

The Family Caregiving Advisory Council Meeting Will Begin Shortly

To turn on closed captioning, click the “CC” icon at the bottom of your screen.



**Family Caregiving Advisory
Council Meeting
January 19, 2021**



Opening Remarks

Lance Robertson

Administrator/Assistant Secretary for Aging
Administration for Community Living




Roll Call

Agenda Overview and Updates

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



Agenda

- 1:00 – 1:30 **Medicaid Supports for Family Caregivers**
 - 1:30 – 2:15 **Listening Sessions Presentation**
 - 2:15 – 2:30 **Break**
 - 2:30 – 3:25 **Overview & Discussion: Inventory of Federal Programs and Initiatives to Support Family Caregivers**
 - 3:25 – 4:15 **Initial Report to Congress: Overview of Council Review Process**
 - 4:15 – 4:30 **Wrap-up and next steps**
- 



Medicaid Supports for Family Caregivers

Kitty Purington, J.D.
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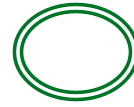
Senior Program Director, Chronic and Vulnerable Populations Team
National Academy for State Health Policy

January 19, 2021



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NASHP's Mission

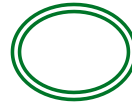


- Uniquely non-partisan, non-membership organization
- Supported by an Academy of regionally and politically diverse cross-agency state leaders

Organizational Expertise	Core Functions
<ul style="list-style-type: none">• Medicaid• Public Health• Children and Families• Behavioral Health and Chronic Care• Access and Eligibility• Cross-sector state innovation and reform	<ul style="list-style-type: none">• Convene state health policy leaders• Identify solutions• Disseminate innovations• Targeted technical assistance, webinars, briefs, meetings, and conferences



RAISE Act

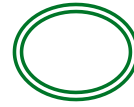


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- RAISE (Recognize, Assist, Include, Support, and Engage Family Caregivers) Act: requires the development of a **national strategy to support unpaid caregivers**
 - Through a grant from The John A. Hartford Foundation, NASHP is supporting the RAISE Act Council developing recommendations for a national family caregiving strategy

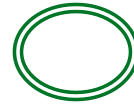


Introduction to Medicaid



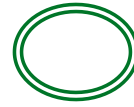
- Medicaid is funded jointly by states and the federal government
 - Federal government sets requirements; states administer Medicaid programs within the requirements
- Result: 50 state health care programs; 50 state systems for long term care
- State Medicaid health care programs are diverse and can be shaped by:
 - Political issues
 - Budgetary issues
 - Cultural issues

Long Term Services and Supports (LTSS)



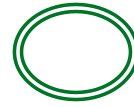
- LTSS: services and supports to assist individuals in routine daily tasks such as bathing, dressing, preparing meals, etc.
- Medicaid is the single largest source of funding for LTSS
- In 2018 State governments spent a projected \$229.6 billion on Medicaid (CMS.gov)
 - In 2017, State and local governments' estimated spending was \$229.9 billion
- In FY 2017, more than 20% of all Medicaid spending was on LTSS

Medicaid Home- and Community-Based Services (HCBS)



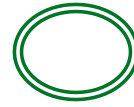
- HCBS support the needs of older adults, people with disabilities, children and youth with special health care needs, and other target populations
 - Care coordination; personal care; home health care; case management; chore services; respite; many other services
- HCBS can help people remain in home and community settings and:
 - Reduce costs
 - Improve quality
 - Honor individual choice
 - More recently: COVID-19 and quarantine/stay-at-home

Medicaid Home- and Community-Based Services (HCBS)



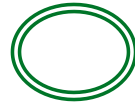
- Federal + state focus on shifting LTSS spending toward home- and community-based services (HCBS) and away from institutional services
- FY 2016: 57% of total Medicaid LTSS expenditures nationally supported HCBS (Medicaid.gov)
 - 53% in 2014
- In FY 2018, state proportions of LTSS spending on HCBS ranged from 30.0% to 83.4% (Medicaid.gov)

Medicaid Home- and Community-Based Services (HCBS)



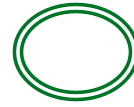
- Family caregivers play an important role in states' efforts to balance Medicaid LTSS systems
- Strong indicators suggest that family caregivers, and the Medicaid enrollees they care for, could benefit from additional supports
 - State examples:
 - ✦ Training and education
 - ✦ Counseling
 - ✦ Family caregiver benefit

Support for Family Caregiving in HCBS



- Benefits must be directed to and ultimately support the needs of Medicaid-enrolled individual
- Supports can include:
 - Enrollee services that include the caregiver (e.g., counseling, respite)
 - Reimbursement for family caregivers via self-direction of services
 - Education and training that includes the caregiver
 - Care coordination

State Medicaid Tools to Support Family Caregivers



State plan options

- 1915 (i) State plan HCBS
- 1915 (j) Self-Directed Personal Assistant Services
- 1915 (k) Community First Choice
- State plan services

