

**APPENDIX Jb:**

**CLASS PROGRAM BENEFIT TRIGGERS  
AND COGNITIVE IMPAIRMENT**

**CLASS PROGRAM BENEFIT TRIGGERS AND COGNITIVE IMPAIRMENT**

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## TABLE OF CONTENTS

### INTRODUCTION

### **PART 1: BENEFIT TRIGGERS IN THE CLASS PROGRAM AND OTHER LONG-TERM CARE INSURANCE PROGRAMS**

Recommendations

### **PART 2: COGNITIVE IMPAIRMENT AND NEED FOR AND USE OF LONG-TERM SERVICES AND SUPPORTS**

#### **A. Need for Substantial Assistance from Another Person To Perform ADLs in Older People with Cognitive Impairment and Dementia**

Impact of Cognitive Impairment and Dementia on Ability to Perform ADLs

Relationship of Ability to Perform ADLs and IADLs

Inability to Perform ADLs in Cognitive and Dementia Rating Scales

Defining “Substantial Assistance from Another Person”

Recommendations

#### **B. Need for Substantial Supervision To Protect the Individual from Threats to Health and Safety in Older People and People with Dementia**

Threats to Health and Safety

- Wandering
- Accidents and injuries in the home
- Falls
- Access to guns
- Driving
- Serious medication errors
- Self neglect

Unawareness of Deficit

Defining “Substantial Cognitive Impairment”

Defining “Substantial Supervision”

Recommendations

**C. Use of Long-Term Services and Supports by Older People with Cognitive Impairment and People with Dementia**

**D. Cognitive Impairment and Need for and Use of Long-Term Services and Supports by Adults with Cognitive Impairment Caused by Other Diseases and Conditions**

Recommendations

**PART 3: OPTIONS FOR MEASURING CONCEPTS IN THE CLASS PROGRAM BENEFIT TRIGGERS THAT ARE IMPORTANT FOR PEOPLE WITH COGNITIVE IMPAIRMENT**

**A. Measuring “Substantial Assistance”**

**B. Measuring “Substantial Cognitive Impairment”**

**C. Measuring “Substantial Supervision”**

**PART 4: OPTIONS FOR THE UNSPECIFIED BENEFIT TRIGGER**

**REFERENCES**

## **INTRODUCTION**

The mandated benefit triggers for the Community Living Assistance Services and Support (CLASS) Program legislation are clearly intended to include people with cognitive impairment. One of the two specified benefit triggers explicitly identifies as eligible an individual who “requires substantial supervision to protect the individual from threats to health and safety due to substantial cognitive impairment.” In addition, some people with cognitive impairment will be eligible based on the other specified benefit trigger, inability to perform at least 2 or 3 activities of daily living (ADLs) without substantial assistance from another person. Over time, for example, virtually all people who have progressive neurological diseases and conditions that cause cognitive impairment, e.g., people with Alzheimer’s disease, Huntington’s disease, and Amyotrophic Lateral Sclerosis (ALS), will need assistance from another person with all 6 ADLs listed in the legislation, unless they die first from another cause.

The CLASS Program benefit trigger that identifies individuals as eligible based on need for supervision to protect them from threats to their health and safety was probably intended by Congress to target people with cognitive impairment due to Alzheimer’s disease and other dementias that mainly affect older people. Certainly, however, some adults of all ages who have cognitive impairment due to other diseases and conditions, e.g., people with mental retardation, other intellectual disabilities, severe mental illness, traumatic brain injury and acquired immunodeficiency syndrome, could also be eligible based on this trigger. Likewise, some adults with cognitive impairment due to any of these diseases and conditions could be eligible based on inability to perform ADLs. Adults with cognitive impairment due to diseases and conditions that preclude them from working throughout their adult lives may not be able to enroll in the CLASS Program because of the work and earned income requirements for enrollment. Nevertheless, in developing regulations to operationalize and implement the CLASS Program benefit triggers, it is important to consider the relevance and impact of proposed regulations for adults with cognitive impairment due to diseases and conditions beyond the targeted group of older people with Alzheimer’s and other dementias.

There is currently a very large and growing body of research on cognitive impairment, measurement of cognitive impairment, and the need for and use of long-term services and supports by people with cognitive impairment. This research, as well as clinical and practice-based experience in determining eligibility for long-term services and supports, suggests various approaches for operationalizing and implementing the mandated CLASS Program benefit triggers as they pertain to people with cognitive impairment. To focus the discussion of findings from these sources, this paper begins by identifying the concepts and wording in the CLASS Program benefit triggers that are particularly important for people with cognitive impairment. The paper then compares the wording and concepts in the CLASS Program benefit triggers with the wording and concepts in the required benefit triggers for qualified long term care insurance policies under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Federal Long-Term Care Insurance Program and summarizes the limited amount of published information about individuals with cognitive impairment who receive long-term services and supports funded at least in part through these policies. Later sections of the paper discuss the relationship of cognitive impairment and need for and use of long-term services and supports and approaches for operationalizing and measuring the relevant concepts in the CLASS Program benefit triggers based on need for supervision to protect an individual from threats to health and safety and inability to perform ADLs. The CLASS Program legislation includes a third, unspecified benefit trigger, and the last section of the paper suggests options the Secretary might consider for this benefit trigger. Throughout the paper, recommendations for the Secretary are noted in text boxes.

## **PART 1: BENEFIT TRIGGERS IN THE CLASS PROGRAM AND OTHER LONG-TERM CARE INSURANCE PROGRAMS**

As noted above, the CLASS Program legislation includes two specified benefit triggers and one unspecified benefit trigger to be determined by the Secretary. Box 1 shows the language from the CLASS Program legislation that describes the benefit triggers. Four concepts (underlined in the box) are particularly important in considering the implications of the benefit triggers for people with cognitive impairment:

1. substantial assistance (as defined by the Secretary) from another individual;
2. substantial supervision;
3. threats to health and safety; and
4. substantial cognitive impairment.

**Box 1: CLASS Program Benefit Triggers**

“A benefit trigger for provision of benefits that requires a determination that an individual has a functional limitation, as certified by a licensed health care practitioner, described in any of the following clauses that is expected to last for a continuous period of more than 90 days:

- (i) The individual is determined to be unable to perform at least the minimum number (which may be 2 or 3) of activities of daily living as are required under the plan for the provision of benefits without substantial assistance (as defined by the Secretary) from another individual.
- (ii) The individual requires substantial supervision to protect the individual from threats to health and safety due to substantial cognitive impairment
- (iii) The individual has a level of functional limitation similar (as determined under regulations prescribed by the Secretary) to the level of functional limitation described in clause (i) or (ii).”

“The term ‘activities of daily living’ means each of the following activities...

- (A) Eating.
- (B) Toileting.
- (C) Transferring.
- (D) Bathing.
- (E) Dressing.
- (F) Continence

Source: Public Law 111-148, Title VIII, Sections 3202 and 3203, March 2010.

The required benefit triggers for tax qualified long term care insurance policies under HIPAA (1996)<sup>a</sup> are similar but not exactly the same as the mandated benefit triggers for the CLASS Program. In specific, the HIPAA benefit trigger based on need for supervision to protect the individual from threats to health and safety states that the threats are due to severe cognitive impairment,” as opposed to “substantial cognitive impairment” in the CLASS Program benefit trigger. In addition, in the HIPAA requirements, the 90-day period applies only to the benefit trigger based on inability to perform ADLs. Also, the words, “due to a loss of functional capacity” are added to the benefit trigger based on ADLs, so that the individual must be “unable to perform (without substantial assistance from another individual) at least 2 activities of daily living, due to a loss of functional capacity.”

The required benefit triggers for the Federal Long-Term Care Insurance Program are similar but not exactly the same as either the mandated benefit triggers for the CLASS Program or the HIPAA benefit triggers. Like the HIPAA benefit trigger based on need for supervision to protect the individual from threats to health and safety, the Federal Long-Term Care Insurance Program benefit trigger based on need for supervision requires that the threats are due to severe cognitive impairment,” as opposed to “substantial cognitive impairment” in the CLASS Program benefit trigger. Also like the HIPAA benefit triggers, the Federal Long-Term Care Insurance Program applies the 90-day period only to the benefit trigger based on inability to perform ADLs, and adds the words, “due to a loss of functional capacity,” to that benefit trigger. Unlike the CLASS Program and HIPAA benefit triggers based on need for supervision, the Federal Long-Term Care Insurance Program benefit trigger on need for supervision does not include the phrase, “to protect the individual from threats to health and safety.”

All three sets of benefit triggers list exactly the same ADLs: eating, toileting, transferring, bathing, dressing and continence. They differ only in that the HIPAA and Federal Long-Term Care Insurance Program benefit triggers specify that the person must need assistance with 2 of the 6 ADLs, while the CLASS Program triggers allow the Secretary to decide whether the person must need assistance with 2 or 3 ADLs.

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<sup>a</sup> The Health Insurance Portability and Accountability Act of 1996 (HIPAA) created a new federal income tax deduction for premiums for long-term care insurance policies that met requirements defined in the Act, including required benefit triggers.



This contractor has not found any published information about the number of individuals with cognitive impairment that has received long-term services and supports through the Federal Long-Term Care Insurance Program or the proportion of all individuals who have received such services that are individuals with cognitive impairment. One study funded by ASPE found, however, that 41 percent of a random sample of 1,474 individuals who had long-term care insurance and had just begun or were about to begin using paid long-term services and supports were individuals with cognitive impairment (Miller et al., 2008). The proportions of individuals that had cognitive impairment differed across care settings. Among those who had begun receiving paid care at home, 28 percent had cognitive impairment, compared with 63 percent of those who were receiving paid care in an assisted living facility and 64 percent of those who were receiving paid services in a nursing home (Cohen et al., 2006). Among those who had not yet begun receiving paid care, 29% had cognitive impairment.

The ASPE-funded study found that the great majority of individuals in the sample would have been eligible based on the HIPAA benefit triggers (Miller et al., 2008), but the study finding about the proportion of individuals that had cognitive impairment was based on the results of a brief mental status test, the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer et al., 1975), which was administered by research nurses for the study. Thus, it is not clear from the reported findings whether these individuals met the HIPAA benefit trigger based on need for supervision to protect the individual from threats to health and safety, the HIPAA benefit trigger based on ADLs, or both.

Another study funded by the MetLife Mature Market Institute found that 42 percent of a sample of 423 individuals who had long-term care insurance and were receiving paid care in the community were individuals with Alzheimer's disease or another dementia (MetLife, 2006). Again, it is not clear from the study finding whether these individuals met the HIPAA benefit trigger based on need for supervision, the HIPAA benefit trigger based on ADLs, both triggers, or another benefit trigger used by their long-term care insurance company. Nevertheless, both studies show that substantial proportions of people who are found to be eligible for long-term

services and supports through their long-term care insurance policy are people with cognitive impairment.

As of Oct. 5, 2010, Marc A. Cohen, PhD, was completing a report for SCAN Foundation on questions about how the HIPAA benefit trigger based on need for supervision to protect the individual from threats to health and safety is implemented in existing long-term care insurance plans.<sup>b</sup> This report should provide valuable ideas about how the CLASS Program benefit trigger based on need for supervision could be operationalized and implemented.

