

Contract No.: 200-2001-00122(08)  
MPR Reference No.: 6290-300

**MATHEMATICA**  
Policy Research, Inc.

**Survey and Research  
Instruments that  
Address the Health  
Effects of Caregiving**

*Final Report*

*February 29, 2008*

*Robert Weathers  
Allison Hedley Dodd  
Krista Harrison*

Submitted to:

Centers for Disease Control and Prevention  
National Center on Birth Defects and  
Developmental Disabilities  
Mail Stop E-88  
1600 Clifton Rd.  
Atlanta, GA 30333

Project Officer:  
Sandra Coulberson

Submitted by:

Mathematica Policy Research, Inc.  
955 Massachusetts Ave., Suite 801  
Cambridge, MA 02139  
Telephone: (617) 491-7900  
Facsimile: (617) 491-8044

Project Director:  
Sam Simon



# CONTENTS

Chapter	Page
I	INTRODUCTION .....1
II	COMPONENTS OF A CAREGIVER SURVEILLANCE SYSTEM.....3
A.	POPULATION UNDER SURVEILLANCE .....3
1.	Type of Assistance .....4
2.	Time Spent Providing Care or Assistance .....4
3.	Relationship of the Caregiver to the Care Recipient.....4
4.	Characteristics of the Care Recipient.....4
B.	PERIOD OF TIME OF DATA COLLECTION.....5
C.	WHAT DATA ARE COLLECTED AND HOW THEY ARE COLLECTED .....5
D.	REPORTING SOURCES OF DATA.....6
III	INVENTORY OF CAREGIVER RESEARCH AND SURVEY INSTRUMENTS AND QUESTIONS.....7
A.	PROCESS USED TO IDENTIFY INSTRUMENTS.....7
B.	TYPE OF INSTRUMENTS INCLUDED .....7
C.	INFORMATION DESCRIBING INSTRUMENTS.....9
D.	CAREGIVER SURVEY QUESTIONS .....10
1.	Caregiver Activity Questions.....10
2.	Caregiver Burden Questions .....16
3.	Caregiver Health Questions .....17
4.	Caregiving Environment Questions .....18
5.	Caregiver Characteristics Questions .....20
6.	Care Recipient Characteristics Questions .....21

**CONTENTS** *(continued)*

<b>Chapter</b>	<b>Page</b>
IV	HIGHLIGHTS FROM AND LIMITATIONS OF EXISTING INSTRUMENTS AND AREAS FOR FUTURE RESEARCH.....23
A.	STRENGTHS OF EXISTING INSTRUMENTS AND QUESTIONS .....23
1.	National Long Term Care Survey (NLTC) .....23
2.	Caregiver Health Effects Study (CHES).....24
3.	Cash and Counseling Informal Caregiver and Paid Worker Surveys.....25
4.	Young Caregivers Instruments .....26
5.	Behavioral Risk Factor Surveillance System (BRFSS) .....26
B.	LIMITATIONS OF EXISTING CAREGIVER INSTRUMENTS .....26
1.	Defining the Caregiver Population .....27
2.	Testing Survey Questions .....27
3.	Developing Data on the Dynamics of Caregiving .....28
4.	Developing Instruments for Child Caregivers and Care Recipients .....28
5.	The Need for State-Level Data .....30
6.	Need for Cross-Agency Collaboration.....30
C.	AREAS FOR FUTURE RESEARCH .....31
1.	Collaboration with AHRQ for Development and Testing of Caregiver Surveillance Questions.....31
2.	Inclusion of a Caregiver Module in the Health and Retirement Study (HRS) .....32
3.	Intervention Studies .....33
V	SUMMARY AND CONCLUSION.....35
	REFERENCES.....37
	APPENDIX A: INSTRUMENTS IDENTIFIED FOR INCLUSION INTO THE CAREGIVER DATABASE 2007

**EXHIBITS**

<b>Exhibit</b>		<b>Page</b>
III.1	TYPES OF INSTRUMENTS INCLUDED IN DATABASE .....	8
III.2	EXAMPLE OF INSTRUMENT INFORMATION INCLUDED IN CAREGIVER DATABASE .....	9
III.3	CAREGIVER ACTIVITY CATEGORIES FOR CAREGIVER DATABASE .....	12
III.4	CAREGIVER BURDEN CATAEGORIES INCLUDED IN CAREGIVER DATABASE .....	16
III.5	CAREGIVER HEALTH CATEGORIES INCLUDED IN CAREGIVER DATABASE .....	18
III.6	CAREGIVING ENVIRONMENT CATEGORIES INCLUDED IN CAREGIVER DATABASE .....	19
III.7	CAREGIVER CHARACTERISTIC CATEGORIES USED FOR CAREGIVER DATABASE .....	20
III.8	CARE RECIPIENT CATEGORIES USED FOR CAREGIVER DATABASE .....	21
IV.1	RESPONDENTS TO CAREGIVING INSTRUMENTS .....	29



## I. INTRODUCTION

More than 44 million people provide unpaid care to individuals with disabilities and chronic diseases in the United States, according to a recent report by the National Alliance for Caregiving and the American Association of Retired Persons (NAC-AARP). Unpaid caregivers are among the largest sources of long-term care for persons with disabilities and chronic disease (Congressional Budget Office 2005). In 2004 alone, family caregivers provided services which, had they been paid, have been estimated as worth approximately \$306 billion (Arno 2006). The projected growth in the elderly population may cause a substantial increase in the demand for unpaid caregivers over the next several decades (Wolf et al. 2005; Wolf 2001). The family or friends who provide this care sometimes are referred to as “informal” or “family” caregivers to differentiate them from paid caregivers and because their contributions lie outside of the market economy (Arno 1999). In this report, the term “caregiver” will refer to those who provide unpaid care.

The health effects of providing unpaid care to persons with disabilities and chronic diseases are emerging as a public health issue (Talley and Crews 2007). A growing body of research indicates that unpaid caregivers are more likely to experience health problems than people not providing care (Schultz et al. 1997; Vitaliano et al. 2003, 2004; Pinguart and Sorensen 2007). Impaired caregiver health may, in turn, reduce the quality of care provided to recipients, increase the recipient’s likelihood of developing additional health problems, and limit the recipient’s activities. Monitoring the health of unpaid caregivers via a public health surveillance system is critical to promoting the health and quality of life of both caregivers and care recipients.

Existing surveillance methods (mostly surveys) do not provide consistent, systematic, and up-to-date data on the health of caregivers. The surveys were constructed to gather information for specific research, rather than as formal surveillance systems. Caregivers are defined in a myriad of ways: by the activities performed, by the amount of time spent performing activities, by the amount of effort required to provide care, by the type of disability or chronic health condition of the care recipient, by the age of the recipient or the caregiver, as well as other factors. The variety of definitions reflects the diversity of research performed in the field, but also leads to vastly differing estimates of the caregiver population. Estimates of the population range from 9.4 million caregivers, based on 1997 data from the Survey of Income and Program Participation (SIPP), which defines a caregiver as someone who provides regular unpaid care to someone with a long-term illness or a disability during the past month, to 54 million caregivers, based on 2000 data from the National Family Caregivers Association (NFCA), which defines a caregiver as anyone either currently caring for a family member or friend, or who has done so within the past year. Ideally, a caregiver surveillance system would track consistently defined caregiver measures over time.

The need for a public health surveillance system for caregivers is recognized by *Healthy People 2010*, a comprehensive, nationwide health promotion and disease prevention agenda managed by the U.S. Department of Health and Human Services (HHS). One objective of *Healthy People 2010* is to “increase the number of Tribes [and] States...that have public health

surveillance and health promotion programs for people with disabilities and caregivers” (U.S. Department of Health and Human Services 2000). The Centers for Disease Control and Prevention (CDC) also are playing an important role in developing effective surveillance strategies for monitoring caregiver health and the complex relationships between caregiver health and recipient well-being. The development of better methods for caregiver surveillance and improvements in available data will assist CDC in its efforts to use current knowledge to design relevant health promotion programs and ensure that the nation makes progress toward these *Healthy People 2010* goals.

As part of this effort, the CDC contracted with Mathematica Policy Research, Inc. (MPR) to build a searchable electronic database that (1) contains a comprehensive inventory of government and non-government survey and research instruments that contain caregiving-related questions, (2) identifies the caregiving and caregiving-related health questions in each instrument, and (3) identifies where and how caregiving research currently is being conducted.

This report describes the inventory and how it was created, and details the results of our assessment of caregiver-related government and non-government survey and research instruments. As a context for available research, Chapter II provides a more theoretical discussion of a caregiver surveillance system and its components: population, time period of data collection, types and sources of data, and methods of data collection. Chapter III describes the electronic database inventory of caregiver survey and research instruments and questions; this chapter includes methods by which instruments were identified and a list of instruments included, as well as explanations of key components within the instruments. Chapter IV highlights important areas that have been covered in existing surveys, describes limitations of existing surveillance instruments that would need to be addressed in developing a national surveillance system, and points to specific areas for potential future scientific activity that could help to improve caregiver surveillance and promote the state of the science on the public health effects of providing unpaid care to individuals with disabilities and chronic diseases. Chapter V summarizes our findings and describes the next steps in the project.

