Massachusetts Family Caregiver Support Program

Program Guidelines and Expectations

March 2013

Introduction
In the reauthorization of the Older Americans Act in 2000, the National Family Caregivers Support Program, Title III-E was established by the Administration on Community Living /Administration on Aging, ACL/AOA. This program focuses much needed attention on the vital role of the informal caregiver who provides essential care to vulnerable family members in the home. The Massachusetts Family Caregiver Support Program (FCSP) is administered by the State Unit on Aging in partnership with the AAA/ASAPs across the state.

The goals of the Massachusetts Family Caregiver Support Program are to:

- Support and promote the ability of caregivers to continue their caregiving role by equipping them to make informed decisions, solve problems, reduce stress and maintain their overall physical and emotional health.
- Ensure that resources are focused on provision of direct services to caregivers to the fullest extent.
- Promote equity across the state regarding the provision of FCSP services.
- Ensure that the program is available to cultural, ethnic and linguistic minorities, LGBT and low-income caregivers and that these caregivers are given priority as appropriate and possible.
- Develop and ensure the availability of core services and standards to be implemented by all FCSPs.
- Integrate the mission of support to family caregivers throughout the culture and service structure of the AAA/ASAPs.
- Build the sustainability of the caregiver program through close coordination with AAA/ASAP operations and collaboration with community stakeholders.
- Offer grandparents who are raising grandchildren support and services to meet their specialized needs.
- Establish a coordinated outreach system using proven methods and leveraging best practices. Incorporate consideration of caregiver needs into the overall mission of AAA/ASAP organization so that home care staff will look at the needs of both caregivers and elders as they perform their work.
- Coordinate the efforts of AAA Planners with input from the Caregiver Program in developing the statewide needs assessment and local needs assessments, plans and procurements.

Family caregivers assist older adults with various aspects of daily living. This ongoing responsibility can prove taxing and challenging, physically, financially and emotionally as well
as be rewarding. With the right supports to meet individual needs, caregivers can become better equipped to make informed decisions and solve problems related to their caregiving roles, take better care of their own physical and mental health, reduce their overall stress, and maintain their capacity as a caregiver as long as possible. The services and assistance provided through the FCSP are designed to achieve these outcomes that potentially lead to avoiding or delaying the need to place care recipients in an institutional settings. Local FCSP services are flexible in meeting the broad range of caregiver needs and are provided through five service categories as defined by ACL/AOA.

- Individual Counseling, Support Groups and Caregiver Training
- Respite Care
- Supplemental Services
- Assistance to caregivers in gaining access to services
- Information/outreach to caregivers about available services

The process of assisting caregivers can take different paths within the structure of an individual AAA/ASAP. It is essential that caregivers be made aware of options for support and services to meet their needs, whether at the initial contact, when an internal referral is made, or at any point along the continuum of service. AAA/ASAP staff should be aware that caregivers may not always present themselves as needing assistance and go unnoticed as potential service recipients.

The availability level of the 5 service categories may vary at the local FCSPs. All local FCSPs shall make every effort to maximize their ACL/AOA Title III-E allocation and other funding sources to offer the full range of FCSP services as feasible with a priority in direct service. The FCSP should work in conjunction with other community based resources in offering support to caregivers. It is expected that referrals to the FCSP shall come from both AAA/ASAP/ staff and community sources.

Each AAA/ASAP should have a designated MFCSP staff or assign the FCSP function to a staff person who could have several roles. See Appendix A FCSP Staff Functions /Models

With the expansion and development of programs that benefit both frail elders and their families such as SHINE, Options Counseling and Care Transitions, the need to focus time and attention on the caregiver should not be overlooked or under estimated. It is essential for the AAA/ASAPs to maintain the integrity of the FCSP by keeping focus on the caregiver and their needs while using dual staff and managing their Title III-E allocation. AAA/ASAPs need to provide a clear distinction between job functions and establish a process to refer a caregiver between or among appropriate programs.

**Family Caregiver Support Program Expectations and Guidelines**

This document establishes expectations and guidelines for the FCSP according to the five service categories as defined by ACL/AOA. These guidelines set forth standards intended to delineate the range of program services and less to dictate how these service are accomplished.

Elder Affairs will assemble data submitted from local programs and review SIMS/SAMS data during the program year to evaluate how these expectations are being met. It is required that
local FCSPs follow the current FCSP Business Rules to ensure that required information is reported correctly. See Appendix B FCSP Business Rules and Practices Edition 2.0

Program Definitions:

Direct Service is a service that specifically involves caregivers regardless of the setting including: information and assistance in accessing services, counseling, assessment, support groups, caregiver training, assistance with supplemental items and respite.

Eligible program participants –

- Adult family members or other informal caregiver age 18 and older providing care to individuals 60 years of age and older;
- Adult family member or other informal caregiver age 18 and older providing care to an individual of any age with Alzheimer’s disease or related disorders;
- Grandparents and other relatives (not parent) age 55 and older providing care to children under the age of 18; and
- Grandparents and other relatives (not parents) 55 years of age and older providing care to adults age 18-59 with disabilities.

Program Income
With discretion, voluntary contributions / donations are allowable in the FCSP. Caregivers, organizations and employers should be provided an opportunity to make a voluntary contribution towards FCSP services and be informed that their donation will help to extend the program’s resources.

Title III-E service categories are organized below by: definition, expectations / guidelines, tools, and reporting instructions. The FCSP Business Rules shall be followed in concert with the following Guidelines and Expectations.

FCSP Service Categories – Group I

1. Counseling, Support Groups and Caregiver Training

Definition:

a.) Counseling is conducted with caregivers to assist them in making decisions, assessing the merits of various options, and solving problems related to their caregiving roles. Counseling is a more intense involvement with a caregiver than the provision of Access Information (service category 4.)
**Expectations / guidelines:**
Caregivers seeking/needing services beyond access assistance (enhanced I&R) and/or exhibiting signs of caregiver stress, depression or burnout, should be offered the opportunity of counseling and/or an assessment meeting with a Caregiver Specialist. It is recommended that these meetings take place in person at the mutual convenience of the caregiver and caregiver specialist. In situations where an in person meeting is not feasible, a phone consultation is acceptable. The use of email can be an efficient option for initial and follow-up contact, if an in person meeting or phone call can’t be arranged.

The goal of counseling is for the caregiver to become informed about options, make decisions/solve problems and implement some or all of a proposed Caregiver Action/Follow-up Plan. Caregiver staff generally provides individual counseling; however, when appropriate, referrals to professional specialists, such as mental health, housing counselors or SHINE, are recommended and arranged for the caregiver. Group counseling/meeting is an option used when appropriate, e.g. when working with families or meeting with a group of caregivers with similar concerns.

Typically during an initial individual counseling session an assessment will be facilitated by the caregiver specialist as appropriate. Caregiver staff may find that while many caregivers benefit from one visit, others need additional visits and/or follow-up. In most situations, the standard caregiver assessment should be used to guide the discussion between the caregiver and the caregiver specialist. The assessment should result in the development of a Caregiver Action/Follow-up Plan to address the caregiver’s concerns. The initial session may last from one to three hours, depending upon the caregiver’s need to discuss his or her situation and ability to absorb new information, as well as the service options being considered.