Recommendation. Because of the similarities among the CLASS Program, HIPAA and Federal Long-Term Care Insurance Program benefit triggers and because the CLASS Program benefit triggers are intended for use in long-term care insurance plans, any available information about how the HIPAA and Federal Long-Term Care Insurance Program benefit triggers have been implemented will be useful to the Secretary in operationalizing the CLASS Program benefit triggers. Such information, which could include research findings and/or clinical and practice-based experience in determining eligibility for long-term services and supports, should be obtained in a timely manner.

## **PART 2: COGNITIVE IMPAIRMENT AND NEED FOR AND USE OF LONG-TERM SERVICES AND SUPPORTS**

The term, *cognitive impairment*, refers to reduced or impaired cognitive or mental abilities, including memory, thinking, learning, awareness, orientation, understanding, recognition, concentration, reasoning, planning, organizing, solving problems and making judgments and decisions. A wide array of genetic and acquired diseases and conditions can cause cognitive impairment.

Cognitive impairment can result in inability to perform activities that are essential for normal, independent functioning, including self-care activities, usually referred to as ADLs and

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<sup>b</sup> Dr. Cohen indicated that ASPE is aware of the report. This contractor has not seen the report as of Oct. 11, 2010.

IADLs (instrumental activities of daily living) in older people, as well as activities that are required for school and work in younger people and activities that are part of normal social interaction for people of all ages. Even if an individual with cognitive impairment is physically able to perform these activities, he or she may be unable to learn or remember how to perform them, know when or where to perform them, or be unable to plan, initiate, or sequence the steps needed to perform them successfully. Depending on the types of activities the individual is unable to perform independently, he or she may need long-term services and supports.

The relationship between cognitive impairment and inability to perform essential self-care and other activities is obvious in a sense, but it is not always fully understood. Two examples pertaining to inability to perform ADLs illustrate the relationship. First, with respect to the ADL, dressing, an individual of any age could be physically unable to dress independently because of weakness or an injury, disease, or condition that makes it impossible for the individual to get out, put on, and fasten clothing. In contrast, an individual could be cognitively unable to dress independently because of inability to learn or remember how to put on clothing; inability to plan, initiate, and sequence the steps in dressing, or inability to understand or remember when to get dressed. Similarly, with respect to the ADL, toileting, which means getting to and using the toilet, an individual could be physically unable to get to or use the toilet independently because of weakness or an injury, disease or condition that makes it impossible walk or otherwise get to the toilet, use it and get back to his or her prior location. In contrast, an individual could be cognitively unable to learn or remember how to use a toilet, unable to recognize a toilet or know what it is for, or unaware of his or her need to use the toilet at a particular time. Although the specific reasons that individuals with cognitive versus physical impairments are unable to perform an ADL differ, and the kinds of help they need to perform the ADL may also differ, the end result with respect to the need for substantial assistance from another person to perform the ADL is often the same.

In addition to inability or reduced ability to perform self-care and other activities that are essential for normal, independent functioning, cognitive impairment can result in behaviors that create threats to the individual's health and safety. Examples of these behaviors include leaving home alone and getting lost; ingesting spoiled food or toxic substances; using household

appliances and sharp objects in an unsafe manner; and failing to follow instructions for needed medical care, e.g. instructions about the amounts of and schedule for taking prescribed medications. Such behaviors can lead to serious injury and death. To avoid these negative outcomes, long-term services and supports, including services often referred to as “supervision” or “monitoring,” may be needed.

The impact of cognitive impairment on an individual’s need for long-term services and supports varies greatly depending on many factors. These factors include how many and which particular cognitive abilities are affected and how severely they are affected; whether the cognitive impairment was present at birth or occurred in childhood or later in life; whether it occurred suddenly or gradually; and whether it is stable, worsening, or improving over time. For a few diseases and conditions that cause cognitive impairment, there is little or no variation among individuals who have the disease or condition with respect to a few of these factors. For example, all people with cognitive impairment due to Down’s syndrome have had the condition since birth. Likewise, almost all people with cognitive impairment due to an accident or a stroke have experienced a sudden onset of cognitive impairment, whereas almost all people with cognitive impairment due to degenerative dementias, such as Alzheimer’s disease, have experienced a gradual onset. As a rule, however, there is considerable variation among individuals with cognitive impairment due to any particular disease or condition in terms of these and other factors that affect the individual’s need for long-term services and supports.

Many individuals with cognitive impairment also have physical impairments. Their cognitive impairment is likely to limit their capacity to compensate for their physical impairments and, therefore, further reduce their ability to perform self-care and other activities that are essential for normal, independent functioning. For these individuals, need for long-term services and supports is affected by both their cognitive and physical impairments and the often complex interactions between the impairments.

Lastly, of course, an individual’s need for long-term services and supports depends on many characteristics of the individual’s family and social environment that are not determined by the disease or condition that is causing his or her cognitive impairment.

The following discussion focuses on the need for and use of long-term services and supports by older people with cognitive impairment and dementia. This focus addresses an important segment of the population of Americans with cognitive impairment, and the segment for which there is the most available information to evaluate the implications of the CLASS Program benefit triggers. Comparable information is needed to evaluate the implications of the triggers for nonelderly adults and people with cognitive impairment due to other diseases and conditions.

#### **A. Need for Substantial Assistance from Another Person To Perform ADLs in Older People with Cognitive Impairment and Dementia**

In older people, cognitive impairment of sufficient severity to result in inability to perform ADLs and other self-care activities is most often caused by dementia. The term, *dementia*, refers to a syndrome of decline in memory and at least one other cognitive ability that is severe enough to interfere with social or occupational functioning (APA, 2000). The requirement for decline distinguishes dementia from life-long mental retardation, although a person with mental retardation can develop dementia if his or her cognitive abilities decline from a previous level. The requirement for decline also means that a person with high previous intelligence can have dementia if his or her cognitive abilities decline to average levels, and this decline interferes with social or occupational functioning.

Many different diseases and conditions can cause dementia. Box 2 lists causes of irreversible dementia, followed by causes of potentially reversible dementia. Alzheimer's disease is said to be the most common cause of irreversible dementia in older people, but recent research shows that many older people who have the brain pathology that defines Alzheimer's disease also have brain pathology that defines other diseases and conditions that cause irreversible dementia, including brain pathology that defines vascular dementia and Lewy body disease (Olde Rikkert et al., 2006; Schneider et al., 2007). Thus, "mixed dementia" may be more common than dementia caused by any single disease or conditions.

## Box 2: Causes of Nonreversible and Potentially Reversible Dementia

### Causes of nonreversible dementia

#### *Degenerative diseases*

Alzheimer's disease  
Frontotemporal lobar degeneration (including Pick's disease)  
Huntington's disease  
Progressive supranuclear palsy  
Parkinson's disease  
Lewy body disease  
Olivopontocerebellar atrophy  
Amyotrophic lateral sclerosis (ALS)  
ALS-Parkinson-dementia complex  
Hallewörden-Spatz disease  
Kuf's disease  
Wilson's disease (if not treated early enough)  
Metachromatic leukodystrophy  
Adrenoleukodystrophy

#### *Vascular dementias*

Binswanger's disease  
Occlusive cerebrovascular disease  
Cerebral embolism  
Arteritis  
Anoxia secondary to cardiac arrest, cardiac failure of carbon monoxide intoxication

#### *Traumatic dementia*

Craniocerebral injury  
Dementia pugilistica

#### *Infections*

Acquired immunodeficiency syndrome  
Primary AIDs encephalopathy  
Opportunistic infections  
Creutzfeldt-Jacob disease  
Progressive multifocal leukoencephalopathy  
Postencephalitic dementia

### Causes of potentially reversible dementia

#### *Neoplasms*

Gliomas  
Meningiomas  
Metastatic tumors; carcinoma, lymphoma, leukemia  
Remote effects of carcinoma

#### *Metabolic disorders*

Thyroid disease - hyperthyroidism and hypothyroidism  
Hypoglycemia  
Hypernatremia and hyponatremia  
Hypercalcemia  
Renal failure

### Causes of potentially reversible dementia (cont.)

Hepatic failure  
Cushing's disease  
Addison's disease  
Hypopituitarism  
Wilson's disease

#### *Trauma*

Craniocerebral trauma  
Heavy metals (lead, manganese, mercury, arsenic)  
Organic poisons, including solvents and insecticides

#### *Infections*

Bacterial meningitis and encephalitis  
Parasitic meningitis and encephalitis  
Fungal meningitis and encephalitis, cryptococcal meningitis  
Viral meningitis and encephalitis  
Brain abscess  
Neurosyphilis: meningovascular, tabes dorsalis, general paresis

#### *Autoimmune disorders*

Central nervous system vasculitis, temporal arteritis  
Disseminated lupus erythematosus  
Multiple sclerosis

#### *Drugs*

Antidepressants  
Antianxiety agents  
Hypnotics  
Sedatives  
Antiarrhythmics  
Antihypertensives  
Anticonvulsants  
Cardiac medications, digitalis and derivatives  
Drugs with anticholinergic effects

#### *Nutritional disorders*

Thiamine deficiency (Wernicke's encephalopathy and Wernicke-Korsakoff syndrome)  
Vitamin B12 deficiency (pernicious anemia)  
Folate deficiency  
Vitamin B6 deficiency (pellagra)

#### *Psychiatric disorders*

Depression  
Schizophrenia  
Other Psychoses

#### *Other disorders*

Normal-pressure hydrocephalus  
Whipple's disease  
Sarcoidosis

Source for Box 2: Costa et al., AHCPR, 1996.

[Note: if a list like this were going to be used publicly, it should be updated with newer terms for some conditions. It could also be shortened.]

Impact of Cognitive Impairment and Dementia on Ability to Perform ADLs. Studies published over the past 20 years show that cognitive impairment in older people is associated with reduced ability to perform ADLs at any point in time (Fultz et al., 2003; Gill et al., 1995; Li and Conwell 2009; Mulrow et al., 1994; Reed et al., 1989; Smith et al., 2010). More important than this finding, however, are findings from longitudinal studies showing that cognitive impairment in older people at one point in time is associated with reduced ability to perform ADLs at a later time (Gill et al., 1996; Gill et al., 2007; Jagger et al., 2007; McGuire et al., 2006; Moody-Ayers et al., 2005; Moritz et al., 1995; Spiers et al., 2005; Wang et al., 2002). Specific findings from two of these studies are as follows:

- A study of 1,103 people age 72 and older who were able to perform all ADLs independently at baseline found that those who had cognitive impairment were 2.4 times as likely as those with no cognitive impairment to become unable to perform at least one ADL over the next year and 2.3 times as likely to become unable to perform at least one ADL over the next 3 years (Gill et al., 1996).
- A study of 5,671 people age 70 and older found that blacks age 70-79 were 2 times as likely as whites in that age group to decline in their ability to perform ADLs over a 2-year period, but the difference was entirely accounted for by differences between the two groups in baseline cognitive impairment (Moody-Ayers et al., 2005). Blacks age 80 and older were not more likely than whites in that age group to decline in their ability to perform ADLs in the two years after baseline assessment, but when cognitive impairment was accounted for, blacks age 80 and older were significantly less likely than whites in that age group to decline in their ability to perform ADLs over the 2-year period.

