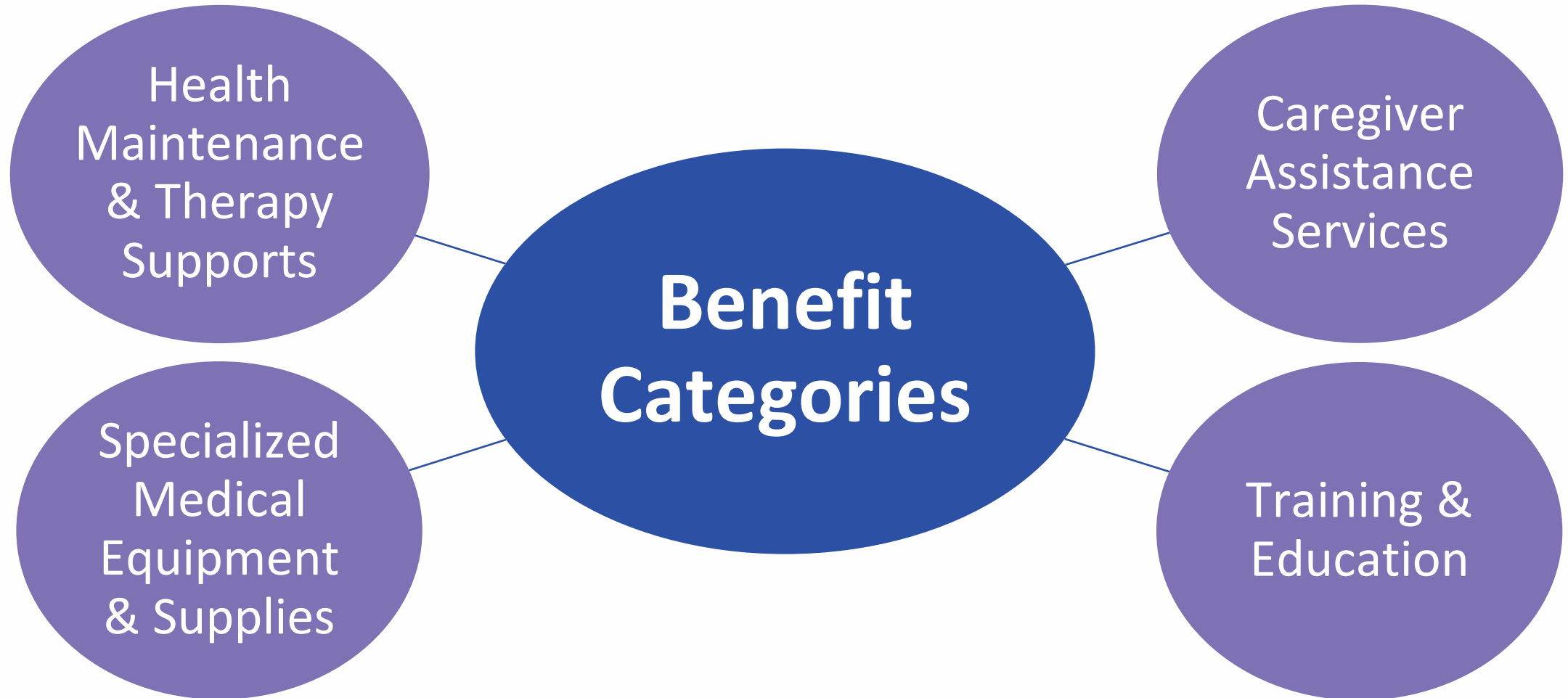
Caregiver Evidence-Based Assessment: T-CARE

