

## CAREGIVERS SUPPORT FOCUS GROUPS

## Veterans Integrated Service Network (VISN) VA Caregiver and Veterans

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Veterans Integrated Service Network (VISN) 5/22) VA Caregiver and Veterans Focus Groups

FOCUS GROUP MEETINGS – August 2010

Caregivers and Veterans Omnibus Health Services Act of 2010 Focus Group Guide

- I. Introductions and Ground Rules
  - A. Focus Group Moderator(s)
  - **B.** Greeting:

Hi everyone. My name is \_\_\_\_\_, and I'm with the Gallup Organization. I want to thank each of you for participating in this call. The Department of Veterans Affairs (VA) has asked us to speak with you today to talk about a new law that was enacted in May 2010 to provide support, services, and programs for caregivers of Veterans. Our goal on today's call is to get your input on how VA can most effectively implement the law in order to help Veterans and their caregivers. Please have a pen and paper handy in case you want to jot down any notes as I explain the new law to you.

Before we get started, I want to lay out a couple of ground rules for this discussion.

First, since there are several of us on the call and I want to keep track of who is talking, please state your name each time you jump into the conversation.

I'm going to be throwing out a bunch of questions to you as a group, and I'd like you to jump in whenever you have an opinion. I'd like to hear as many opinions as I can on each topic.

If you have any problems with the conference call you can hit "\*0" and reconnect with an operator. If you get disconnected, please dial the number you called initially, and let us know that you've rejoined. Your participation in this study is purely voluntary. Your participation, comments or answers to specific questions in no way compromises or affects your VA care or services. All information will be combined and reported in a way that prevents linking any individual to a specific comment. I look forward to hearing about your experiences, concerns and your opinions about this new law.

Inform of audio taping, observers if applicable

- C. Introduction of focus group participants
  - For Caregivers: First Name, what city you are calling from, types of caregiver responsibilities
  - For Veterans: First Name, branch of Service, when you left active duty
- 1. What are some of the biggest challenges (CAREGIVER you face as a caregiver of a Veteran who has) (VETERAN facing caregivers of Veterans who have) been seriously injured in the line of duty after 9-11?
- 2. What supports and services are available for you?
- 3. Before today, were you aware of the new law that was enacted in May 2010 called the Caregivers and Veterans Omnibus Health Services Act of 2010? If so, what do you know about it?

## II. Law

A. I'm going to read a summary of the law to you to get us started, and then we will get your ideas on how to actually implement some parts of the law. Feel free to jot down some notes on a piece of paper as I read it to you. Here is the description of the law.

On May 5, 2010 the President of the United States signed Public Law (P.L.) 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010.

Under the new law, primary caregivers of Veterans seriously injured in the line of duty on or after September 11, 2001 may be eligible to receive a stipend, access to health care coverage, mental health services, travel, lodging, and respite care. In addition, caregivers may receive training and support.

**1.** Based on what I've just read to you, how would you summarize what this law will do for caregivers and Veterans, in your own words?

- 2. After hearing this description, what questions or concerns do you have about it? (Moderator is not to answer the questions, just to gather what the questions are).
- III. Eligibility

Let's focus on specific parts of the law so that we can start to get your ideas on how to implement it. First, the first part of the law on the family caregiver program states that an eligible Veteran is any individual who 1) is a Veteran or member of the armed forces undergoing medical discharge, 2) has a serious injury incurred or aggravated in the line of duty after 9/11/01, and 3) is in need of personal care services because of, a) an inability to perform one or more activities of daily living, including things like bathing, eating, dressing and so on, b) because of a need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury, or c) such other matters as the VA Secretary considers appropriate.

- 1. When you hear these criteria for eligibility that are written in the law what do they mean to you?
- 2. What process should be used to determine eligibility?
- IV. Caregiver training

Part of the law states that caregivers will receive training and ongoing technical support in order to provide personal care services to the Veteran.