## **II. COMPONENTS OF A CAREGIVER SURVEILLANCE SYSTEM**

The goal of a public health surveillance system is to monitor public health problems effectively. Surveillance systems can be classified as either active or passive. A passive system relies on someone reporting a condition, such as a notifiable-disease surveillance system that relies on health care provider reports to the local health department when certain conditions are met. While useful for conditions that require timely reporting, such surveillance systems may suffer from incomplete reports. An active surveillance system relies on a designated entity to contact a reporting source and elicit reports. A survey can be considered an active surveillance system, because it reaches out to respondents and stimulates reporting of the event of interest.

The nature of the public health problem determines the type of system. For example, infectious diseases often require a detailed case definition and a timely reporting system so that immediate action can be taken. In the case of caregiving as a public health issue, the goal of a surveillance system is to gather information that helps to characterize the public health consequences associated with caregiving. The data from such a system will inform the design and enable evaluation of policies and programs that could relieve the burden of caregiving and improve the health of caregivers and care recipients.

The active surveillance model is more relevant for caregiver surveillance, as evidenced by the fact that the majority of entries in our database are from surveys. A survey is a particularly useful surveillance system for caregiving because it can be designed to collect extensive data regarding the situation of both the caregiver and care recipient to yield representative results that can be generalized. Other entries in the database are from assessment tools. Health professionals, such as long-term care specialists or physicians, can use assessment tools to identify (1) the extent of caregiver burden; and (2) whether that burden could be relieved through modified behavior, respite care, or other available support programs. For example, the American Medical Association developed the “Caregiver Self-Assessment Questionnaire,” filled out by self-identified caregivers when (1) they accompany the care recipient to an appointment, or (2) at the behest of their personal physician. By using the self-assessment score as an index of caregiver distress, a physician can discuss any need for supportive services, encourage service utilization, and make referrals to community resources. We included assessment tools in the database because they potentially could form the foundation of a passive surveillance system if, in addition to a referral, the results of the assessment were reported to a centralized database.

In general, the key components of a public health surveillance system are (1) the population under surveillance; (2) the period of time of the data collection; (3) what data are collected, and how; and (4) the reporting sources of data for the system (CDC 2001). Each component is described below in terms of how it relates to the surveillance of caregivers.

### **A. POPULATION UNDER SURVEILLANCE**

For any surveillance system, it is important to define the population under surveillance to ensure that the data gathered are useful for identifying public health issues and intervention areas. For an infectious disease, a case definition may include the presence of a certain bacteria.

For caregiving, creating a case definition is more difficult because there are so many factors that differentiate caregiving across people, such as the type of assistance provided, the level of assistance, the relationship of the caregiver to the care recipient, and characteristics of the recipient. If the case definition is too broad (such as, a caregiver is defined as someone who provides assistance or support to a friend or relative who needs it), the health effects of caregiving may be minimized, because people whose caregiving roles are limited or do not cause burden will be included in the dataset. If the definition is too narrow, important data on caregivers will be missed. Previous studies have varied in how they defined caregiving. While such variations may make it difficult to compare data across surveys, they also may lead to useful insights, especially when surveys that use different questions produce varying estimates of the prevalence of caregiving. The main ways in which the definitions of caregiving vary are described below.

### **1. Type of Assistance**

The type of caregiver assistance provided may be addressed in a general sense (“Did you provide any regular unpaid care or assistance during the past month?”), or more specifically (“Did you help with medical needs, such as taking medicines or changing bandages?”). In some surveys, a general question may identify the person as a caregiver, which leads to more specific questions about the type of assistance provided. The advantage of a survey model that uses a broad definition to identify the caregiver and then collects more detailed information is that future researchers can vary the definition of caregiving to address more specific situations in their analyses.

### **2. Time Spent Providing Care or Assistance**

The amount of time spent providing care or assistance also may affect whether someone is identified as a caregiver. Questions regarding time may evaluate the *intensity* of caregiving in terms of hours spent during a specific period of time (such as hours per week), or the *duration* of caregiving in terms of years or months spent providing care.

### **3. Relationship of the Caregiver to the Care Recipient**

Some surveys may be administered only to a specific family member of the care recipient, such as the spouse, parent, or child. The relationship of the caregiver to the care recipient may affect the emotional burden of providing care in a particular way.

### **4. Characteristics of the Care Recipient**

The population under surveillance may be determined by characteristics of the care recipient, rather than the caregiver. For example, a survey may focus on the parent of a disabled child. For this reason, although our focus is on the health of the caregiver, it is the characteristics of the care recipient that determine the caregiver’s inclusion in the surveillance system. Caregiving has been referred to as a “lifespan experience” because it “bridges the concerns from birth through end of life” (Talley and Crews 2007). A caregiver may provide care to a child,

spouse, or parent with disabilities, and perhaps assist people in different life phases at the same time. Although the use of care recipient characteristics to define the population under surveillance may result in caregiving populations that are not comparable across surveillance systems, this approach may prove useful to policymakers in identifying populations in need of a health program or policy change.

## **B. PERIOD OF TIME OF DATA COLLECTION**

For public health surveillance related to disease outbreaks, the period of time in which the data are collected is important in determining the source of the outbreak, and which cases are related. For chronic disease and health promotion, the period of time is important for establishing trends. By monitoring the health of caregivers over a period of time, either through longitudinal surveys or a series of surveys, the need for and the effects of program and policy interventions may be measured.

There are three ways that time can affect the data collected for the surveillance system: (1) The timing of the data collection in relation to when the caregiver started to provide care may affect the level of burden or health effects reported. Those who respond to a survey shortly after becoming caregivers may not have changed their health behaviors (such as missing doctor's appointments), or noticed any negative health effects (such as weight gain). A survey that occurs later in the caregiving cycle may yield different responses. (2) The amount of time covered by the surveillance system also may affect the results. For a time use survey that measures how time is spent each day, more data will be available when more days are included, allowing a better assessment. For general surveys, the length of time covered by the survey question, such as "in the last year" versus "in the last week," may affect the number of respondents who report a health issue. (3) Whether the respondent currently is providing or has in the past provided care may affect the responses, particularly if the care recipient is deceased.

## **C. WHAT DATA ARE COLLECTED AND HOW THEY ARE COLLECTED**

Another unique aspect of a caregiver public health surveillance system is that the health of both the care recipient and the caregiver are of concern. Tally and Crews (2007) describe a dyadic relationship, in which caregiver and care recipient health cyclically affect one another. The greater the burden of care, the more likely it is that the caregiver's health will be affected either directly (through injury) or indirectly (through neglect of his or her own health). If the caregiver's health deteriorates, the recipient's care and health may suffer accordingly, leading in turn to an increased caregiver burden.

Chapter III describes the process that we used to organize the data collected by previous caregiver surveillance efforts. The data collected were classified into six areas: (1) caregiver activities, (2) caregiver burden, (3) caregiver health, (4) caregiving environment, (5) caregiver characteristics, and (6) care recipient characteristics. Questions related to caregiver health may capture the impacts of caregiving in health outcomes and/or health behaviors. All of the other areas help to characterize the caregiving experience. Within these areas, subcategories were created to further delineate the types of data collected and identify data needs for the future, as shown in exhibits III.3 through III.8. Surveys vary in the number of areas covered, as well as the

level of specificity within each area. An ideal caregiver surveillance system would collect data in all of the areas identified above.

The way that data are collected can vary by mode of collection as well as by type of survey. The mode (in-person, telephone, mail) may affect the results of the survey and should be taken into account when comparing survey results. The type of survey will most likely impact the amount and specificity of the data available. Instruments focused on caregiving are more likely to include more questions related to caregiving and the factors that may influence caregiver health than a general survey that includes caregiving components among many others.

#### **D. REPORTING SOURCES OF DATA**

For active surveillance systems, the reporting source will be either the caregiver or the care recipient. Sources may affect the data collected: for example, the SIPP data suggested a caregiving population of 9.4 million when caregivers were interviewed, whereas that estimate rose to 11.1 million when care recipients were questioned (Lewin Group 2002).<sup>1</sup> Differences in reporting sources also may reflect differences in the perceived burden of caregiving, which may be important for implementing and evaluating interventions. Care recipient perspectives may be difficult to capture, depending on age and health status, particularly in the case of children.

