



## Activating Family Caregivers to Help Keep Care at Home

July 2018

# Meeting Goals

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- Introduce Structured Family Caregiving: a new in-home service option for HOPE Waiver participants
- Review characteristics of the new service
- Identify participants who may benefit from Structured Family Caregiving

# Seniorlink supports States to help family caregivers keep care at home

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- Seniorlink has been providing Structured Family Caregiving since 2005
  - We currently serve Medicaid members and their caregivers in seven States (CT, IN, LA, MA, OH, PA and RI)
  - We have supported over 15,000 family caregivers to support their loved ones (adults of all ages and disabilities)
- Seniorlink is experienced in engaging family caregivers to:
  - Provide personal care
  - Understand and manage behaviors
  - Understand the implications and progression of complex conditions
  - Recognize signs and symptoms of changing health care needs
  - Communicate their observations from the home
  - Become effective care coordinators - asking the right questions of health care providers and supporting the appropriate utilization of health care resources

**93%** *Caregivers said they felt very confident in managing medical incidents for the person they are caring for (2017 Seniorlink Satisfaction Survey)*

# Why is South Dakota introducing a new service now?

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- South Dakota is continuing to rebalance LTSS towards home-based care
  - Identifying ways of expanding and enhancing community-based LTSS
  - Leveraging existing resources and informal support networks, including family caregivers
- The number of seniors and adults with disabilities continues to increase; population changes, health needs, and individual preferences drive where participants most want to receive care
- Multiple surveys identified the need to develop additional supports for family caregivers who help participants remain at home

# Family members are providing care but need support

## What we know:

- Caregivers are providing care to family members who need it
- They are largely unsupported and taking on increasingly complex care as chronic conditions progress

## South Dakota



### Overall...

Caregivers

85,000

% of population

10.0%

Hours of care

79 million

Value

\$1.0B

Source AARP Valuing the Invaluable: 2015 Update, July 16, 2015; Alzheimer's Association 2018 Alzheimer's Disease Facts and Figures, March 29, 2018.

# Solution: A new service option for HOPE Waiver participants

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## Structured Family Caregiving

- A service that leverages existing resources (motivated family members and housing):
  - Enables participants to receive care from trusted caregivers in a preferred setting
  - Empowers caregivers to continue caregiving with financial and professional support

# Structured Family Caregiving (SFC)

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## **Service Description**

Structured Family Caregiving is a service through which:

- A participant receives assistance with daily personal care and other needs from a caregiver who lives in the same home
- The caregiver receives education, ongoing coaching, and a financial stipend from a Structured Family Caregiving provider agency so the caregiver can support the participant to live at home