Tailored Caregiver Assessment and Referral



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

1115 Medicaid Alternative Care Benefits



Dementia Support for Caregivers

Resources and Information for Caregivers

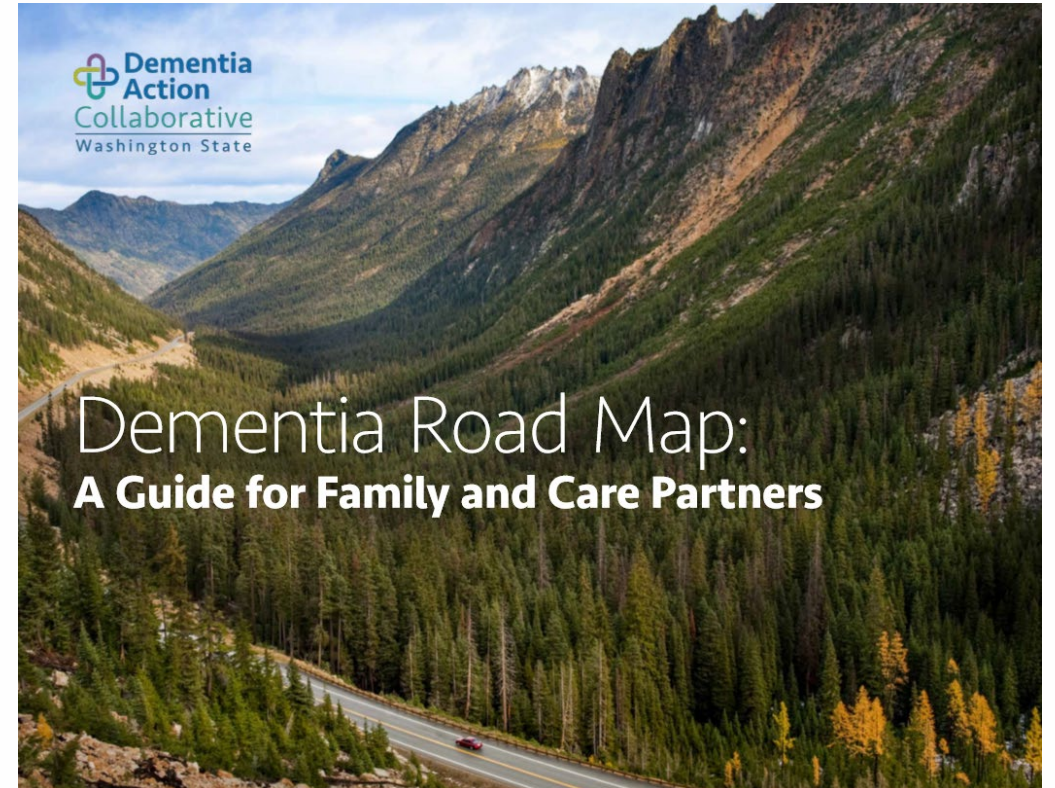
Publication

Dementia Roadmap:

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](#)

TRUALTA - Caregiver Support Platform in Washington



SKILL-BASED TRAINING

Offering family members access to training that builds the skills required to provide care at home.



CLINICALLY VALIDATED

Co-designed with families and backed by an evidence base from ongoing clinical validation in a range of care settings.



PERSONALIZED LEARNING JOURNEY

Deliver families content that is tailored to their care situation and learning style.



TRACK ENGAGEMENT

Understand how families engage with the resources provided to them.

Paid Family and 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.

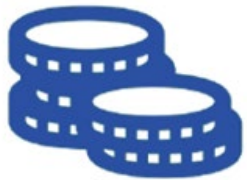


Receive up to 90% of weekly pay, maximum of \$1,000 per week.

Long-Term Care Trust Act



All W-2 workers contribute.



They pay 58 cents per \$100 of W-2 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.

Transforming
Lives

Questions?

Bea Rector

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RAISE Actions to Support Family Caregivers

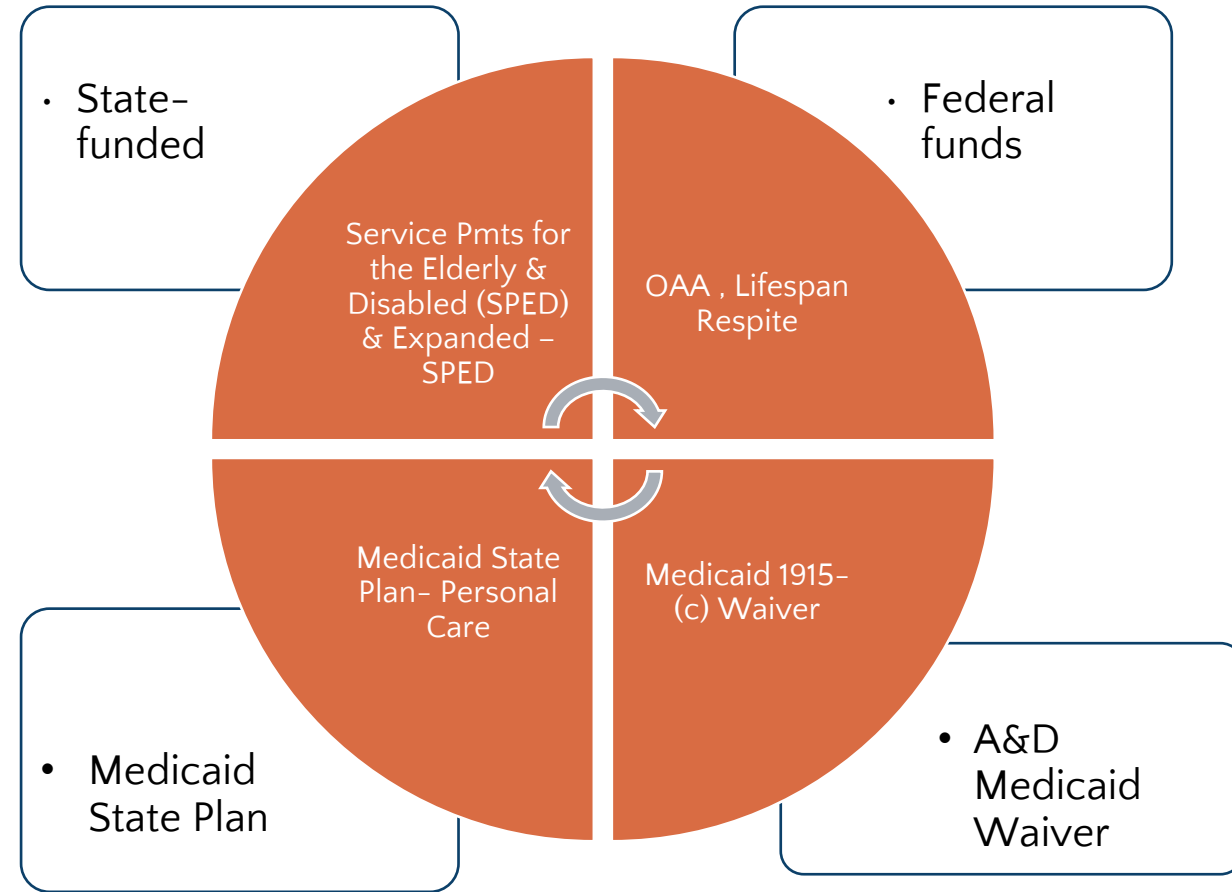
Nancy Nikolas Maier, Director, North Dakota Department of Health and Human Services Adult and Aging Services Section