During these sessions/meetings, the Caregiver Specialist typically will:
- Gain a better understanding of the needs and concerns of the caregiver;
- Discuss options with the caregiver;
- Bring attention to the caregiver’s health, well-being and skills as a caregiver;
- Become aware of the emotional and mental health status of the caregiver and determine when an additional course of action is warranted, including presenting the situation to the multi-disciplinary team if the care recipient is a consumer receiving services from an AAA/ASAP or making a referral to an outside counseling resource.

The Caregiver Specialist should have effective skills to facilitate counseling and assessment meetings, strong knowledge and understanding of resources and the ability to recognize indicators of caregiver burden such as depression, stress and social isolation. The National Association of Social Workers developed Standards for Social Work Practice with Family Caregivers of Older Adults in partnership with AARP and ACL/AOA which offers best practices that FCSPs might find useful.

**Tools:**
*FCSP Caregiver Assessment Form* captures essential information including: Caregiver contact information and the caregiving situation; the care recipient’s characteristics and the level of
assistance the caregiver gives to the care recipient; the caregiver’s self-assessment of personal health and well-being; an assessment of their capacity to continue performing in the caregiver role and identification of any problems or concerns currently troubling the caregiver.

See Appendix C PI-10-13 FCSP Caregiver Assessment

**Reporting Instructions:**
All counseling sessions are reportable in SIMS/SAMS as “Counseling” whether facilitated by the Caregiver Specialist or by an outside resource that is funded through the FCSP.

**Required by ACL/AOA (Annual NAPIS report)**
- Unduplicated number of caregivers served
- All caregiver characteristic as listed on NAPIS report
- The unit of service is one session (total units reported)

**Required by Elder Affairs**
SIMS/SAMS is used to record counseling services and associated documentation, e.g., journal entries and assessment information.

Caregiver Action/Follow-up Plan is developed.
The Caregiver Specialist and the caregiver will develop together a plan that identifies the areas of concern the caregiver wants to focus upon, explains how the caregiver specialist will support the caregiver, identifies resources the caregiver can access, and outlines next steps toward addressing the caregivers concerns. The caregiver specialist can either leave the plan with the caregiver at the close of an assessment session or send it to the caregiver within seven business days. The format of the required plan is at discretion of the local MFCSP.

See Appendix D Caregiver Action/Follow-up Plan Sample

MFCSP Caregiver Satisfaction Survey is conducted.
The AAA/ASAP will follow up with caregivers to assess their satisfaction with the quality of the counseling and other services that they may have received as a result of an assessment.

See Appendix E PI-12-01 FCSP Caregiver Satisfaction Survey

**Definition:**

**b.) Support Groups** involves facilitating caregiver participation in peer support groups, diagnosis-specific support groups (e.g. Alzheimer’s diseases), and thematic groups (e.g. support group for grandparents raising grandchildren) so that the caregiver receives assistance in making decisions and solving problems related to their caregiving role, while benefiting from social interaction.

**Expectations /guidelines:**
Support groups are designed to offer purposeful discussions in which information is exchanged to support decision-making and methods for improving coping skills are shared. The therapeutic value of peer-led and professionally facilitated groups has been verified by the experience of
many caregivers. There are many types of support groups; the local AAA/ASAP may fund a group through a contract with an independent entity or directly host a group at its agency or other convenient location. The FCSP should create linkages with existing groups as well as initiate groups, when needed, to aid in caregiver support.

Program staff should identify community needs for specifically focused support groups, such as Alzheimer’s disease, developmental disabilities, LGBT, or culturally appropriate caregiving.

Caregiver staff may facilitate a caregiver’s participation in a support group, whether by ensuring respite for the care recipient, accessing transportation for the caregiver or offering other forms of assistance.

- Each FCSP shall develop and maintain a list of support groups with pertinent contact information including contact names of group leaders, location, meeting times, focus of the group, its size and accessibility, or be able to obtain such information from a contact person. The AAA planner should work with the FCSP staff to ensure that the Regional Community Needs Assessment will address the need for and identify gaps in availability of various types of support groups in the area.
- Participants of FCSP funded Support Groups shall complete a caregiver satisfaction survey that should be reviewed by the FCSP staff.

**Tools:**
As a result of using the FCSP Caregiver Assessment Tool or through other caregiver contact a need for a support group may be indicated.

**Reporting Instructions:**

Required by ACL/AOA (Annual NAPIS report)
- Unduplicated number of caregivers served by support group programs
- All caregiver characteristics as listed on NAPIS report
- The unit of service is one session

Required by Elder Affairs
- SIMS/SAMS is used to record services units
- Current list of support groups offered in service area
- FCSP Caregiver Satisfaction Survey should be conducted

**Definition:**

c.) **Caregiver Training** provides or supports training and instruction to the caregiver on how to manage certain aspects of direct care, such as involving Alzheimer’s disease or Activities of Daily Living; increases their capacity to make decisions and solve problems; and/or mitigates negative effects upon their own health and well-being. Both individual and group training are included.
Expectations/guidelines:
Elder Affairs is committed to the support and improvement of training provided to caregivers through local FCSPs. Group education programs, particularly evidence-based, one time seminars or conferences for caregivers offer effective and efficient means to assist caregivers in managing many aspects of their caregiving role and personal needs.

Local FCSP should facilitate training by:
- Identifying appropriate training for caregivers. Specific training needs should be identified through the caregiver assessment process; options for individual or group training should be discussed.
- Making available one-on-one training for caregivers when possible. AAA/ASAPs should identify needs for such training and balance this with local needs and ability to respond.
- Offering evidence-based programs such as Powerful Tools for Caregivers. Local FCSPs that offer Powerful Tools for Caregivers are encouraged to collaborate where feasible in conducting this training.
- Encourage group training sessions to maximize outreach to caregivers and offer needed skill building. Group trainings can offer rich opportunities for some caregivers to listen to and learn from each other.
- Using http://fcsp.800ageinfo.com to post training on the statewide training calendar. This is an opportunity for FCSPs to refer caregivers to out-of-area training when appropriate.
- Collaborating with diagnosis specific groups such as Alzheimer’s Association to maximize appropriate referral and enrollment in their training opportunities.
- Fostering cooperation between the AAA planner and the caregiver staff to monitor and evaluate training sessions that are funded through MFCSP funds.
- Include Caregiver training needs in the AAA/ASAP community needs assessment.

Reporting Instructions:
Required by ACL/AOA (Annual NAPIS report)
Unduplicated number of caregivers served
All caregiver characteristics as listed on NAPIS report
The unit of service is one session

Required by Elder Affairs:
All training units should be entered in SIMS/SAMS
FCSP Caregiver Satisfaction Survey shall be conducted

2. Respite Care

Definition:
Respite Care offers temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief for caregivers.
**Expectations/guidelines:**
Respite is a means of reducing caregivers’ stress and promoting continuity of caregiving. A variety of respite services can be authorized, including but not limited to in-home respite, non-residential day programs for elders, companion care, short-term institutional residence for elders, and child-appropriate respite options for grandparents. Respite services may vary among local FCSP.