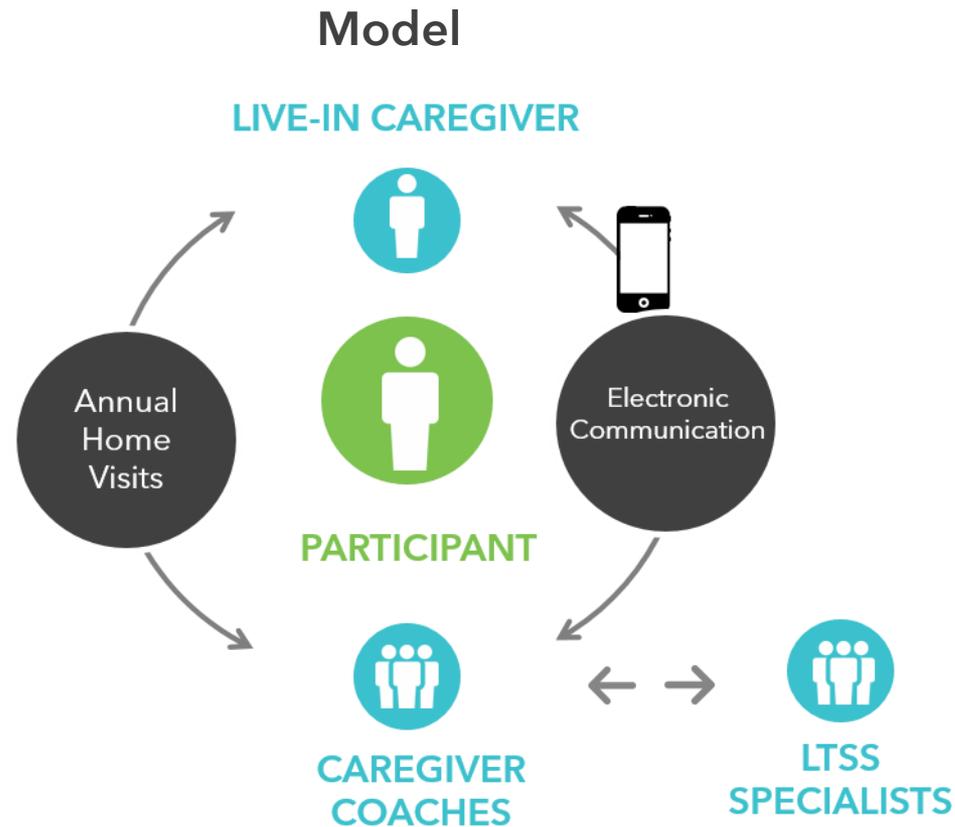
## **SFC Provider Agency Role**

- Qualifies the caregiver and home, based on State requirements (caregiver background checks, etc.)
- Provides the caregiver with education and coaching specific to the needs of the participant
- Communicates regularly with the caregiver about the participant's health status and the caregiver's support needs
- Conducts home visits on an annual basis, supplementing visits by LTSS Specialists; may do more visits (at the home or elsewhere) based on the needs of the caregiver and the participant

## **Caregiver Role**

- Lives with the participant and provides personal care, helps manage behaviors (if needed), and performs supportive services (e.g. homemaker, meal preparation)

# Example: How Seniorlink Administers Structured Family Caregiving



# SFC: Qualified Caregivers

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- May be related or “fictive kin”
- Must live in the same home with the participant
- Must pass State fingerprint background checks
- Must be determined by the SFC Provider Agency to be able to perform the daily care the participant needs, as documented in the participant’s person-centered service plan
- Must contract with the SFC Provider Agency and agree to collaborate with the provider agency (e.g. reporting changes in the participant’s needs and health, providing notes, participating in visits)

*Key Takeaway: A caregiver can be any adult who lives with and is responsible for providing care to the participant, and who agrees to communicate with the SFC Provider Agency regularly.*

# SFC: Qualified Home

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- Is a private residence owned, rented, or leased by the participant or the caregiver
- Is safe, accessible, and allows for the comfort and privacy of the participant(s) receiving care
- Has no more than 2 participants receiving SFC

*Key Takeaway: A home can be any private residence that is appropriate for the participant's needs.*

# SFC: Provider Agency Responsibilities (1)

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The SFC Provider Agency has responsibility for supporting caregivers to ensure the best outcomes for participants:

- Credential the caregiver and ensures s/he continues to meet qualifications
- Assess the caregiver to determine her/his ability to meet the needs of the participant and the caregiver's education and support needs
- Provide individualized, initial and ongoing, coaching to each caregiver
- Communicate regularly with each caregiver to understand a participant's health status and assess the quality of care provided
- Provide support as needed during "trigger events"
- Issue financial stipends to each caregiver

*Key Takeaway: After a caregiver is qualified, the caregiver will contract with the Provider Agency, and receive ongoing caregiver coaching and financial stipends.*

# SFC: Provider Agency Responsibilities (2)

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Working with LTSS Specialists, SFC Provider Agencies will:

- Establish communication protocols
- Ensure the assessed needs of the participant (as established by the LTSS Specialist) are addressed by the caregiver and any new needs are communicated and managed
- Collaborate on the development of an emergency back-up plan for times when the caregiver is unable to provide care, including identifying alternate caregivers and informal supports
- Report critical incidents and significant changes in the participant's status
- Provides LTSS Specialists with timely information on health changes or circumstances that could be "trigger events"

*Key Takeaway: The SFC Provider Agency will communicate regularly with LTSS Specialists to report changes in the participant's needs or other circumstances that may impact community tenure.*

