

WA State Unpaid Family Caregiver Data Journey

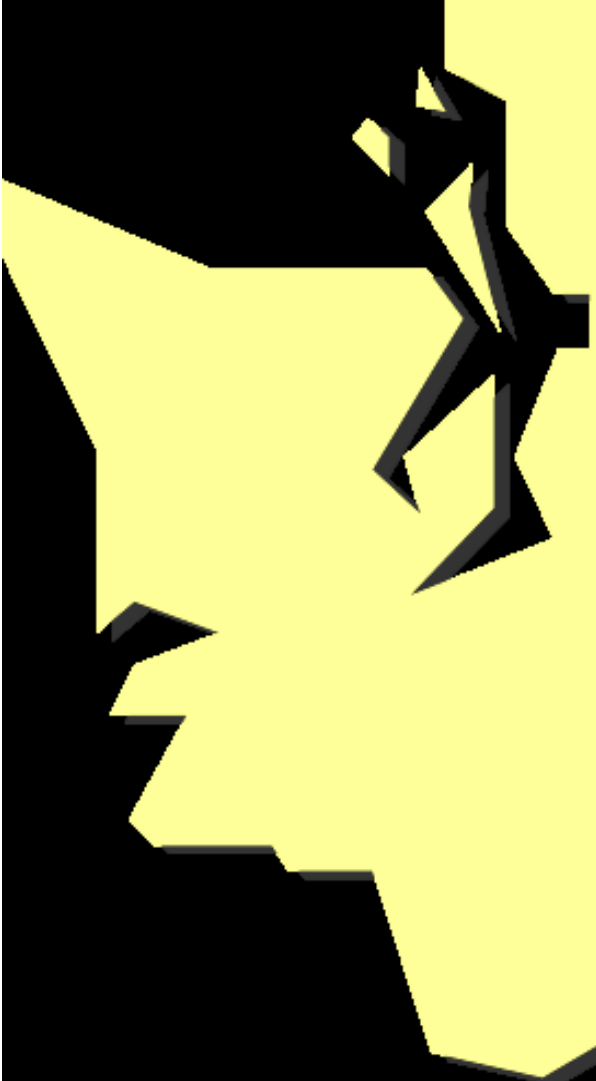
Susan Engels, Office Chief, State Unit on Aging
Aging and Long-Term Support Administration
Washington State Department of Social and Health Services

Transforming
Lives



Supporting Family Caregivers
The Backbone of the Long-Term Care System

WA History of Unpaid Caregiver Support

- 
- A stylized map of Washington state is shown on the left side of the slide. The map is filled with a bright yellow color and has a thick black outline. It is set against a black background that also contains some abstract, jagged shapes.
- ❖ 1984—State Respite Pilot—3 AAAs
 - ❖ 1989—Statewide Respite Care Services
 - ❖ 2000—State Family Caregiver Support Program (FCSP)
 - ❖ 2001—Title III E OAA, National FCSP
 - ❖ 2007/2008—Increased funding, mandate for evidence-based caregiver assessment,
 - ❖ 2008—statewide survey (BRFSS)
 - ❖ 2009—Family Caregiver-TCARE[®] Assessment
 - ❖ 2012/13—State FCSP expansion
 - ❖ 2017–1115 Medicaid Demonstration Waiver –Caregiver Initiative

Outcomes for Family Caregivers

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

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

Spousal caregivers also showed a decreased “intention to place.”