Health & Human Services

North Dakota Adult & Aging Services Home and Community Based Services

- State Unit on Aging - Older Americans Act (OAA)
- Medicaid fee for service model
- Primarily serve older adults and adults with physical disabilities
- Mix federal and state funds
- Recipients must be both functionally and financially eligible
- May have client cost share based on income
- Currently implementing many system change projects to make it possible for more adults with a physical disability to live in the most integrated setting that meets their needs



RAISE Supporting Family Caregivers – Activities in North Dakota



Public Awareness and Outreach

- Public Service Announcements (PSA) and HCBS public awareness campaign
- Long Term Services and Supports Options Counseling (LTSS-OC)
- Aging and Disability Resource Link (ADRL) – centralized intake



Services and Support for Family Caregivers

- Dementia Care Services –family caregivers
- Flexible respite options



Direct Care Workforce

- Leveraging family as part of the workforce
- Qualified service provider resource hub (QSP Hub)



Financial and Workplace Security

- Futures planning
- Partnerships with Social Security in ND, and human resource professionals

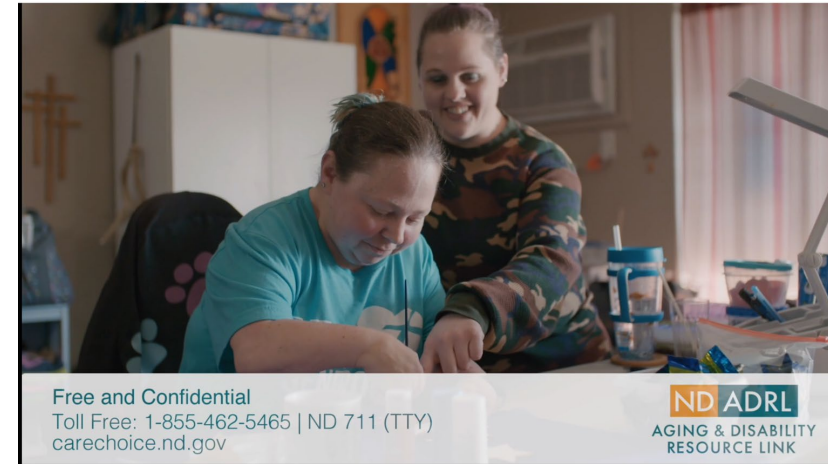
Public Awareness and Outreach



<https://vimeo.com/manage/videos/786379876>

Public service announcements

- Video defines respite and discusses the importance of caregivers taking a short break
- Partnered with ND Broadcasters Association to air on TV and radio for three (3) months
- Aired 11,401 times
- Estimated cost \$186,161
- State cost was \$15,000 for 3-months
- Funded Lifespan Respite Grant