---

<sup>1</sup> The large differences between the SIPP estimate (9.4 million), the NAC-AARP estimates of 44.4 million and the NFCA estimate of 54 million are due primarily to definitions of “caregiver.” The SIPP defines a caregiver as a person who has provided regular unpaid care to someone with a long-term illness or a disability during the previous month. The NAC-AARP definition is anyone age 18 or older who has provided unpaid care to a person age 18 or older within the previous 12 months. The NFCA estimate is anyone either currently caring for a family member or friend, or who has done so within the past year. The Lewin Group (2002) provides a summary of estimates from the SIPP and the NFCA, and how the estimates of number of caregivers change when the question is asked of the caregiver compared to when the question is asked of the care recipient. See NAC-AARP for the estimate of 44.4 million caregivers.

### **III. INVENTORY OF CAREGIVER RESEARCH AND SURVEY INSTRUMENTS AND QUESTIONS**

The database we developed to assess previous caregiver surveillance efforts includes 64 survey and research instruments, comprising more than 1,900 questions that are relevant to a public health surveillance system for caregivers. In this chapter, we detail in Section A the methods used to identify survey instruments, in Section B the types of instruments reviewed, in Section C the information describing each instrument, and in Section D the caregiver questions contained in the database, organized by type of question.

#### **A. PROCESS USED TO IDENTIFY INSTRUMENTS**

The foundation of our database was a list of caregiver instruments compiled while developing a caregiver module for the Medical Expenditure Panel Survey (MEPS). We added to this list by conducting a systematic web and Medline search of survey instruments produced in the last 10 years that focused on caregivers of children, working-age adults, or elders with a disability or chronic disease. To capture the breadth of instrument types and purposes, we targeted caregiver- and care recipient-specific instruments, as well as general purpose, time-use surveys and caregiver assessment tools. The initial search yielded 79 instruments. This number was whittled down to 64 instruments; 15 were discarded because the instruments were redundant or an examination of the questions revealed that they did not focus on the health effects of caregiving. The list of 64 instruments is shown in Appendix A.

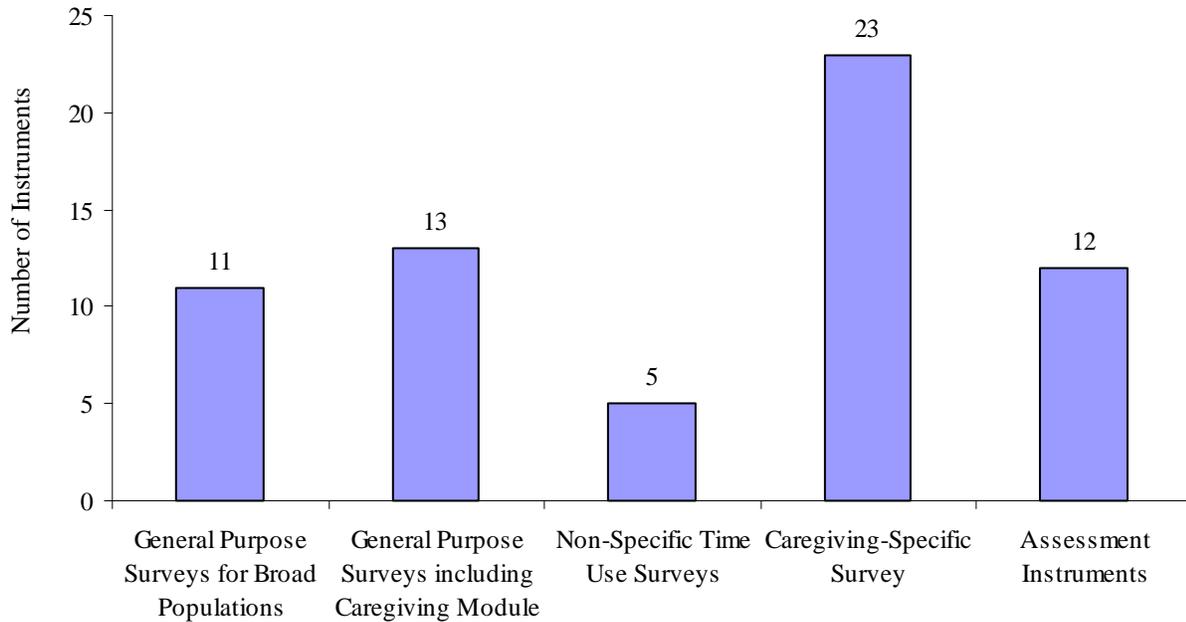
#### **B. TYPE OF INSTRUMENTS INCLUDED**

A variety of different types of instruments related to caregiving are included in the database. The instruments include (1) general purpose surveys for broad populations, (2) general purpose surveys that include a caregiving module, (3) non-specific time use surveys, (4) caregiving-specific surveys, and (5) assessment instruments. Exhibit III.1 shows the distribution of the types of instrument included in the database.

*General purpose surveys* collect information on a broad population; for example, the population of people living in the United States. They ask questions on a variety of different topics applicable to all population members, such as their demographic characteristics, health conditions, employment, and income. Some surveys also will ask about participation in a specific program, and/or the prevalence of persons who either give or receive unpaid care to a person with a disability or chronic disease. The 2000 Behavioral Risk Factor Surveillance System (BRFSS) is an example of a general purpose survey that focuses on health conditions and risk behaviors in the United States, but also includes two questions that identify caregivers. The breadth of topics in these surveys generally limits the amount of information collected on caregiving.

EXHIBIT III.1

TYPES OF INSTRUMENTS INCLUDED IN DATABASE



Some *general purpose surveys include a caregiving module*, which collects more detailed information on different aspects of caregiving. The core survey will identify the caregiver, asking if the person gives or receives aid, and in the latter case, asks for information about the person providing aid. The module is administered either to the care recipient or, more typically, the caregiver; this may or may not be the same person who answered the core survey. For example, the National Long Term Care Survey (NLTCS), which collects information on the health and functioning of elderly Americans, includes a special module administered to the primary caregiver of a person in the NLTCS who reports that they require the assistance of a family caregiver. In other cases, the module is administered to anyone in the core survey who was identified as a potential caregiver, as with the 2001 SIPP. These surveys are more likely than the general purpose surveys to gather data on caregiver physical health, mental health, health practices, levels of burden, and employment status.

*Time use surveys* document how people spend their time during a typical day or week, often through a journal. The surveys or journals can be analyzed later to determine how people balance their time among competing demands such as employment, personal needs (exercise or relaxing), religious or volunteer commitments, and caregiving. These surveys also may provide additional details on the type of caregiving activities performed during each care period.

*Caregiving-specific surveys* target the caregivers or care recipient population directly. This population is identified in several ways. Sometimes a larger population is screened to identify caregivers or care recipients to whom the more detailed survey is administered, as with the Young Caregivers/Child Caregivers studies. Sometimes the caregiver or care recipient population is identified in a separate survey, such as the Caregiver Health Effects Study (CHES) sample that was drawn from the Cardiovascular Health Study (CHS). Other surveys, like the

Survey of Self-Identified Family Caregivers, depend on caregivers identifying themselves and volunteering to participate in a study. Regardless of the method by which the population is identified, these caregiving-specific surveys, like the caregiving-specific modules, are more likely to ask about caregiver physical health, mental health, health practices, levels of burden, and employment status than the general purpose surveys.

*Assessment instruments* are used for identifying and treating individual caregivers. They are self-administered or professionally administered, and target either the caregiver or care recipient. Assessments targeting the caregiver often are self-assessments, such as the Evercare Study of Caregivers in Decline, which was posted online. Care recipient assessments usually are given in the context of an assessment of need for services, such as the Massachusetts Real Choice Functional Needs Assessment, which assists in the determination of eligibility for community-based services and programs that promote community living. The caregiver section of care-recipient assessments can either ask the recipient to report on caregivers, or can be a separate module administered directly to the caregiver.

### C. INFORMATION DESCRIBING INSTRUMENTS

The specific purpose and design of a caregiver instrument can have an important influence on the information collected relative to the health effects of providing unpaid care. We reviewed the literature on each of the caregiver instruments, paying specific attention to features that may be related to components of a public health surveillance system on caregivers. Based on our review, we created an entry for each instrument in the database that includes a description of the purpose of each instrument, the design and methods used to administer it, the caregiver definition, and the content that may be relevant to caregiver surveillance. We also identified and included the year(s) that each instrument was implemented, the agency that sponsored its development, the organization that implemented it, the link to the website that contains further information when possible, and references. Exhibit III.2 provides an example of the information contained in the database for the NLTCS.

#### EXHIBIT III.2

##### EXAMPLE OF INSTRUMENT INFORMATION INCLUDED IN CAREGIVER DATABASE

Field	Sample Data
Study Instrument Name	National Long Term Care Survey (NLTCS)
Years Conducted	2004, 1999, 1994, 1989, 1984
Sponsoring Agency	National Institute on Aging
Lead Institution	Duke University
Study Description	The NLTCS is a longitudinal survey of Americans over 65 years old. It is designed to study changes in health and functional status, but also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for caregiving. It includes a supplemental survey administered to the primary caregiver of sample members who report receiving unpaid help.