84%

of caregivers show
a significant
improvements on
key outcomes

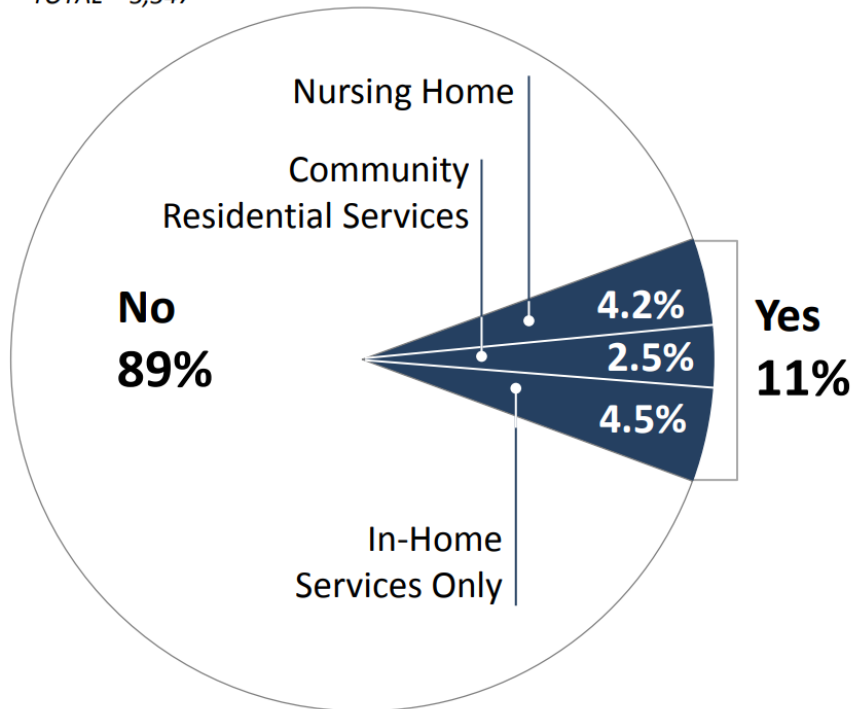
Family Caregiver Support Program

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

PRE-EXPANSION

SFYs 2010, 2011

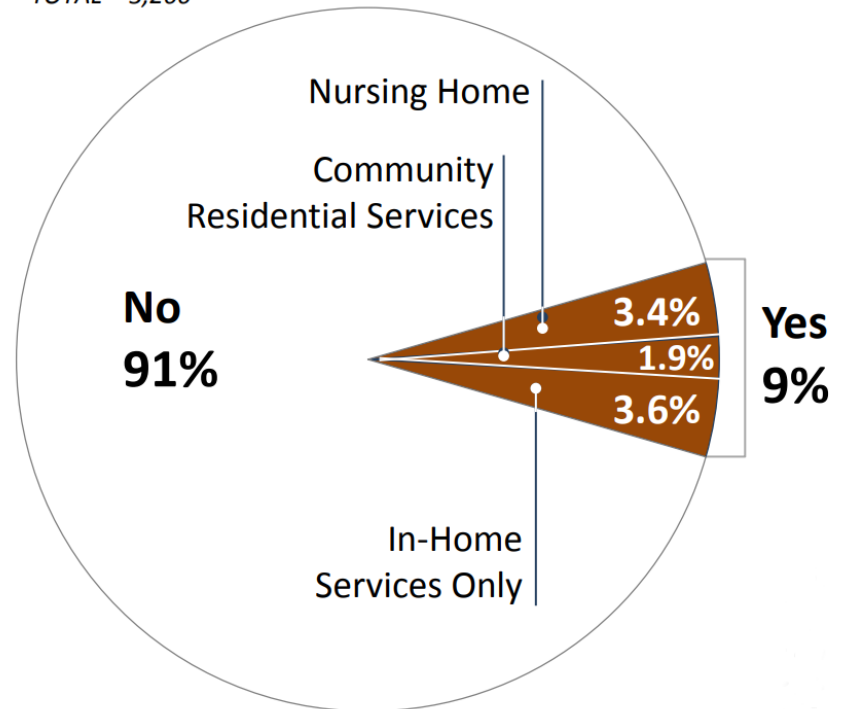
TOTAL = 3,347



POST-EXPANSION

SFY 2012

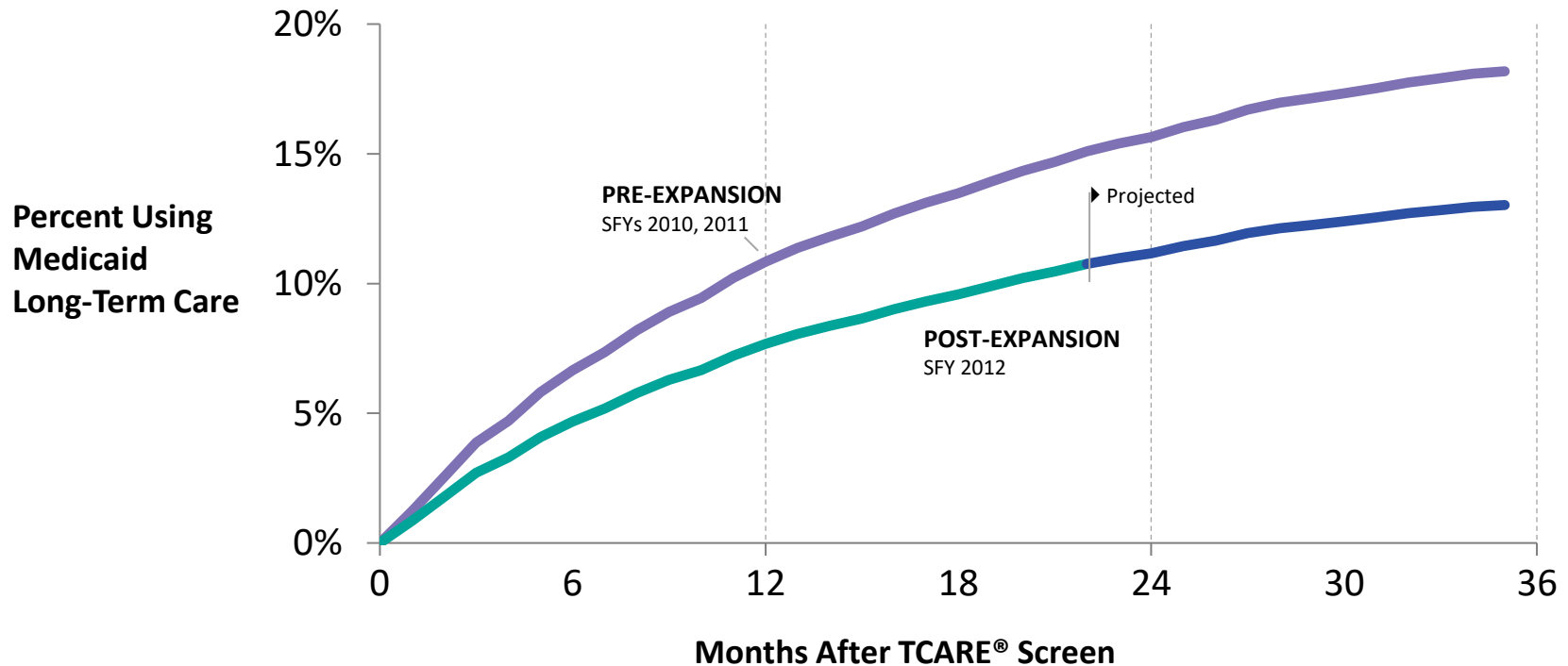
TOTAL = 3,266



Family Caregiver Support Outcomes

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

Pre- and Post-Expansion, Controlling for Baseline Differences



Expanding Supports: 1115 Waiver

Medicaid Alternative Care (MAC)

Designed to support unpaid caregivers in continuing to provide quality care.

Tailored Supports for Older Adults (TSOA)