Waivers

- 1915 (c)
- 1115

Medicaid Managed Care

- Acute Benefits
- Managed LTSS

Medicaid: State Plan Option Examples

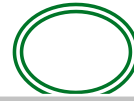


Medicaid Authority	Purpose	What can be waived?	Target groups	Other eligibility criteria
1915 (i) home- and community-based services state plan option	HCBS for individuals who need less than institutional levels of care/are ineligible for 1915 (c)	Comparability; community income rules for medically needy population	States can define	Depending on income group, must be eligible for HCBS under a 1915 (c), (d), (e) waiver or 1115 demonstration program
1915 (j) self-directed personal assistance services	Participant-directed option for individuals eligible for state plan personal care or 1915 (c) services	Statewideness; comparability	States can define	n/a; must be eligible for and receiving either Medicaid 1915 (c) or state plan services
1915 (k) Community First Choice Option	Provides a 6% FMAP increase for consumer-directed home- and community-based attendant services and supports	Community income rules for medically needy population	Cannot target; services must be provided statewide	Must meet institutional level care of requirements; may include special income group / those receiving at least one 1915 (c) service per month

Source: http://www.hcbs-ta.org/authority-comparison-chart?field_hcbs_authority_target_id%5B9%5D=9&field_hcbs_authority_target_id%5B10%5D=10&field_hcbs_authority_target_id%5B11%5D=11



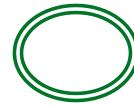
Medicaid: Waivers



Medicaid Authority	Purpose	What can be waived?	Other eligibility criteria	Target groups
1915(c) home- and community-based services waiver	Allows state to pay for HCBS in lieu of institutional care; expand eligibility; create targeted services	Statewideness; comparability; community income rules for medically needy population	Must require institutional level of care	Aged/disabled; intellectually/developmentally disabled; mentally ill (under age 22 or over age 64)
1115 Demonstration Waiver	Allows states to waive certain Medicaid requirements in order to test innovative programs or pilots that promote Medicaid goals	Multiple requirements under §1902 of the Social Security Act based on demonstration waiver's promotion of the Medicaid program's goals	State determines	State determines

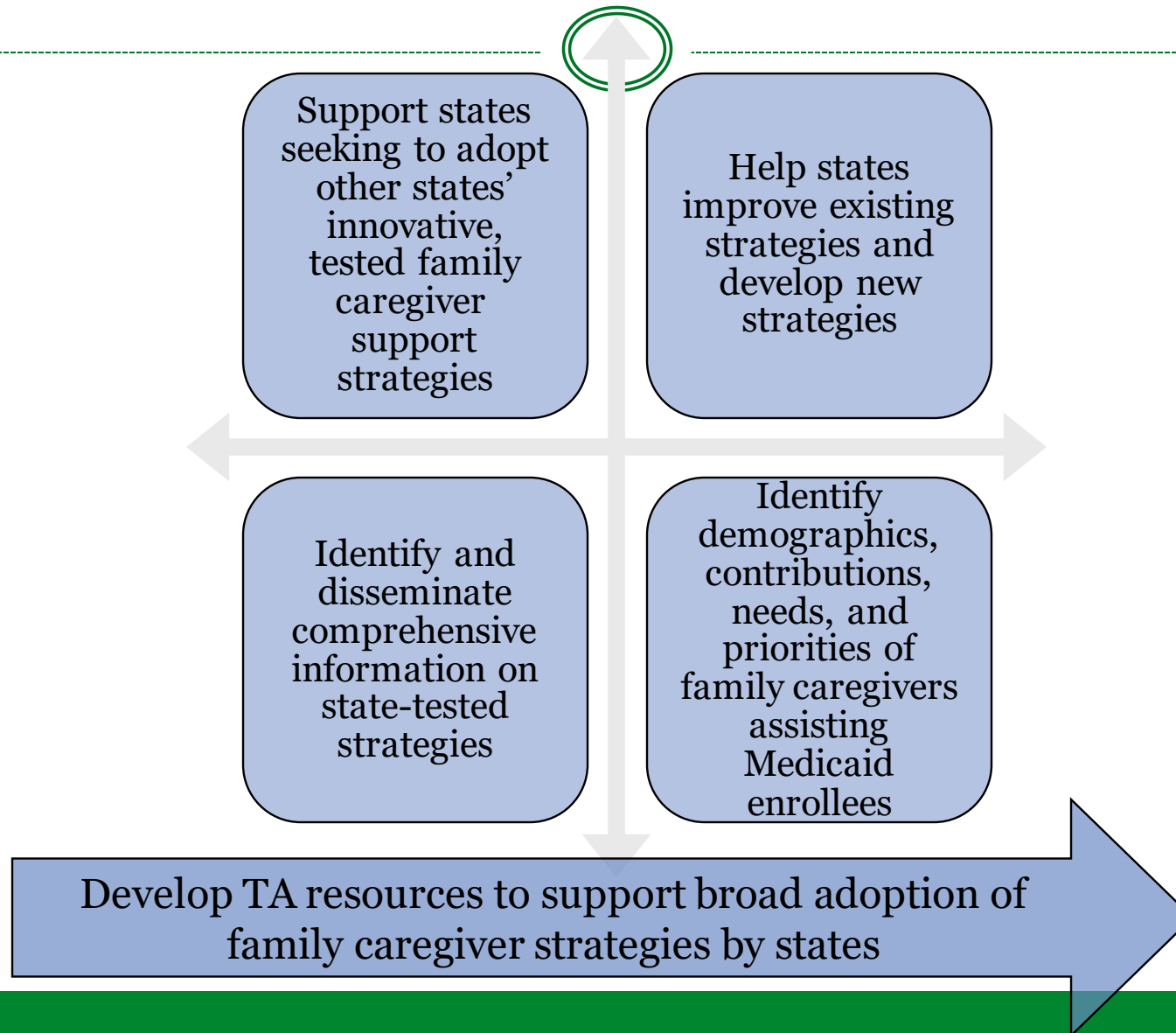
Source: http://www.hcbs-ta.org/authority-comparison-chart?field_hcbs_authority_target_id%5B7%5D=7&field_hcbs_authority_target_id%5B8%5D=8