EXHIBIT III.2 (continued)

---

Field	Sample Data
Sample Design	The NLTCS is based on a sample of 35,789 persons identified from national Medicare enrollment files in 1982. The first interview was conducted in 1984, and subsequent interviews have been conducted in 1989, 1994, 1999, and 2004. It has incorporated 20,000 new sample members over time by adding 5,000 persons who turn 65 between survey years to each survey. It includes persons who live in the community (regardless of disability) and those who live in institutions.
Caregiver Definition	A caregiver is defined as the person who provides the most help to the NLTCS sample member with a disability or health problem during a typical week.
Relevant Content	The NLTCS supplemental survey of the primary caregiver contains detailed information on the activities performed by the caregiver, the caregiving environment, and the caregiver burden, health outcomes, and characteristics. The supplemental survey can be merged into the NLTCS core survey that contains detailed information on the care recipient.
Key words	Aging, Long-term Care, Health Expenditures, Health Status, Functional Status, National Survey, Health Survey, Longitudinal Data
Website	<a href="http://www.nltcs.aas.duke.edu/index.htm">http://www.nltcs.aas.duke.edu/index.htm</a>
References	Wolff, Jennifer L., and Judith D. Kasper. "Caregivers of Frail Elders: Updating a National Profile." <i>The Gerontologist</i> , vol. 46, no. 3, 2006, pp. 344–356.

---

## D. CAREGIVER SURVEY QUESTIONS

Many of the instruments we identified collect data about caregivers by asking either the caregivers themselves or care recipients a series of questions on different aspects of caregiving. Although not all instruments were publicly available, they yielded approximately 1,900 questions for the project's database. We organized these questions into six topical areas relevant to a public health surveillance system for caregivers, including (1) caregiver activities, (2) caregiver burden, (3) caregiver health, (4) caregiving environment, (5) caregiver characteristics, and (6) care recipient characteristics. Within these topics, we identified subcategories that further detail the caregiver experience.

### 1. Caregiver Activity Questions

Caregiver activity questions ask about the type of activities and the amount of assistance that a care recipient needs to perform certain activities. For example, a caregiver may be asked if he/she helps a family member or friend to eat, bathe, use the toilet, dress, get in and out of bed, or get around the house. The types of activities performed may be used to classify someone as a caregiver, or to identify caregiving situations that might increase health risks. For example, family caregivers who help with physically demanding activities, such as helping a person get in and out of bed, may be at greater risk of sustaining a physical injury. The caregiver activity questions may be nonspecific and ask about general assistance provided, or may ask about specific activities.

*Nonspecific Activities.* Several of the instruments identify caregivers by asking whether the person provides any help to a family member or friend with a disability. An example of this type of question is as follows:

“People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?”

We refer to these activities as “nonspecific activities” because the activity is not specified. In the searchable database, it is the first category within the list of caregiver activity questions because it is one of the more frequently used questions in the instruments we identified.

*Activities by Type.* Detailed questions on the specific types of activities a caregiver performs also are contained in many of the instruments. We organized the specific type of caregiver activities using the World Health Organization (WHO) designed International Classification of Functioning, Disability and Health (ICF). The ICF describes how people live with their health conditions, and includes nine categories that define health-related activity limitations and restricted participation in activities. The nine categories provide a useful way to classify the specific type of help that a caregiver provides to a person with a disability or chronic disease. The categories include (1) learning and applying knowledge; (2) general tasks and demands; (3) communicating; (4) mobility; (5) self-care; (6) domestic life; (7) interpersonal relationships; (8) education, employment, and economic life; and (9) participation in community, social, and civic life. Exhibit III.3 provides a more detailed description of these categories, and includes examples of survey questions for each.

EXHIBIT III.3

CAREGIVER ACTIVITY CATEGORIES FOR CAREGIVER DATABASE

Activity and Participation	Specific Activities	Survey Question
Unspecified Activity	The nature of the caregiving activity is not specified.	People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend? (660) (1) Yes (2) No (7) Don't Know/Not Sure (9) Refused (Source: 2005 BRFSS North Carolina Supplement)
Learning and Applying Knowledge: Purposeful Sensory Experiences	Includes help with: watching, listening, other purposeful sensing, copying, rehearsing, learning to read, learning to write, learning to calculate, acquiring skills, focusing attention, thinking, reading, writing, calculating, solving problems, and making decisions.	Given this condition, with which TWO of the following areas does he/she most need your help? <b>CHECK UP TO TWO</b> 1 Learning, remembering, and confusion; 2 Seeing or hearing; 3 Taking care of oneself, such as eating, dressing, bathing, or toileting; 4 Communicating with others; 5 Moving around; 6 Getting along with people; or 7 Feeling anxious or depressed; 9 Don't Know; 10 Refused (Source: 2005 BRFSS North Carolina Supplement)
General Tasks and Demands	Includes help with: undertaking a single task, undertaking multiple tasks, carrying out a daily routine, handling stress, and other psychological demands.	Given this condition, with which TWO of the following areas does he/she most need your help? <b>CHECK UP TO TWO</b> 1 Learning, remembering, and confusion; 2 Seeing or hearing; 3 Taking care of oneself, such as eating, dressing, bathing, or toileting; 4 Communicating with others; 5 Moving around; 6 Getting along with people; or 7 Feeling anxious or depressed; 9 Don't Know; 10 Refused (Source: 2005 BRFSS North Carolina Supplement)
Communicating	<p>Receiving communication includes help with: receiving spoken messages, nonverbal messages, formal sign language, and written messages.</p> <p>Producing communication includes help with: speaking, producing nonverbal messages, and producing messages in formal sign language.</p> <p>Conversation and the use of devices and techniques include help with: conversation, discussion, and using communication devices such as the telephone or the Internet.</p>	In the past week, that is since last [day], did you, BECAUSE OF [SAMPNAME]'s DISABILITY, help (him/her) by – Making telephone calls for [SAMPNAME]? (Source: 2004 NLTCS)

EXHIBIT III.3 (continued)

Activity and Participation	Specific Activities	Survey Question
Mobility	<p>Changing body position includes help with: lying down, squatting, kneeling, sitting, standing, and bending; and maintaining body position with such activities.</p> <p>Carrying and moving objects includes help with: lifting and carrying objects, moving objects with lower extremities, fine hand use such as grasping objects, and hand and arm use such as pulling, pushing, and reaching.</p> <p>Getting around includes help with: walking, moving, moving around using equipment, driving a car, using a bicycle, and using animals for transportation.</p>	<p>I am going to mention some activities for which a person might need help, and ask whether you helped [SAMPNAME] with them in the past week. Did you help [SAMPNAME] walk around inside or get around inside with a wheelchair or similar device? (Source: 2004 NLTCs)</p>
Self-Care	<p>Includes help with: washing oneself, caring for body parts, toileting, dressing, eating, drinking, and looking after one's health.</p>	<p>I am going to mention some activities for which a person might need help, and ask whether you helped [SAMPNAME] with them in the past week. Help [SAMPNAME] get dressed by – Getting and putting on the clothes [he/she] wears during the day? (Source: 2004 NLTCs)</p>
Domestic Life	<p>Acquisition of necessities includes help with: acquiring a place to live, buying groceries, shopping, and other forms of gathering daily necessities. Household tasks include preparing meals and doing household chores.</p> <p>Caring for other household objects and assisting others includes help with: making repairs to clothes, maintaining the dwelling (e.g., painting and repairs to a house), maintaining vehicles, maintaining assistive devices, assisting others with self-care, assisting others in movement, assisting others in communication and other personal assistance activities.</p>	<p>In the past week, that is since last [day], did you, BECAUSE OF [SAMPNAME]'s DISABILITY, help (him/her) by – Preparing special foods or fixing extra meals? (Source: 2004 NLTCs)</p>

EXHIBIT III.3 (continued)