New eligibility group to support individuals who need Long-Term Services and Supports and are at risk of spending down assets to impoverishment with or without unpaid caregivers.



1115 Positive Outcomes

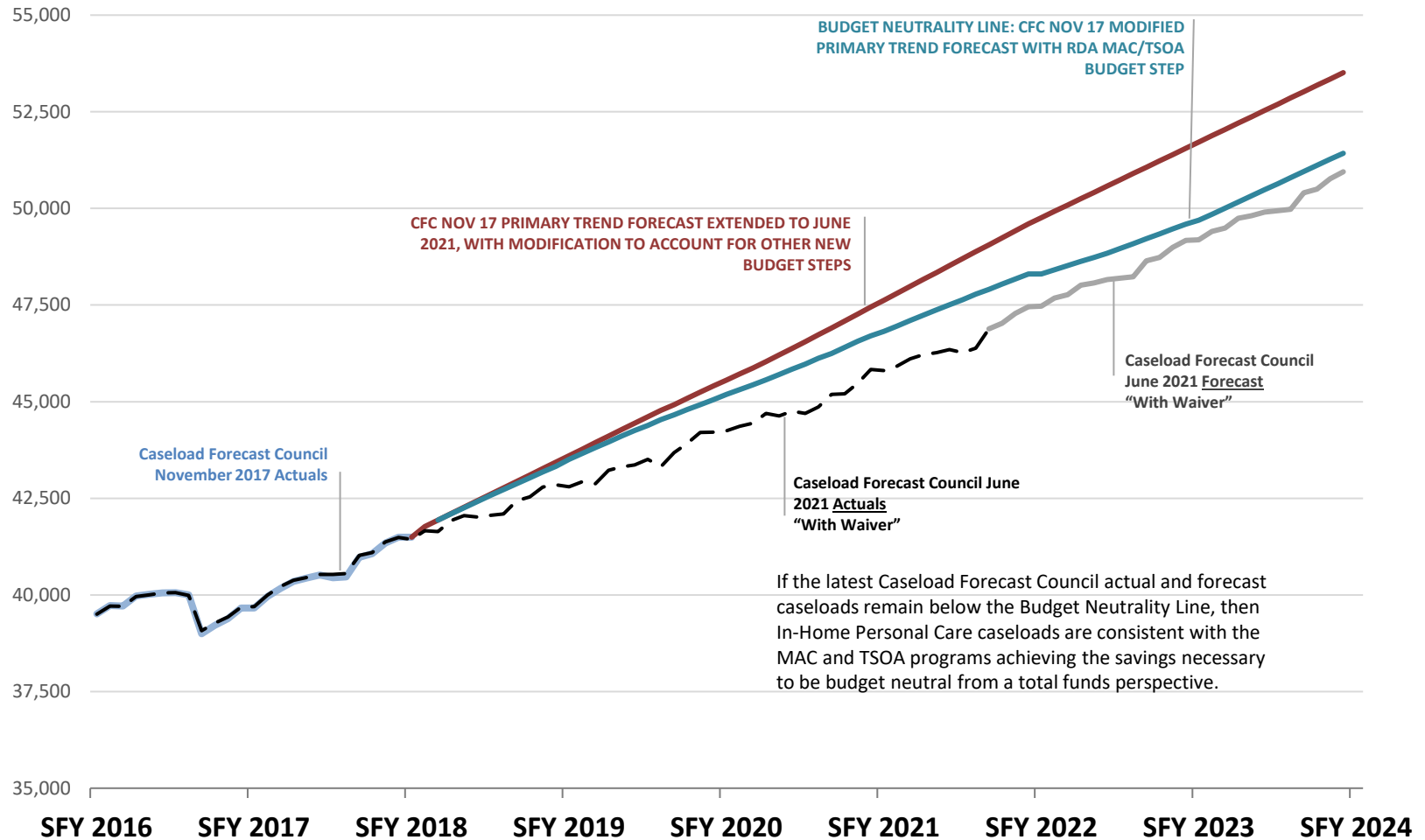
“Program participation appears to help delay or avoid the use of more intensive traditional Medicaid LTSS”



When family caregivers access support early in their caregiver journey, before they experience the highest levels of stress and burden:

- [1115 Interim Evaluation](#) showed significant improvement in ED and hospital use of care receivers 6 months after caregivers received supports.
- The likelihood of the care receiver using Medicaid LTSS is reduced.
- The caregiver's health and well-being is improved.