Family Caregiving Support – State Medicaid Innovations

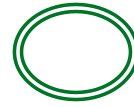


- Washington: outreach to inform enrollees and caregivers about available caregiver supports
 - 1115 Medicaid Transformation Demonstration Waiver: Medicaid Alternative Care (MAC) program
- Utah: training to help caregivers better meet the needs of their loved ones
 - 1915(c) waiver services
- Tennessee: caregiver assessment to identify and address caregiver needs as part of care planning for the enrollee
 - 1115 TennCare Waiver: CHOICES program
- Florida: requires MCOs to provide behavioral health services for family caregivers
- Colorado: waiver of scope of practice laws for certain services

How the Federal Government Can Help States Implement Family Caregiver Strategies



Key Takeaways



- States have a vested interest in supporting individuals and their families in home and community settings:
 - Cost, quality, culturally/linguistically services, COVID, US demographics...
- Varied, flexible options to support family caregivers through Medicaid:
 - Partnering with organizations such as AAA on outreach
 - Offering training, counseling, and other supports for beneficiary's family caregivers through waivers/MCOs
 - Respite care
 - Building out caregiver assessment practices
- Critical for policy makers:
 - Evidence-based practices, understanding cost/scope/need; programs + services for underserved communities

Read the Report

Medicaid Supports for Family Caregivers

October 2020

Authored by **Neva Kaye** and **Salom Teshale**

Supported by The John A. Hartford Foundation

Read the report at:

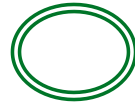
<https://www.nashp.org/medicaid-supports-for-family-caregivers/>



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Thank You!



- **State officials: Colorado, Florida, Georgia, Idaho, North Carolina, Tennessee, Utah, and Washington**
- **LTC Steering Committee, State Leadership Council on Palliative Care**
- **Greg Link and the US Administration for Community Living**
- **Rani Snyder, Scott Bane, and The John A. Hartford Foundation**

Caregiver Listening Sessions



Presentation to the ACL RAISE Family Caregiver
Advisory Council Meeting
19 January 2021

Presentation Outline

- Research design
- Solutions that resonate most with family caregivers
 - Long Term Services and Supports
 - Financial Well-Being and Workplace Accommodations
- Differences in caregiver perspectives
- Issues amplified by COVID-19

Research Design and Methods

About the Listening Sessions



Research bridging policy and practice



Research Objectives

- What do caregivers think and feel about the support they need?
- What are their greatest challenges?
- How do caregivers prioritize the issues that emerged from the RFI?
- Do perspectives differ by the type of caregiver and caregiving situation?

Fifteen (15) Caregiver Listening Sessions

- 6 groups of **parents caring for disabled/special needs child**
 - 2 covered all topics
 - 2 focused on caregiver services and supports
 - 2 exclusively on financial and workplace issues
- 6 groups with **caregivers for aging/disabled adult relative**
 - 2 covered all topics
 - 2 focused on caregiver services and supports
 - 2 exclusively on financial and workplace issues
- 1 group with **Spanish-speaking (only) and Spanish-English speaking** caregivers
- 1 group of **teen caregivers**
- 1 group of **kinship/grandparent caregivers**

Discussion Guide

- Open-ended inquiry:
 - What types of services/supports have been helpful?
 - Would have been helpful?
- Priority Concerns – Identify and discuss priorities from the RFI list:
 - Asked participants to vote on and discuss which recommendations were most important to them.
- Groups focused on one or both of the following:
 - Caregiver Services and Supports
 - Financial and Workplace Solutions

Areas of Inquiry for Caregiver Solutions

Caregiver Services and Supports

Respite Care

Adult Day Care

Information & Referral

Caregiver Training/Education

Care Transitions

Financial Well-Being

Workplace Protections

Tax Incentives

Retirement Support

Direct Pay Support

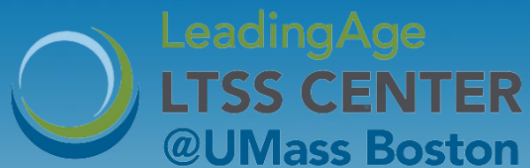
Technology

Participant Characteristics

- Ages 28 to 77 [teen caregiver group ages 13-18]
- 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
 - Live together or apart

Major Findings

What Caregivers Need



Research bridging policy and practice



Priority Concerns

- Caregiver training and education
- Respite care
- Financial considerations
 - Workplace accommodations
 - Direct pay for caregiving
 - Tax policy and other solutions
- Information and referral
- Care coordination and care transitions

Caregiver Training

- Need training both for the medical aspects of caregiving and to help support everyday care, especially managing behavioral issues.