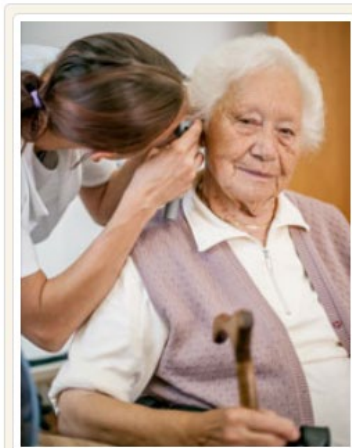
Sustainable social media campaign

- Videos highlight individuals in need of services and their caregivers
- Digital campaign view-through rate was 74% versus typical 15%
- Saw a significant increase in call volume to the Aging and Disability Resource Link (ADRL)
- Plan to run the campaign eight (8) times per year
- Funded with state general fund allocated for the ADRL

Public Awareness and Outreach

Website

- [Native Elder Caregiver Curriculum – National Resource Center on Native American Aging \(nrcnaa.org\)](http://nrcnaa.org)



Native Elder Family Caregiver Module

This module is an interactive version of the NECC that was developed and specifically designed for family members providing care for an older adult.

Public Service Announcements

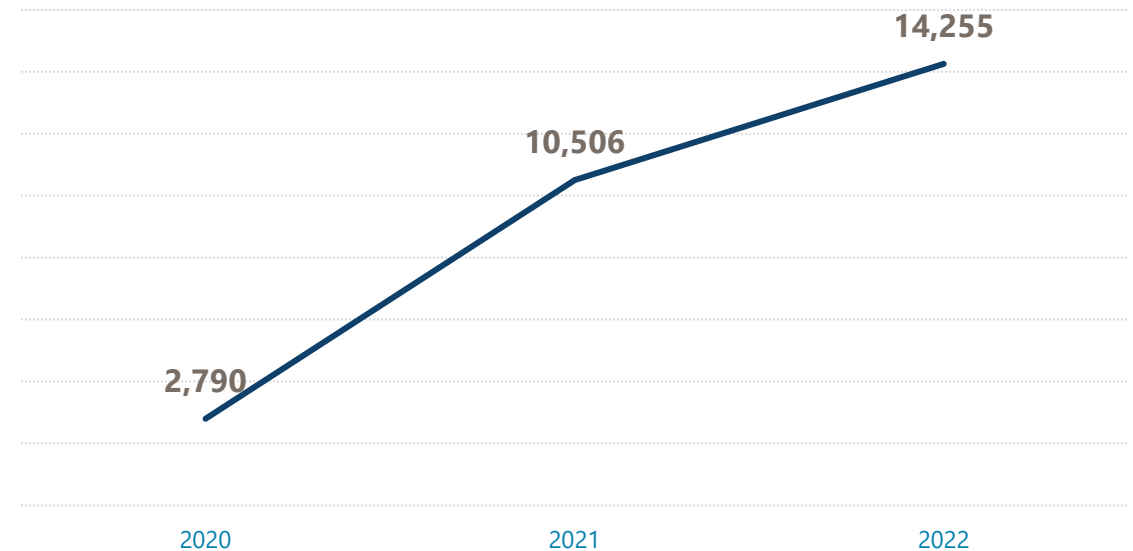
- All tribal radio stations willing and excited to air the PSAs for no cost
- “Voice” from the Tribal Nations in ND
- Turtle Mountain Band of Chippewa Indians



Aging and Disability Resource Link (ADRL) – Centralized Intake

- Process to receive referrals and provide information
- Based on the “no wrong door” approach
- Network built to support individuals needing long-term care services by simplifying and streamlining access to information and services
- 6 FTE dedicated to centralized intake
- Fully implemented January 2021

ADRL Call Volume

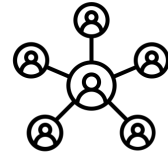


7 in 10

Americans 65+ will need LTC services for an average of 3 years

Outcomes – Public Awareness and Outreach

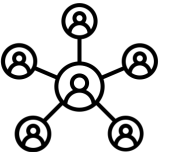
Increase in ADRL Inquiries



Year	Phone Calls	Unique Website Hits	Web Referrals
2020	2,318	8,154	N/A
2021	11,207	23,280	576
2022	14,255	29,220	1,198
2023*	7,308	14,623	724

*As of 6.30.23

- There was a 27% increase in calls made to the ADRL in 2022 and a 26% increase in unique website hits
- Claim Medicaid administrative expenditures for staff salary
 - Claiming amount based on the number of Medicaid-related contacts – currently 60%



Outcomes – Public Awareness and Outreach

Increase in HCBS referrals coming to the ADRL

Year	HCBS Referral	Average Referrals Per Month	% Referral to Open Case
2021	1,893	158	48%
2022	1,854	155	55%
2023*	774	78	60%

*As of 6.30.23



Long-Term Services and Supports Options Counseling (LTSS OC)

The department provides information on the options that may be available for long term services and supports in an integrated setting.



