Section 14

Informal Support CAP

Problem

The Informal Support CAP looks to situations where a person will need the help of others, seeking to identify situations where agencies or companies may have to step in to provide help. In these situations, the needs of the person usually exceed the response capabilities of the informal care network. Informal care reflects instrumental and personal support provided to the person by family, friends, and neighbors. Instrumental support (IADL) includes meal preparation, housework, managing finances, and so on. Personal support (ADL) includes mobility in bed, dressing, toilet use, and so on.

On any given day, independent adults will spend a certain amount of time performing instrumental activities, such as tidying up the residence and cooking, as well as carrying out personal activities of daily living, such as bathing, grooming, and dressing. They typically perform all or almost all instrumental and personal activities of daily living on their own. The principal exception is persons living with others, where some of the tasks of daily life may be shared or performed by others in the household.

Nevertheless, with aging, as chronic diseases and disabilities increase, instrumental activities are usually the first areas in which a loss of partial or full personal self-sufficiency can be expected. As that loss occurs, family members and friends typically step forward to help the person carry out these tasks, including help with meals, shopping, and transportation. Alternatively, when there is a close personal relationship with a paid domestic helper, that person may assume additional responsibilities. The total time needed to carry out these activities will remain about what it was before, only now the person performs less of the activity, with that time replaced by family and friends performing more. Such increases in informal support seldom tear at the bonds that tie the person to the family. Love and a sense of duty drive the family to step forward. The process is usually natural and unspoken, with family simply stepping in to do what is necessary. The person is seldom left in a dangerous or untenable situation, and as a new need arises, family and friends almost always step forward to pick up all or most of the slack.

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Overall Goals of Care

- Identify families who cannot provide informal care that will fully compensate for the care needs of persons with a decline in IADL and ADL, and develop a family-agency plan to meet the needs of the person.
- Identify persons with no primary informal caregiver and consider formal care services intervention.
- Identify persons whose problems may improve and thus whose needs may decrease, and assist the family to step forward on a short-term basis.

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In this CAP, however, we seek to identify persons whose informal support systems may be at a higher risk of not fully responding to their unfolding needs. What distinguishes these persons is that when first seen they are likely to be receiving lower levels of informal help, irrespective of their functional disability level.

This CAP does not seek to isolate informal helpers having stress or strain, for this factor by itself is not crucial to the level of informal care provided to the person. Informal helpers usually continue to provide help even when stress and strain are present.

Informal Support CAP Trigger

This CAP trigger identifies persons who currently require help with instrumental activities of daily living, focusing on those who have families that are challenged to respond fully to the emerging needs of the person. While the family members will almost always be sympathetic to the needs of the person, formal agencies need to prepare to step in to provide higher levels of formal support services to such persons. Where formal agencies are not yet involved, family members must be encouraged to reach out for help.

This CAP is not designed to assign blame or make a judgment on a particular person's informal care network. Rather, it seeks to identify persons who have an informal support network that will benefit from having a "back-up" plan or alternative arrangement in place as the person declines over time. Informal support systems in situations such as this are called "brittle."

TRIGGERED IF BOTH OF THE FOLLOWING ARE TRUE

- Not independent (setup help permitted) in one or more of the following IADL difficulty (capacity to perform) areas: meals, housework, shopping, and transportation.
- Two or more of the following apply:
  - Alone for long periods of time or all of the time during the day
  - Lives alone or in a group setting with nonrelatives
  - No primary informal helper present

For those in the community, every point of decline in IADL capacity translates into about a 10% loss of personal self-sufficiency in instrumental activities. The triggered

group includes about 40% of persons receiving home care and 10% of older adults living independently in the community.

For this triggered group, informal replacement levels are less than one-half of the levels of those not triggered. However, should there be a change in the factors comprising the trigger (for example, no longer lives alone), the informal support system responsiveness will change. Nevertheless, for those triggered, the person is likely to find him- or herself having to continue to carry out a higher proportion of instrumental activities. This can challenge the person and result in these functional activities being less well performed.

In a home care environment, the goal would be to identify where there is a gap in family response potential, and to provide a formal maintenance service whenever possible. When such service is provided, the person will receive help in completing activities that exceed his or her functional abilities.

NOT TRIGGERED — All other persons.

Informal Support CAP Guidelines

Check for declines in IADLs and ADLs, establish care needs, and identify families who cannot provide informal care that will fully compensate. A discussion with the family (or the person) should take place to determine the nature of the difficulties being faced and explore available alternatives such as the following:

- Help the person move in with a loved one; the agency could consider moving support.
- Draw up a joint family-agency plan for meeting the needs of the person. To create such a plan often requires that the person is eligible for formal services and that there is a payment mechanism in place to provide the needed level of services. Where this has not been determined, a formal application for service coverage will need to be made.
- If access to more intensive formal care is not an option, efforts should be made to assist the family members to explore areas where they might be able to do more. In addition, a review of the other CAPs may help to identify whether there is a possibility for the person to improve. If the answer is “yes,” this may be helpful information for the family to be aware of because the increase in help can then be seen as a temporary measure. If the answer is “no,” the need to provide more prolonged support should be anticipated.
- Some family members may be strained or burdened; relieving these conditions could make them willing or able to do more for the person. As a first step, review the Abusive Relationship CAP; if abuse is present, it must be addressed first. Assuming this is not the case, consider the following:
  - Would respite care for the person provide an opportunity for family members to improve their health or relieve their strain?
  - Are the family members misinformed of the person’s status? Should family contact levels be increased? Should family members in contact with the person keep other potential helpers “in the loop”?

- Do family members have the capacity to purchase services to help the person?
- Has the person refused offers of help? Some persons will refuse efforts to address their needs, whether from informal or formal sources. Often, in such situations, the person has a history of refusing help, and all the assessor or the family can do is provide oversight and wait for a suitable time to offer informed counseling.
- Family members may be concerned about taking on more than they can handle, and a simple educational exchange may help to counter their fears about the extent to which the person will continue to decline in the immediate future.
- The primary caregiver needs specialized instruction and interim oversight on specialized care tasks (for example, how to deal effectively with new personal care needs, giving injections, or addressing emerging behavior problems).
- Direct counseling and enrollment in support groups may provide family members with effective strategies to manage the stress and feelings of burden. It may be helpful to inform the family about resources available to them in the community such as Alzheimer's family support groups or mental health agencies.
- Caregivers of such persons who are experiencing feelings of severe stress and burden may even decrease their informal care if these problems are not addressed.

No primary informal caregiver is present. The 15% of persons triggered with no primary informal caregiver receive the least amount of informal care. For persons in this group, 50% are widowed, 22% never married, and 17% are divorced. Most (80%) live in private homes or apartments. As these persons' health declines, they experience an increase in informal care similar to the persons triggered in the other groups, but at a lower level than the group not triggered.

- For persons with no primary informal caregiver, who are receiving some informal help (for example, a grandniece calls once a week), the agency should explore the options listed in the previous section.
- For persons with no primary informal caregiver who are receiving no informal care at all, formal care services need to be considered. As stated in the previous section, some persons consistently refuse formal and informal help. At times, the remaining course of action is to provide limited oversight and wait for a better time to offer informed counseling.

Review other triggered CAPs for areas in which the person might improve and thus need less help in the future. If such changes are possible and likely, the family may be more willing to step forward in the short term as the level of need by the person for long-term formal care can be expected to decrease as the person becomes more self-sufficient.

- CAPs of special relevance include IADL CAP, ADL CAP, Cognitive Loss CAP, Prevention CAP, Behavior CAP, Mood CAP, and Delirium CAP.

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