Local FCSP shall:

- Refer caregivers to Home Care respite services or/and other community based options, as appropriate. FCSP respite funds are used when other resources are exhausted or when other sources cannot meet the unique respite needs of the caregiver.
- Negotiate payment of a percentage of the cost of the respite service with caregivers as appropriate.
- Develop a policy regarding FCSP expenditures for respite services. Such policy shall address the financial parameters of the agency’s FCSP respite services, the types or amounts of caps on expenditures; the time period for which the cap is applicable, and other components as appropriate.
- Promote the use of family members and volunteers to provide respite when appropriate and feasible.

**Tools:**
As a result of using the FCSP Caregiver Assessment Tool or through other caregiver contact a need for respite may be indicated.

**Reporting Instructions:**

- **Required by ACL/AOA (Annual NAPIS report)**
  - Unduplicated number of caregivers served
  - All caregiver characteristic as listed on NAPIS report
  - The unit of service is one hour

- **Required by Elder Affairs:**
  - FCSP Caregiver Assessment shall be conducted before respite services are offered
  - All respite services shall be reported in SIMS/SAMS
  - FCSP Caregiver Satisfaction Survey shall be conducted

**3. Supplemental Services**

**Definition:**
Supplemental Services provides a one-time, ad hoc purchase to complement the care provided by caregivers. The benefit should focus on the caregiver, although in many situations, the care recipient will benefit as well. Supplemental services may include Service Scholarships/Subsidies and Durable /Adaptable Equipment or Home Modification.
Expectations/Guidelines:
The program component of supplemental services allows staff to be flexible and open to unique purchases of supportive services. The goal is to meet the caregiver where she/he needs help, with supplemental services viewed as limited interventions, rather than long term funding. Supplemental services may vary among local FCSPs.

- Service Scholarships/Subsidies proving financial assistance to caregivers for one-time service rendered, such as specialized therapy for the elder or caregiver; personal care items such as incontinence supplies; emergency response systems; assistive technology or legal assistance.
- Durable /Adaptive Equipment or Home Modification includes purchased or services rendered to assist caregivers such as exterior ramps, lift chairs, grab bars and other assistive devices that can ease the physical dependence of the care recipient on the caregiver.
- In general, purchases of durable medical equipment, medical supplies, and assistive devices should be coordinated with programs that pay for these same items through Medicare (DME), the Commission for the Blind, the Commission for the Deaf and Hard of Hearing, and other organizations. Caregiver staff should identify such resources and establish linkages as appropriate.
- All other available funding sources should be explored before using FCSP funds. The practice of leveraging, maximizing and pooling funding sources should be used to the best advantage. Some examples of best practices include creating local Ramp Building Squads, negotiating contracts for carpentry services, purchasing building supplies at reduced rates, and developing lists of volunteer or reduced-fee handymen. Civic groups and COAs may be sources of or willing to recruit such resources. Flexibility and resource choices are based on local resources.
- For Legal Services in particular, the agency should explore utilization of pro bono or reduced fee for legal services through local legal services and bar associations.
- The AAA/ASAP will establish and publish a protocol that outlines the management of expenditures for supplemental services. For example:
  - The Caregiver staff should exercise conservative discretion and generally have flexibility for expenditures at or below a specified amount established by the AAA/ASAP;
  - The AAA/ASAP should have internal review and approval processes for all expenditures.

Tools: As a result in using the FCSP Caregiver Assessment Tool or through other caregiver contact a need for supplemental service(s) may be indicated.

Reporting Instructions:
Required by ACL/AOA (Annual NAPIS report)
Unduplicated number of caregivers served
All caregiver characteristic as listed on NAPIS report
The unit of service is one service or purchase
ACL/AOA Service Categories – Group 2

4. Access Assistance

Definition:
Access Assistance assists caregivers in obtaining access to the services and resources available within their communities. Information and assistance to caregivers is Access Assistance when it:

- Provides information to individuals on services available within their communities;
- Links individuals to these services and opportunities; and,
- Establishes adequate follow-up procedures, to the maximum extent practical.

Expectation/guidelines
Regardless of the AAA/ASAP structure, it is essential that the I&R staff or other staff member having initial contact does not overlook the caregiver in the process of gathering and providing information. Either a caregiver specialist or I&R staff may send out requested information; generally, the caregiver specialist will provide assistance and linkage with referrals and follow-up with the caregiver.

- The I&R or other initial contact person should be aware of and consider the needs of caregivers and make referrals to the caregiver specialist when appropriate. The initial contact person will make an effort during the call to solicit details about the needs of the caregiver, will document such needs as expressed by the caregiver, and will be proactive in describing the range of services and assistance the FCSP can offer. It is important that agency staff is oriented to caregiver needs.
- Caregivers should be asked a key trigger question of whether they need assistance with their caregiver role. While many callers may not identify their own needs at first, the goal should be to help them clearly understand that the door is open for them to receive assistance at present or to request it later, depending on their needs and comfort level.
- AAA/ASAPs should maintain a standard I&R caregiver package of printed materials for distribution to caregivers. Basic caregiver program and service information should be available, along with information about the full range of AAA/ASAP services, a schedule of local training opportunities, and information on support groups in the area. The packet will be sent to caregivers upon request, or as deemed appropriate, by the I&R or FCSP staff person. The packet should include a means for the caregiver to request additional information, (e.g. a response card and agency addressed envelope or a contact list with specific phone numbers and/or email addresses.
- The FCSP staff will follow-up on caregiver referrals made by I&R, other AAA/ASAP staff and external resources.
• The AAA/ASAP shall have access to qualified interpreters who can provide interpreter services for both telephone contacts and in-person sessions.

Tools:
• Basic intake and demographic data shall be collected at the initial contact and entered into SIMS/SAMS; when appropriate, referrals should be made to the FCSP staff.
• Additional related data, collected on caregivers who need more direct service than I&R, will be available to the Caregiver Specialist by the I&R staff or other staff making the referral to the FCSP.

Reporting Instructions:
Required by ACL/AOA (annual NAPIS report)
Unduplicated number of caregivers served (“served” means there was a contact, and information was sent and where possible follow-up with the caregiver occurred)
The unit of service is one contact

Required by Elder Affairs
Reporting all of the access assistance services provided in SIMS/SAMS using the required business rules

5. Information Services

Definition:
Information Services are services that provide the public and individual caregivers with information on resources and services available within their communities. Outreach and marketing efforts are included within this category.

Expectations/Guidelines:
Local FCSPs conduct broad media outreach to inform the public about the availability of services. Activities include: presentations to groups in a variety of settings (i.e. workplace, faith communities, civic and social groups) and participation in health fairs, conferences and local cable programs.

• AAA/ASAPs will ensure that outreach and marketing materials, supported by FCSP funding have a primary focus on caregiver services and resources.
• Where appropriate local FCSP materials and ideas can be leveraged for statewide development and use
• The use of outreach strategies will be driven by proven outcomes and new creative approaches. Elder Affairs uses the FCSP quarterly meetings to share outreach best practices including print media, social media, and/or group forums.
• Local FCSP collaboration with Elder Affairs is required in implementing statewide outreach strategies.
Tools:
- A collaborative process between local FCSPs, AAA/ASAPs and Elder Affairs will be undertaken to develop outreach strategies
- Local FCSP’s programs and events can be posted on http://fcsp.800ageinfo.com

**Reporting Instructions:**
**Required by ACL/AOA (Annual NAPIS report)**  
Documentation of estimated audience size is recorded  
The unit of service is one activity or publication

**Required by Elder Affairs**  
Reporting access assistance services in SIMS/SAMS  
Local FCSP shall participate in statewide caregiver outreach efforts

**Grandparents Raising Grandchildren**

Under the provisions of Title III-E, services for grandparents who are raising grandchildren include the five service categories described above for caregivers of elders. The same service definitions, guidelines/expectations and reporting instructions apply with a grandparent orientation. Although services are optional, AAA/ASAPs are encouraged, within their capacities, to:

- Assist grandparents with information and referral and, when appropriate, counseling services;
- Offer respite services;
- Offer support to existing grandparent groups and/or assist in establishing new groups; and,
- Offer supplemental services.