Activity and Participation	Specific Activities	Survey Question
Interpersonal Interactions	<p>Includes two subcategories—general interpersonal interactions and particular interpersonal interactions. General personal interactions describe how people conduct themselves across all types of relationships, including help with: showing respect, appreciation, and tolerance in relationships; responding to criticism; using appropriate physical contact; forming and terminating relationships; interacting according to social rules; and maintaining social space.</p> <p>Particular interpersonal interactions describe needing assistance with how to behave in specific interactions, such as the relationships with employers, subordinates, friends and acquaintances, and family members.</p>	<p>Given this condition, with which <b>TWO</b> of the following areas does he/she most need your help? <b>CHECK UP TO TWO</b> 1 Learning, remembering, and confusion; 2 Seeing or hearing; 3 Taking care of oneself, such as eating, dressing, bathing, or toileting; 4 Communicating with others; 5 Moving around; 6 Getting along with people; or 7 Feeling anxious or depressed; 9 Don't Know; 10 Refused (Source: 2005 BRFSS North Carolina Supplement)</p>
Education, Economic Life	<p>Employment, Education includes carrying out tasks and actions required to engage in education at all levels. Employment includes engaging in apprenticeship programs; acquiring, keeping, and terminating a job; engaging in self-employment; engaging in part-time employment; and engaging in full-time employment.</p> <p>Economic life includes help with: basic transactions, such as using money to purchase goods and services; complex transactions, such as maintaining a bank account or securing a loan; and economic self-sufficiency, defined as having command over resources to ensure economic security for both present and future needs.</p>	<p>Identify the frequency, daily support time, and type of support that is reported necessary for the person to be successful: 1. Accessing/receiving job/task accommodations; 2. Learning and using specific job skills; 3. Interacting with co-workers; 4. Interacting with supervisor/coaches; 5. Completing work-related tasks with acceptable speed; 6. Completing work-related tasks with acceptable quality; 7. Changing job assignments; 8. Seeking information and assistance from an employer. (Source: The Division of Developmental Disabilities Assessment, 2007)</p> <p>In the past week, that is since last [day], did you, BECAUSE OF [SAMPNAME]'s DISABILITY, help (him/her) by – Managing [SAMPNAME]'s money, like keeping track of bills or handling cash? (Source: 2004 NLTCS)</p>

EXHIBIT III.3 (continued)

Activity and Participation	Specific Activities	Survey Question
Community, Social, and Civic Life	Includes providing help with participation in community life, recreation, and leisure; religion and spirituality; human rights; political life; and citizenship.	Identify the frequency, daily support time, and type of support that is reported necessary for the person to be successful in the following activity domains: 1. Getting from place to place throughout the community (transportation); 2. Participating in recreation/leisure activities in the community settings; 3. Using public services in the community; 4. Going to visit friends and family; 5. Participating in preferred community activities (church, volunteer, etc.); 6. Shopping and purchasing goods and services; 7. Interacting with community members; 8. Accessing public buildings and settings. (Source: The Division of Developmental Disabilities Assessment, 2007)

## 2. Caregiver Burden Questions

Caregiver burden is the amount of stress or strain involved with the act of providing family care. Burden measures are an important element of a public health surveillance system for caregivers, because studies have shown that increases in the amount of burden are associated with health risks. The NAC-AARP study shows that those with the most caregiver burden are, among all caregivers, the most likely to report their health as being fair or poor. High levels of caregiver burden also are associated with an increased risk of institutionalization of the care recipient (Yaffe et al. 2002; Spillman and Long 2007). Measuring the risk factors associated with the health effects of caregiving is crucial for insight into methods and factors that could ameliorate its health effects. Interventions could be identified or designed to address these risk factors and reduce the incidence of health problems resulting from caregiving.

There are a wide variety of caregiver burden measures. NAC designed a five-level measure of burden based on a combination of the number of activities of daily living performed and the usual number of hours spent per week providing unpaid care (National Alliance of Family Caregivers and AARP 2004). Others have developed sets of questions used to construct a caregiver burden scale, such as the Zarit Caregiver Burden Index (Zarit et al. 1980). We organized caregiver burden questions into eight categories. These include hours of care per week; number of years providing care; physical strain; emotional strain; mental strain; financial strain; employment effects; and a category “other burden,” for questions that do not fit into the others. These questions may be used on their own to measure specific types of burden, or may be combined into a caregiver burden index. Exhibit III.4 describes the categories, and provides examples of survey questions for each.

### EXHIBIT III.4

#### CAREGIVER BURDEN CATEGORIES INCLUDED IN CAREGIVER DATABASE

Caregiving Burden	Description	Example
Hours per week	The number of hours spent providing care in a given week	On average, about how many hours do you spend helping [SAMPNAME] in a typical week? 0-168 Hours (Source: 2004 NLTCS)
Duration	The number of years spent providing care	How long ago did you start taking care of [SAMPLENAME] because of (his/her) disability? (Source: 2004 NLTCS)
Physical strain	Measure of the physical strain related to caregiving	Using a scale from 1 to 5 where 1 is not a strain at all and 5 very much a strain, how much of a physical strain would you say that caring for [SAMPNAME] is for you? (Source: 2004 NLTCS)
Emotional strain	Measure of the emotional strain related to caregiving	Using a scale from 1 to 5 where 1 is not at all stressful and 5 very stressful, how emotionally stressful would you say that caring for [SAMPNAME] is for you? (Source: 2004 NLTCS)

EXHIBIT III.4 (continued)

Caregiving Burden	Description	Example
Mental strain	Measure of the mental strain related to caregiving	How much of a mental or emotional strain is it on you to stay with or supervise your friend or relative – either directly by doing it yourself or indirectly by arranging for someone else to do it? (1) No mental or emotional strain (2) Some mental or emotional strain (3) A lot of mental or emotional strain (4) I don't do this (Source: Caregiver Health Effects Study, 1998)
Financial strain	Measure of the financial strain related to caregiving	Using a scale from 1 to 5 where 1 is no hardship and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for [SAMPNAME] is for you? (Source 2004 NLTCs)
Employment effects	Measure of the impact of caregiving on employment	Did your caregiving responsibilities cause you to quit work or retire early? (Source: National Survey of Participants in Older Americans Act Programs, 2003)
Other activities	Measure of other normal activities affected by caregiving	Does helping [SAMPNAME] ever bother you? (Source 2004 NLTCs)

### 3. Caregiver Health Questions

Caregiver health questions include some about the caregiver's health status, as well as health behaviors. The most common caregiver health measure we identified in the instruments is a variation of a question that asks caregivers to rate their overall health, with some variation of: "How would you rate your overall health: excellent, good, fair, poor?" Variations of this question focus either on mental or physical health. Other instruments use responses to a series of questions to construct a health index, such as the SF-12 health measures.<sup>2</sup> Caregiver health also may be inferred from questions that ask about the utilization of health services, whether the caregiver has experienced an injury as a result of caregiving, or health behaviors, such as drug and alcohol use. Health measures enable researchers to look for associations between caregiver activities and burden and caregiver health, and are considered the key outcomes for any caregiver public health surveillance system.

We organized caregiver health outcomes into categories that include: self-reported health status, physical health, mental health, health care utilization, injuries, and health behaviors. Exhibit III.5 provides a brief description of these measures, and examples of questions used to collect information on them in the survey and research instruments.

---

<sup>2</sup> The SF-12 is a 12-item instrument that measures eight domains of health. See <http://www.qualitymetric.com/products/sf12v2.aspx> for more information on the SF-12.

EXHIBIT III.5

CAREGIVER HEALTH CATEGORIES INCLUDED IN CAREGIVER DATABASE

Caregiver Health	Description	Example
Self-Reported Health (Overall)	Self-reported assessment of a person's overall health	Compared to other people your age, would you say your health, in general, is excellent, good, fair, or poor? (Source: NLTCs, 2004)
Physical Health	Self-reported assessment of a person's physical health	Now, thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? (Source: 2005 BRFSS North Carolina Supplement)
Mental Health	Self-reported assessment of a person's mental health	To what degree, if at all, do you have depression now? (Source: Evercare Study of Caregivers in Decline, 2006)
Health Care Utilization	Measure of a person's use of health care services	At any point since you have been providing care, have you (a) Missed any doctor's appointments? (Source: Evercare Study of Caregivers in Decline, 2006)
Injuries	Measure of whether a person has experienced a caregiving-related injury	In the past 12 months, have you sustained an injury while helping him/her? (1) Yes (2) No (77) Don't know/Not sure (99) Refused (Source: 2005 BRFSS North Carolina Supplement)
Health Activities	Measure of the effect of caregiving on other health activities, such as sleep, exercise, alcohol use, drug use, nutrition, or meditation/prayer.	Here are some things that some people do when they are under stress from caregiving. How often do you do them? (a) Smoke (Source: NLTCs, 2004)

**4. Caregiving Environment Questions**

The ICF guidelines include a chapter on environmental factors, which describes the physical, social, and attitudinal environments in which people live their lives. These factors can affect the activities performed and burden perceived by caregivers, and can have negative or positive effects on caregiver health. For example, a physical environment that makes it difficult for a caregiver to provide care to the recipient—such as the absence of a ramp to move the care recipient to and from a building easily—can increase the physical strain and health risks involved in performing caregiving activities.

On the other hand, the environment can reduce the burden of caregiving, either by allowing the care recipient to be more independent, or by providing services and supports to the caregiver. An environment that makes the world more accessible to people with disabilities—such as modifications to buildings, improvements to public transportation, or policies that improve access to assistive technologies—can substantially reduce the amount of family care required by people with disabilities. An environment that provides easily accessible information on how to provide quality care, or that provides access to respite services, can substantially reduce the level of caregiving burden. In either of these cases, the burden of caregiving is mitigated by reducing the level of required caregiving.