“When your mom starts balking at taking these different medications, how can you explain this to her?”

“It’s kind of like going to a battlefield in war. You learn as you go. There’s no training program.”

“She had a serious infection. I had to be trained to deal with her PICC line. I got 15 minutes of training. That was really uncomfortable. It would have been nice to have more training before I did that.”

“He went from able-bodied to ‘can’t do anything.’ I didn’t know how to handle that. That was really hard. I definitely would have benefitted from a checklist of strategies.”

“Caregiver training is a service that’s needed that you don’t know that you need.”

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 just to help with the day to day activities."

"The best [help] came from the support groups, from other family caregivers that were sharing."

"I'd like to see more parent advisory councils."

"I think it would be helpful [if] doctors can give you more information on how to do your job even better."

Respite Care

- Participants strongly desired respite, but worried about:
 - Finding qualified resources
 - Assuring the well-being of the care recipient
- Talked about:
 - Guilt and worry
 - Challenges with finding adequate respite care
 - Worry about care recipients' resistance to help from outsiders
 - Wanting time alone at home
- 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. “

“I know it’s hard to find. It’s like interviewing a caregiver, but it’s harder because you can’t promise them regular hours, but you need someone who meshes with your child. It is so hard to get and so needed.”

“I definitely think it’s an important service...It doesn't have to be a lot of time, just time to get a shower, to go do something that you wouldn’t normally be doing.”

“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 butI get afraid of the notion just because we don’t really know what’s happening when we’re not there.”

Care Coordination and Transitions

- Care needs change, situations change and families re-locate
- Parent caregivers say finding support for the child's disability once they age out of the school system is especially challenging

“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.”

“There is no communication between [providers], sometimes they'd give medications that harmed him. Thankfully I was on top of everything....keeping track of every single medicine and talking to each of the doctors; it was crazy.”

“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 assistance the things he needed.”

Information and Referral

- Participants want more transparency and confidence in I&R services
- Are agencies making referrals out of convenience or self-interest?
- Want 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.”

“I’d want...a better understanding of the information that we need to perform our services.”

“Education on what’s out there, what works for some people, what doesn’t work for others.”

The Financial Impact of Caregiving

Participants spoke about the financial impact – in direct costs, loss of income from not being able to work, loss of retirement funds, and more.

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

“I looked at my last 15 years of Social Security benefits....it’s sad because I got zero for several years. What am I going to do...when I’m 62?”

“I had not planned to use my 401(k) until I was 72....I had no one else that would care for [mom]. I had to tap into my 401(k)...That has been a critical impact financially.

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

“If you have a lot of money, then you can afford the care. If you’re lower income, you get assistance. But everybody else somewhere in the middle – there seems to be quite a gap. It’s...sad to lose everything you own because the care is so expensive.”

Preferred solutions

- Workplace accommodations
 - Flexible schedules, work from home, part-time, paid FMLA, broader categories and easier process for FMLA and sick time, adult day care at employer worksite, support not stigma
- Tax incentives
 - Caregiving expenses, technology support, diagnosis-based
- Direct pay for caregiving work
- Credits toward Social Security
 - Penalty-free withdrawal for caregiving expenses
- Some mentioned COVID-relief measures as example

Workplace Accommodations

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

“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 PTO or as sick leave...it has to be taken as vacation days.”

“A lot of jobs have warnings and attendance issues. They don’t understand if you have to stay home and take care of your loved one.”

“I just wish... they would have a little bit of leeway to assist the people that take care of [family.]”

Direct Pay for Caregiving

- Significant interest in direct pay to caregivers
 - Those participating in state programs that train and pay family caregivers spoke highly of them (not available in all states)
 - Some interest in financial help with other out of pocket expenses

“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.”

“We need to get some sort of financial relief, to look after our parents or partners and all.”

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
 - Getting extra credit toward Social Security for caregiving hours

“If your family member has a diagnosis and you take care of them....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.”

“If you don’t work enough hours, you don’t get a chance to pay into retirement.”

Differences Among the Caregiver Groups

- Parents caring for children with disabilities/special needs
 - Their caregiving training needs were more pressing and encompassed a broader spectrum of medical, behavioral, and other issues
 - Direct pay for caregiving and workplace accommodations were more important to them
 - They needed respite care, but had greater reluctance to use it
 - Future planning was a worry, especially among older caregivers
- Other family caregivers
 - More open to using respite care
 - Tax incentives and retirement security (including Social Security credits) were of interest

Teen caregivers

- More reluctant to “open up” about their caregiving role – protective of their privacy and that of the person they care for
- Describe feeling stressed, isolated and having difficulty controlling anger or impatience, but don’t want to add to the stress of other family members
- Need for training especially around providing medication, helping with mobility and doing care transfers
- Would like more support (both in and outside of school)
 - Peer programs, summer camp, on-line groups, therapy, meditation and relaxation techniques
- Would like extra support regarding school
 - Flexible assignments, on-site support programs, tutoring, safe space to relax

Teen caregivers (continued)

- Take pride in what they do, despite the stress and worries
- Show a strength and wisdom well beyond their years

“I would cry about it because I don’t see any other kids doing this...Then my mom would start crying because she feels bad, she doesn’t want me to do this.”

