Medicaid Structured Family Caregiving: Enabling Caregivers to Make Caregiving Their Primary Focus

NASHP Webinar
March 8, 2023
NASHP Report on Structured Family Caregiving

• Georgia
• South Dakota
• Missouri
1. Neva Kaye, Senior Policy Fellow, NASHP
   • Basics of structured family caregiving

2. Rena Cox, Bureau Chief, Long-Term Services and Supports, Missouri Department of Health and Senior Services
   • Missouri's approach and lessons learned

3. Charles Duarte, Public Policy and Advocacy Director, Alzheimer’s Association of Northern California and Northern Nevada
   • Advocacy perspective and progress in Nevada
Webinar Logistics

• Use the Q&A function at the bottom of your screen to enter your questions and comments throughout the presentations

• We will address questions and comments after each presentation and at the end of the webinar

• The slides and webinar recording will be posted after the webinar on the NASHP website and sent out to all webinar registrants
Structured Family Caregiving: Findings from the NASHP Report
What is structured family caregiving (SFC)?

SFC is a package of services that support home and community-based services (HCBS) waiver participants’ primary caregivers and includes:

- Payment
- Individualized training based on the needs of the waiver participant
- Coaching
- Back-up or respite care
- Other supports
What is structured family caregiving (SFC)?

• SFC is delivered as part of a HCBS 1915(c) waiver

• **Georgia and South Dakota**
  • Added to an existing waiver that includes other services
  • Enables states to leverage other services to support caregiver/waiver participant duos
  • Waiver’s care planning and administrative structures are already in place

• **Missouri**
  • SFC-only waiver for beneficiaries with Alzheimer’s or related disorder
  • Enables design of policies to meet the specific needs of eligible beneficiaries
What sets SFC apart from other services?

• Multiple services to support a caregiver managed as a single package by an agency

• Services provided in a home where both the participant and the caregiver live

• Caregiver is often a relative or spouse of the participant

• Payment, usually a stipend, to caregiver

• Agency frequently checks in to support and oversee the caregiver

• Intended for participants who do not self-direct their services
Elements of the SFC Service Package
Caregiver Payment Flows Through Agencies

• Per diem payments to agency vary (2022)
  • Georgia: $90.20 ($99.22 due to public health emergency)
  • South Dakota: $73.14, $91.43, or $102.40
  • Missouri: $74.76

• Agencies required to pass on a specified percentage of their payment to caregivers
Individualized Caregiver Support Delivered by Agencies

• Individualized coaching and training based on current and anticipated participant needs

• Caregiver notes reviewed by the agency to identify needs and oversight

• Agencies required to provide back-up care or access to respite care
What did State Officials Report?

• SFC services are achieving their purpose; waiver participants are receiving personal care they need, at home and from someone they know and trust

• States needed funding to pay for services but no new resources for administration

• Participants and caregivers chose SFC for payment but also valued the support

• The agency that administers the SFC package plays a critical role
Key Takeaways

• SFC services can be an effective way to enable family caregivers to:
  • Make caregiving their primary focus
  • Increase their ability—and confidence in that ability—to care for their loved one
• SFC policies in South Dakota, Georgia, and Missouri can serve as models to develop effective SFC programs in your states
Thank you!

Questions?
Welcome

Missouri Structured Family Caregiving Waiver (SFCW)
Need for Structured Family Caregiving Waiver

✓ Due to the increased population of individuals with Alzheimer’s and Dementia, MO realized the current Home and Community Based Services (HCBS) program was not meeting the elevated needs of this population

✓ Best serve our participants!
Next Steps:

- 208.896 RSMo was established from General Assembly 2019 Senate Bill 514
- Structured Family Caregiving Waiver was required to be established before 07/02/2020
Diagnosis:
Diagnosed with Alzheimer’s or related disorders, as defined by 172.80 RSMo by a physician licensed in the State of Missouri

HCBS Providers:
• HCBS providers are in-home service provider agencies
• Caregivers are employees of the provider

Caregivers:
• Can be anyone including family caregivers
  • Must be able to pass a background check
• Shall reside full-time in the same home as the participant

Daily Payment:
• Daily payment rate does not exceed sixty (60) percent of nursing home cost cap
• Provider payment is not to exceed thirty-five percent of daily reimbursement rate
Structured Family Caregiving Waiver

• Approved on 02/04/2020 with an effective date 07/01/2020
  • Stumbling block: COVID hit, waiver was not funded to start 07/01/2020
• Waiver effective date was changed to 07/01/2021
  • Currently have 108 participants enrolled in the waiver
**Biggest Successes:**

- MO biggest success was CMS approving spouse and legal guardian to be the paid caregivers within this waiver
- This waiver has assisted participants to remain in their homes
  - Quality of life is greater when they are able to remain in a home setting with caregivers already with whom they are familiar with

**Lessons Learned:**

- Be careful about limiting the diagnosis and who the diagnosis must come from
- Ensure you clarify expectations of both the caregiver and the provider
  - For example, the development in relation to minimum wage
  - Trainings
  - Documentation
QUESTIONS

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Nevada Medicaid Structured Family Caregiving Waiver
Nevada Caregiving Facts and Figures  
(Source: 2022 Alzheimer’s Association Facts and Figures Report)

3rd Fast Rate of Growth of Dementia between now and 2025

Caregiving (2021)
- 48,000
  Number of Caregivers
- $1,346,000,000
  Total Value of Unpaid Care
- 79,000,000
  Total Hours of Unpaid Care
- 80.2%
  % of caregivers with chronic health conditions
- 18.3%
  % of caregivers with depression
- 10th highest average number of hours per caregiver

In 2020, Nevada Medicaid Spent $203M on People with Dementia
Lead Up to Legislature

- Interim Legislative Committee on Senior Citizens
  - March 22, 2022 Meeting
  - Presentation of SFC concept
- Nevada Commission on Aging
  - April 29, 2022 Meeting of Legislative Subcommittee
    - Presentation on SFC by Neva Kaye, NASHP
- July 6, 2022 - Bill Draft Request submitted to Interim Legislative Committee.
- August 16, 2022 - Interim Legislative Committee adopts SFC as a committee bill for the 2023 Legislative Session.
- Feb. 7, 2023 – Letter of support from Commission on Aging.
Family Caregiver Waiver – A.B. 208

- Based on work out of Indiana, Georgia and Washington, with model legislation from Missouri.
- Creates a dementia-specific HCBS SFC waiver.
- Choice of caregiver, including spouses and guardians.
- Additional supports including respite.
- Focused training for family caregivers based on Medicaid enrollee’s functional assessment.
- Easier enrollment and payments for family caregivers.
- Pass-through 65% of payments as stipends.
Discussions with State HHS Staff

• Jan. 27, 2023 Meeting with HHS
  – Medicaid HCBS and Aging Services staff
  – Review of draft bill
• Medicaid HCBS concerns:
  – Proposal will not be cost neutral.
  – Concerns with business rules restricting requirement to pass-through percentage of Medicaid payments to caregivers.
  – Medical determination may require confirmation of dementia diagnosis.
  – Medicaid Management Information System changes may be costly.
  – New provider type may be required necessitating new regulations.
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Questions?
Submit in the Q&A box at the bottom of your screen.
Learn more: nashp.org/family-caregiving

- Report on Structured Family Caregiving
- State Policy Roadmap for the National Strategy to Support Family Caregivers
- Respite Care research and maps by state
- Examples of state strategies for family and professional caregiving
- More regularly updated and published resources!
Thank you!

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