Daily Referrals

- In June 2022 started seeing all individuals over age 21, who were referred for a long-term stay in a nursing facility
- State receives a daily report with the name and location of individuals found eligible for care in the nursing home
 - 10 LTSS OC staff check the list daily and make face-to-face visits within 14 days of referral
 - 1,170 visits completed in 2022
 - 437 in 2023



Skilled Nursing Facility Presentations

- Started in 2020 and are done annually
- Invite all residents, family, and facility staff
- Provides follow-up contact opportunities for residents
 - 443 individuals (residents, family, staff) attended in-person presentations in 2021
 - 952 individuals (residents, family, staff) attended in-person presentations in 2022



Annual Person-Centered Care Planning with SNF Medicaid Eligible Residents

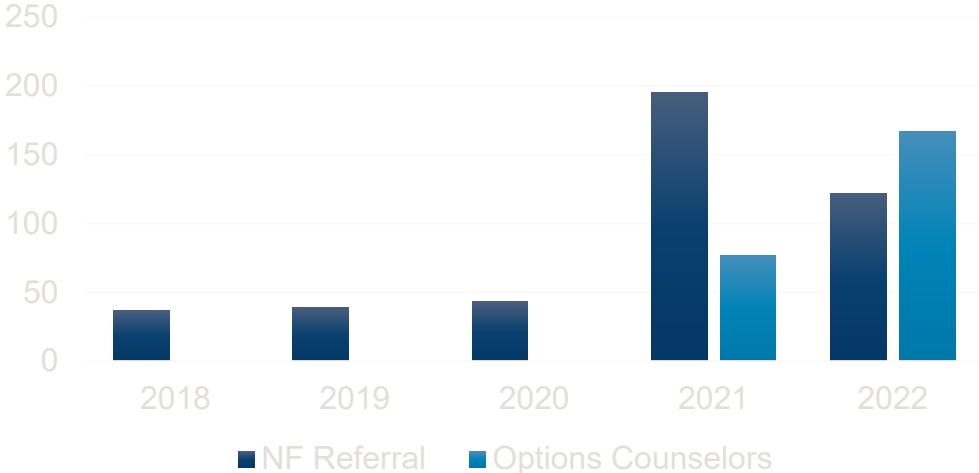
- Started June 14, 2022
- Complete a Person-Centered Plan of Care and Risk Assessment & Health and Safety Plan
- Focuses on Medicaid members who have lived in the facility long-term
- Annual nursing facility level of care functional eligibility determination for Medicaid members

Outcomes – Increase in referrals to Money Follows the Person (MFP)

Increase in MFP referrals coming directly from the nursing facility staff

Year	NF Referral	Options Counselors	Total Referrals
2018	37	N/A	37
2019	39	N/A	39
2020	43	0	43
2021	195	77	272
2022	122	167	289

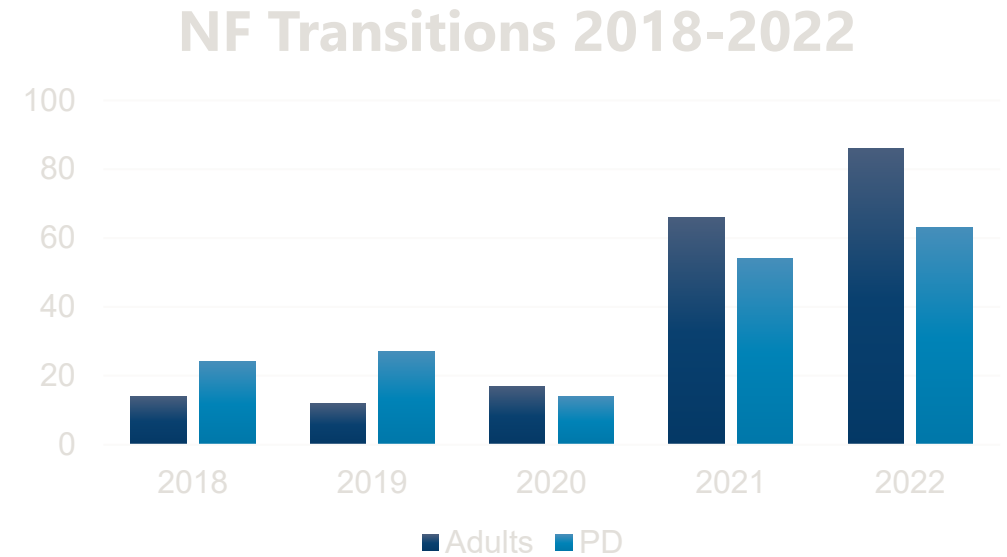
NF Referrals 2018-2022



Outcomes - Increase in MFP transitions

- Increase in overall transition numbers
- Increase in number of transitions involving older adults