There are five broad subcategories used to explicate the ICF environmental factors component: products and technology; natural environment and human-made changes to environment; support and relationships; attitudes; and services, systems and policies. Further details on the items that fall within these categories are in WHO (2001). Exhibit III.6 provides a description for each of the categories, and an example of a survey question that may be used to describe the caregiving environment.

EXHIBIT III.6

CAREGIVING ENVIRONMENT CATEGORIES INCLUDED IN CAREGIVER DATABASE

Environmental Factor	Description	Example
Products and Technology	Includes: any product, instrument, equipment, or technology adapted or specially designed for improving the functioning of a person with a disability	There are many services available to help you provide help to an older person such as [SAMPNAME]. Please tell me whether you have ever used the following service or not. Have you ever obtained assistive devices, such as wheelchairs, walkers, etc. for [SAMPNAME]? Who provided you with this service? (Source: 2004 NLTCS)
Natural Environment and Changes to Environment	Includes all aspects of the natural or physical environment, and components of that environment that have been modified by people, as well as characteristics of human populations	There are many services available to help you provide help to an older person such as [SAMPNAME]. Please tell me whether you have ever used the following service or not. Have you ever had modifications made to [SAMPNAME]'s house to make things easier for (him/her)? Who provided you with this service? (Source: 2004 NLTCS)
Support and Relationships	Includes people or animals that provide practical physical or emotional support, nurturing, protection, assistance, and relationships to other persons, in their homes, places of work, schools, at play, or in other aspects of their daily activities	There are many services available to help you provide help to an older person such as [SAMPNAME]. Please tell me whether you have ever used the following service or not. Have you ever taken part in support groups for caregivers? Who provided you with this service? (Source: 2004 NLTCS)
Attitudes	Includes attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs, and religious beliefs	Why do you like the idea of caregivers being considered a special group within the general population? Possible response: I am more aware of the contributions caregivers are making to society (Source: Survey of Self-Identified Caregivers, 2001)
Services, Systems, and Policies	Services that provide benefits, structured programs, and operations in various sectors of society, designed to meet the needs of individuals	Have you ever received any respite or caregiver support services from a government source to assist you in providing care for [SAMPNAME]? (Source: 2004 NLTCS)

## 5. Caregiver Characteristics Questions

Measuring characteristics of caregivers allows researchers to better delineate family care providers in the U.S., as well as monitor any changes in the population over time. Characteristics include demographic information, such as age, gender, and race, as well as the relationship of the caregiver to the care recipient, and the location of a caregiver relative to a care recipient. Exhibit III.7 provides a description and examples of questions for each of these characteristics.

Caregiver characteristics are important because differences in the age, gender, and race of caregivers may explain or be linked to other issues of caregiving, such as health outcomes. For instance, older caregivers may be at greater risk of experiencing a care-related injury or illness than younger caregivers. Racial or ethnic minorities may face discrimination or communication barriers that increase the burden of providing care, which may in turn increase health risks. Caregiver characteristics, such as relationship and location relative to the care recipient, also may help to explain the nature of the caregiving experience. For example, unpaid caregivers who live outside of the recipient’s home may face different challenges than a caregiver living with the recipient.

EXHIBIT III.7

### CAREGIVER CHARACTERISTIC CATEGORIES USED FOR CAREGIVER DATABASE

Care Recipient	Description	Example
Age	Age of caregiver	How old are you? (Source: California Statewide Survey of Caregivers, 2002)
Gender	Gender of caregiver	Ask only if not obvious: What is your gender? (Source: California Statewide Survey of Caregivers, 2002)
Race	Race/Ethnicity of caregiver	What is your race or ethnicity? Check all that apply: White or Caucasian/Black or African American/Asian/Indian/Cambodian/Chinese/Filipino/Japanese/Laotian/Korean/Vietnamese/Other Asian/American Indian or Alaska Native /American Indian Tribe Name/ Native Hawaiian or Pacific Islander Native Hawaiian/Guamanian or Chamorro/Samoan/Other Pacific Islander/Other (Source: California Statewide Survey of Caregivers, 2002)
Relationship	Relationship of unpaid caregiver to the care recipient	What is your relationship to him/her? For example, are you his/her (mother/father)? (Probe for relationship – if more than one, ask “Which is the person you take care of the most often?”) 01 Aunt 02 Brother 03 Daughter 04 Daughter-in-law 05 Father 06 Father-in-law 07 Friend 08 Granddaughter 09 Grandfather 10 Grandmother 11 Grandparent-in-law 12 Grandson 13 Husband 14 Mother 15 Mother-in-law 16 Neighbor 17 Nephew 18 Niece 19 Other Relative 20 Paid caregiver/assistant 21 Partner 22 Sister 23 Son 24 Son-in-law 25 Uncle 26 Wife 77 (Source: 2005 BRFSS North Carolina Supplement)

EXHIBIT III.7 (continued)

Care Recipient	Description	Example
Location	Where caregiver lives in relation to care recipient	Typically, how long does it take you to travel to (his/her) residence, each way? Less than 15 minutes/15-30 minutes/30 minutes to an hour/More than an hour (Source: California Statewide Survey of Caregivers, 2002)
Marital Status	Marital status of caregiver	Ask only if not spouse or partner of CR: Are you married? Married/Living with partner/Separated/Divorced/Widowed/Never Married (Source: California Statewide Survey of Caregivers, 2002)

**6. Care Recipient Characteristics Questions**

Just as the caregiving experience and associated health outcomes vary by the characteristics of the caregiver, so too are they affected by the characteristics of the care recipient. The specific needs of a care recipient, and the level of burden required to provide care, may differ substantially, depending on the care recipient’s age, gender, health impairment, and disability type. Racial and ethnic minorities may be more likely to experience social barriers, such as discrimination, that may increase the burden placed on the caregiver, regardless of the caregiver’s racial or ethnic background. Identifying these differences, and how they are associated with health outcomes, may be crucial to developing public health interventions.

Care recipient characteristics are organized into five subcategories: age, gender, health impairment, disability type, and receipt of professional assistance. Exhibit III.8 provides a brief description of these measures, and examples of questions used to collect information on them.

EXHIBIT III.8

CARE RECIPIENT CATEGORIES USED FOR CAREGIVER DATABASE

Care Recipient	Description	Example
Age	Age of care recipient	What age is the person whom you are giving care? Code age in years [0-115] (Source: 2005 BRFSS North Carolina Supplement)
Gender	Gender of care recipient	What is the gender of the person you are caring for? (1) Male (2) Female (7) Don’t Know or Not Sure (9) Refused (Source: 2005 BRFSS North Carolina Supplement)
Relationship	Care recipient’s relationship to caregiver	Now I’d like to ask a few questions about the person to whom your child gives help or care. What is that person’s relationship to [CHILD’S NAME]? (Source: Young Caregivers in the U.S., 2005)

EXHIBIT III.8 (continued)

Care Recipient	Description	Example
Impairment Type	Health impairment of care recipient	What do you think or what has a doctor said is the major health problem that he/she has? CHECK ONE CONDITION ONLY: 1 Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder (ADD/ADHD) 2 AIDS/HIV 3 Arthritis/rheumatism 4 Asthma 5 Cancer 6 Cerebral Palsy 7 Chromosomal anomaly 8 Dementia 9 Depression 10 Down's syndrome 11 Anxiety and/or other emotional problem 12 Developmental delays 13 Diabetes 14 Eye/vision problem (blindness) 15 Hearing problems (deafness) 16 Heart disease 17 Hypertension/high blood pressure 18 Lung disease/emphysema 19 Multiple Sclerosis 20 Muscular Dystrophy 21 Osteoporosis 22 Parkinson's 23 Spinal Cord Injury (SCI) 24 Stroke 25 Traumatic Brain Injury (TBI) 26 Other (Source: 2005 BRFSS North Carolina Supplement)
Activity Limitation/ Participation Restriction of Care Recipient	Describes the activity limitations or participation restrictions of care recipient	Which of the following best describes the person's ability to get around? Can the person walk without help from another person or does he/she need help from another person? (Source: Young Caregivers in the U.S., 2005)

## **IV. HIGHLIGHTS FROM AND LIMITATIONS OF EXISTING INSTRUMENTS AND AREAS FOR FUTURE RESEARCH**

Throughout the course of developing the database, we identified strengths and limitations of existing instruments in terms of the surveillance of caregiver health. In this section, we begin by highlighting the features of existing instruments that seem important for studying the health effects of caregiving. We then describe their limitations, such as gaps in information, which we were able to identify while developing the database. Finally, we identify several areas for future research.