“We’re trying to behave like an adult to support the person we’re taking care of, but we’re still children.”

“I think it might be helpful [if] the doctors can give you more information on how to do your job even better.”

“I sometimes worry...When [my dad] is late on a bill I kind of feel bad, like, ‘Oh, should I get a job to help out?’”

“It makes me feel good that I know I make them feel good.”

“The more you pour into others, the more you have to pour into yourself. “

Latinx Caregivers

- Different cultural attitudes toward family support
 - Taken as a given that your role in the family will include being a caregiver when/if the need arises
 - But pushing back against that to reach out for help
- May be more likely to be the sole family caregiver, limited outside supports
- Need for bilingual programs, information and referral
- Cultural stigma around disease in Latinx community
 - Further isolates experience of caring for people with Alzheimer's or dementia

Grandparent and Kinship Caregivers

- Reluctant to ask for help – afraid doing so might give authorities reason to question their capability or remove the children
- Several concerns focused on less favorable treatment and less support provided to grandparent/kinship vs. foster caregivers
- Most important needs:
 - Financial and legal assistance
 - Information and education
 - Peer support/interaction
 - Respite
 - Future planning especially critical

Grandparents/Kinship Caregivers

“CPS is always lurking in the background.” [CPS is Child Protective Services.]

“If I mentioned any kind of stress...or difficulties, they would say, ‘Well, we could just put them with a trained foster parent and we’ll just take them away.’ So, it made me feel as if I could not...ask for help.”

“I have never been able to understand why foster parents’ benefits are so much more than kinship or grandparent benefits.”

“Money, money, money...that’s our biggest need.”

“I think there is a stigma around if family asks for financial help....[as if] we’re just doing it for the money.”

“Our biggest struggle is looking for legal advice.”

“There is no guidance, no direction, no information, no resources.”

Issues unique to COVID-19

Pros

- Flexibility for work from home
- More time to spend with family/less time pressure
- Expanded delivery services
- Tele-health (doesn't work for all)
- Other siblings/family around to help

Cons

- Economic impact of job loss
- Social isolation
- Limited access to respite, daycare, and in-home care workers
- Many therapies don't transition well to virtual platform
- Added burdens for parents/grandparents becoming teachers
- Excess screen time
- Kids missing friends and usual activities

Some unexpected findings

- Extent of agreement on interest in pay for direct care and other types of financial solutions across all caregiver types/situations
- Desire for respite care, but concerns about using it (financial, emotional and logistical)
- Lack of awareness and understanding of available services
 - 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/craving for social supports

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

Break

Inventory of Federal Programs and Initiatives to Support Family Caregivers

Sarah Markel, PMP

Aging Service Program Specialist, AoA
Administration for Community Living

Greg Link, Director

Officer of Supportive and Caregiver Services
Administration for Community Living



Congressional Charge: Federal Inventory

“The Advisory Council’s initial report under paragraph (1) shall include— (A) **an inventory and assessment of all federally funded efforts to recognize and support family caregivers** and the outcomes of such efforts, including analyses of the extent to which federally funded efforts are reaching family caregivers and gaps in such efforts...”

Information Gathering Process

- ACL developed a template to increase informational consistency
 - Included multiple fields to address a broad range of approaches
- Federal members of RAISE Council and the Supporting Grandparents Raising Grandchildren (SGRG) Advisory Council collected information from their home agencies
 - Council members also provided referrals to agencies not represented on the council

Information Received

As of December 2020, the council has collected information from the following agencies:

- U.S. Department of Health and Human Services (9 Operating Divisions)
- U.S. Department of Education
- Consumer Finance Protection Bureau
- Corporation for National and Community Service
- Veterans Health Administration

Agencies submitting information in 2021 include:

- U.S. Social Security Administration
- U.S. Department of the Treasury
- U.S. Department of Labor

Findings

- 50+ unique programs and initiatives of varying scope:
 - Consumer-based fact sheets
 - Comprehensive caregiver support programs
- Considerable variability in program size, level of administration, services provided, and targeted consumers
- Multiple mechanisms by which programming was carried out
- Funding sources varied significantly affecting program flexibility
- All tended to be linked to Congressional authority and organizational mission
- Overlaps identified in multiple areas (i.e., rural programs, programs for older adults, consumer information)

Developing the Inventory

- ACL staff reviewed submissions and synthesized the information into the following categories:
 - Agency and program URL
 - Statute and authority
 - Population/beneficiaries
 - Program summary
 - Opportunities
- In Nov-Dec 2020, Federal agencies reviewed and revised content as necessary

Sample Entry

Department of Health and Human Services

Administration for Community Living (ACL), Administration on Aging National Family Caregiver Support Program

AUTHORITY: Section 371 of the Older Americans Act of 1965, as amended, Title III E

POPULATION(S): Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older; Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders; older relatives, not parents, age 55 and older relatives including parents, age 55 and older providing care to adults age 18-59 with disabilities.