Services for grandparents are optional with federal funding limited to 10% of the state’s Title III-E grant. The AAA planner should ensure that the local community needs assessment will address the needs of grandparents raising grandchildren.

**Reporting Instructions:**
**Required by ACL/AOA (Annual NAPIS report).**  
All documentation reported using the standards and guidelines for services as outlined in FCSP Guidelines and FCSP Business Rules

**Required by Elder Affairs**  
All program documentation is reported in SIMS/SAMS using the standards and guidelines as outlined in the FCSP Guidelines and the FCSP Business Rules
APPENDIX A: FCSP STAFF FUNCTIONS/MODELS

The Administration on Aging designed the Family Caregiver Support Program as a flexible and multifaceted program that requires broad integrated support throughout an agency. Within individual AAA/ASAP organizational structures, staff funded with Title III-E funds should be assigned appropriately to specific functions which support caregivers through the implementation and maintenance of the FCSP. Depending on agency staffing and resources, individual agencies can determine how best to fulfill these functions, which are directly related to the five service program categories as discussed in this document.

It is recommended that the title Caregiver Specialist be used in situations where a position is funded by federal funds and the staff person is primarily dedicated to assisting caregivers. Should an alternative job title be used, a clear association to supporting caregivers must be made. There should be consistency throughout the state, that when a caregiver contacts an AAA/ASAP the caregiver is recognized as a potential consumer of the agency and connected to an appropriate staff person for assistance.

The integrity of the program including specific, direct attention and support to family caregivers should not be compromised in situations where functions of the FCSP staff are combined with other positions such as Care Manager, SHINE Counselor, Options Counselor or Care Transition Counselor, Community Liaison responsible for agency outreach and training or an Elder Care Advisor who counsels elders not eligible for home care services.

Below is a broad list of functions that are usually associated with the staff of the FCSP.

Provides Caregiver Support/Assistance

◆ Provides personal assistance in connecting caregivers with resources and service
◆ Provides one-on-one counseling and coaching
◆ Conducts caregiver assessments
◆ Develops a caregiver follow-up/action plan
◆ Facilitates family meetings
◆ Maximizes service options available

Training/Education

◆ Identifies, refers, and/or coordinates and facilitates caregiver training in group settings or for individuals
◆ Utilizes evidence based programs e.g. Powerful Tools for Caregivers and other programs viewed as successful for maximum benefits of caregivers

Support Group

◆ Establishes and facilitates support groups as appropriate
◆ Makes referrals to community support groups
◆ Assists existing or new support groups with logistics, materials, etc.
Information Services/Outreach

- Builds relationships with local service providers, employers, and community groups
- Conducts caregiver informational sessions in the community, e.g. Senior Centers, public and private work places
- Promotes caregiver outreach using a broad range of local contacts and media
- Distributes caregiver information and materials to community locations, e.g. libraries, community centers, fairs and faith communities
Appendix B  


Compiled practices superseding all previous versions

Overview
With the implementation of SIMS in 2006, standard business rules were established and other practices have since been added for the Massachusetts Family Caregiver Support Program (FCSP). The following are these rules used for data entry in SAMS. These business rules and practices embrace all previous practices identified. AAA/ASAPs will be notified of any additions, updates or changes to these business practices.

All FCSP required program information is accountable for in SAMS. Maintaining the integrity of the FCSP and ensuring that consumer records and services are documented in SAMS is the responsibility of each AAA/ASAP. Despite the uniqueness and flexibility of FCSP services, the Executive Office of Elder Affairs (Elder Affairs) expects agencies to follow its business practices and that local practices support efficient and accurate entry of consumer information in SAMS. Each AAA/ASAP has a designated person(s) who has the technical expertise to advise and assist FCSP staff regarding SIMS application and procedures. The SIMS Support Unit at Elder Affairs should be contacted by the designated agency’s SIMS contact when further technical assistance is needed. Instructional materials such as the Family Caregiver Training Guide (MA Edition) and Job Aids offer specific information in utilizing SAMS: these can be found at http://fcsp.800ageinfo.com under Program Directives. Contact the MFCSP State Director at Elder Affairs for all program questions. It is recommended that the MFCSP Guidelines and Addendum be used as a primary reference to program information.

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**1. Annual Caregiver Assessment Summary**

Elder Affairs will provide AAA/ASAPs with an annual FCSP summary of assessment data that reflects all assessments reported in SIMS between January 1 through December 31. The summary will provide the statewide and agency frequencies and percentages for each assessment question. AAA/ASAPs will receive the annual summary in March. All assessments conducted on or before December 31 should be entered in SAMS as required to be included in the annual summary.

**2. Birth dates and ages**

If the caregiver or care recipient’s birth year is known and the month and/or day is not, January 1st can be used to substitute for the actual month and day.

Although reporting a birth date is preferred, Elder Affairs is aware this is not always possible and accepts a skipped response indicating the date is Unknown.

To ensure grandparent services are counted in NAPIS SRT, the birth date of the child/care recipient is necessary. If the birth date of the child is not entered, by default, services will always be reported in NAPIS SRT as a service to a caregiver of an elder. When establishing the consumer record for a care recipient under 18 years of age be sure the record is associated with a caregiver age 55 years or older and with the correct relationship.

**3. Care Recipient**

A care recipient must be identified for all service deliveries that involve Category I services by establishing a consumer record in SAMS. Every caregiver who receives a Group I service (including counseling, training/education, respite services, supplemental services and/or group support) must be identified and associated with a care recipient.

In group training situations or for support groups, every effort should be made to identify specific care recipients of the caregiver. However, in situations when it is difficult or inefficient to identify specific care recipients the “generic care recipient” option can be used.

Using a “generic care recipient” to substitute a real name is acceptable in group training and support group situations only. A generic care recipient record should be established in SAMS consumer data base by the local AAA/ASAP for this purpose and
can be used as often as needed. The naming convention should include the AAA/ASAP’s unique identifier, for example, HESSCO generic care recipient or BayPath Elder Services generic care recipient.

To ensure that a caregiver (55 and older and not a parent) of a **disabled care recipient (age 18 through 59)** is correctly reported in the NAPIS Report, make sure that in the characteristic section of the consumer detail record the **disabled care recipient question** is answered “Yes” from the drop down list. In the NAPIS report a caregiver of a disabled care recipient is counted with grandparents and other elder relatives (not a parent) caregivers.