- 1. What kind of training do you think caregivers need?
- 2. What topics should be included in this training?
- 3. What would be the best way to deliver this training? (PROBE: In person, online, etc.)
- 4. (CAREGIVER ONLY) The law states that for certain family members, VA will provide for necessary travel, lodging, and per diem expenses incurred by a family member of an eligible Veteran during caregiver training. Also, the law states that for certain family members, if a family member's participation in caregiver training would interfere with the provision of personal care services to the eligible Veteran, VA will provide respite care during the family member's training. If you knew you could get respite care and all of your travel costs would be covered, would you be willing to travel to attend this training?
  - i. If so, how far? (Probe: within state, to another state)
  - ii. For how many days?
  - iii. Where would be the best place to hold this training? (PROBE for both location and type of facility)
- 5. What do you think should happen if the training reveals that this person is not fit to be a caregiver?

- 6. Thinking about ongoing technical support for caregivers, what does this mean to you?
  - i. What kinds of ongoing support do you think caregivers should have access to? (PROBE)
  - ii. What are the different ways that ongoing support should be provided (LISTEN FOR: By phone, online, email, in person visits?)
- V. Other services provided by the new law
- 7. The law also states that the primary caregivers of eligible Veterans can receive a monthly stipend, health care coverage if they are not entitled to care or services under another health plan contract, mental health services, and in-home respite care. What are your reactions to these benefits?
  - a. The law states that, to the extent practicable, the stipend amount should be not less than the monthly amount a commercial home health care entity would pay an individual in that geographic area to provide equivalent personal care services to the eligible Veteran. How does that sound to you?
  - b. Let's talk about whether the caregiver should receive a stipend when the Veteran is hospitalized or not at home for a period of time because of health reasons. At what point should the stipend stop if the Veteran is going to be in the hospital or rehab care for an extended period?
  - c. If there are other reasons why the primary caregiver is no longer providing care, at what point should their benefits stop?
  - d. What about mental health services? What kind of services should be included? How do you think those should be offered to caregivers?
- VI. Application for the benefits
- 8. Let's take a step back for a moment and think about the process of applying for this program. The law states that an eligible Veteran and a family member seeking to participate in the caregiver program shall jointly submit an application.
  - a. What are your reactions to this?
  - b. Let's brainstorm how this application process should be implemented.
    - i. First, do you think the application forms should be available just on paper, or also online? (PROBE to find out if they have a computer, go online, know how to access and fill out forms online)

- ii. What kinds of questions do you think should be covered on the application? Are there any special circumstances that should be addressed on the application?
- iii. What are your thoughts about the overall length of the application form?
- iv. How should the Veteran and caregiver be notified if they qualify, or do not qualify, for the program?
- VII. Monitoring
- 9. The law states that the well-being of each Veteran receiving personal care services under the family caregiver program shall be monitored.
  - a. What are your thoughts about how often the monitoring should occur?
  - b. How should this monitoring program be designed?
    - i. Who should do the monitoring?
    - ii. How should the monitoring be done?
    - iii. What should the monitor be looking for? (PROBE: What do you think is meant by monitoring the "well-being" of the Veteran?)
  - c. If it found that the caregiver is not effectively caring for the Veteran, what should be done?
  - d. If the Veteran or the caregiver disagrees with the monitor's assessment, what recourse, if any, should the Veteran or primary caregiver have?

**VIII. Revocation** 

10. Suppose it is no longer in the best interest of the Veteran to be receiving care from the designated primary caregiver or other approved caregiver. What are some situations you can think of in which a caregiver should no longer provide care for the Veteran?

a. If the caregiver is determined not suitable to provide care, what do you think should happen? How should the Veteran be cared for during this transition?

b. What if the Veteran or the caregiver disagrees with this decision? What should they be entitled to, if anything, in terms of appealing the decision?

## IX. Outreach

**11.** What do you think is the best way for VA to spread the word to Veterans and their caregivers about this new law and the programs and services it offers?

a. How would you like to get information about this?

b. What concerns do you think Veterans or caregivers might have about applying for this benefit?

12. What one recommendation do you have for VA that you think they absolutely must do to make sure this law is implemented in the best way possible for Veterans and caregivers?

Thank you so much for your assistance with these important considerations. We greatly appreciate your help.