

SOUTH DAKOTA STRUCTURED FAMILY CAREGIVING GUIDE

Developed by the South Dakota Department of Human Services,
Division of Long Term Services and Supports

Updated December 2018

Division of Long Term Services and Supports Guide to Structured Family Caregiving

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What is Structured Family Caregiving?

Structured family caregiving is a shared living arrangement that offers participants an opportunity to reside with a primary/principal caregiver in the participant's own home or in the home of the primary caregiver. The principal caregiver provides assistance with personal cares, supervision, cueing, meals, homemaker, chore services, medication management (to the extent permitted under State law), and other instrumental activities of daily living (e.g. transportation for necessary appointments and community activities, shopping, managing finances, and phone use). The goal of this service is to provide the participant with the opportunity to remain living in his/her community while receiving necessary care and supervision.

Structured family caregiving is an option for any person who is 65 or over, or 18 or older with a disability that is interested in this type of living arrangement and is a current participant of the Home and Community Based Options and Person Centered Excellence (HOPE) waiver through the Department of Human Services (DHS) Division of Long Term Services and Supports (LTSS) or is eligible for the HOPE waiver.

Benefits of Structured Family Caregiving:

- Assists the State with expanding and enhancing community-based long term services and supports as an alternative to institutional care;
- Leverages existing resources and informal support networks, including family caregivers;
- 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;
- Participants have the choice of a trusted family member or friend to provide care;
- Participants receive care that is culturally-competent and participant-directed;
- Participants have another option to receive care where s/he wants to (her/his home or the caregiver's home);
- Caregivers receive a financial stipend;
- Caregivers receive ongoing, individualized education;
- Caregivers have resources they need to provide the best possible care and support to manage challenging behaviors;
- Caregivers are prepared for the progression of their loved one's medical conditions;
- Caregivers are engaged in care planning and become effective collaborators to support the appropriate utilization of health care resources and long-term services and supports.

Definitions

Eligible Consumer: Any person who has been determined eligible for the HOPE Waiver by LTSS.

Medicaid Enrolled Structured Family Caregiving Provider Agency: The entity responsible for the oversight of the structured family caregiving service. The Medicaid enrolled structured family caregiving provider agency provides coaching and support to the principal caregiver and passes through a portion of the Medicaid reimbursement to the principal caregiver.

Staff: Individuals employed by the Medicaid enrolled structured family caregiving provider agency to complete the tasks necessary to oversee the provision of the structured family caregiving service.

Principal Caregiver: The primary caregiver for the eligible consumer. The principal caregiver receives a stipend from the Medicaid enrolled structured family caregiving provider agency. A principal caregiver is not an employee of the Medicaid enrolled structured family caregiving provider agency and is not subject to employee regulations such as wage/hour laws, workers compensation, and unemployment.

Care Plan/Service Plan: A written plan developed with each consumer and whomever he/she wishes to participate. The Medicaid enrolled structured family caregiving provider agency must also participate in the development of the Care Plan. The Care Plan/Service Plan summarizes the consumer's identified needs and the strategy for addressing unmet needs.

Level of Care: The level of care is based on an assessment of needs completed by the LTSS Specialist/Case Manager. Individuals eligible for the HOPE waiver meet the nursing facility level of care.

Person Centered Philosophy: Values, concepts, and tools that are used to promote a person's positive control over the life they have chosen for themselves. The core concept of what is important to (happy, content, satisfied) and important for (healthy, safe and seen as a valued member of their community) a person is the core concept and is foundational during care planning process.

Roles and Responsibilities

Medicaid Enrolled Structured Family Caregiving Provider Agency

- Credential the caregiver and ensure s/he continues to meet qualifications;
- Assess the home environment to ensure it is safe and accessible to the eligible consumer;
- 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;
- Issue financial stipends to each caregiver;
- The SFC Provider Agency has responsibility for supporting caregivers to ensure the best outcomes for participants;
- Must provide the structured family caregiving oversight statewide.

Principal Caregiver

- Participate in the development of the care plan, team meetings, and check ins with the Medicaid enrolled structured family caregiving provider agency;
- Provide routine intermittent personal care, supervision, cueing, meals, homemaker, chore services, medication management (to the extent permitted under State law), and other instrumental activities of daily living (e.g. transportation for necessary appointments and community activities, shopping, managing finances, and phone use) as written in the Care Plan;
- Maintain the home ensuring it is safe and accessible;
- Follow the policies and procedures of the Medicaid enrolled structured family caregiving provider agency and LTSS;
- Complete written documentation as required by the Medicaid enrolled structured family caregiving provider agency and LTSS;
- Limit the number of consumers being supported in structured family caregiving to no more than two.

Department of Human Services/LTSS

The Division of Long Term Services and Supports will provide on-going case management for each consumer. The case manager is an LTSS Specialist, employed by LTSS, who acts as an advocate for the participant and assists the participant and their families in locating providers and services that align with their identified goals/needs. The case manager is responsible for:

- Reassessing the consumer's needs and eligibility at least annually;
- Facilitating the development of the Care Plan/Service Plan;
- Determining changes to the Care Plan/Service Plan;
- Resolving any consumer concerns and other consumer-related issues;
- Completing quarterly monitoring;
- Educating participants about LTSS services, including shared living option.

Next Steps

Becoming a Medicaid Enrolled Structured Family Caregiving Provider Agency

Agencies interested in providing Structured Family Caregiving should:

- Review the FY2019 Structured Family Caregiving Provider Provision available at <http://dhs.sd.gov/ltss/ltssproviders.aspx>;
- Develop policies and procedures related to Structured Family Caregiving as outlined in the FY2019 Structured Family Caregiving Provider Provision;
- Become familiar with US Department of Labor regulations. Payment for these services is very different from the compensation typically provided.

Structured Family Caregiving Participants

Structured Family Caregiving may be a good option for individuals that:

- Have an engaged family member who might be willing to live with the participant and provide support 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 related dementia;
- Have a medical or behavioral health condition that manifests in disruptive behaviors (e.g. wandering, behavior that is considered socially inappropriate)
- Are eligible or may be eligible for the HOPE Waiver:
 - Age 65 or older; or age 18 and over with a qualifying disability
 - Meet a nursing facility of level of care
 - Participate in an assessment of needs
 - Receive one or more waiver services at least one time per month
 - Meet financial eligibility as determined by Economic Assistance

Individuals and/or families interested in participating in Structured Family Caregiving may contact Dakota at Home at 1-833-663-9673.

Resources

- Department of Human Services
 - <http://dhs.sd.gov/>
- Division of Long Term Services and Supports
 - <http://dhs.sd.gov/ltss/default.aspx>
- Administrative Rules of South Dakota
 - Home and Community-Based Services
 - <http://sdlegislature.gov/Rules/DisplayRule.aspx?Rule=67:40:19>
 - Nursing facility care classification
 - <http://sdlegislature.gov/Rules/DisplayRule.aspx?Rule=67:45:01:03>
- Department of Labor Shared Living regulations
 - <https://www.dol.gov/whd/regs/compliance/whdfs79g.htm>
- Person Centered Thinking tools
 - <http://www.learningcommunity.us/home.html>
 - <http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/>
- IRS Difficulty of Care payments:
 - <https://www.irs.gov/individuals/certain-medicaid-waiver-payments-may-be-excludable-from-income>
 - <https://www.irs.gov/pub/irs-drop/n-14-07.pdf>
- Social Security Administration-When People Need Help Managing Their Money:
 - <https://www.ssa.gov/payee/>