If a **caregiver is assisting more than one care recipient**, information regarding the care recipient that is receiving the most time and attention of the caregiver shall be used in answering the assessment questions. **However**, in situations where the caregiver has another care recipient - - particularly one who requires significant attention - - the note option of each appropriate assessment question should be used to explain the caregiver’s additional efforts. For example, these following questions in Section II: “How long has the caregiver provided assistance?”, “How many hours per week does the caregiver spend on caregiving?”, “Is the caregiver also a caregiver of another person?” and “Do the responsibilities include anyone with special needs/medical conditions/disabled?” In Section III there are a number of questions that might warrant using the note option to highlight the second care recipient’s characteristics. It is at the discretion of the caregiver specialist who is reporting on the assessment to use the note option. Use the assessment summary narrative to reiterate that the caregiver has responsibility for more than one care recipient and explain with detail as needed.

If a specific grandparent or other elderly person is serving more than one grandchild, the NAPIS report will only calculate one care recipient per caregiver. In order to report the total number of care recipients (children 18 years old and younger), a manual entry on the NAPIS report is required before it is submitted by the AAA.

**4. Care Plan**  
The **care plan** feature in SIMS is not recommended for caregiver information. All pertinent caregiver information should be documented in the **consumer journal** associated with the consumer’s record

**5. Caregiver Action Plan**  
It is expected that every caregiver who is assessed will receive a written **action plan** based on the concerns that the caregiver identifies and wants to focus on. The action plan may include reiterating directives/information discussed during the assessment, resources that the caregiver and/or the caregiver specialist will follow-up on, and outline short term and/or long term goals. It should include offered service information such as respite, supplemental support or counseling.
The caregiver action plan should be copied into the Caregiver record in the consumer journal. Local AAA/ASAP programs have the discretion to establish a protocol for creating and distributing an action plan to individual caregivers.

If an individual action plan is not developed, an explanation should be reported in the Assessment Tool’s note section of the last question, “Was a caregiver action plan developed after the assessment was completed?”

Refer to PI 11-13 for complete instructions and SIMS Job Aid, Family Caregiver Support Program Assessment Functionality and Creating a New Assessment

It is expected that caregivers who are experiencing stress, burnout and/or complex family situations shall be assessed using the FCSP Caregiver Assessment Tool as determined by the FCSP staff. A caregiver assessment should be completed before a referral to counseling (beyond what the Caregiver specialist offers), a respite or supplemental service is offered to the caregivers.

Gathering answers to all assessment questions is the ideal; however, there are certain circumstances which warrant the FCSP staff’s discretion in not asking certain questions. Such circumstances include when it is culturally inappropriate or would seriously increase caregiver stress. The program relies on the experience and skills of the FCSP staff to complete the caregiver assessment in a manner that includes sensitivity and creativity in gathering important caregiver information. It is critical that the assessment process doesn’t become a drill of questions and answers between the caregiver and caregiver specialist. The assessment questions are used as a guide for a purposeful discussion. If certain assessment information was not gathered, use the assessment summary to explain.

An assessment summary shall be entered in the narrative section at the end of the each initial caregiver assessment and reassessment. The summary should include specific information essential for understanding the caregiver’s situation, immediate needs and reference to the action plan. The assessment summary should be copied to the consumer journal in the caregiver’s consumer record.

Caregiver assessments shall be entered in SIMS within seven business days of the assessment meeting(s)/gathering assessment information. Once an assessment is started in SIMS, there is a limit of five business days to edit and complete the assessment. If a change to the assessment is needed after it is completed, agencies must follow their corrections policy.
7. Caregiver Consumer Enrollment

A caregiver who is first enrolled in SAMS by one AAA/ASAP (the default agency) can be later shared with another AAA/ASAP. Follow the shared process as outlined by SIMS Support Unit. Note: If a caregiver assessment needs to be shared, the requesting agency should gain consent from the caregiver, consult with the appropriate FCSP staff of the agency where the assessment was conducted, and follow the shared consumer process as outlined by SIMS Support.

8. Caregiver Consumer Record

It is recommended that in SAMS the caregiver consumer record status remain active and only in circumstances of death of the care recipient and/or caregiver should it be deactivated. There is no adverse effect in leaving a caregiver record active in SAMS.

A caregiver that doesn’t exist in SAMS can enroll in a FCSP even though she/he is living outside of the catchment area of the local AAA/ASAP.

A caregiver can enroll in a FCSP other than the AAA/ASAP where the care recipient is receiving services.

A caregiver can transfer to another AAA/ASAP’s FCSP. Follow the transfer process as outlined by SIMS Support.

To determine the number of current caregivers, run a report filtered by dates and services delivered. Although we recommend leaving the Family Caregiver Care Enrollment active after serving the caregiver, AAA/ASAPs can decide to end date the FCSP care enrollment if local agency business practices require it.

9. Caregiver Relationships

To ensure the NAPIS reports calculates services to the appropriate category of caregivers the correct relationship needs to be chosen when the consumer record is established. The following relationships are only for grandparents and other relatives (not parents) 55 years of age or older providing care to children under the age of 18 or providing care to adults age 18-59 with a disability.

- Grandparent
- Other Elderly Relative
- Other Elderly Non-Relative

The relationship options of Other Elderly Relative and Other Elderly Non-Relative are only used for caregivers of children and adults 18-59 with a disability.

The following relationships are only for an adult family member or other informal caregivers age 18 and older providing care to individuals 60 years of age and older or providing care to individuals of any age with Alzheimer’s disease and
related disorders. Please note: using any other relationship type will cause the relationship numbers on the NAPIS report to be inaccurate.

- Husband
- Wife
- Son/son-in-law
- Daughter/daughter-in-law
- Other relative
- Parent
- Non-relative.

10. Caregiver Satisfaction Survey

Review PI-12-01 for details

AAA/ASAPS are required to survey, using the Caregiver Satisfaction Survey, all caregivers who were assessed with the FCSP Caregiver Assessment Tool regardless of whether they received an action plan and/or additional services. All caregivers receiving counseling, supplemental or respite services are required to be surveyed. Agencies may use their own discretion in administering the Survey by mail, phone, email or in-person.

A summary of caregiver satisfaction surveys based on the records recorded during the program year is available annually to AAA/ASAPS. Each AAA/ASAP is required to designate a contact person that will use a web-based secure site designated by Elder Affairs to record survey results and report the number of surveys distributed each quarter in a program year. An annual return rate of at least 45% is expected.

11. Caregiver Services

Caregivers receiving Category 1 Services that include counseling, training/education, support groups, respite and supplemental services, are required to have an associated care recipient. Every effort should be made to obtain all caregiver characteristics requested by AOA that include: age, gender, geographic information, race, and ethnicity. If an attempt to gain characteristics information is unsuccessful, the “missing information” option should be used. Do not use consumer groups for Category 1 Services.

Caregivers receiving Category II Services, that include access assistance or information through print media, multimedia or group outreach, are accounted for in SAMS through consumer groups. There is no requirement to gather characteristics information on caregivers in consumer groups; however, it is necessary to record the estimated count of caregivers in each such consumer group.

12. Consumer groups

Consumer groups are used only to report access assistance (enhanced I&R) or information services (print and mutli-media outreach) to large numbers of similar caregivers or aggregated numbers of individual caregivers with commonalities. The
following distinct consumer groups should be created in SAMS at the AAA/ASAP level using the following naming structure for example: newspaper readership, TV/local cable stations viewership, radio station audience, working caregivers, COA/Senior Center participants, civic organizations membership, and health fairs participants and general caregiver inquiries.