At least four studies have found that older people with cognitive impairment are also less likely than older people with no cognitive impairment to recover their ability to perform ADLs independently after an illness or hospitalization (Gill et al., 1997; Gill et al., 2009; Givens et al., 2008; Sands et al. 2003). Sands et al. (2003) found that in a sample of 2,557 people age 70 and

older who were hospitalized, those with cognitive impairment before the hospitalization were much less likely than those with no cognitive impairment to recover their preadmission ability to perform ADLs. Among those who were able to perform all ADLs independently before their hospitalization, 57 percent of those with moderate to severe cognitive impairment recovered their preadmission ability to perform ADLs by 90 days after discharge, compared with 72 percent of those with mild cognitive impairment and 86 percent of those with no cognitive impairment. Likewise, among those who were unable to perform at least one ADL independently before the hospitalization, only 35 percent of those with moderate to severe cognitive impairment recovered their preadmission ability to perform ADLs by 90 days after discharge, compared with 62 percent of those with mild cognitive impairment and 73 percent of those with no cognitive impairment.

Still other studies show that older people whose cognitive abilities decline faster are, on average, more likely than those whose cognitive abilities decline more slowly to develop new inability to perform ADLs (Schmidler et al, 1998; Yaffe et al., 2010).

As one would expect, people with diagnosed dementia are more likely than people without dementia to have reduced ability to perform ADLs at any point in time, to decline in their ability to perform ADLs over time, and to be unable to recover their ability to perform ADLs after an illness or hospitalization (Aguero-Torres et al., 1998; Mulrow et al. 2004; Penrod et al. 2008; Wolff et al. 2005). In a sample of 4,968 people age 65 and older, Wolff et al (2005) found that those with newly diagnosed dementia were 14 times as likely as those without diagnosed dementia to have new inability to perform ADLs independently after one year, even after controlling for age, gender, education, and other chronic and newly diagnosed conditions. Those with diagnosed dementia were 6 times and 7 times as likely to have new inability to perform ADLs after 2 years and 3 years, respectively. Likewise, in a sample of 1,745 people age 65 and older, Aguero-Torres et al. (1998) found that after 3 years, those with diagnosed dementia were 25 times as likely as those without diagnosed dementia to have new inability to perform ADLs. Lastly, in a sample of 240 people with diagnosed Alzheimer's disease, Freels et al (1992) found those who also had behavioral symptoms, such as unsafe wandering and aggressiveness,



were 8 times as likely as those who did not have behavioral symptoms to have difficulty performing ADLs.

Relationship of Ability to Perform ADLs and IADLs. Many studies of ability to perform ADLs in older people and people with dementia also address ability to perform IADLs. Some researchers have suggested that IADLs and ADLs constitute a hierarchy of functional abilities and that they can be ordered from abilities that are likely to be lost first to abilities that are likely to be lost last, as an individual's functioning worsens (see, e.g., Kempen and Suurmeijer, 1990; Spector 1987). In proposed hierarchies based on this concept, IADLs, such as using the telephone, shopping, food preparation, housekeeping, managing medications and managing money, are usually listed first and are expected to be lost first. The IADLs are followed by ADLs, which are expected to be lost last. The most commonly listed ADLs are those described by Katz et al. (1963), and they are usually listed in the following order, from the ADL likely to be lost first to the ADL likely to be lost last: continence, dressing, bathing, transferring, toileting, and feeding (or eating).

Some researchers who have studied ability to perform ADLs and IADLs in older people have shown that ability to perform two IADLs, using the telephone and managing money, and one ADL, eating, is strongly associated with cognitive ability (Fitzgerald et al., 1993; Wolinsky and Johnson, 1991.) The researchers refer to these functions as “advanced ADLs,” and others sometimes refer to the two IADLs as “cognitive IADLs.”

One study of 5,874 people age 65 and older found that the pattern of loss of ability to perform ADLs and IADLs in people with cognitive impairment did not match the usually cited hierarchies in which IADLs are lost before ADLs (Njegovan et al., 2001). The study found that inability to perform the ADL, bathing, occurred much earlier (that is, in people with less severe cognitive impairment) than would be expected on the basis of the usually cited hierarchies and before inability to perform IADLs such as using the telephone, managing money, and managing medications. Inability to perform the ADL, toileting, also occurred earlier than inability to

perform the same three IADLs.<sup>c</sup> These findings suggest that inability to perform certain IADLs indicates more severe cognitive impairment than inability to perform certain ADLs, including two of the ADLs listed in the CLASS Program benefit trigger.

Inability to Perform ADLs in Cognitive and Dementia Rating Scales. At least three widely cited dementia rating scales identify stages of cognitive decline or dementia and include both cognitive and noncognitive abilities. These three scales are described very briefly below, and for each scale, the placement by stage of inability to perform the ADLs listed in the CLASS Program benefit trigger is noted:

- The Clinical Dementia Rating (CDR) scale (Morris et al., 1993) identifies five stages of dementia: 1) none; 2) questionable dementia; 3) mild dementia; 4) moderate dementia; and 5) severe dementia. The CDR places need for assistance with the ADL, dressing, in stage 2, “moderate dementia,” and the ADL, incontinence, in stage 3, “severe dementia.” The CDR scale does not name the other four ADLs in the CLASS Program benefit trigger but states that the need for “much help with personal care” occurs in stage 3, “severe dementia.”
- The Functional Assessment Staging (FAST) scale (Reisberg et al., 1985) identifies seven stages of dementia of the Alzheimer’s type by diagnostic levels: 1) normal adult; 2) normal aged adult; 3) compatible with incipient dementia; 4) mild dementia; 5) moderate dementia; 6) moderately severe dementia; and 7) severe dementia.<sup>d</sup> The FAST places the need for assistance with the ADLs, dressing, bathing, toileting, and incontinence, in stage 6, “moderately severe dementia.” The FAST scale does not mention the ADLs, transferring and eating.
- The Global Deterioration Scale (GDS) (Reisberg et al., 1982) identifies seven stages of cognitive decline: 1) no cognitive decline; 2) very mild cognitive decline; 3) mild

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<sup>c</sup> The ADLs and IADLs listed in the order in which they were lost in the study by Njegovan et al. (2001) are as follows, from those lost first (i.e., in people with less cognitive impairment) to those lost last (i.e., in people with more cognitive impairment): doing housework, shopping, bathing, walking, transportation, meal preparation, toileting, using the telephone, managing money, transferring, managing medications, dressing, grooming, and eating.

<sup>d</sup> The FAST scale also includes substages in stages 6 and 7. At least one of these substages is used for determining eligibility for services, in this case, eligibility for Medicare-covered hospice care.

cognitive decline; 4) moderate cognitive decline; 5) moderately severe cognitive decline; 6) severe cognitive decline; and 7) very severe cognitive decline. The GDS places “difficulty choosing the proper clothing to wear” in stage 5, “moderately severe cognitive decline.” It places “need for some assistance with ADLs, e.g., may become incontinent” in stage 6, “severe cognitive decline.” The scale places the ADLs, incontinence and need for assistance with toileting and feeding, in stage 7, “very severe cognitive impairment.” The GDS does not mention the ADLs, bathing and transferring.

Staging instruments like the CDR, the FAST, and the GDS, provide a general picture of the pattern of loss of cognitive and other abilities in progressive dementias. Some, and perhaps many, individuals do not fit neatly into the identified stages, however, and may become unable to perform ADLs at the level of cognitive impairment or dementia indicated in the scale. In fact, research shows that there is not a one-to-one correspondence between level of cognitive impairment and loss of ability to perform any particular ADL (Brinkman et al., 2002; Cohen-Mansfield et al., 1995; Galasko et al., 1991; Reed et al., 1989; Weintraub et al., 1992). Cognitive impairment and inability to perform ADLs are certainly related, as shown in the studies discussed earlier in this section, but they are not the same, and studies conducted in various settings shows that individuals who have essentially the same level of cognitive impairment vary considerably in their ability to perform particular ADLs. On the other hand, it is also clear that all individuals with progressive, nonreversible dementias will eventually be unable to perform any ADLs and will need total assistance from another person to survive.

Defining “substantial assistance from another person.” For purposes of determining which long-term services and supports can be deducted as medical expenses in federal income tax calculations, the term, “substantial assistance,” has been broadly defined to include two concepts: “hands-on assistance,” described as physical help without which the person would not be able to perform an ADL, and “standby assistance,” described as the presence of another person within arm’s reach to prevent injury, for example, when the person is bathing and might fall.

Some of the kinds of assistance that are most often needed by a person with cognitive impairment who is unable to perform ADLs are not encompassed by the concepts, “hands-on assistance” and “standby assistance.” As noted earlier, a person with cognitive impairment may be unable to perform ADLs because he or she is unable to learn or remember how to perform them, know when or where to perform them, or plan, initiate, and sequence the steps needed to perform them successfully. Although the term, “standby assistance,” could be construed to encompass the kinds of assistance needed by a person with these deficits, it is not usually described in that way.

A person with cognitive impairment who is unable to perform an ADL independently needs assistance to initiate the ADL at the appropriate time and in the appropriate place and to perform each of the steps required to complete the ADL successfully. The assistance needed by the person is “substantial” in the sense that the helper must be physically present and must remain involved in the activity until it is completed. Some ADLs can be effectively scheduled for certain times in the day (e.g., dressing) or even some days of the week (e.g., bathing). Others, especially toileting, cannot be scheduled in periods as long as a day, or even as long as 5 or 6 hours. Assistance with toileting can be needed at any time of the day or night, and failure to complete the ADL, toileting, is likely to result in failure with respect to another ADL, incontinence. Adult diapers can be used, but they must be changed on a timely basis to avoid the development of skin problems and decubitus ulcers. In this context, it is also important to note that the study by Njegovan et al. (2001) showed that inability to perform the ADL, toileting, can occur before (i.e. in people with less cognitive impairment) than the ADL, dressing.

Without substantial assistance, the person with cognitive impairment who cannot perform an ADL independently is no more able to perform the ADL than another person who is physically unable to perform it. The belief that the amount of assistance with ADLs that is needed by people with cognitive impairment is much smaller than the amount of assistance with ADLs that is needed by people with physical impairment is pervasive and difficult to dispel. It is possible that some individuals who hold this belief are not aware of the cognitive abilities that are needed to perform activities that are generally regarded as simple and routine once the abilities are acquired in childhood. It is also possible that some individuals are not aware that

accidents, injuries, progressive dementias and other diseases and conditions can result in cognitive impairment sufficient to leave an individual unable to remember how to perform these basic activities, unable to know when or where to initiate the activities and unable to sequence the steps needed to perform the activities successfully. Frequent use of the terms “cueing” and “reminding” to describe the kinds of help needed by some people with cognitive impairment to perform ADLs may contribute to this lack of awareness, by suggesting, for example, that all the person needs is “a reminder” to bath, dress, use the toilet or eat.