### **A. STRENGTHS OF EXISTING INSTRUMENTS AND QUESTIONS**

Several instruments in the database include a large set of questions on the topics we identified as important to studying the health effects of caregiving. Most of them focus on caregivers of elderly persons with disabilities and chronic conditions, with a particular focus on those caring for persons with Alzheimer's or dementia. Here, we identify five instruments that contain an extensive set of questions on the health effects of caregiving, and include unique features important to gaining a more comprehensive picture of the health effects of caregiving. The instruments include (1) the National Long Term Care Survey, which is unique in that it collects detailed information on both the caregiver and the care recipient; (2) the Caregiver Health Effects study, one of the few prospective studies of the health effects of caregiving; (3) the Informal Caregiver and Paid Worker surveys of the Cash and Counseling evaluation, one of the few intervention studies that focuses on the health effects of providing unpaid care to a population of persons with a variety of different disabilities and chronic diseases; (4) the Young Caregivers in the U.S. survey, which describes the specific issues that children between the ages of 8 and 18 face as caregivers of persons with disabilities and chronic diseases and illustrates the importance of considering caregiving as a life span issue; and (5) the recent efforts to incorporate caregiving questions into the Behavioral Risk Factor Surveillance System, the world's largest ongoing telephone health survey system.

#### **1. National Long Term Care Survey (NLTC)**

The NLTC is a nationally representative longitudinal survey of Americans over 65 years old. It is designed to study changes in health and functional status, but also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for caregiving. It includes a supplemental survey administered to the primary unpaid caregiver of sample members who report receiving unpaid help. The survey thus contains a combination of information—on the care recipient, drawn from the core component of the survey, and on the primary caregiver, drawn from the supplement—which may be used to examine the public health effects of caregiving on both the caregiver and the care recipient.

The caregiver supplement contains 90 questions associated with the six categories related to the health effects of caregiving (described in Chapter III). Because including questions on caregiver characteristics, care recipient characteristics, and caregiver health is fairly standard on

surveys measuring caregiver health, we will focus on the more distinctive features focusing on caregiver activities, the caregiver environment, and caregiver burden.

The supplement includes 21 questions on *caregiver activities* (see Exhibit III.3), such as providing help with: (1) telephone communication; (2) mobility, such as walking or using transportation; (3) performing activities of daily living; (4) performing instrumental activities of daily living; and (5) major life activities, such as managing money. The survey thus may be used to precisely identify the number and the type of different tasks that a caregiver may perform for the care recipient.

Another feature of the NLTCs is its 22 questions related to the *caregiving environment*. These questions cover four of the five ICF environment subcategories, including (1) products and technology; (2) changes to the natural environment; (3) supports and relationships; and (4) services, systems, and policies. Descriptions of these areas are included in Exhibit III.6. The one subcategory not covered in the NLTCs is attitudes.

The NLTCs also contains several questions related to *caregiver burden*, including the type and amount of care provided in a typical week; the degree of physical strain involved with caregiving; the degree of emotional stress; the number of times sleep has been interrupted because of caregiving; the frequency of problem behaviors by the care recipient; types of assistance received by the caregiver; reasons caregiving assistance is not used by the caregiver; and supports that the caregiver needs (see Exhibit III.4). The NLTCs also includes questions that have been used to develop caregiver burden scales, such as the Zarit Caregiver Burden Interview questions (Zarit et al. 1980).

The unique combination of information on the caregiving dyad (that is, the caregiver and the care recipient) and the detailed burden measures available in the NLTCs have been used to show how caregiver burden also may affect care recipient outcomes. Spillman and Long (2007), for example, used the NLTCs to show that high levels of caregiver burden are associated with substantial increases in the probability that the care recipient will enter a nursing home. They conclude that policies aimed at alleviating caregiver burden have the potential to substantially reduce or defer nursing home entry among care recipients. The NLTCs has great potential to examine other key relationships between caregiver activities, the caregiving environment, and caregiver burden on the public health of both the primary caregiver and the care recipient.

## **2. Caregiver Health Effects Study (CHES)**

The CHES is one of the few prospective population-based cohort studies on caregivers. Its sample was drawn from the Cardiovascular Health Study (CHS), a prospective, observational study designed to determine the risk factors for and consequences of cardiovascular disease in older adults. The CHES component includes a total of 819 persons, divided between 392 caregivers and 427 non-caregiver comparisons, matched for age and gender, which were distributed evenly across four recruitment sites. The study took place from 1993 to 1998 and followed the cohort for an average of 4.5 years.

The project database includes 106 questions from the CHES instrument. In addition to containing information on caregiver activities, caregiver characteristics, and care recipient characteristics, the CHES includes 22 questions related to caregiver burden and 23 questions on

the caregiver's health. The caregiver burden questions include all of the burden subcategories. The caregiver health questions cover self-reported physical and mental health measures, health behaviors (e.g., sleeping, exercise, drinking, smoking), and health care utilization.

The CHES demonstrates the power of a prospective study to examine the key health effects of caregiving. Its design and detailed information on burden and health have contributed to the some of the most influential studies on the health effects of caregiving. For example, Shultz and Beach (1999) showed that caregiving is a risk factor for mortality—caregivers who experienced emotional or mental strain had mortality risks that were 63 percent higher than the matched non-caregiver comparisons. It also has been used to show that caregivers experiencing mental and emotional strain, when compared with age- and sex-matched non-caregiving comparisons, have significantly higher levels of depressive symptoms and anxiety, and lower levels of perceived health. In addition, they are less likely to get enough rest, have time to rest when they are sick, or have time to exercise (Schultz et al. 1997).

### **3. Cash and Counseling Informal Caregiver and Paid Worker Surveys**

The instrument was developed for an independent evaluation of the national Cash and Counseling Demonstration, a randomized experiment that gave interested Medicaid beneficiaries in Arkansas, Florida, and New Jersey the opportunity to receive a monthly allowance to purchase disability-related supportive services of their choice (the cash component) and access to professionals who can provide consumers with information and advice on how to manage the cash component and services (the counseling component). The evaluation included a comprehensive analysis of the program's effects on beneficiaries' primary informal caregivers, a substantial proportion of whom became paid workers under the cash component of the program. The Cash and Counseling instruments are noteworthy in that they are used to examine the impact of an intervention on the health and well-being of family caregivers who provide care to Medicaid adult beneficiaries with physical disabilities and, in Florida, to adults and children with developmental disabilities. A total of 4,497 unpaid caregivers in three states were interviewed as part of the Cash and Counseling evaluation.<sup>3</sup>

The caregiver survey collected information about the frequency, amounts, timing, and types of assistance caregivers had provided just prior to the interview, and about their labor force participation and income. Caregivers were asked about the quality of their relationships with care recipients, their satisfaction with the care they provided, and their own emotional, financial, and physical well-being, as well as life satisfaction.

The data collected using these instruments show how the Cash and Counseling intervention has had a positive impact on caregiver burden, health, and satisfaction with life. When compared to the control group, the caregivers of Medicaid beneficiaries who received Cash and Counseling services experienced substantially lower levels of emotional, financial, and physical strain. They were less likely than control group members to report that their physical health suffered as a result of caregiving, that their health was fair/poor relative to their peers, and that they were dissatisfied with their own lives. (Indeed, they were substantially more likely than control group

---

<sup>3</sup> See Foster, Dale, and Brown (2007) for more information.

members to report that they were very satisfied with their own lives.) The findings were consistent across subgroups based on the age of the care recipients, indicating that the intervention was able to improve health for caregivers of care recipients who may have a variety of different needs. This indicates that interventions allowing persons with disabilities to have greater choice in how to spend the Medicaid resources available to them may improve the health and quality of life of a variety of different types of caregivers.

#### **4. Young Caregivers Instruments**

The survey instrument used by the Young Caregivers in the U.S. study and the Child Caregivers: A First Look at an Unstudied Population study is the only one that focuses specifically on the experiences and issues faced by children who provide care to persons with disabilities and chronic diseases. Children may experience different challenges and issues, and there may be different caregiving health effects on children who are caregivers. The instrument provides an initial glimpse into these issues but, because these surveys are fairly new, the main finding is that there are approximately 1.4 million children who provide unpaid care to people with disabilities and chronic diseases. The variety of issues children face in their caregiver roles, such as balancing their time between caregiving activities and schoolwork, has been the focus of recent media attention (Chandler 2007). However, further research is required to gain a better understanding of the public health effects associated with child caregivers.

#### **5. Behavioral Risk Factor Surveillance System (BRFSS)**

Finally, there is an effort underway to include caregiver questions in the BRFSS, a telephone survey that provides annual state-level estimates of health conditions and risk behaviors in the United States. Recently, a set of caregiver questions has been developed and included in a supplement to the BRFSS conducted in North Carolina. The results from the North Carolina effort provide a description of the demographic, socioeconomic, and health characteristics of caregivers, as well as the nature of the caregiver activities and the burden associated with them (CDC 2007b). By including the caregiver questions in the national BRFSS core survey, states will have an information base that may be used to make policy decisions, plan for the allocation of resources to caregiver and care recipient programs, and develop and track interventions that promote the public health of caregivers and care recipients.