For reporting information services, the estimate of the number of caregivers in a specific consumer group should be entered only once for a program year to avoid a duplicated estimate of caregivers. For example, information regarding the local FCSP is aired on radio station A in which the estimated audience of the radio station is 10,000 listeners and the radio station airs the information 7 times each week for 4 weeks. Recording this service delivery in SAMS: enter the consumer group radio station audience, the units of service = 28 and the estimated number of caregivers = 10,000. Several months later the same radio station airs similar information 14 additional times. In this situation, enter the service unit of 14 and the estimated number of caregivers is 1. The estimated number of 1 is used to avoid duplication of the audience of 10,000 which has already been recorded in SAMS.

Consumer groups should not be used for reporting any Group I Services.

13. The Consumer Journal

The Consumer Journal is used for recording details associated with individual consumers and consumer groups. The level of detail is dictated by its usefulness for future reference. All journal entries should meet local agency standards.

Use the consumer journal associated with the consumer’s record to record specific caregiver information that is noteworthy to understanding the caregiver and the situation, such as: results of a caregiver assessment, caregiver action plan, telephone or email contact and other relevant information. From the journal type menu select the most appropriate type: program enrollment, referral (internal/external), and phone call to caregiver, phone call from caregiver and others as appropriate.

Use the consumer journal entry associated with a particular consumer group to record pertinent information such as outcomes, any unusual circumstance. For example, an informational session is held at a local COA. The consumer group COA/Senior Center Participants should be used. In the consumer journal entry select “progress note” from the journal type menu: on the subject line, enter the specific COA/Senior Center (e.g., Waltham). The entry should include pertinent information that is useful for evaluation or future planning.
AAA/ASAPs are required to submit FCSP monthly invoices and back-up electronically to ELDInvoice@state.ma.us. Annual instructions are sent to AAA/ASAPs by the State Planner-Title III Programs.

14. **FCSP Invoice back-up**

The **FCSP Characteristic Quality Control Report** identifies required caregiver characteristic data that is missing from a consumer record and service delivery records. Every effort should be made to identify characteristic data and enter it in SAMS; however, there are situations when it is necessary to use a “missing” data option.

After a FCSP Characteristic report is generated, all missing data should be recorded in the consumer's record. It is important to check the consumer's service delivery records as well for missing data and that the care recipient information is correctly identified. After all corrections are made, you must run the FCSP Characteristics Quality Control Report again to make sure there is no data missing. It is recommended that agencies run this report monthly to ensure all consumer and service delivery records are accurate.

The **FCSP Characteristic Quality Control Report** will identify Service Delivery Records missing the following required data.

A. If a **“gender”** is not selected in the Consumer Record.

B. If **“ethnicity”** is left “Unknown” in the Consumer Record. Users are encouraged to do their best to select an ethnicity, and if necessary use “Unknown.” **Note** the report will always display a record with “Unknown” ethnicity selected, as a blank /missing field to be edited. If the ethnicity is not known, no edit is required.

C. If **“ethnic race”** is omitted in the Consumer Record. Users are encouraged to always select one of the options for a consumer’s Ethnic Race; this includes “Missing” or “Other.”

D. If the **“caregiver’s relationship”** to care recipient is omitted in the Consumer Record. When entering the caregiver by relationship data, use only the following relationship options that are consistent with AOA reporting: husband, wife, son/son-in-law, daughter/daughter-in-law, other relative, non-relative, grandparents, and other elderly relative, other elder non-relative. Users are encouraged to always select one of these option or if necessary “missing”.

E. If the **“care recipient”** is indicated as missing on the FCSP Characteristic Quality Control Report, check the caregiver’s Service Delivery first to see if the care recipient was selected from the drop down menu on the caregiver recipient line. If
the care recipient doesn’t appear in the drop down menu, this indicates a caregiver recipient was not identified in the caregiver’s Consumer Record.

F. If the “caregiver’s or care recipient’s age” is “Unknown.” In the Consumer’s Record, if the “Birth Date” is overlooked or intentionally skipped, SIMS will display the age field as “Unknown.” Users are always encouraged to include a valid date of birth for consumers when possible. Currently, the FCSP Characteristic Quality Control Report will always display a record missing the birth date/age even though the “unknown” option is selected.

16. NAPIS SRT Reporting (National Aging Program Information System / State Reporting Tool)

Preparing the agency NAPIS SRT should be a joint task involving the appropriate Program and Fiscal staffs and the AAA planner to ensure that expenditures and the program data reported are accurate. The State Planner (Title III Programs) issues annual NAPIS directives.

Given that all FSCP Service Deliveries and Consumer Records are current in SAMS, the required program data generated for the NAPIS SRT should be accurate. Program data includes information by service category: the number of caregivers served, units of service, number of providers and all required characteristic data. However, the NAPIS Report only generates expenditure data from delivered services in SAMS; it does not take into account all the expenditures for the caregiver program. Therefore, agency fiscal staff needs to calculate these expenditures and manually enter all expenditures for the appropriate service categories to produce the NAPIS SRT.

17. Reports using SIMS

AAA/ASAPs have the option to use existing report templates or to create reports in SIMS using their own SAMS data. It is recommended that AAA/ASAPs use this option in managing their programs. Elder Affairs generates and uses SIMS reports for program development and monitoring purposes.

18. Service Deliveries

Service deliveries must be documented for all caregiver services. Accurate service delivery information is critical since data from service deliveries is used to generate monitoring reports and the NAPIS SRT. Typically, caregiver staff will record as service deliveries their direct service to a caregiver such as counseling, access assistance, training and other services which do not require service orders. The AAA/ASAPs must set-up a contract within SAMS specifying the services that they render directly through their staff as well as for scholarships and stipends. AAA/ASAP business practices will dictate caregiver staff involvement and specific business processes regarding service deliveries.
When completing a service delivery for a session service in Category I (caregiver counseling, Alzheimer's coaching, support group and training) it is necessary that the actual date of delivery is captured in the service delivery record by using Daily Unit Details. It is especially important to put the actual delivery date on the service delivery record when two or more units of the same session service are rendered in a given month. If the actual dates of delivery are not entered, only one service unit of a specific service session will be reported in a given month in the NAPIS report.

Example: Rose Southerland received 2 counseling sessions during October. When entering the Service Delivery for these services enter the units and the dates of services.

1 counseling session - October 1
1 counseling session - October 24

If a caregiver receives a service (i.e. training/support group) from an AAA/ASAP other than the one she/he is enrolled, the AAA/ASAP that provided the services can record that delivery of service.

In situations where several (or more) AAA/ASAP sponsor a training or information session, equitable unduplicated caregiver reporting should be determined between the agencies prior to entering the data in SAMS.