Whatever the reason for the belief that the amount of assistance with ADLs needed by people with cognitive impairment is much smaller than the amount of assistance with ADLs needed by people with physical impairment, it is important to clarify that individuals who are unable to perform ADLs because of physical or cognitive impairments or both need substantial assistance to perform the ADLs, even though the precise types of assistance they need may differ.

Recommendations. The term “substantial assistance” should be defined to include not only hands-on and standby assistance but also the assistance needed by a person with cognitive impairment who cannot perform the ADL independently, that is, assistance to initiate the ADL at the right time and in the right place and to complete the steps required to perform the ADL successfully.

Information about the kinds of difficulties that are frequently associated with inability to perform ADLs in people with cognitive impairment (that is, difficulty in knowing or remembering when or where to initiate the ADL and inability to plan and sequence the steps required to complete the ADL successfully) and the kinds of assistance that is needed to address these difficulties should be conveyed to anyone who is responsible for implementing the CLASS Program benefit trigger.

Information about both the strong relationship between cognitive impairment and inability to perform ADLs and, at the same time, the lack of one-to-one correspondence in some individuals between level of cognitive impairment and inability to perform a specific ADL should be conveyed to anyone who is responsible for implementing the CLASS program benefit triggers.

## **B. Need for Substantial Supervision To Protect the Individual from Threats to Health and Safety in Older People and People with Dementia**

Far more research has been conducted on the relationship of cognitive impairment and inability to perform ADLs than on the relationship of cognitive impairment and the need for supervision to protect an individual from threats to health and safety, at least as these relationships exist in older people and people with dementia. To operationalize and implement the CLASS Program benefit trigger on need for supervision, it will be necessary to define the concepts, “threats to health and safety,” “substantial supervision” and “substantial cognitive impairment” and clarify their interrelationships and the implications of those interrelationships with respect to need for long-term services and supports. This section reviews available research findings to support these objectives.

It is obvious, at least upon reflection, that cognitive impairment can result in threats to health and safety. Cognitive impairment can reduce an individual’s ability to recognize such threats. Some, and perhaps many, people with cognitive impairment and people with dementia are not aware or only partially aware of their cognitive impairment and therefore may not know that they can no longer recognize threats as well as they once could. Moreover, once they are in a dangerous situation, they often lack specific cognitive abilities, such as reasoning, judgment and ability to plan, initiate and sequence behaviors, that would allow them to reduce their risk and get needed help.

As noted earlier, many people with cognitive impairment also have physical impairments, and their physical impairments often exacerbate threats to their health and safety. Such physical impairments can result from the same disease or condition that causes the person’s cognitive impairment, for example, in the case of individuals with neurological conditions that cause cognitive impairment and also cause impairments in gait and balance that increase the individual’s risk of falls. Alternatively, the physical impairments can result from a disease or condition that is unrelated to the disease or condition that causes the individual’s cognitive impairment, for example, in the case of individuals with cognitive impairment who also have

another disease and condition that causes serious vision impairment and therefore, increases their risk for accidents. Even vision and other impairments associated with normal aging can increase threats to health and safety for older people with cognitive impairment and dementia.

Threats to health and safety. Older people with cognitive impairment and people with dementia are at high risk for a wide array of threats to their health and safety as a result of wandering and other unsafe behaviors inside and outside the home. The following information about specific threats is intended to support the definition and clarification of the concept, “threats to health and safety,” as part of the overall operationalization and implementation of the CLASS Program benefit triggers.

*Wandering.* Probably the most frequently discussed threat to the health and safety of older people with cognitive impairment and people with dementia is wandering, getting lost and, as a result, becoming seriously injured or dying. No population-based data are available about the number or proportion of older people with cognitive impairment and dementia that wanders. Studies that were conducted in a sample of 193 older people with diagnosed Alzheimer’s disease and another sample of more than 15,000 veterans with moderate or severe cognitive impairment used medical and nursing home records to identify wandering incidents. The studies found that 20 to 25 percent of sample members had wandered at least once, and smaller proportions had wandered many times in the multi-year periods covered by the studies (Logsdon et al., 1998; Schonfeld et al., 2007). Findings from these and other studies show that wandering occurs in people at all levels of cognitive impairment but is more likely to occur in people with more versus less severe cognitive impairment; people who have had cognitive impairment and/or dementia for a longer time; people who also have depression, delusions, hallucinations, sleep disorders, and behavioral symptoms; and people who are taking antipsychotic medications (Kiely et al., 2000; Klein et al., 1999; Logsdon et al., 1998; Schonfeld et al., 2007)

It is sometimes said that most people with Alzheimer’s disease and other progressive dementias will wander and become lost at least once during the course of their disease (Rowe and Glover 2001). The studies described above may have missed wandering incidents, either because of the limited duration of the studies or because they relied on medical and nursing

home records that probably did not include all wandering incidents. Thus, it is possible that wandering is more common than the study findings indicate. If many wandering incidents were missed, it is also possible that the study findings about the characteristics of older people with cognitive impairment and people with dementia who wander could differ in unknown but important ways from the true characteristics of all such people who wander.

An older person with cognitive impairment or dementia who wanders may have a purpose or destination in mind (Algase et al., 1996; Schonfeld et al., 2007), but when the person is found to be missing, others may not be able to guess what that purpose or destination was and therefore, may not know where to look for the person. Once the person is lost, cognitive impairment, including reduced memory, judgment and ability to plan, initiate, and sequence behaviors, mean that the person may be unable to find his or her way home or get help.

Wandering and getting lost are risks for older people with cognitive impairment and people with dementia who are living in the community or in an assisted living facility or nursing home. One research team analyzed data from the Alzheimer's Association Safe Return program on 531 individuals with cognitive impairment who wandered and got lost in a 13-month period beginning in 1997 (Rowe and Glover, 2001). The study found that two-thirds of the individuals were living with a relative, and the remaining individuals were living in the community, either alone (15%) or with a paid caregiver (2%), or in an assisted living facility or nursing home (17%). Some of the individuals were found in a neighbor's yard, but others were found in the middle of intersections, walking along busy streets or highways, or in stores where their unusual behavior was noticed by store employees. Four of the individuals died, including three who died from prolonged exposure and one who was hit by a train. An additional 30 individuals experienced injuries, dehydration and the late effects of exposure to cold.

A retrospective review of newspaper accounts about 98 older people with dementia who died as a result of wandering and getting lost between 1998 and 2002, provides more information about the circumstances of their deaths (Rowe and Bennett, 2003). The most common cause of death in the 98 individuals was exposure (68%), followed by drowning (23%), falling (4%), being hit by a vehicle (3%), and asphyxiating in mud (1%). One-quarter of the individuals were



found dead within 24 hours of leaving their home or residential care facility, but one third were not found for more than a week. Most were found in a secluded place in the woods. Those who died in urban areas were also found in secluded places, such as a junkyard, a vacant lot, or the top of a building. Many of the newspaper reports indicated that the person had gotten to a secluded spot and stayed there until he or she died. Some seemed to have further concealed themselves under brush or other materials.

The risk of wandering ends when the person is no longer able to walk or otherwise ambulate independently, for example with a wheel chair. Interestingly, one study of wandering in nursing homes operated by the Department of Veterans Affairs (VA) found that 25 percent of wanderers were wheel chair users (Schonfeld et al., 2007).

One of the most important aspects of wandering in the context of the CLASS Program benefits triggers is its unpredictability. Even in people who have wandered numerous times, it is not clear when they will wander again, thus creating a possible need for supervision over long periods of time to reduce threats to the person's health and safety.

*Accidents and injuries in the home.* In addition to wandering, other threats to the health and safety of older people with cognitive impairment and people with dementia are caused by accidents, injuries, and illnesses that occur at home as a result of handling sharp objects, leaving the stove on, using water that is too hot, smoking or ingesting non-food, spoiled food or poisonous substances (Hurley et al. 2004; Oleske et al., 1995; Reed et al., 1990; Tierney et al., 2004). No data are available to determine how many older people with cognitive impairment and people with dementia experience accidents, injuries or illnesses as a result of these behaviors.

*Falls.* Most, but not all, studies of falls in older people and people with dementia have found that cognitive impairment is associated with increased risk (American Geriatrics Society, 2001; Ganz et al., 2007). More importantly, a study of fall-related injuries in a sample of 1,103 people age 72 and older found that cognitive impairment doubled the risk of serious injury associated with a fall (Tinetti et al., 1995). Another study of fall-related injuries in a sample of

157 individuals age 60 and older with diagnosed Alzheimer's disease found that wandering was associated with a greater likelihood that individuals who fell would sustain a fracture (Buchner and Larson, 1987).

Fall-related injuries account for a substantial proportion of all injuries in older people with cognitive impairment and people with dementia. One study of injuries incurred by 281 individuals age 44 to 92 with diagnosed Alzheimer's disease found, for example, that 44 percent of the injuries were caused by falls (Oleske et al., 1995).

*Access to guns.* Substantial proportions of older people with cognitive impairment and people with dementia have guns in their homes. One study of 106 individuals with symptoms of dementia who were seen at an outpatient memory disorders clinic in South Carolina found that 60 percent of the individuals had one or more guns in their homes, and the guns were loaded in 45 percent of these homes (Spangenberg et al, 1999). Likewise, a study conducted in 2002 by the Department of Veterans Affairs (VA) in a sample of 307 veterans with cognitive impairment found that 40 percent of the veterans had at least one gun at home, and 21 percent of these veterans had loaded guns (Veterans Health Administration, 2004). Most of the veterans with guns in their home had mild cognitive impairment, but 25 percent had moderate or severe cognitive impairment. No data are available to determine whether or how often the guns were used by the person with cognitive impairment or dementia or how many or what kinds of injuries may have resulted from this use. The presence of loaded guns in the homes of people with cognitive impairment and dementia would seem, however, to create a clear threat to their health and safety and the health and safety of others around them.

*Driving.* Many older people with cognitive impairment and people with dementia continue to drive. The 2002 VA study found that 44 percent of the 307 veterans with cognitive impairment were still driving (Veterans Health Administration, 2004). Most of those who were still driving had mild cognitive impairment, but 16 percent had moderate or severe cognitive impairment.

Most, but not all, studies of older drivers show that drivers with cognitive impairment and dementia are more likely than other older drivers to have vehicle crashes. A study of 3,238 drivers age 65 and older who agreed to a test of cognitive impairment at the time they were applying for renewal of their driver's license found that those with cognitive impairment were significantly more likely than those without cognitive impairment to have a crash documented in their state driving record (Stutts et al., 1998). A review of 23 studies of older drivers found that those with diagnosed dementia performed more poorly on road tests and in driving simulations, and caregivers reports indicated that the drivers with diagnosed dementia were 2.2 to 8 times more likely to have had a crash, but only one of the three studies that used state driving records to document crashes found that drivers with diagnosed dementia had more crashes than other older drivers (Mon-Son-Hing et al., 2007).