Year	Older Adults	Physical Disability	Total
2018	14	24	38
2019	12	27	39
2020	17	14	31
2021	66	54	120
2022	86	63	149



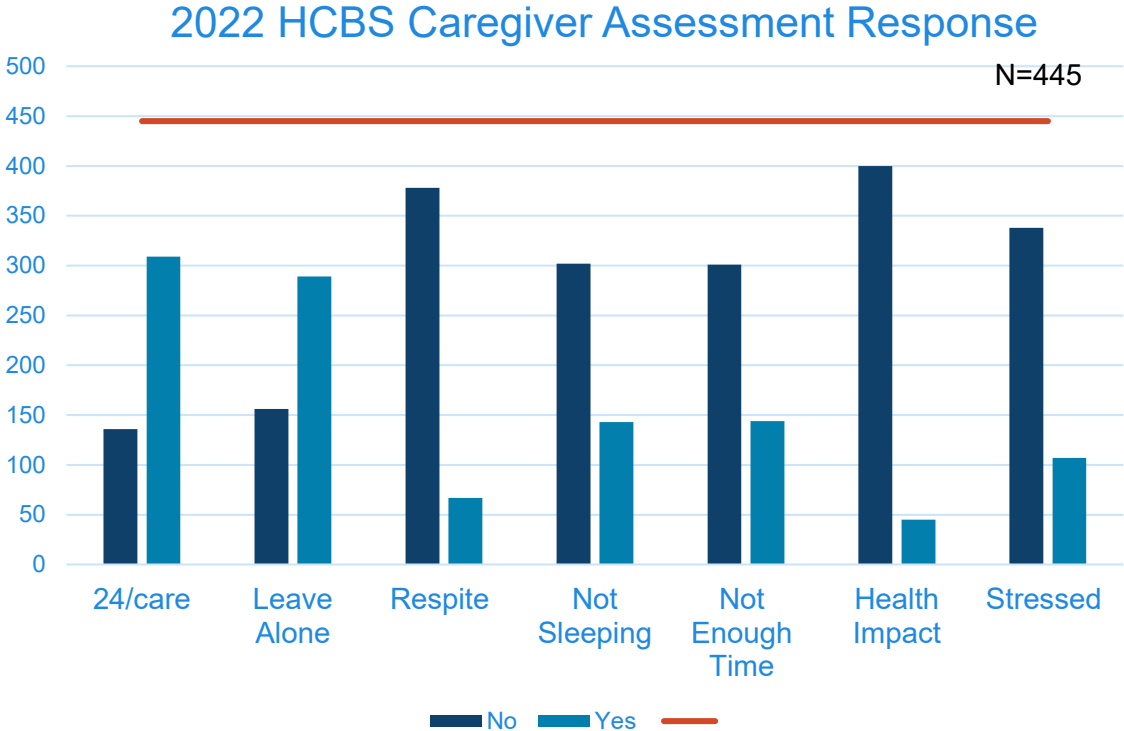
Services and Supports for ND Caregivers

Dementia Care Services – Contract Alzheimer’s Association

- Care consultations for family caregivers and facility staff
- Information and assistance services
- Public and professional training
- Funded with State General Funds



19,000 caregivers support 15,000 individuals 65+ who are living with Alzheimer’s in North Dakota





Services and Supports ND Caregivers – Respite

Flexible policies include:

- Virtual respite
- Providers may assist with personal care, light housekeeping, and meal preparation
- Participants can use supplemental funds to purchase technology devices and be provided training on the technology to decrease isolation
- Individuals/parents/ guardians can pick their own respite provider including family
- Lifespan respite can be used to go to work
- Respite providers can provide community integration and recreation for the care recipient
- Funding caps can be exceeded with approval

Direct Care Workforce

Family Home Care and Family Personal Care

- Funded through state-funded home and community-based services (HCBS) and HCBS aged and disabled 1915 (c) Medicaid waiver
- Allows spouse and other family members to receive payment for providing care
- Utilizes caregiver assessment to determine caregiver needs
- Daily rate based on the amount of care needed
- Maximum rate of up to \$150 per day
- Program includes access to respite services





info@ndqsphub.org

- Qualified Service Providers QSPs are individuals or agencies that provide direct care to clients who receive services funded by North Dakota Health and Human Services
- The North Dakota QSP Hub serves as the resource center for agency and individual QSPs and family caregivers throughout North Dakota
- Events & Training
 - Provider orientation, peer support, business acumen training i.e., documentation, billing, etc.
- Enrollment support and help with self-direction



Financial and Workplace Security

Futures Planning -Partnerships

- Connecting with Human Resource professionals across the state
 - Presenting at the ND Society of Human Resource Management Conference with staff from Social Security
 - Combine financial retirement planning with other futures planning i.e., durable power of attorney, health care directive, etc.
- Creating a partnership with Legal Services of North Dakota to hold futures planning events across the state