For recording “Information and Assistance” service use a service delivery template which allows users to quickly deliver units and automatically enroll a caregiver into a care program. See Job Aid: Recoding Information and Assistance for Caregivers using Service Delivery Templates

19. Service orders

Service orders are necessary for all services that involve an external provider (or may be required by the AAA/ASAP’s local business practices.) In SAMS there is a full range of services to accommodate the five MFCSP service categories. In a situation where, for example, the caregiver and caregiver staff decide that a respite service would be helpful, the potential range of options include such services as adult day health through a contracted provider; respite-nursing facility through a contracted provider, both of which would require a service order and a contract to exist in SIMS; or a respite stipend through the AAA/ASAP which would not require a service order unless the AAA/ASAP requires this per a local business rule. When supplemental or respite service scholarships/stipends are used, and there is no external contracted provider involved and no AAA/ASAP business rules apply, there is no need to create a service order for this service.

20. Standards for Reporting Consumer Information

The caregiver information reported in SAMS, including caregiver consumer records and assessments, have the same standards as other AAA/ASAP client/consumer documentation and shall comply with Elder Affairs privacy and confidentiality requirements.
21. **Start date**  The FCSP **service start date** is when direct contact is made between the FCSP staff and the family caregiver.

22. **Units of Service**  The **units of service** in SAMS will be recalculated automatically to agree with the required units of service for NAPIS reporting purposes, for example in SAMS respite is recorded in 15 minute units, but will convert to one hour units on the NAPIS report.
APPENDIX C: PI-10-13 FCSP Caregiver Assessment

The Caregiver Assessment Tool is a means for gathering essential caregiver information and focusing more in-depth discussion on the caregiver’s needs. This tool should be considered a basic and flexible guide to assist the FCSP staff and the caregiver through a discussion of the caregiver’s situation and strategies to relieve the caregiver’s concerns. FCSP staff should use their discretion on the appropriate approach to how questions are posed. The assessment process is a discussion, not a check list and should be approached holistically to avoid overlooking potential needs as well as to determine ways to assist the caregiver.

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PROGRAM INSTRUCTION
EOEA-PI-10-13

TO: Area Agencies on Aging
Aging Services Access Points

FROM: Ann L. Hartstein

DATE: December 20, 2010

RE. Family Caregiver Support Program (FCSP) Caregiver Assessment

Purpose: The purpose of this Program Instruction, EOEA-PI-13-10, is to inform local Family Caregiver Support Programs of required family caregiver assessment procedures.

Background and Program Implications:
In 2001, the Family Caregiver Support Program (FCSP) was implemented through local Area Agencies on Aging (AAA) and Aging Services Access Points (ASAP). The purpose of the FCSP is to support and promote the ability of caregivers to maintain their caregiving roles. Local programs have discretion in developing and managing their programs within the National Family Caregiver Program parameters and within the 2006 Program Guidelines issued by Elder Affairs. Those Guidelines established expectations and offered recommendations to promote statewide consistency including reporting data and caregiver assessment practices. The program has evolved to warrant additional statewide standards and practices to ensure consistency among all local programs particularly in how caregivers are assessed.

Currently, local program standards to assess caregivers vary across the state. This Program Instruction reviews the requirements and practices in using a standard caregiver assessment approach and a specific assessment tool, the FCSP Caregiver Assessment.
Required Actions:
Local program caregiver specialists* shall use the FCSP Caregiver Assessment to assess caregivers, who are primarily experiencing stress, burnout, and/or have complex family situations, to determine what assistance the caregiver may need and the outcomes the caregiver wants for support. A FCSP Caregiver Assessment is required before counseling services (beyond the counseling offered by a caregiver specialist), respite or a supplemental service is authorized.

FCSP Caregiver Assessment Tool
- Local programs shall use the FCSP Caregiver Assessment as a means of gathering essential caregiver information and a guide to focus on the caregiver. There are four sections to the assessment: Section I: Referral Source; Section II: Caregiver Contact Information and Caregiving Situation; Section III: Care Recipient’s Characteristics; Section IV: Caregiver Service Assessment. Responses to assessment questions reported in SAMS should be those of the caregiver. Information from the caregiver record will automatically populate specific questions in Section II. To the extent that information from another source is obtained, the information may be used, provided it is verified by the caregiver.
- Currently, there is no caregiver reassessment requirement. A caregiver reassessment is completed at the discretion of the caregiver specialist.

Caregiver Assessment Approach
- The caregiver assessment shall not be conducted as a checklist but rather a focused discussion between the caregiver and the caregiver specialist. The skill of the caregiver specialist in using conversation to gather a range of comprehensive caregiver information is essential to avoid overlooking potential needs as well as determining ways to assist the caregiver.
- There may be situations where the caregiver specialist observes discrepancies with a caregiver response. In these situations the caregiver specialist should use the note pane of that assessment question to comment.
- If a caregiver is assisting more than one care recipient, information regarding the care recipient that is receiving the most time and attention of the caregiver shall be used in answering the assessment questions. In a situation where the caregiver has another care recipient who requires notable assistance from the caregiver, use the note pane of specific questions to explain. For example in Section II, “How many hours per week does the caregiver spend on caregiving?” In this instance the caregiver specialist would add a note describing the additional time the caregivers spends assisting the second care recipient. In Section III, there are a number of questions where a note is appropriate to give more detail regarding the caregiver’s situation. Use the assessment summary to reiterate that the caregiver has responsibilities of more than one care recipient and explain with detail as needed.
- Complex caregiver situations might require more than one meeting/conversation to complete the caregiver assessment.

Required Action
- Local programs shall enter caregiver assessments in SIMS within seven business days of the assessment meeting(s)/gathering assessment information. All assessment information should be compiled before entering a new assessment or reassessment in SIMS. Once an assessment is started in SIMS, there is a limit of five business days to edit and complete the assessment. If a change to the assessment is needed after it is completed, agencies must follow their correction policy.
• Generally, all assessment questions must be answered. The caregiver specialist has the discretion on how and when to ask specific questions. There may be circumstances when a caregiver specialist would not ask certain questions such as when it is culturally inappropriate or would seriously increase caregiver stress. An explanation of why a question is not answered should be documented in that specific question’s note pane.

• A summary of each new assessment and reassessment shall be entered in the narrative section at the end of each assessment. The summary should include specific information essential for understanding the caregiver’s situation, immediate needs and suggested Action Plan.

• All caregivers who participate in an assessment or reassessment are expected to receive an Action Plan based on the concerns that the caregiver identifies and wants to focus on. It may include reiterating directives/information discussed during the assessment, resources that the caregiver and/or caregiver specialist will follow-up on and, an outline for short term and/or long term goals. Local AAA/ASAP programs have the discretion to establish a protocol for developing and distributing an Action Plan to caregivers. If a caregiver declines an Action Plan, this should be noted in the assessment summary.

• All caregiver information reported in SIMS, including the caregiver assessment’s notes and summaries, have the same standards as other AAA/ASAP client/consumer documentation and shall comply with Elder Affairs privacy and confidentiality requirements.

For additional instructions refer to SIMS Job Aid, Family Caregiver Support Program Assessment Functionality.

Effective Date:
December 31, 2010

Contact:
Questions regarding this Program Instruction may be directed to Sheila Donahue King, Director of the Family Caregiver Support Program at 617-722-7421 or Sheila.Donahue-King@state.ma.us .