BENEFICIARIES: Caregivers; Federal, state and local governments, organizations, and communities

SUMMARY: Established in 2000, the NFCSP provides grants to states and territories, based on their share of the population age 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. NFCSP grantees provide five types of services: information to caregivers about available services; assistance to caregivers in gaining access to the services; individual counseling, organization of support groups, and caregiver training; respite care; and supplemental services, on a limited basis

These services work in conjunction with other state and community-based services to provide a coordinated set of supports. Studies have shown that these services can reduce caregiver depression, anxiety, and stress as well as enable caregivers to provide care longer, thereby avoiding or delaying the need for costly institutional care.

Publication and Release

- RAISE Act Initial Report to Congress will include an overview and analysis of the inventory content
- Inventory will be available to the public and researchers
 - Searchable HTML
 - Posted to the RAISE website
 - Linked from the RAISE Dissemination Center
- ACL developing an RFI process for periodic updates

INITIAL REPORT TO CONGRESS: OVERVIEW OF COUNCIL REVIEW PROCESS



Congressional Charge: Initial Report to Congress

- The Secretary shall establish a **process for public input** to inform the development of, and updates to, the Strategy
- “The Advisory Council’s initial report shall include:”
 - **Inventory** and assessment of federally funded efforts to recognize and support family caregivers
 - **Council recommendations**
 - “the **identification of challenges** faced by family caregivers...”
 - Discussion of how family caregiving impacts:
 - **Medicare,**
 - **Medicaid,** and
 - **other Federal programs.**

Development Process

Commissioned the following works:

1. **In Their Own Words-Caregiver Priorities and Recommendations: Results from a Request for Information** (UMASS Boston & Community Catalyst)
2. **[Issue Brief: Medicare and Family Caregivers](#)** (CMA)
3. **[Medicaid Supports for Family Caregivers](#)** (NASHP)
4. **Federal Inventory of Programs to Assist Family Caregivers**

Development Process (cont.)

Focus: Sustained stakeholder engagement to ensure the report reflects the values, experiences, and needs of today's family caregivers

- Released an RFI (~1600 comments)
- Reviewed council discussion transcripts (incl. chat)
- Considered all sources and materials submitted (NASHP inventory, reports, definitions, concerns)
- Solicited input from JAHF, NASHP faculty, ACL

Result: ~85 page report with the following elements:

Textual Elements

Caregiver Voices

25 Caregiver stories with photos

25 Direct quotations from the RFI

5 Council member statements

6 Statements from caregivers in Tribal communities

Analysis and Discussion

Youth caregivers

International efforts to support family caregivers

Supporting family caregivers in Tribal communities

Challenges faced by family caregivers

Overviews of and links to

RFI analysis paper

Medicare brief

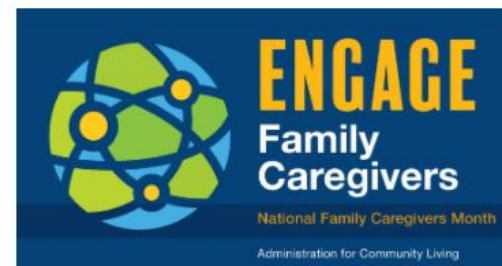
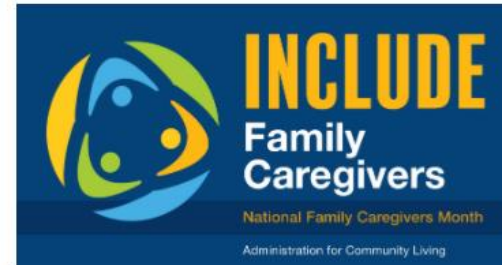
Medicaid white paper