MAC/TSOA Budget Neutrality Model for In-Home Personal Care Caseload Offsets



Next Steps for WA

- Renewal of the 1115 Waiver with strong Interim Evaluation data to support
- Sharing data with health payers to find partnering opportunities with the Aging Network
- Washington's LTC Trust Act: WA Cares

TCARE Inc. use of WA's and other states' data has led to exciting refinement of the EBP tool itself.

The future is now for expanding reach of clinical staff with AI.

Questions?

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360-725-2527



“Care” for “Caregivers”

Evidence-based caregiver support program
preventing caregiver burnout



CMS 1115/1915 Approved



HHS-Accredited
Evidence-Based



Preferred
Partner



EVIDENCE-BASED | CMS-APPROVED | HHS-ACCREDITED

FAMILY CAREGIVER SUPPORT



Hours of Care ≠ Caregiver Burnout



92 Peer-reviewed published papers



Identity Discrepancy

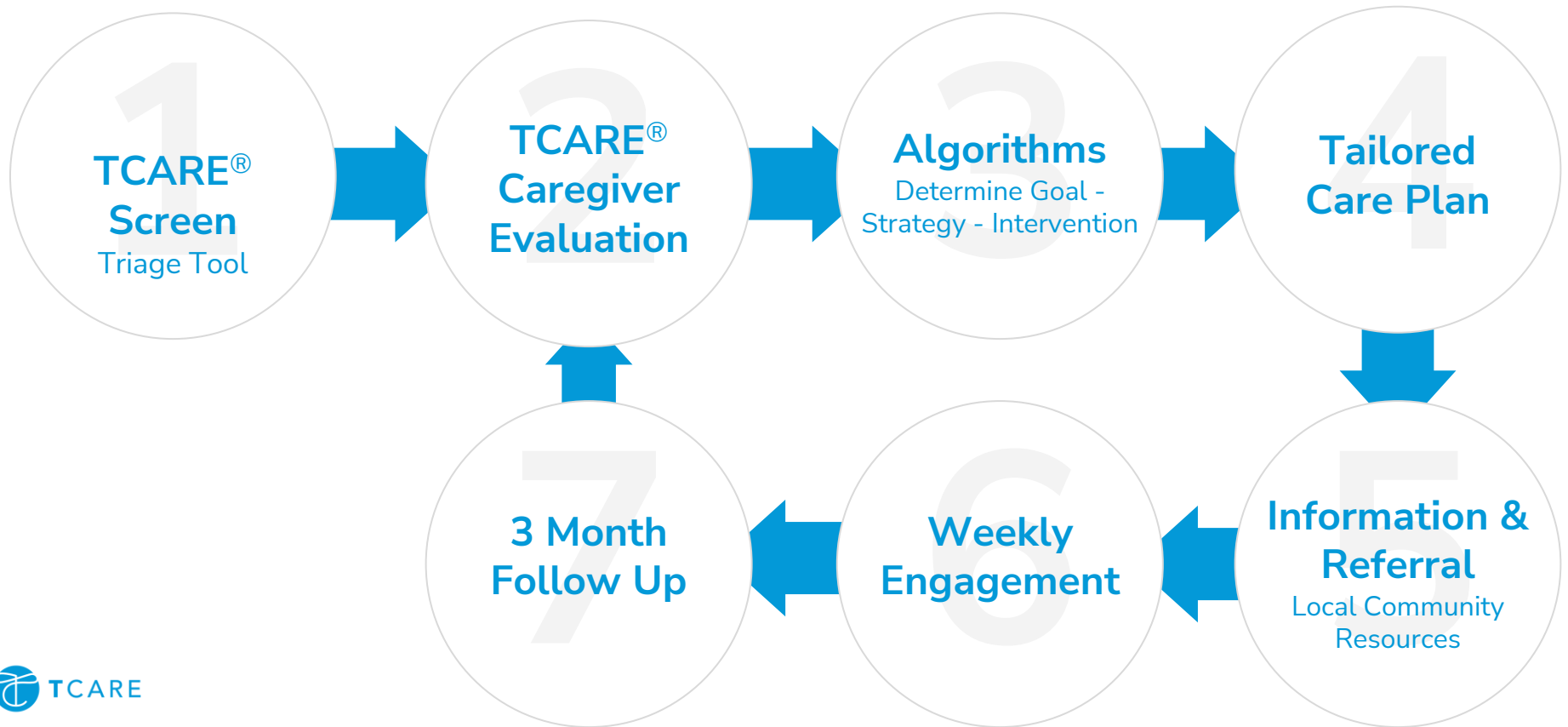


“Am I her **daughter** or her **caregiver**?”