# Benefits of Structured Family Caregiving

Participants	Caregivers	LTSS Specialists
<ul style="list-style-type: none"><li>• Have the choice of a trusted family member or friend to provide care</li><li>• Receive care that is culturally-competent and participant-directed</li><li>• Have another option to receive care where s/he wants to (her/his home or the caregiver's home)</li></ul>	<ul style="list-style-type: none"><li>• Receive a financial stipend</li><li>• Receive ongoing, individualized education</li><li>• Have resources they need to provide the best possible care and support to manage challenging behaviors</li><li>• Are prepared for the progression of their loved one's medical conditions</li><li>• Are engaged in care planning and become effective collaborators to support the appropriate utilization of health care resources and long-term services and supports</li></ul>	<ul style="list-style-type: none"><li>• Receive relevant information from Provider Agencies about a participant's health and other needs and circumstances that may impact community tenure</li><li>• Are able to intervene in a more timely manner to improve outcomes</li></ul>

# Potential Participants

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## Consider participants who...

- Are new to the HOPE Waiver or who have a new need for LTSS
- Live with someone who currently provides personal care (that meets the definition of SFC services) or are currently receiving personal care and/or homemaking
- Have an engaged family member who might be willing to live with the participant to provide care to help the participant remain in the community
- Are expressing frustration, or whose family is expressing frustration, with intermittent personal care services
- Have family members who are expressing concern about the participant's safety when s/he is alone
- Have family members who are worried about the participant's increasing needs, declining health, or "progression" towards institutional care
- Have an increasing need for more units of personal care and related services
- Have Alzheimer's or dementia
- Have a medical or behavioral health condition that manifests in disruptive behaviors (e.g. wandering, behavior that is considered socially inappropriate)

# SFC: Rate Tiers

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- SFC has three rate tiers that are based on the level of support that a participant requires
- The rates are the daily payment to the SFC Provider Agency and include the payment to the provider and the stipend to the caregiver
- The participant's tier is established by the LTSS Specialist based on the information collected through the intake and assessment process and in consultation with the SFC Provider Agency
- When an SFC Provider Agency notes a significant change in the participant's status and daily care needs, the provider may request a reassessment by the LTSS Specialist
- Rate Tiers:
  - Tier 1 = \$40.57
  - Tier 2 = \$50.65
  - Tier 3 = \$56.72

## Questions about the service....

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**Q. Can a participant receive other services if s/he chooses SFC?**

A. Meals, homemaker and/or chore services are not allowed at the same time. Other Waiver services may be available based upon assessment and authorization by the LTSS Specialist.

**Q. What is a financial stipend and why is it tax free for federal purposes?**

A. The caregiver stipend is considered a “foster care payment” under the Internal Revenue Code (Section 131) because the program meets certain conditions; the IRS excludes these stipends from income.

**Q. What is the amount of the daily stipend that will be paid to a caregiver?**

A. The amount of the daily stipend will vary depending on the needs of the participant . SFC Provider Agencies will discuss the amount with the caregiver once the caregiver is determined to be credentialed.

# Questions about caregivers...

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## **Q. Can relatives be paid caregivers in SFC?**

- A. Yes. Family members, including spouses and other legally responsible relatives, are eligible to be caregivers. All caregivers - family members, friends, and others - must meet State-specified qualifications, including background checks, and must be assessed by the SFC Provider Agency as able to provide the care and support needed by each participant.

## **Q. Can caregivers become SFC caregivers if they are already providing "informal" care?**

- A. Yes. The caregiver must meet the qualifications and agree to contract with and receive support from the SFC Provider Agency.

## Questions about caregivers (cont...)

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### **Q: May a caregiver work outside of the home?**

- A. A caregiver is not prohibited from working unless doing so would interfere with the caregiver's obligation to support the participant. A caregiver must tell the SFC Provider Agency about activities in which she is engaged outside the home (including employment) so the provider can evaluate the circumstances and determine whether the participant can be left alone and/or whether others are available to provide intermittent, informal support.

### **Q. Shouldn't we be worried about family caregivers burning out?**

- A. Yes but SFC Provider Agencies are responsible for making sure the caregiver is supported to take care of herself/himself. Providers will work with a caregiver over time to ensure the caregiver takes planned breaks. SFC Provider Agencies will work closely with LTSS Specialists to ensure a shared understanding about the participant's individualized back-up plan in the event the caregiver needs to take an unplanned break (e.g. caregiver becomes ill).

# Thank You

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