Most older people with cognitive impairment and people with dementia stop driving as their cognitive impairment increases, but some do not (Carr et al., 2005; Foley et al. 2000; Perkinson et al., 2005). A study of 201 people with diagnosed Alzheimer's disease found that 183 individuals (71%) had stopped driving, and 58 individuals (29%) had not (Carr et al., 2005). There were no significant differences in the cognitive test scores between the two groups. Most of the individuals in both groups had very mild cognitive impairment, as indicated by their score on the Clinical Dementia Rating (CDR) Scale, but almost one third (31%) of those who were still driving had a CDR score of 1.0 or higher. A CDR score of 1.0 indicates moderate dementia that is more marked for recent events and interferes with daily activity; possible geographic disorientation; and moderate difficulty with problem solving (Hughes et al., 1982; Morris, 1997). Higher CDR scores indicate higher levels of impairment. Another study of 643 men who were evaluated using the CDR as part of a larger study of heart disease found that 22 percent of the 98 men with a CDR score of 1.0 and one of the 23 men with a CDR score higher than 1.0 were still driving (Foley et al. 2000).

*Serious medication errors.* Many people of all ages fail to take their prescribed medications exactly as directed. Taking prescribed medications as directed means planning, initiating and sequencing the steps needed to take them at the right time, in the right amount and manner, e.g., with or without food, and remembering whether the medication was taken (Insel et

al., 2006). Understandably, older people with cognitive impairment and people with dementia are less likely than other people to take their prescribed medications as directed (Hurley et al., 2004; Insel et al., 2006; Ownby 2006). Anecdotal evidence indicates that such people sometimes take their medications erratically, not at all, or too much at one time, and later may not remember what they have taken. One study of 95 people age 67 and older who were managing their own medications tracked the extent to which they adhered to the directions for one of their medications (Insel et al., 2006). The study found that 62 percent of the sample adhered to the medication directions at least 85 percent of the time, and the remaining 38 percent adhered to the medication directions anywhere from zero to 84 percent of the time. Those with cognitive impairment were significantly more likely than those without cognitive impairment to adhere to their medication directions.

No data are available on the number or proportion of older people with cognitive impairment or people with dementia who have serious negative health outcomes as a result of failure to take their medications as directed. One study of 139 people age 65 and older who were living alone in the community and experienced harm due to cognitive impairment, identified 3 individuals who required emergency medical care because of delirium and cardiac complications of failing to take prescribed medications as directed (Tierney et al. 2004).

*Self-neglect.* Cognitive impairment is the most widely recognized cause of self-neglect, which has been defined as failure to attend adequately to one's own health, hygiene, nutrition or social needs (Abrams et al., 2002; Paveza et al., 2008). One study of 2,812 community dwelling people age 65 and older found that self-neglect was four times as likely in those with cognitive impairment as those without cognitive impairment (Abrams et al., 2002).

Self-neglect is the most common problem of adults referred to Adult Protective Services (APS) agencies in the U.S. (Heath et al., 2005; Lachs et al., 1997; Pavlik et al., 2001), and many studies of self-neglect in older people use samples of APS clients. Findings from these studies show that APS clients who are referred for self-neglect are much more likely than other APS clients to have cognitive impairment (Dyer et al., 2000; Heath et al., 2005). One study of 538

older APS clients who were referred for self-neglect found that 50 percent had cognitive impairment (Dyer et al., 2007)

Unawareness of deficit. Some, and perhaps many, older people with cognitive impairment and people with dementia are not aware of their cognitive impairment or related inability to perform activities that are essential for normal, independent functioning. Many researchers and clinicians say that this problem, generally referred to as “unawareness of deficit,” is much more common in people with cognitive impairment caused by certain diseases and conditions, e.g., Alzheimer’s disease and frontotemporal lobar degeneration, than by other diseases and conditions, e.g., vascular dementia (DeBettignies et al., 1990; Pia and Conway 2008; Wagner et al., 1997), but other researchers and clinicians are doubtful about some of these distinctions (see e.g., Aalten et al. 2005). No data are available to determine the number or proportion of older people with cognitive impairment, people with dementia, or people with any particular disease or condition that has unawareness of deficit.

Unawareness of deficit adds to the vulnerability of older people with cognitive impairment and people with dementia (Aalten et al. 2005; Lehmann et al., 2010; Wagner et al., 1997). Even if these people are able to recognize a threat to their health or safety, they may not be aware that they lack the cognitive abilities needed to respond effectively. As a result of unawareness of deficit, they may be unwilling to modify behaviors, such as driving, even when they recognize the risks created by the behaviors (Aalten et al., 2005; Cotrell and Wild, 1999; Wagner et al., 1999). For the same reason, they may unwilling to accept needed help.

Researchers and clinicians have noted that there is wide variability in the extent of unawareness of deficit in older people with cognitive impairment and people with dementia (Aalten et al. 2005; Feher et al., 1991; Wagner et al., 1999). Individuals with unawareness of deficit also vary in the extent to which they are aware of deficits in particular cognitive and related abilities (DeBettignies et al., 1990; Seltzer et al., 1997; Vesterling et al., 1997; Zanetti et al., 1999). Thus, for example, some people are unaware of deficits in their thinking and memory but unaware of deficits in other cognitive abilities that are important for independent living. In contrast, other people are unaware of deficits in their thinking and memory but aware of deficits

in other cognitive abilities that are important for independent living.

Unawareness of deficit is a complex condition that is not well understood. Some researchers and clinicians believe that it results entirely or almost entirely from neurological or other changes in the brain that are caused by the same disease or condition that is causing the person's cognitive impairment (Clare et al., 2002). Other researchers and clinicians believe that unawareness of deficit is often due to a psychological defense mechanism, usually referred to as "denial," through which the person protects himself or herself from thinking about and being upset by the reduction or loss of cognitive abilities. Most studies show that unawareness of deficit increases over time as a person's cognitive impairment worsens (McDaniel et al., 1995; Vesterling et al., 1997; Wagner et al., 1997; Zanetti et al., 1999), thus suggesting that it may be caused primarily by the disease or condition that is causing the person's cognitive impairment. Certainly, however, some older people with cognitive impairment and people with dementia also exhibit the psychological defense mechanism, denial.

Because unawareness of deficit increases vulnerability to threats to health and safety, it is a relevant factor in determining a person's need for supervision. Increased understanding about which people with cognitive impairment are likely to have unawareness of deficit, when it is likely to occur and how it can be recognized would be useful for anyone who is trying to implement the CLASS Program benefit trigger on need for substantial supervision to protect an individual from threats to health and safety.

Defining "substantial cognitive impairment." Taken out of the context of the CLASS Program benefit trigger, the term "substantial cognitive impairment," could be defined in many different ways. Since the CLASS Program trigger based on need for supervision uses the term "substantial cognitive impairment," instead of the term "severe cognitive impairment" that is used in the HIPAA and Federal Long-Term Care Insurance Program benefit triggers, one could assume that the legislative intent was to expand the definition to include people with moderate as well as severe cognitive impairment.

Considered within the context of the CLASS Program benefit trigger, the term, “substantial cognitive impairment,” seems to mean cognitive impairment at a level that results in threats to health and safety to which the individual is not able to respond effectively. Data are not available about the level of cognitive impairment at which many of the threats to health and safety described earlier in this report are likely to occur. The data on access to guns and driving indicate that these threats to health and safety are less likely to occur as the person’s cognitive impairment worsens. In contrast, the data on wandering indicate it is more likely to occur as the person’s cognitive impairment worsens. Unawareness of deficit, which makes the person less able to respond effectively to any threat to health and safety, is also more likely to occur as cognitive impairment worsens.

As described earlier, at least three widely cited dementia rating scales identify stages of cognitive decline or dementia and include both cognitive and noncognitive abilities. For each scale, the placement by stage of threats to health and safety and impairments in cognitive abilities that would allow individuals to respond effectively to any threat to health and safety is noted:

- The Clinical Dementia Rating (CDR) scale (Morris et al., 1993) places “moderate memory loss” and “moderate difficulty in handling problems” in stage 1, labelled “mild dementia.” The CDR places “severe memory loss, new material rapidly lost,” “usually disoriented to time, often to place,” and “severely impaired in solving problems,” in stage 2, labelled “moderate dementia.” It places “severe memory loss; only fragments remain,” “oriented only to person,” and “unable to make judgments or solve problems” in stage 3, labelled “severe dementia.”
- The Functional Assessment Staging (FAST) scale (Reisberg et al., 1985) places “difficulty in traveling to new locations” in stage 3, labeled “compatible with incipient dementia.” The FAST scale does not explicitly address other threats or related cognitive impairments.
- The Global Deterioration Scale (GDS) (Reisberg et al., 1982) places “patient may have gotten lost when traveling to an unfamiliar location” and “denial begins to become manifest” in stage 3, labeled as “mild cognitive decline.” The GDS places deficits in

memory and concentration and decreased ability to travel to new locations in stage 4, labeled “moderate cognitive decline,” and states that, “denial is a common defense mechanism in this stage.” It places “some disorientation to time and place” in stage 5, labeled “moderately severe cognitive decline. The GDS places “generally unaware of their surroundings,” “will require travel assistance but occasionally will display ability to travel to familiar locations” and loss of ability to “carry a thought long enough to determine a purposeful course of action,” in the next-to-last stage, stage 6, labeled “severe cognitive decline.”

In these dementia rating scales, most of threats to health and safety and most of the impairments in cognitive abilities that would allow individuals to respond effectively to threats are placed in the moderate or severe stage, but some are placed in earlier stages. The FAST scale and the GDS place difficulty traveling in new or unfamiliar locations in the mild or very mild stages of dementia and cognitive decline, and the CDR scale places moderate memory loss and moderate ability to handle problems in the mild stage of dementia. The GDS also places the first signs of denial in the mild stage.

As noted earlier, staging instruments like the CDR, the FAST, and the GDS, provide a general picture of the pattern of loss of cognitive and other abilities in progressive dementias, but some, and perhaps many, individuals do not fit neatly into the identified stages. Thus, the stage-specific placement of threats to health and safety and related cognitive abilities is informative, but one cannot assume a one-to-one correspondence for any particular individual between stage of cognitive decline or dementia and threats to health and safety to which the individual is not able to respond effectively.

Defining “substantial supervision.” Like “substantial cognitive impairment,” the concept, “substantial supervision,” could be defined in many different ways when considered generally. When considered in the context of the CLASS Program benefit trigger, “substantial supervision” seems to mean an amount of supervision that is sufficient to protect an individual with cognitive impairment or dementia from threats to his or her health and safety. Operationalizing and implementing the benefit trigger will require understanding about the level or amount of



supervision that is needed to protect such an individual from threats to health and safety and ideas about how to measure it.