* For the purpose of this PI, the term caregiver specialist indicates the professional in the Family Caregiver Program that assesses caregivers and offers counseling.
Appendix D:  Caregiver Action/ Follow-up Plan

The Caregiver Action/Follow-up Plan should be attached to or included in a brief notice/letter to the caregiver. This notice should explain that the plan is the outcome of assessment discussion between caregiver and the caregiver specialist. The plan should be clear and easy to follow with immediate/short term actions and if appropriate long term plans. The Caregiver Specialist’s name and contact information should be included.

A Caregiver Action/Follow-up Plan can be given to caregiver at the end of the assessment session or completed and sent back to the Caregiver via mail or email. The format of the plan is at discretion of the local FCSP. However, it should be efficient and is expected to include key elements: the list of caregiver’s concerns and the specific action/tasks that the caregiver and caregiver specialist will follow-up. The plan should be recorded in the caregiver’s SIMS/SAM record. Below is an example.

### Caregiver Action/Follow-up Plan - EXAMPLE

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Action</th>
<th>Details</th>
<th>Follow-up by (name of caregiver)</th>
<th>Responsibility Of (name of caregiver specialists)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A one hour family caregiver meeting to discuss the care recipients needs and support to the primary caregiver.</td>
<td>The meeting arranged by the end of March.</td>
<td>Will invite the Family members.</td>
<td>Will facilitate a one hour meeting.</td>
</tr>
<tr>
<td>Support Group participation</td>
<td>List of Alzheimer Support groups / information</td>
<td></td>
<td>Will send info</td>
</tr>
<tr>
<td>Education and training participation</td>
<td>Spring training list will be sent to Caregiver</td>
<td></td>
<td>Will send info</td>
</tr>
<tr>
<td>Health insurance consultation</td>
<td>SHINE counselor information left with caregiver</td>
<td>Will call the SHINE counselor</td>
<td></td>
</tr>
<tr>
<td>Visit several adult day health centers</td>
<td>Materials and contact information left with caregiver</td>
<td>Will read over material and visit an ADH program</td>
<td></td>
</tr>
<tr>
<td>Phone reassurance call (from the caregiver specialist to the CR</td>
<td>Caregiver will receive a call in two weeks</td>
<td></td>
<td>Will call</td>
</tr>
<tr>
<td>Reduce Stress</td>
<td>Information on reducing stress and local yoga classes left with caregiver</td>
<td>Will read over stress material and visit a yoga class</td>
<td></td>
</tr>
</tbody>
</table>
Appendix E:  PI-12-01  FCSP Caregiver Satisfaction Survey

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PROGRAM INSTRUCTION

PI-12-01

TO: Area Agencies on Aging
    Aging Services Access Points

FROM: Ann L. Hartstein

DATE: January 10, 2012

RE. Family Caregiver Support Program (FCSP) Caregiver Satisfaction Survey

Purpose:
The purpose of this Program Instruction, PI-12-01, is to inform local Area Agencies on Aging (AAAs) and Aging Services Access Points (ASAPs) of the required Family Caregiver Support Program Satisfaction Survey (Survey).

Background and Program Implications:
In 2001 the FCSP was implemented through AAAs and ASAPs. The purpose of the FCSP is to support and promote the ability of caregivers to maintain their caregiving roles by equipping them to make informed decisions, solve problems, reduce stress and maintain their overall physical and emotional health.

The 2006 Massachusetts FCSP Guidelines issued by the Executive Office of Elder Affairs (Elder Affairs) established expectations for agencies that included gathering caregiver satisfaction and quality assurance information. To ensure statewide consistency in collecting information on caregiver satisfaction and outcomes associated with FCSP services, a standard practice in using the FCSP Caregiver Satisfaction Survey, is now required.
Local FCSP staff input and the results from a pilot and statewide field test were used in
developing the FCSP Caregiver Satisfaction Survey. This Survey captures opinions from family
caregivers on the assistance provided and the outcome of services as a result of the FCSP
assessment. The information gained through the Survey will supplement local programs and
Elder Affairs' efforts to evaluate programs and assess on-going improvements and quality
assurance.

**Required action:**

1. **Caregivers targeted to receive a Survey:**
   - All caregivers assessed with the FCSP Caregiver Assessment Tool, regardless of whether
     they received or did not receive an action plan and/or additional services as a result of the
     assessment.
   - All caregivers receiving counseling, supplemental services or respite services.

2. **When to administer the Survey:**
   The following time frames are required in an effort to gain a broader understanding of
caregivers' opinions and views of outcomes over time.
   - A minimum of 6 to 10 weeks after a FCSP assessment.
   - Administering after 10 weeks is appropriate in situations when assistance or services are
     not completed prior to 10 weeks.
   - If during a 12 month period there is a significant change in the caregiver's needs that
     warrant a reassessment and additional services are provided, a second Survey should be
     administered.

3. **Survey Administration:**
   - Caregivers should be informed at the close of an assessment/counseling session that they
     will be surveyed regarding their opinion of FCSP services.
   - Agencies may use their own discretion in administering the Survey -- by mail, phone,
     email or in-person.
   - Regardless of what method is used to administer the Survey, the caregiver specialist*
     should not be involved in administering the Survey or receiving the Survey responses
     back from the caregiver.
   - Special consideration should be given to caregivers who do not speak English.
   - The Survey is not a replacement for specific training and support group evaluation.

4. **Customize the Survey and cover letter:**
   - Insert agency letterhead or facsimile at the top of the Survey form.
   - Check off the service(s) that the caregiver received in the top section of the Survey.
   - Insert the name of the staff person who conducted the assessment in question # 2.
   - Insert the caregiver's consumer ID at the bottom of the Survey. The consumer ID
     (generated in SAMS) is used only to verify a Survey return. Confidentiality of the
     caregiver responses should be maintained unless otherwise indicated by the caregiver.
   - If the Survey is mailed, a cover letter on agency letterhead with reference to
     the caregiver specialist* who assisted the caregiver should be included.

* For the purpose of this Program Instruction, the term caregiver specialist indicates the
professional associated with the Family Caregiver Support Program who has direct contact with
caregivers.
5. Recording Survey responses:
   - All agencies are required to use a web-based, secure site located through the following link, https://www.keysurvey.com/survey/401147/d88a/, to record Survey responses.
   - Survey data should be recorded by all agencies on an on-going basis.
   - If an agency has technical questions regarding the Survey site, or needs to make a correction after a Survey is submitted, please contact Mildred Asano at Mildred.Asano@state.ma.us

6. Survey return rate:
   - All agencies are required to report to Elder Affairs the number of surveys they distributed/administered during each quarter in a program year. A web-based, secure site will be used to gather this information. The link to the site will be forwarded to the agency contact person.
   - An annual return rate of at least 45% is expected.

7. Agency Survey Report:
   - All agencies will have the ability to view and print their own Survey report based on the records they submitted during the program year. All agencies will receive a unique access link for this purpose. The link will be forwarded to the agency contact person.

8. Agency contact person:
   - All agencies are required to forward the name and email of the agency contact person who is responsible for managing the tasks related to the FCSP Caregiver Satisfaction Survey to Sheila Donahue King by January 30, 2012.

Effective Date: February 1, 2012

Contact:
Questions regarding this Program Instruction may be directed to Sheila Donahue King, Director, Family Caregiver Support Program, at 617-222-7421 or at Sheila.Donahue-King@state.ma.us.

Attachment: FCSP Caregiver Satisfaction Survey