Federal Inventory

Recommendations

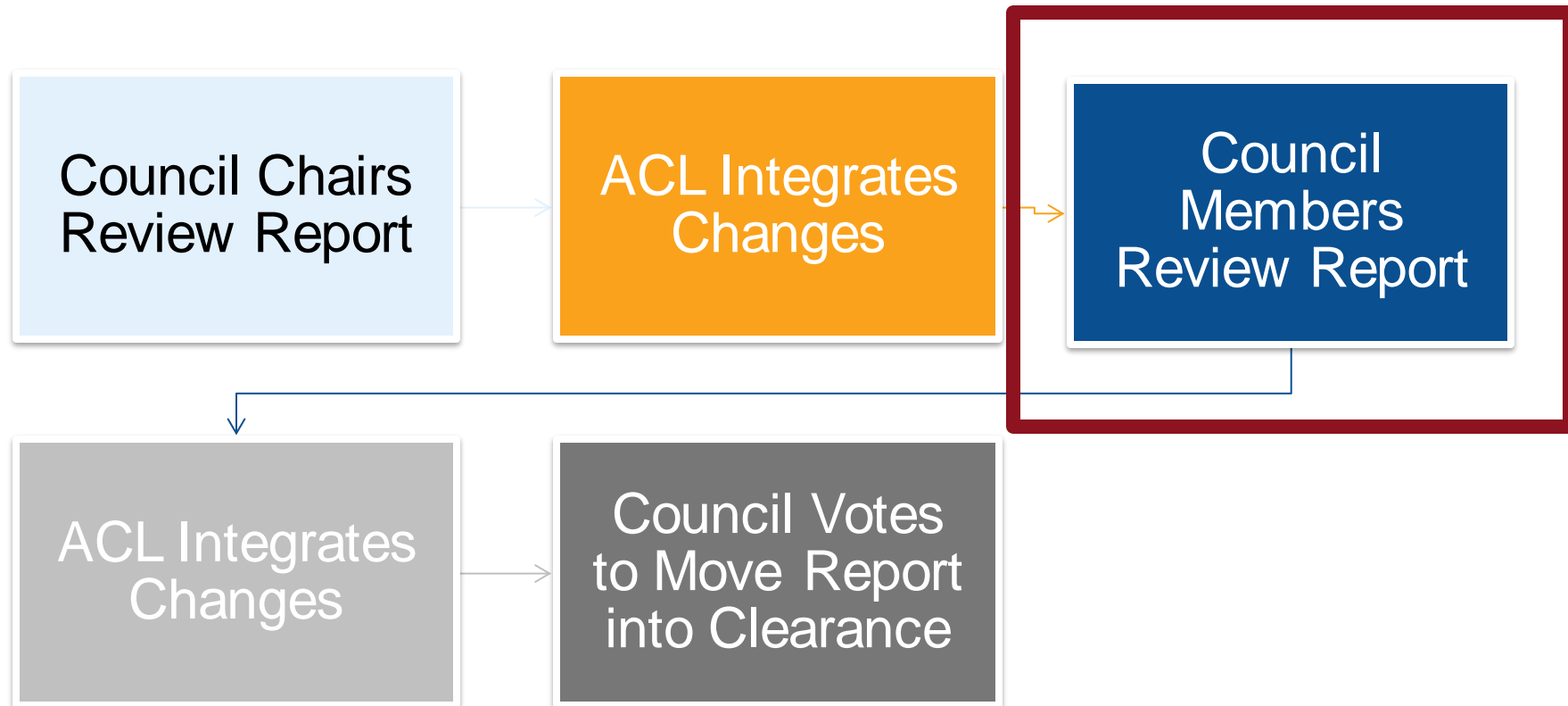
26 Recommendations with rationale statements