The “Supervision Rating Scale,” a 13-step scale that was developed to measure the amount of supervision received by individuals with traumatic brain injury (TBI) provides ideas that may be helpful in thinking about levels of supervision. The scale identifies the following broad levels of supervision, ranging from no supervision to the highest amount of supervision that may be needed: 1) independent; 2) overnight supervision; 3) part-time supervision; 4) full-time indirect supervision; and 5) full-time direct supervision (Boake, 1996). The 13 steps are defined in terms of many factors, including whether the supervision occurs in particular time periods (e.g., at night, during waking hours); whether the person goes out of the home alone; how long the person is left alone (e.g., always, in the day, for the amount of time the caregiver needs to work full-time, for less than that amount of time, for less than an hour); how often the caregiver checks on the person if they are not in the same room (e.g., once every 30 minutes or less often); whether the person’s door locked from the outside at night; and, at the highest level of supervision, whether the person is in the caregiver’s direct line of sight. The scale is designed to be completed by a clinician based on interviews with the person and an informant, usually the caregiver.

[Note: This contractor has not found any other supervision staging instruments that see useful in thinking about level of supervision for the CLASS program benefit trigger.]

With respect to amount of supervision, one study of 35 family members and other unpaid caregivers of individuals with diagnosed Alzheimer’s disease identified the amount of supervision actually received by the individual and the relationship of amount of supervision actually received and the caregivers’ perceptions about the individuals’ need for supervision, the severity of the individuals’ dementia, and the occurrence of hazardous behaviors (Reed et al., 1990). For the study, “supervision” was defined as having a family member or responsible person in close proximity to the individual, even if they are not in the same room, and it was measured by caregiver reports about the number of hours the individual was left alone. Caregivers’ perceptions about individuals’ need for supervision were measured by their

responses to a question about whether the individual needed “watching to be safe,” and “hazardous behavior” was defined as an action by the person that the caregiver believed could lead to an accident if allowed to continue.

The study found that the amount of supervision actually received by the individuals (defined in terms of the number of hours they were left alone) was not significantly related to the severity of their dementia as measured by their CDR stage.

- Individuals in CDR stage 0.5 (questionable dementia) were left alone an average of 5.1 hours a day (range: 0-12 hours).
- Individuals in CDR stage 1.0 (mild dementia) were left alone an average of 2.9 hours a day (range: 0-8 hours).
- Individuals in CDR stage 2.0 (moderate dementia) were left alone an average of 3.4 hours a day (range: 0-12 hours).
- Individuals in CDR stage 3.0 (severe dementia) were left alone an average of 2 hours a day (range: 0-4 hours)

Although these findings suggest a trend toward more hours of supervision received (fewer hours left alone) for individuals with more severe dementia, the researchers note that at least one individual with moderate dementia was left alone for 12 hours a day, and at least one person with severe dementia was left alone for 4 hours a day (Reed et al., 1990).

In contrast to the lack of a statistically significant relationship between the amount of supervision received (number of hours left alone) and severity of dementia, there was a strong, significant relationship between caregivers’ perceptions about the individuals’ need for supervision and the severity of their dementia (Reed et al., 1990). Caregivers of most (87%) of the individuals in CDR stages 0.5 and 1.0 (questionable and mild dementia) said the individuals did not need watching to be safe; whereas caregivers of most (91%) of individuals in CDR stages 2.0 and 3.0 (moderate or severe dementia) said the individuals did need watching to be safe.

Interestingly, caregivers’ perceptions of the individuals’ need for supervision were not significantly related to the occurrence of hazardous behavior in the previous year (Reed et al.,

1990). On the other hand, the amount of supervision the individuals actually received was significantly related to the occurrence of hazardous behaviors: among individuals with one or more incidents of hazardous behavior in the previous year, 57% were receiving constant supervision, compared with only 5% of those with no incidents of hazardous behavior.

The relationships among these factors are complex. The researchers note the wide array of hazardous behaviors among the individuals, the heterogeneity of the life situations of the individuals and their caregivers and, as a result, the large number of potentially confounding variables in the study (Reed et al., 1990). Nevertheless, they comment that the study findings fit with their clinical experiences. They note that people with dementia often get to the moderate stage before their families acknowledge that there is a significant problem, and cite the study finding that caregivers generally did not perceive individuals with mild dementia as needing “watching to be safe.” Likewise, the researchers note that, “Supervision is a natural response to perceived hazardous behaviors” and cite the study finding that most (57%) of the individuals with hazardous behaviors in the preceding year were receiving constant supervision, compared with only 5 percent of individuals with no hazardous behaviors in the preceding year.

Another study analyzed data on need for supervision and related factors from the Medicare Alzheimer’s Disease Demonstration (MADD), a federally funded demonstration project implemented in 8 states from 1989-1994 (Fox et al., 1999). The study sample included more than 8,000 older people with dementia and their family and other unpaid caregivers. The MADD findings are based on data about factors that are defined and measured somewhat differently than the factors analyzed in the study described above. In MADD, caregivers’ perceptions about individuals’ need for supervision were measured by their responses to a question about whether the individual needed “minimal supervision,” “daytime supervision,” or “round-the-clock supervision.” Also, caregivers were asked about the number of hours of unpaid care provided for the individual by the primary caregiver and any other unpaid caregivers, and that number is used in the analysis, instead of number of hours the individual was left alone, that was used as to measure the amount of supervision provided in the study described above. Lastly, MADD used an individual’s score on a brief mental status test, the Mini-Mental State

Examination (MMSE), to measure severity of dementia, instead of the CDR score used in the study described above.

Using these somewhat different factors and ways of measuring them, the analysis of the MADD data found that caregivers' perceptions about individuals' need for supervision were significantly related to the number of hours of unpaid care provided for them (Fox et al., 1999). The data show that 25 percent of the caregivers said the individual needed "minimal supervision;" 19 percent said the individual needed "daytime supervision," and 56 percent said the individual needed "round-the-clock supervision." Individuals who were said to need "minimal supervision" received an average of 97 hours per week of unpaid care (including hours provided by the primary caregiver and any other unpaid caregivers); those who were said to need "daytime supervision" received an average of 129 hours of unpaid care per week; and those who were said to need "round-the-clock supervision" received an average of 176 hours of unpaid care.

The MADD data also show that caregivers' perceptions about individuals' need for supervision were strongly related to the severity of the individual's cognitive impairment. Individuals with very mild cognitive impairment (MMSE scores above 23) were generally said to need "minimal supervision;" those with moderate to severe cognitive impairment (MMSE scores 13 to 23) were generally said to need "daytime supervision;" and those with very severe cognitive impairment (MMSE scores below 13) were said to need "round-the-clock supervision." Average hours of unpaid care provided were also related to severity of cognitive impairment. Individuals with very mild cognitive impairment (MMSE scores above 23) were provided an average of 75 hours of unpaid care per week, compared with 94 hours of unpaid care for those with moderate to severe cognitive impairment (MMSE scores 13 to 23), and 120 hours per week for those with very severe cognitive impairment (MMSE scores below 13).

The concepts, terms and particularly the different ways of measuring them in the Supervision Rating Scale and the two studies described above are useful in thinking about how to operationalize and implement the concept "substantial supervision" in the CLASS Program benefit trigger. With respect to measuring need for supervision, Reed et al (1990) comment that

using the number of hours the individual is left alone as a measure of the amount of supervision the individual receives is not ideal because time spent with the caregiver may occur for other reasons than for supervision. The same caveat might apply to an even greater extent to using the number of hours of unpaid care provided for the individual as an indicator of need for supervision, as was done in the study by Fox et al. (1999).

In the Supervision Rating Scale and the studies by Reed et al. (1990) and Fox et al., (1999), it is assumed that “supervision” is provided in person; that is, the caregiver is physically present, at least, for example, in the same dwelling place, as the individual who needs supervision. Recently, there is increasing interest in and use of home monitoring technologies to observe older people with cognitive impairment and people with dementia in their homes and monitor their safety from a distance. Certainly the CLASS Program cash benefit will allow individuals and families to pay for home monitoring technologies. The question with respect to defining “substantial supervision” for the CLASS Program benefit trigger is whether use of such technologies should be considered an indicator that the individual either needs or is receiving supervision. In the context of the benefit trigger, “substantial supervision” is intended to protect the individual from threats to his or her health and safety. One might argue that home monitoring technologies do not protect the individual from such threats because no one can be present with the individual fast enough to avert the threat created, for example, by wandering and getting lost, leaving the stove on, using water that is too hot, or taking too little or too much of prescribed medications. Yet a recent report prepared for the Administration on Aging by O’Keeffe et al. (2010) provides numerous examples of technologies that monitor each of these behaviors and alert a caregiver or other emergency responder immediately, meaning that someone could be present with the individual very quickly, assuming that the monitoring technology is working and someone is paying attention to it. As such technologies are used more widely, and particularly as they become more reliable, it will be important to determine whether their use is evidence that an individual needs and/or is receiving “substantial supervision.”

Recommendations. The terms “substantial cognitive impairment” and “substantial supervision” should be defined in the context of the CLASS Program benefit trigger as opposed more generally. Defining the terms in this way will narrow the range of possible definitions and better reflect the intent of the legislative language.

Information about the kinds of threats to health and safety that are likely to affect older people with cognitive impairment and people with dementia should be conveyed to anyone who is responsible for implementing the CLASS Program benefit trigger. It should be emphasized that the risk to these individuals can come from their inability to recognize the threat, their inability to respond to the threat, or both, and that unawareness of deficit, that is, being unaware that they cannot recognize a threat, cannot respond to it, or both, is likely to increase their risk.

Information about the strong relationship between cognitive impairment and need for supervision and, at the same time, the lack of one-to-one correspondence between level of cognitive impairment or dementia and need for supervision in any particular individual should also be conveyed to anyone who is responsible for implementing the CLASS program benefit triggers.

Consideration should be given to the question about whether use of home monitoring technologies should be considered evidence that an individual either needs or is receiving supervision in the context of the CLASS Program benefit trigger.

### **C. Use of Long-Term Services and Supports by Older People with Cognitive Impairment and People with Dementia**

Older people with cognitive impairment and people with dementia are high users of residential long-term care services. In 2009, 47 percent of all nursing home residents had a diagnosis of dementia in their nursing home record (American Health Care Association, 2009), and 68 percent had some degree of cognitive impairment (USDHHS, 2010). Virtually all studies of risk factors for nursing home placement that have been conducted in the United States over the past 30 years and have measured either cognitive impairment or dementia have found that

they are strong predictors of placement (see, e.g., Banaszak-Holl et al., 2004; Bauer et al., 1996; Bharucha et al., 2004; Black et al., 1999; Branch et al. 1982; Freedman et al., 1996; Greener et al., 1995; Jette et al., 1995; Salive et al., 1993; Shapiro et al., 1988; Temkin-Bauer 1995; Weissert et al., 1990; Wolinsky et al., 1993).

Older people with cognitive impairment and people with dementia also constitute about half of all residents of assisted living facilities (45%-67% according to a recent report) (Hyde et al., 2007). Moreover, the proportion seems to be growing as assisted living facilities increase their capacity to serve and their marketing to such people and their families.

These findings are consistent with the findings from the ASPE-funded study, described earlier, of a sample of 1,474 individuals who had long-term care insurance and had just begun or were about to begin using paid long-term services and supports. In that sample, 64 percent of the individuals who were receiving paid care in a nursing home and 63 percent of those who were receiving paid care in an assisted living facility were people with cognitive impairment (Cohen et al., 2006).