FAMILY MEMBER | **CAREGIVER**



TCARE[®] User Journey



4 Tailored Care Plan

1. Caregiver Status					
<u>Caregiver Phase:</u> Phase 2		<u>Intention to Place:</u> No		<u>Caregiver Type:</u> No Way Nasturtium	
2. CG Emotional Needs		3. Care Receiver Needs		4. Caregiver Obligations	
<u>Relationship Burden:</u>	HIGH	<u>ADL:</u>	LOW	<u>Employment:</u>	Work full-time
<u>Objective Burden:</u>	MED	<u>IADL:</u>	LOW	<u>Personal Care Hours:</u>	0
<u>Stress Burden:</u>	HIGH	<u>Problem Behaviors:</u>	HIGH	<u>Household Care Hours:</u>	0
<u>Uplifts:</u>	LOW	<u>Memory:</u>	No	<u>Other Assistance Hours:</u>	0
<u>Depression:</u>	MED			<u>Total Dependents:</u>	2
<u>Identity Discrepancy:</u>	MED				

4
Tailored Care
Plan

Over 168+ categories of SDOH services...

7
Information &
Referral
Local Community
Resources



Health Goal

D. Reduce generalized stress

(15) Medical or Behavioral Health Related Services

E. Improve overall health

(15) Medical or Behavioral Health Related Services

Goal 2: Embrace Caregiver Identity

A. Change personal rules for care

(3) Counseling or (4-2) CG Education psycho-social

(4-1) Education for caregiver to obtain information about services and assist with planning for the future

(4-3) Education to build caregiving skills (e.g. direct care and communication)

Skills for responding to mood and behavior changes **

PRIMARY CARE CLINIC
20 UNION ST N
MORA

Amount/Frequency

1x Week

PRIMARY CARE CLINIC
20 UNION ST N
MORA

Amount/Frequency

(13) Support Groups (Expand and sustain networks of support)

B. Reduce or minimize work load

(1) Adult Day Services (Experience time away from care responsibilities)

(2) Assistive Technologies (Promote safety and functional abilities of care receiver)

(4-1) Education for caregiver to obtain information about services and assist with planning for the future

(4-3) Education to build caregiving skills (e.g. direct care and communication)

(5) Education for care receiver (Facilitate self care and/or reduce need for assistance)

(6) Financial and/or Legal Services and Protection (Obtain assistance or counsel)

(8) In-home Supports and Services (Reduce responsibility or workload)



- Self-Directed caregivers
- Direct Care caregivers
- Foster Care

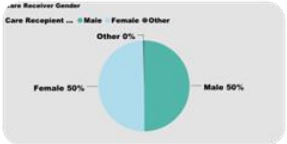
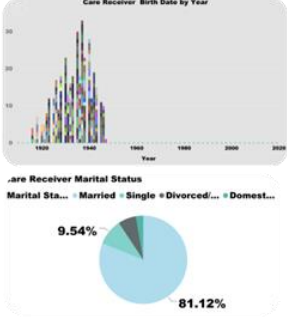
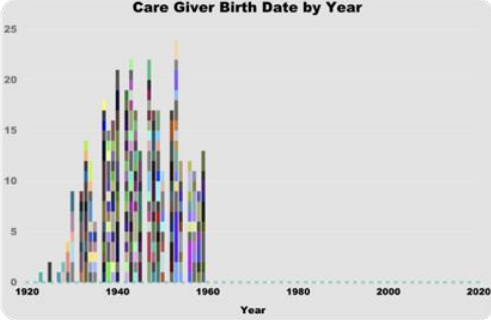
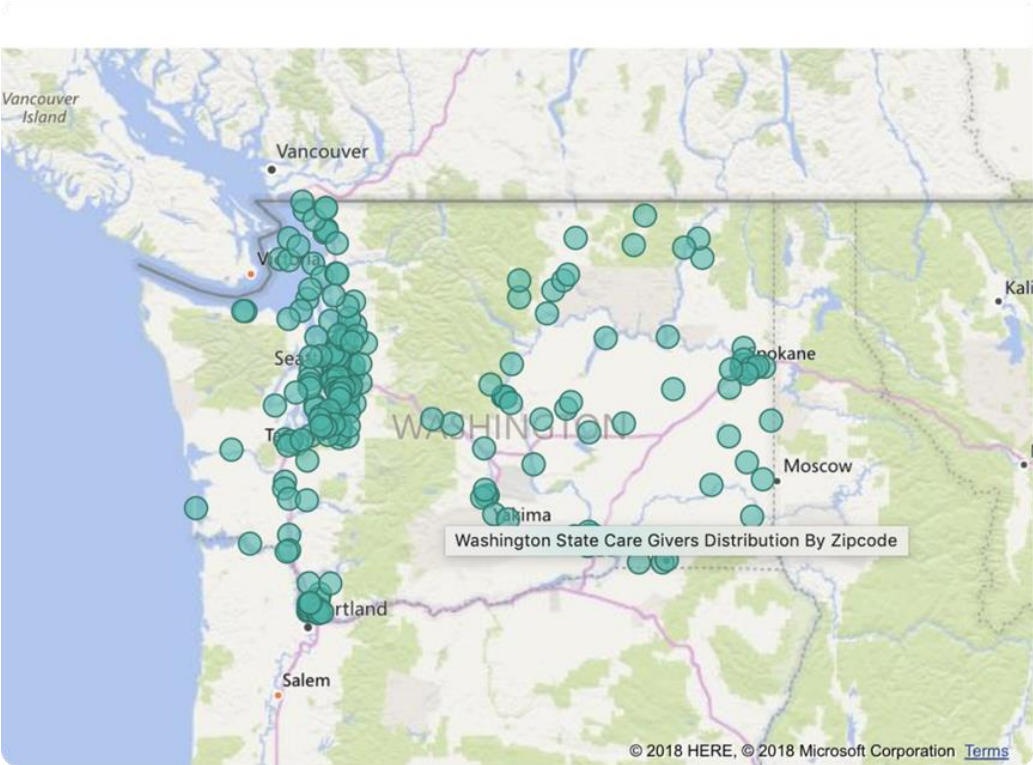
MILITARY