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ADvancing States 2023 HCBA Conference

RAISE Actions to Support Family Caregivers



August 30, 2023

Scott Bane, JD, MPA
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The John A. Hartford Foundation



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A private philanthropy
based in New York City,
established by family
owners of the A&P
grocery chain in 1929



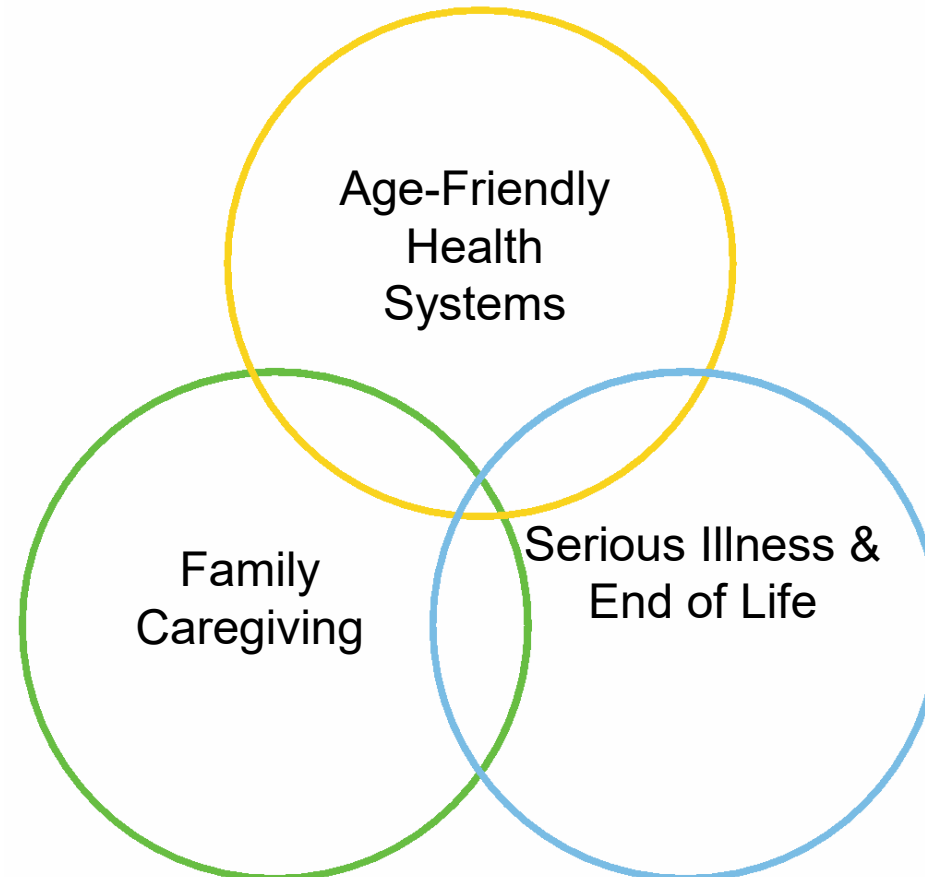
Mission & Priorities



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DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

PRIORITY AREAS



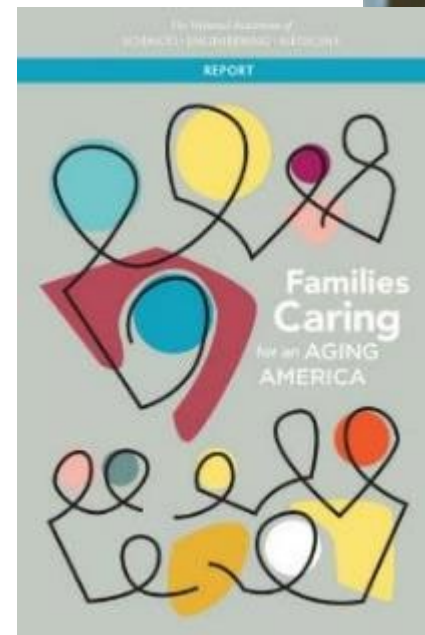
Families Caring for an Aging America (2016)



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- Focus needs to be on person- and family-centered care
- Support of family caregivers needs to be an integral part of the nation's responsibility for caring for older adults
- 4 recommendations, one of which calls for a **national family caregiver strategy**