Despite the large proportions of nursing home and assisted living residents that are people with cognitive impairment and dementia, the majority of people with these conditions are living in the community at any point in time. Most of them receive substantial amounts of help from family members and other unpaid caregivers, but they are also high users of home and community-based long-term care services and supports. One study of community-living older people who needed help to perform ADLs and IADLs found that those who had cognitive impairment were more than twice as likely as those who did not have cognitive impairment to receive paid home care Johnson and Weiner (2006). In addition, those who had cognitive impairment and received paid home care used almost twice as many hours of care monthly as those who did not have cognitive impairment.

It is sometimes said that older people with cognitive impairment and people with dementia generally do not receive Medicare- and Medicaid-funded home health care, but available data show that is not true. In 2004 and 2005, 36 percent of Medicare beneficiaries age

65 and older who received home health care services paid for by either Medicare or Medicaid were people with cognitive impairment (Murtaugh et al., 2009)

Older people with cognitive impairment and people with dementia are also high users of adult day services. One study of older people in adult day centers found that more than half had cognitive impairment or dementia (O’Keeffe and Siebenaler, 2006).

Lastly, available data from three states indicate that more than one-third of older people who receive Medicaid home and community-based waiver services are people with cognitive impairment and dementia (Fortinsky et al., 2004; Hirdes et al., 2004; Mitchell et al., 2006).

This high use of residential and home and community-based long-term services and supports reflects the high need among older people with cognitive impairment and people with dementia for help to perform daily activities and their need for supervision to avoid threats to health and safety. It is important in this context to note the finding of the ASPE-funded study of long-term care insurance policyholders that only 28 percent of policyholders who were receiving paid care at home were people with cognitive impairment, compared with the much higher proportions of people with cognitive impairment among policyholders who were receiving paid care in an assisted living facility or nursing home (63% and 64% respectively) (Cohen et al. (2006). Doty et al. (2010) point out that having long-term care insurance coverage reduces the importance of cost in decisions about where to receive paid care, thus allowing individuals and their families to choose the service setting that meets their needs. Thus, the higher proportions of policyholders with cognitive impairment among all policyholders receiving paid care in nursing homes and assisted living facilities speaks again to their high need for help to perform daily activities and their need for supervision to avoid threats to their health and safety.

From the perspective of families, the care needs of older people with cognitive impairment and people with dementia, and especially the need for supervision to avoid threats to health and safety, often result in high stress and burden. In several studies, more than half of the family caregivers of people with dementia have said they feel they have to be “on duty” 24 hours a day in order to anticipate and prevent problems and ensure the person’s safety (Mahoney et al.,



2003; Schulz et al., 2003). This perceived need for 24-hour vigilance has been found in caregivers of people in all stages, including caregivers of people who are in the mild and moderate stages of dementia and may be at risk of wandering and getting lost or other unsafe activities (Adams et al., 2006).

#### **D. Cognitive Impairment and Need for and Use of Long-Term Services and Supports by Adults with Cognitive Impairment Caused by Other Diseases and Conditions**

The discussion in this report has focused on the need for and use of long-term services and supports by older people with cognitive impairment and people with dementia. As noted at the beginning of the report, some, and perhaps many, adults of all ages who have cognitive impairment due to diseases and conditions, such as mental retardation, other intellectual disabilities, severe mental illness, traumatic brain injury (TBI) and acquired immunodeficiency syndrome (AIDS), will also be eligible for long-term services and supports based on the two specified CLASS Program benefit triggers. Adults with cognitive impairment due to diseases and conditions that preclude them from working throughout their adult lives may not be able to enroll in the CLASS Program because of the work and earned income requirements for enrollment. Nevertheless, in thinking about how to operationalize and implement the CLASS Program benefit triggers, it is essential to consider the implications of any proposed approaches for adults with cognitive impairment due to these other diseases and conditions.

By definition, people with mental retardation and many people with other intellectual disabilities have cognitive impairment. Most people with mental illness do not have cognitive impairment, but some individuals with severe depression, schizophrenia, bipolar disorder, and other severe mental illnesses do (Aleman et al., 1999; Butters et al., 2004; Friedman et al., 2001; Mojtabai and Olfson, 2004; Moore et al., 2004; VanGorp et al., 1998). Likewise, some people with TBI and AIDS have cognitive impairment, and others do not.

Individuals with cognitive impairment caused by mental retardation, other intellectual disabilities, severe mental illness, or other diseases and conditions can develop dementia, especially as they get older. Older people with intellectual disabilities caused by Down's syndrome, for example, are very likely to develop Alzheimer's disease (Janicki et al., 1996).

Similarly, some people with severe depression, lifelong schizophrenia, and other severe mental illnesses develop dementia as they age (Knopman et al., 2006; Kales et al., 1999).

In the United States, older people with cognitive impairment and dementia, people with mental retardation and other intellectual disabilities, people with mental illness, and people with TBI and AIDS generally receive long-term services and supports in separate service systems. These service systems comprise different agencies, different professionals and service providers, different funding sources and different eligibility criteria for long-term services and supports. The extent to which each service system focuses on cognitive impairment differs, and the way cognitive impairment is defined and measured also differs across service systems.

Adults with cognitive impairment who are receiving or could receive long-term services and supports in any one of these service systems often have care needs that are not the main focus of the system. One example is people with mental illness who also have other serious physical health conditions and care needs related to those conditions that may not be met within the mental health service system. Another example is older people with dementia who have psychiatric and behavioral health conditions and care needs related to those conditions that may not be met within the service system for older people.

Policy analysts and researchers often note that the care needs of many individuals who need long-term services and supports cross the boundaries between the existing service systems. Professionals and care providers within each service system decry the lack of services within their system to meet all the care needs of the people they serve and frequently try to expand their services to meet all these needs. An alternative would be a more broadly based system of long-term services and supports that would provide services for people of all ages who need the services care, regardless of the disease or condition that causes that need. When such a system is proposed, however, many professionals, service providers, individuals, families, and advocacy organizations worry that important clinical expertise and other features of the age-based and condition-based service systems would be lost.

The problem of separate service systems and people whose needs for care cross the boundaries between those systems will certainly not be solved through the definition and operationalization of terms and concepts in the CLASS Program benefit triggers. On the other hand, one can hope that the benefit triggers can be defined and operationalized in ways that do not exclude adults with cognitive impairment caused by any disease or condition. In the short term, that objective can probably be best achieved through consultation and review of proposed approaches for operationalizing the benefit triggers by clinical experts and policy analysts who are knowledgeable about how cognitive impairment is defined and measured in each service system. In the longer term, it will be important to collect and analyze data on people with cognitive impairment who are enrolled in the CLASS Program and are later either allowed or denied long-term services and supports.

Recommendations. The CLASS Program benefit triggers should be operationalized and implemented to include not only potentially eligible older people with cognitive impairment and dementia but also potentially eligible adults of any age with cognitive impairment caused by any disease or condition.

Proposed definitions of terms and concepts in the benefit triggers and any proposed assessments of cognitive impairment for the CLASS Program should be reviewed by clinical experts and policy analysts who are knowledgeable about how cognitive impairment is defined and measured in the separate systems that provide long-term services and supports for adults with cognitive impairment and adjusted to the extent possible to address their concerns.

Once the CLASS Program is implemented and the 5-year waiting period for benefits has passed, data should be collected on people with cognitive impairment who determined to be eligible or ineligible for services based on the existing benefit triggers, and adjustments should be made in the benefit triggers to reduce any noted disparities in eligibility for people with the same or similar levels of cognitive impairment, regardless of the disease or condition that causes the impairment.

### **PART 3: OPTIONS FOR MEASURING CONCEPTS IN THE CLASS PROGRAM BENEFIT TRIGGERS THAT ARE IMPORTANT FOR PEOPLE WITH COGNITIVE IMPAIRMENT**

Many different assessment instruments could be used to measure the concepts in the CLASS Program benefit triggers that are most important for people with cognitive impairment. The CLASS Program legislation says that the eligibility determinations based on the benefit triggers will be made by “a licensed health care practitioner.” Procedures for determining eligibility for CLASS Program services and supports have not yet been developed, and it is unclear whether there will eventually be a single organization that conducts eligibility determinations or, more likely, many organizations and individuals that determine eligibility, as is the case with most existing long-term care insurance plans. In this context, this contractor believes that no specific assessment instruments or procedures should be required to determine eligibility for CLASS Program services and supports. On the other hand, it is important to provide information about such instruments and their use to anyone who is responsible for implementing the CLASS Program benefit trigger. Some organizations and individuals may choose to use certain instruments. Equally important, awareness of the content of the instruments could help such organizations and individuals better understand and implement the intent and meaning of the concepts in the benefit triggers.

This section lists assessment instruments that measure concepts in CLASS Program benefit triggers that are most important for people with cognitive impairment. Further analysis of these instruments will be needed, but the objective of the analysis will differ depending on the decision that is made about whether specific assessment instruments and procedures will be required to determine eligibility for CLASS Program services and supports.

#### **A. Measuring “Substantial Assistance”**

The CLASS Program benefit trigger requires that an individual must be unable to perform at least the minimum number (which may be 2 or 3) of activities of daily living as are required under the plan for the provision of benefits without substantial assistance (as defined by the Secretary) from another individual. As noted earlier, this contractor recommends that

“substantial assistance” should be defined to include not only hands-on and standby assistance but also the assistance needed by a person with cognitive impairment who cannot perform the ADL independently, that is, assistance to initiate the ADL at the right time and in the right place and to complete the steps required to perform the ADL successfully.

Need for assistance to perform ADLs is usually determined with generic assessment instruments developed by Katz et al. (1963), Lawton and Brody (1969) and others. Some researchers and clinicians have developed assessment instruments intended specifically for people with cognitive impairment and dementia. Many of these instruments measure IADLs as well as ADLs, and many provide potentially useful wording to identify the kinds of difficulties people with cognitive impairment often experience in performing ADLs, and therefore the kinds of assistance they need to perform the ADLs successfully.

Assessment Instruments To Measure ADLs and IADLs  
in People with Cognitive Impairment and Dementia

- *AD Situational Test* (Skurla et al. 1988)
- *Dependence Scale* (Rating based on informant responses to 13 questions about functional activities) (Stern et al., 1994)
- *Direct Assessment of Functional Status (DAFS)* (Observation and rating on tasks in 7 functional areas) (Lowenstein et al., 1989)
- *Dressing Performance Scale* (Observation and rating on 34 steps in dressing) (Beck 1988)
- *Functional Activities Questionnaire* (Informant report on 10 functional activities (Pfeffer et al. 1982)
- *Refined ADL Assessment Scale* (Observation and rating on 14 tasks) (Tappen 1994)
- *Self-Care Performance Tool* (Observation and rating on 4 self-care activities (Thralow and Rueter 1993)

**B. Measuring “Substantial Cognitive Impairment”**

The CLASS Program benefit trigger requires that the individual must need substantial supervision to protect him or her from threats to health and safety due to substantial cognitive impairment. As noted earlier, this contractor recommends that “substantial cognitive impairment” be defined in the context of the CLASS Program benefit trigger specifically, as the level of cognitive impairment that results in threats to health and safety to which the individual is not able to respond effectively.