**OLDER ADULTS
/DEMENTIA**

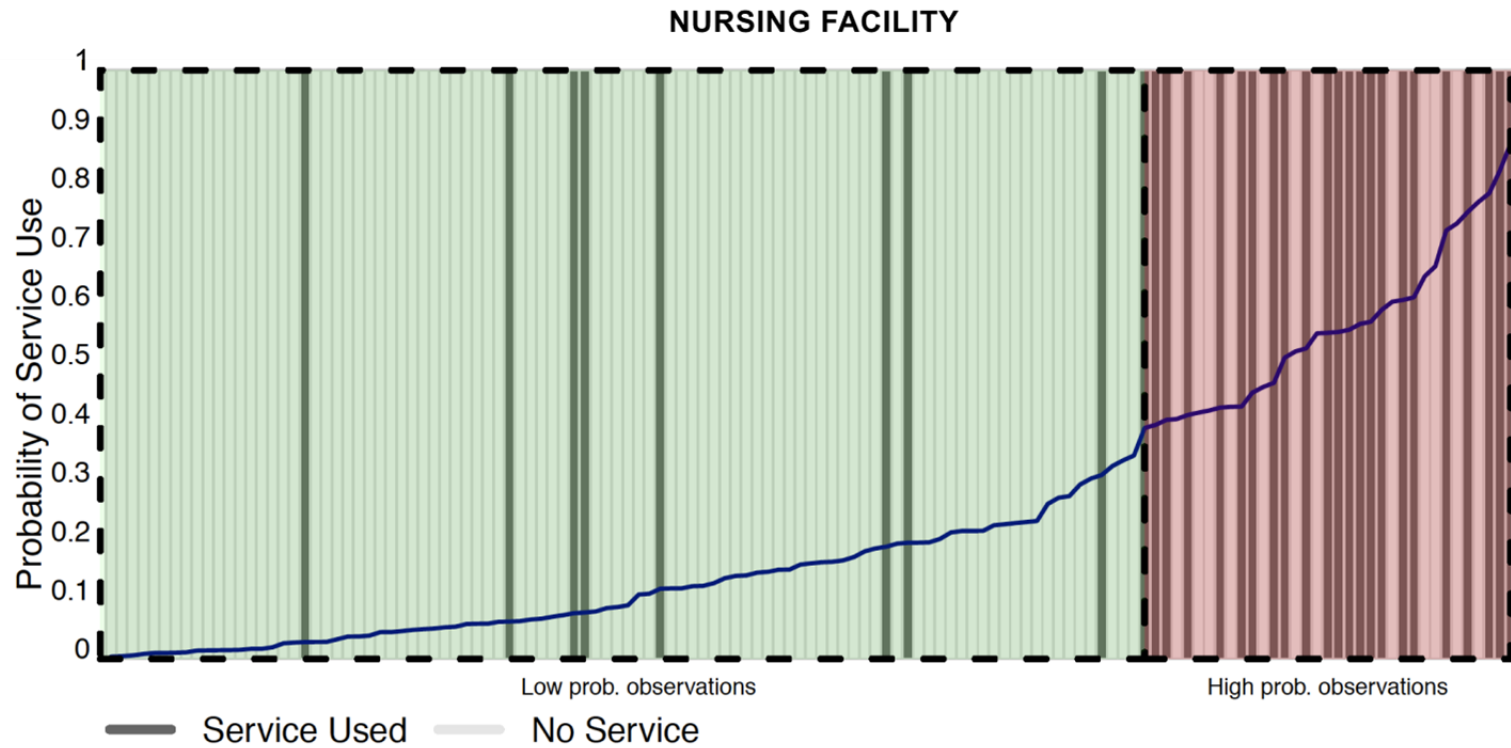
**DEVELOPMENTALLY
DISABLED (IDD)**



Predictive, data dashboards



Predictive Data Models



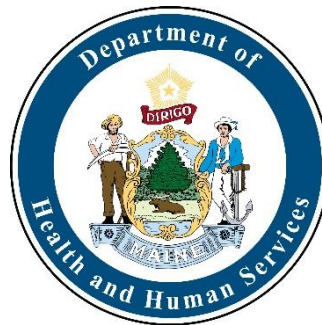


EVIDENCE-BASED | CMS-APPROVED | HHS-ACCREDITED AGING-IN-PLACE SOLUTION



Maine Caregiver Programs: Current Data Status and Future Directions

Maine Department of Health and Human Services
Office of Aging and Disability Services