Graphic Elements



Source: <https://acl.gov/news-and-events/downloads-and-multimedia/NFCM>

Council Review Process



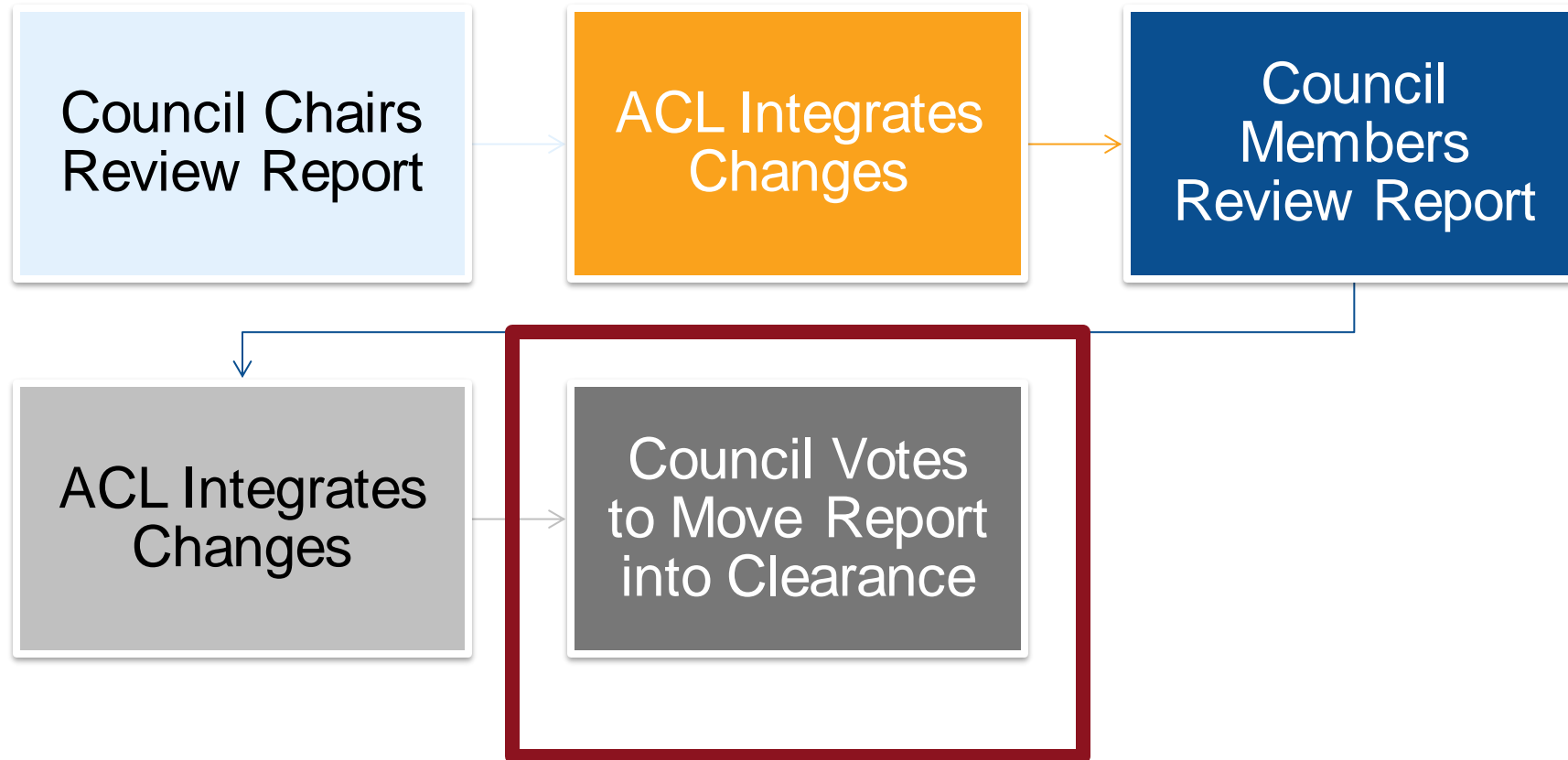
How the Council will Review

- Editing will be collaborative
- Reviewers will receive a link to a secure custom platform
- An instructional user guide will be available
- ACL team can provide assistance by phone

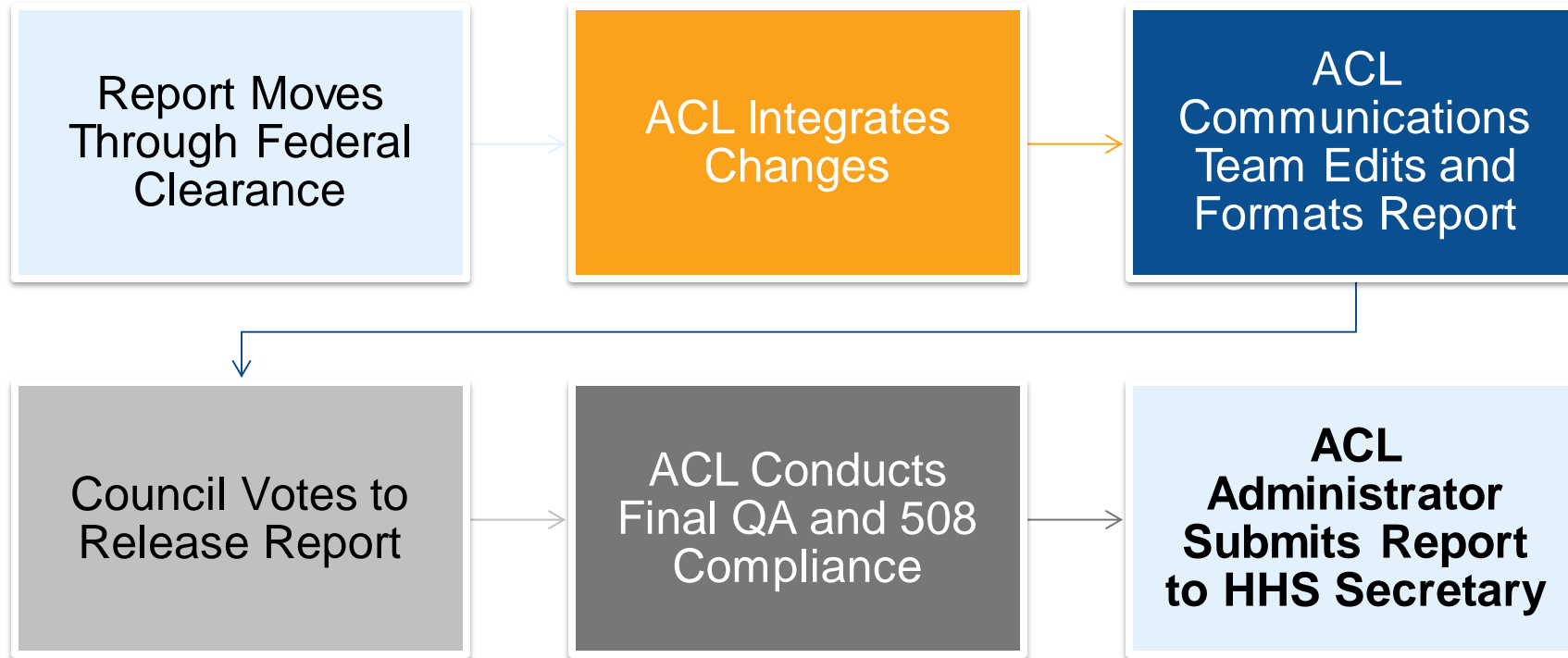
Tips for Council Review

- Select sections to focus on based expertise and interest (index table will be included with draft)
 - Some sections will be flagged for specific reviewers
- Use tracked changes to make edits
 - Remember: the council is the notional author of this report
- To the extent possible, prioritize editing over commenting within draft
 - Use email to initiate directional discussions
- Be prepared for content to change during clearance

Council Review Process (cont.)



Looking Ahead: Post-Clearance Production Process



Wrap-up and next steps

- Council members given access to the “Custom Platform”
 - Sign agreement
 - Optional training
 - User Manual
- February subcommittee meetings
- March, 2020: Full council meeting (TBD)

Thank you