Many assessment instruments have been developed to measure cognitive impairment, and some of these instruments may be particularly useful for organizations and individuals that are implementing the CLASS Program benefit triggers. The lists of assessment instruments below include brief mental status tests, performance tests, and instruments for informant interviews.

#### Brief Mental Status Tests

- *Alzheimer’s Disease Assessment Scale: Cognitive Behavior (ADAS-Cog)* (11 items) (Rosen et al., 1984)<sup>c</sup>
- *Blessed Information-Memory-Concentration Test (BIMC)* (26 items) (Blessed et al., 1968)
- *Blessed Information-Memory-Concentration Test (BIMC)* (26 items) (revised by Katzman et al., 1983).
- *Blessed Orientation-Memory-Concentration Test (BOMC)* (Also called the Short Blessed Test (SBT)) (6 items) (Katzman et al., 1983)
- *Clock Drawing Tests* (many sources for scoring clock drawing tests)
- *CLOX* (an executive clock drawing test (Royall et al., 1998b))
- *Cognitive Abilities Screening Instrument (CASI)* (25 items) (Teng et al., 1994)
- *Cognitive Abilities Screening Instrument-Short form (CASI-Short)* (4 items) (Teng et al., 2001)

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<sup>c</sup> The Alzheimer’s Disease Assessment Scale has 11 items to measure “noncognitive behavior,” but these items seem to be rarely used.)

- *Community Screening Interview for Dementia (CSI 'D')* (28 items for the person and other items for an informant (Hall et al., 1993)
- *EXIT (The Executive Interview)* (Royall et al., 1992) This is a 25-item bedside measure
- *General Practitioner Assessment of Cognition (GPCOG)* (6 items for the person and other items for an informant (Brodaty et al., 2002).
- *Isaacs Set Test (IST)* (4 category verbal fluency test) (Isaacs et al., 1973)
- *Memory Impairment Screen (MIS)* (4 items)(Buschke et al., 1999)
- *Mental Status Questionnaire (MSQ)* (10 items) (Kahn et al., 1960)
- *Mini-Cog* (3 items) (Borson et al., 2000)
- *Mini-Mental State Examination (MMSE)* (~12 items) (Folstein et al., 1975)
- *Montreal Cognitive Assessment (MoCA)* (30 points) (Nasreddine et al., 2005)
- *Modified Mini-Mental State Examination (3MS)* (~ 16 items )(Teng and Chui 1987)
- *Ottawa 3D and Ottawa 3DY* (3 items and 4 items, respectively) (Molnar et al. 2008)
- *Saint Louis University Mental Status Examination (SLUMS)* (11 items) (Banks and Morley 2003)
- *Seven-Minute Screen* (includes 4 tests: cued recall: naming animals for 1 minute; the Benton Temporal Orientation Test, and Clock Drawing) (Solomon and Pendlebury, 1998)
- *Short Portable Mental Status Questionnaire (SPMSQ)* (10 items (Pfeiffer 1975)

#### Performance Tests

- *Drug Regimen Unassisted Grading Scale (DRUGS)* (Edelberg et al., 1999)
- *Everyday Problems Test for Cognitively Challenged Elderly (EPCCE)* (Willis et al., 1996)
- *Face-Hand Test (FHT)* (Fink et al., 1952)
- *The Home Visit* (Kapust and Weintraub, 1988)
- *The Medication Management (MM) Test* (Gurland et al., 1994)
- *The Time and Change Test* (Inouye et al., 1998)

### Instruments for Informant Interviews

- *AD8* (8 items) (Galvin et al., 2005)
- *Blessed Dementia Scale* (22 items) (Blessed et al., 1968)
- *Dementia Severity Rating Scale* (11 domains) (Clark and Ewbank 1996)
- *Everyday Cognition Scale (E-Cog)* (39 items) (Farias et al., 2008)
- *General Practitioner Assessment of Cognition (GPCOG)* (6 items for the informant and other items for the person) (Brodaty et al., 2002).
- *Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)* (26 items) (Jorm and Jacomb 1989)
- *The Community Screening Interview for Dementia (CSI'D')* (30 items for the informant and other items for the person) (Hall et al., 1993)

### **C. Measuring “Substantial Supervision”**

The CLASS Program benefit trigger requires that the individual must need substantial supervision to protect him or her from threats to health and safety due to substantial cognitive impairment. This contractor recommended earlier that “substantial supervision” should be defined specifically as the amount of supervision needed to protect an individual from threats to health and safety. The concepts and wording in the Supervision Rating Scale, described earlier, and in the two studies of amount of supervision provided and perceived need for supervision for older people with cognitive impairment and people with dementia may be useful for organizations and individuals that are implementing the CLASS Program benefit triggers

### **PART 4: OPTIONS FOR THE UNSPECIFIED BENEFIT TRIGGER**

The preceding analysis suggests options the Secretary might consider for the unspecified benefit trigger.



- A trigger that addresses cognitive impairment in people with mental illness, including people with severe depression, who need long-term services and supports but would not be eligible based on the two specified benefit triggers; such a trigger might focus specifically on executive dysfunction.
- A trigger that addresses cognitive impairment in people with multiple diseases and conditions who need long-term services and supports but would not be eligible based on the specified benefit triggers.

In addition to benefit triggers, this contractor believes it will be important to consider the types of help people with cognitive impairment need to manage the cash benefit they receive through the CLASS Program.

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# **A REPORT ON THE ACTUARIAL, MARKETING, AND LEGAL ANALYSES OF THE CLASS PROGRAM**

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## Files Available for This Report

[HTML versions of Appendices will be added as they are formatted]

Main Report	[48 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/index.shtml">http://aspe.hhs.gov/daltcp/reports/2011/class/index.shtml</a> <a href="http://aspe.hhs.gov/daltcp/reports/2011/class/index.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/index.pdf</a>
APPENDIX A: Key Provisions of Title VIII of the ACA, Which Establishes the CLASS Program	[6 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appA.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appA.htm</a> <a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appA.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appA.pdf</a>
APPENDIX B: HHS Letters to Congress About Intent to Create Independent CLASS Office	[11 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appB.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appB.htm</a> <a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appB.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appB.pdf</a>
APPENDIX C: <u>Federal Register</u> Announcement Establishing CLASS Office	[2 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appC.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appC.htm</a> <a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appC.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appC.pdf</a>
APPENDIX D: CLASS Office Organizational Chart	[2 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appD.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appD.pdf</a>
APPENDIX E: CLASS Process Flow Chart	[2 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appE.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appE.pdf</a>
APPENDIX F: <u>Federal Register</u> Announcement for CLASS Independence Advisory Council	[3 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appF.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appF.htm</a> <a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appF.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appF.pdf</a>
APPENDIX G: Personal Care Attendants Workforce Advisory Panel and List of Members	[6 PDF pages]
Full Appendix	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appG.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appG.htm</a> <a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appG.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appG.pdf</a>
Ga: <u>Federal Register</u> Announcement for Personal Care Attendants Workforce Advisory Panel	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appGa.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appGa.pdf</a>
Gb: Advisory Panel List of Members	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appGb.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appGb.pdf</a>

APPENDIX H: Policy Papers Discussed by the LTC Work Group	[36 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appH.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appH.htm</a>
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appH.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appH.pdf</a>
APPENDIX I: CLASS Administration Systems Analysis and RFI	[10 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appI.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appI.htm</a>
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appI.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appI.pdf</a>
APPENDIX J: Additional Analyses for Early Policy Analysis	[150 PDF pages]
Full Appendix	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appJ.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appJ.pdf</a>
Ja: A Profile of Declined Long-Term Care Insurance Applicants	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appJa.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appJa.pdf</a>
Jb: CLASS Program Benefit Triggers and Cognitive Impairment	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appJb.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appJb.pdf</a>
Jc: Strategic Analysis of HHS Entry into the Long-Term Care Insurance Market	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appJc.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appJc.pdf</a>
Jd: Managing a Cash Benefit Design in Long-Term Care Insurance	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appJd.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appJd.pdf</a>
APPENDIX K: Early Meetings with Stakeholders	[4 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appK.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appK.htm</a>
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appK.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appK.pdf</a>
APPENDIX L: In-Depth Description of ARC Model	[62 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appL.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appL.pdf</a>
APPENDIX M: In-Depth Description of Avalere Health Model	[23 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appM.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appM.htm</a>
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appM.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appM.pdf</a>
APPENDIX N: September 22, 2010 Technical Experts Meeting	[61 PDF pages]
Full Appendix	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appN.htm">http://aspe.hhs.gov/daltcp/reports/2011/class/appN.htm</a>
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appN.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appN.pdf</a>
Na: Agenda, List of Participants, and Speaker Bios	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appNa.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appNa.pdf</a>
Nb: Presentation Entitled "Actuarial Research Corporation's Long Term Care Insurance Model"	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appNb.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appNb.pdf</a>
Nc: Presentation Entitled "The Long-Term Care Policy Simulator Model"	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appNc.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appNc.pdf</a>
Nd: Presentation Entitled "Comments on 'The Long-Term Care Policy Simulator Model'"	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appNd.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appNd.pdf</a>
APPENDIX O: Actuarial Report on the Development of CLASS Benefit Plans	[47 PDF pages]
	<a href="http://aspe.hhs.gov/daltcp/reports/2011/class/appO.pdf">http://aspe.hhs.gov/daltcp/reports/2011/class/appO.pdf</a>

APPENDIX P: June 22, 2011 Technical Experts Meeting  
Full Appendix

[77 PDF pages]

<http://aspe.hhs.gov/daltcp/reports/2011/class/appP.htm>

<http://aspe.hhs.gov/daltcp/reports/2011/class/appP.pdf>

Pa: Agenda and Discussion Issues and  
Questions

<http://aspe.hhs.gov/daltcp/reports/2011/class/appPa.pdf>

Pb: Presentation Entitled "Core Assumptions and  
Model Outputs"

<http://aspe.hhs.gov/daltcp/reports/2011/class/appPb.pdf>

Pc: Presentation Entitled "Actuarial Research  
Corporation's Long Term Care Insurance  
Model"

<http://aspe.hhs.gov/daltcp/reports/2011/class/appPc.pdf>

Pd: Presentation Entitled "The Avalere Long-  
Term Care Policy Simulator Model"

<http://aspe.hhs.gov/daltcp/reports/2011/class/appPd.pdf>

Pe: Presentation Entitled "Alternative Approaches  
to CLASS Benefit Design: The CLASS  
Partnership"

<http://aspe.hhs.gov/daltcp/reports/2011/class/appPe.pdf>

APPENDIX Q: Table 2: Actuarial and Demographic Assumptions

[2 PDF pages]

<http://aspe.hhs.gov/daltcp/reports/2011/class/appQ.htm>

<http://aspe.hhs.gov/daltcp/reports/2011/class/appQ.pdf>

APPENDIX R: Figure 1: Daily Benefit Amount for Increased Benefit

[2 PDF pages]

<http://aspe.hhs.gov/daltcp/reports/2011/class/appR.pdf>