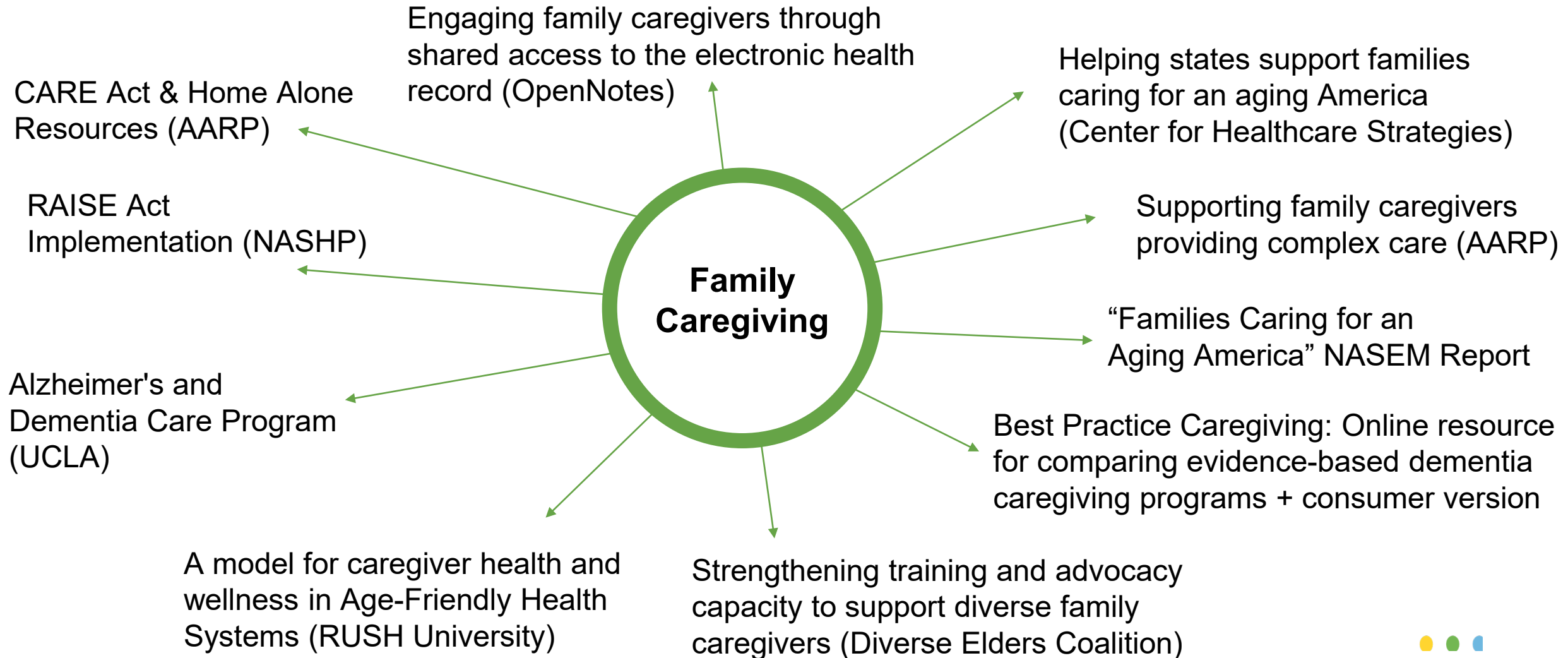
<https://nam.edu/families-caring-for-an-aging-america>



JAHF - Family Caregiving



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NASHP: The RAISE Act Family Caregiver Resource and Dissemination Center



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Supporting work of the RAISE Act Advisory Council assembled by the Administration for Community Living

- Research policies and evidence-based programs, convene experts, provide information to the public
- Test the Advisory Council's recommendations for family caregiving policies and programs in select states
- National Strategy to Congress released in September 2022



**Supporting Family Caregivers:
A Roadmap for States**

The 2022 National Strategy to Support Family Caregivers provides a roadmap for states to better support family caregivers. This overview highlights policy strategies and promising practices for states.

The Challenge


The pandemic heightened reliance on family caregivers and the shortage of direct care workers who provide care. States are being called upon to address these crises.

A Historic Solution

The [National Strategy to Support Family Caregivers](#), as required by the RAISE Act, was presented to the U.S. Congress in September 2022. The strategy lays out actions — by federal and state governments, communities, employers, and others — to increase recognition and support for family caregivers.

State Roadmap

To inform the National Strategy, the National Academy for State Health Policy (NASHP) created the [RAISE Act State Policy Roadmap for Family Caregivers](#). The roadmap helps states interested in expanding supports for family caregivers by offering the following policy strategies and promising practices.



www.nashp.org/the-raise-family-caregiver-resource-and-dissemination-center



Complementary Power of Public & Private Funding



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- Flexibility
- Convenings, communications, evaluations & technical assistance
- Relationship building on both sides

Next steps:

Explore Grantmakers In Aging –
NYS & MN Depts. of Aging are joining and
so can other similar entities!





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Thank You!

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Q&A



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NATIONAL ACADEMY
FOR STATE HEALTH POLICY



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