Maine Family Caregiver Programs/Services

Federally Funded Programs

- National Family Caregiver Support Program (OAA, Title III-E)
- Section 19: HCBS Older Adults & Adults w/ Disabilities (MaineCare)
 - Respite is a covered service
- Section 26: Day Health Services (MaineCare)

State Funded Programs

- Section 61: Adult Day Services
- Section 63: Home Based Care (HBC)
 - Respite is a covered service, cannot exceed annual cap
- Section 68: Respite Care Services for Adults with ADRD

Statewide Needs Assessment

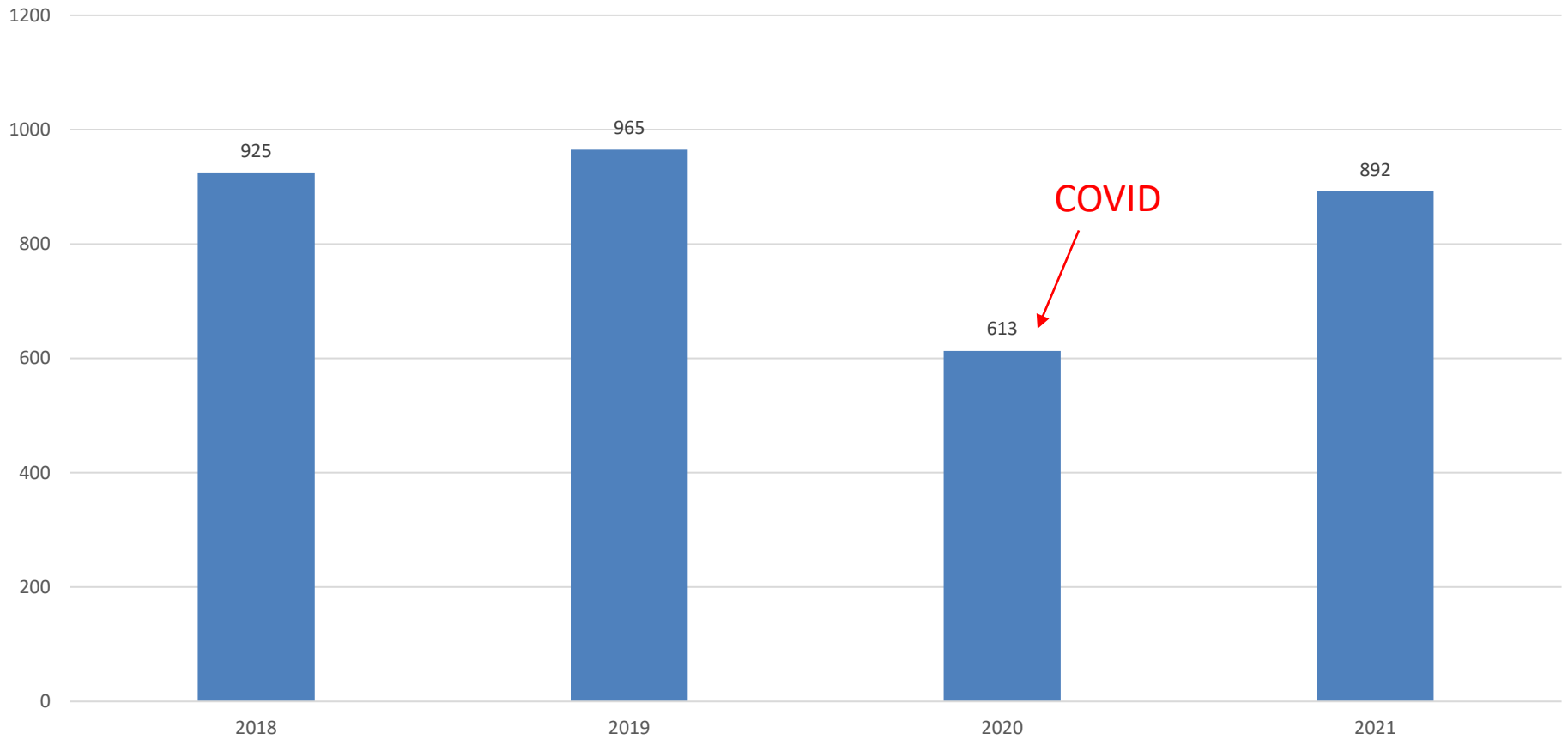
Statewide Needs Assessment

- >26% reported **finding information about available services and programs** either very or somewhat difficult
- Those who said they had not received all of the help they needed, 40% said they **did not know whom to ask for help**
- Caregivers who said they were not getting the help they needed, 26% said they **did not know whom to ask or where to get the information**
- Expressed the need to get information from a trusted or reliable source

https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/2020-2024_Maine_State_Plan_on_Aging_Needs_Assessment_Report.pdf

ADRC Calls

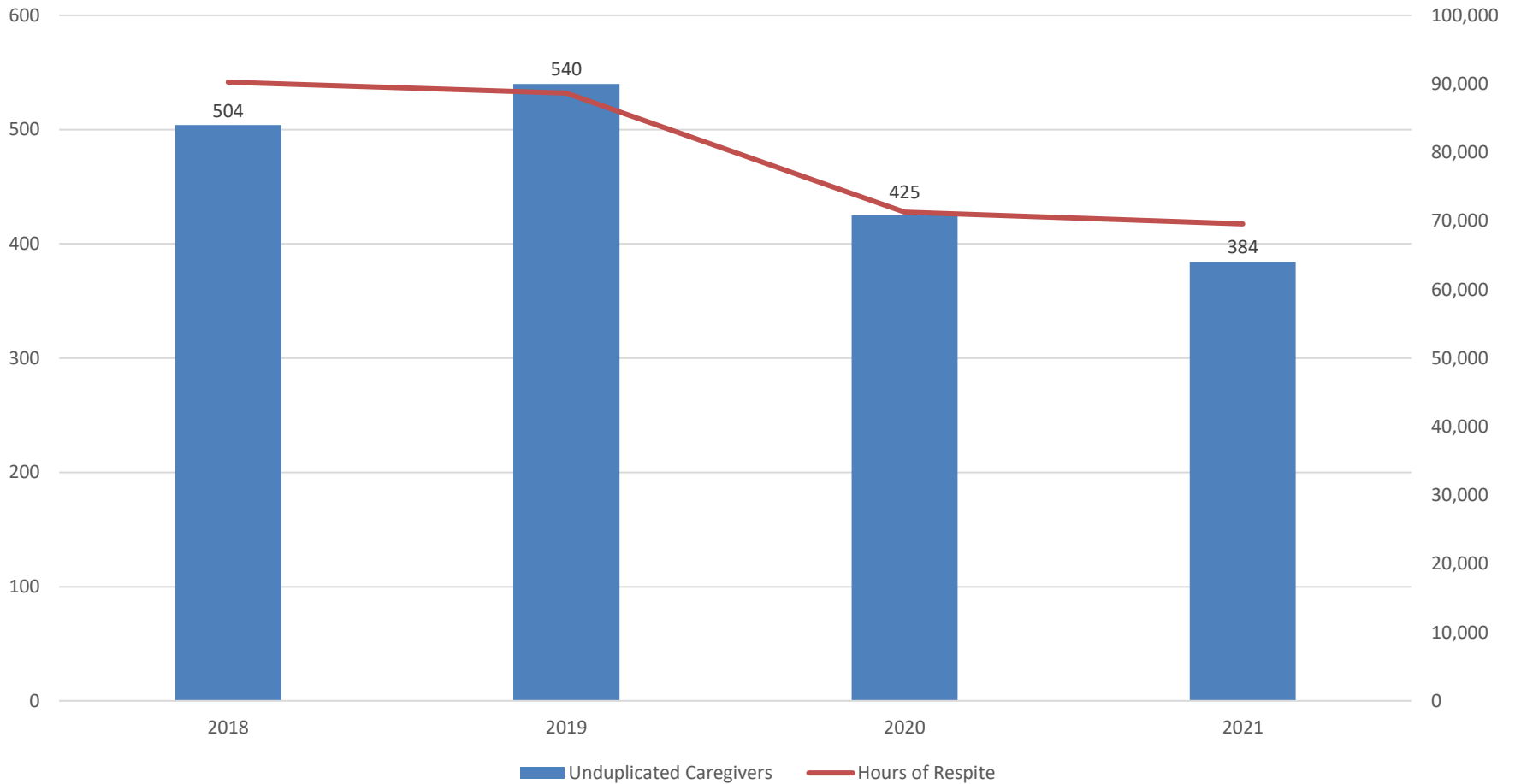
Unduplicated Calls from Caregivers by Federal Fiscal Year



Data pulled from WellSky Aging & Disability on 11/18/2021

AAA Respite Care Program

Number of Caregivers & Respite Hours Served by Federal Fiscal Year



Data pulled from WellSky Aging & Disability on 11/18/2021

Current Data Gaps

- Limited to units, persons, and expenditures
- No population health outcomes being measured
- Only tracking Alzheimer's Disease diagnosis
- Assessment data is inconsistent across AAAs and programs
- Only tracking race and ethnicity, no data on sexual orientation and gender identity
- Lack of ability to track clients across their life course

Future Family Caregiver Initiatives

- TCARE Assessment and Management Protocol (MFP Capacity Building)
 - Starting with AAAs, but looking to expand into other populations
 - Stakeholder group developing implementation plan
- Family Caregiver Grants Pilot (ARP)
 - \$2,000 grants to eligible family caregiver impacted by the pandemic
 - \$5.1 million allocated to the project (\$4.5 for direct grants)
 - Stakeholder group guiding design, implementation, and evaluation

Related Initiative

- Community Information Exchange (CIE)
 - Connecting various databases to better track SDOH and across systems

What data do we want to collect and analyze?

- TCARE
 - Better assessment data on caregiver burden and stress over time
 - Correlations between caregiver demographics and outcomes
 - Delayed entry into long-term care and potential savings
 - More accurate dementia diagnosis of care receivers (e.g., frontal temporal, vascular, Parkinson's, Alzheimer's, etc.)
- Family Caregiver Grants Pilot
 - How are we going to measure “negatively impacted and/or suffered economic harm because of COVID-19”?
 - For working caregivers, did this assistance continue participation in the workforce?
 - Did the assistance delay entry into long-term care?
 - What other benefits, services, programs, etc. did the family caregiver access through this project?

Questions?

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