### **B. LIMITATIONS OF EXISTING CAREGIVER INSTRUMENTS**

In addition to these strengths, the existing caregiving instruments also suffer from substantial limitations in terms of using them in developing a surveillance system. These limitations include (1) inconsistency in defining the caregiver population, (2) a lack of testing of survey questions, (3) a lack of data that capture the dynamics of caregiving, (4) the need for instruments to capture the perspectives of child caregivers and care recipients, (5) the need for state-level data collection, and (6) the need for cross-agency collaborations. These limitations are described in more detail below.

## 1. Defining the Caregiver Population

The existing caregiver instruments use a wide variety of definitions to identify the population of caregivers and, as a result, there is a wide range of estimates of the prevalence of caregiving in the U.S. We find estimates that range from 9.4 million caregivers, based on 1997 data from the 1996 SIPP panel, to 54 million caregivers, based on 2000 data from the National Family Caregiver Association (The Lewin Group 2002).<sup>4</sup>

The differences can be related to the specification, or interpretation, of the type of activities that constitute caregiving, the amount of burden associated with the act of caregiving, or some combination of the two (The Lewin Group 2002). For public health surveillance, a useful definition for identifying the public health risks of caregiving to both the caregiver and the care recipient would be valuable. One area for future research is to identify a definition suitable for monitoring and developing public health interventions for the population of caregivers.

## 2. Testing Survey Questions

While there are a substantial number of caregiver instruments and questions, there is relatively little information on the development of the questions used to assess key aspects of the public health effects of caregiving, as well as on the methods for developing and results of evaluations of the questions. As a result, there is little evidence as to whether the caregiving questions are providing valid and reliable information on key aspects of caregiving. Some of the key issues include (1) using questions originally developed for one population with other populations, (2) differences in responses to questions between care recipients and caregivers, (3) whether questions are accurately measuring certain concepts (e.g., extra time), and (4) whether questions are adequately capturing new concepts, such as the caregiving activities and the environment, as described in the ICF. Each of these key issues is briefly described below.

Many of the questions were developed initially for studying caregivers of persons with dementia or Alzheimer's disease, and appear to be applied to the broader population of caregivers without rigorous testing. This may result in misleading information on caregivers of persons with disabilities and other chronic diseases.

Research has shown that there are large differences in the population of caregivers when questions are directed to the caregiver, compared to the care recipient (The Lewin Group 2002; Lyons et al. 2002), and depending on the questions used to identify caregivers (The Lewin Group 2002). Despite these facts, we were unable to identify research studies that carefully examined the reasons for these differences and, given the extent of the differences, whether the questions used to identify caregiving activities and the caregiving environment were effective at capturing these aspects of caregiving. This is in stark contrast to the disability literature, which has begun to examine how persons with disabilities and chronic diseases respond to disability questions on different types of activity limitations (Lee et al. 2007). Research that can shed light on how caregivers and care recipients interpret and respond to survey questions on caregiving is important for developing a reliable and valid caregiver surveillance instrument.

---

<sup>4</sup> The difference in estimates is due to differences in the definition of a caregiver as described in footnote 2.

In addition to testing questions on the performance of caregiver activities, there are methodological issues related to measuring the amount of time spent performing caregiver activities. Specifically, some of the activities performed by the caregiver, such as the time spent preparing meals, are activities that the caregiver also may have to perform for themselves, and so present the problem of identifying the “extra time” associated with performing the activity for the care recipient. In addition, identifying the amount of “extra time” associated with providing care to a child with a disability, compared to a child without a disability may be difficult to measure. MPR has begun to conduct cognitive interviews for the Agency for Healthcare and Research Quality (AHRQ), as part of a project to develop a caregiver module for a national health survey, on methods that may be used to more accurately measure the time spent providing caregiver activities (Schwartz and Marton 2006). The results of the research may be particularly important for improving measures of caregiving activities performed and the time spent providing care in a public health surveillance system.

Finally, the emergence of the ICF as a conceptual model for describing disability and chronic disease has important implications for the measurement of caregiving activities and the caregiving environment. The ICF is now used to identify activity limitations and participation restrictions that persons with disabilities face in their everyday lives, and also is used to specify aspects of the environment that act either as facilitators or barriers to the performance of these activities. Caregivers play an important role in helping persons with disabilities perform and participate in normal life activities, and the same environmental characteristics that the ICF uses for persons with disabilities are relevant to caregivers. The ICF thus provides a useful framework for characterizing the caregiver role and the public health effects of caregiving. Because most of the survey questions used to identify caregiver activities and the caregiver environment were developed before the introduction of the ICF, the development of valid and reliable questions that describe aspects of the ICF related to caregivers is an important area for future research.

### **3. Developing Data on the Dynamics of Caregiving**

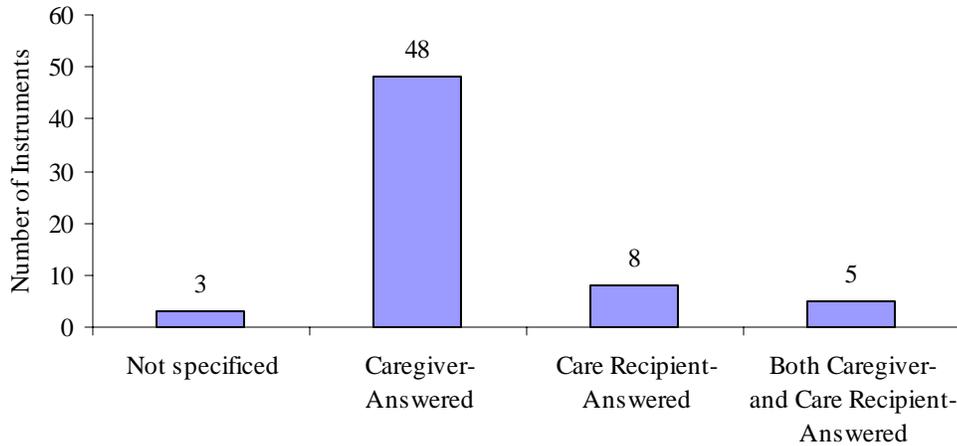
Most of the instruments identified in the database are cross-sectional surveys of caregivers, and the few prospective studies are drawn from samples of caregivers. These studies draw conclusions on the health effects of caregiving by comparing caregiver and non-caregiver health. However, drawing conclusions on the health effects of caregiving from these studies may be misleading, because those who are more likely to have health problems also may be more likely to take on the role of a caregiver because, for example, their health limitations prevent them from maintaining a full work schedule (Schultz 2007). One way to begin to overcome these limitations is to develop longitudinal data that follows persons as they enter the caregiving role, as this role changes over time, and as they exit the role. By tracking health over the course of these events, and observing how it changes, it is possible to draw more convincing conclusions on the health effects of caregiving and the type of events that may trigger adverse health outcomes.

### **4. Developing Instruments for Child Caregivers and Care Recipients**

Although substantial progress has been made in developing instruments to measure the burden of caring for individuals with dementia, relatively fewer instruments exist that describe

(1) children who serve as caregivers, and (2) the care recipient’s perspective. Exhibit IV.1 illustrates the limited number of surveys in the database that capture the care recipient’s perspective.

EXHIBIT IV.1  
RESPONDENTS TO CAREGIVING INSTRUMENTS



Recent instruments have been developed to address populations of caregivers that had been overlooked previously. The vast majority of surveys include only adult caregivers, aged 18 years and older. However, the role of caregiver can fall to children as well. The “Young Caregivers in the U.S.” report (2005) summarized the results of two studies that focused on children as caregivers. These studies sought to fill the gaps in the literature collecting data to estimate the prevalence of child caregivers aged 8 to 18 years, and to learn about the nature and impact of their caregivers’ roles. The study found that there are 1.3 to 1.4 million child caregivers between the ages of 8 and 18 years in the U.S.

One reason that children often are not included in surveys that capture information on caregiving is that the age at which respondents can consent to participate is 18 years. The first young caregiver study, and the screening portion of the second study, relied on mail questionnaires. For the second study, after the screening, telephone interviews were conducted with 213 child caregivers and 250 non-caregiving children. For the telephone interview, an adult provided information about the child, including behavior problems, information about the care recipient, and permission to interview the child. The child responded to questions regarding his or her caregiver tasks and self-perceptions of well-being, responsibility, and the impact of caregiving on schoolwork. The study was able to capture the nature of child caregiving, as well as highlight potential behavioral and health impacts. For example, child caregivers are more likely to show anxious or depressed behaviors than non-caregivers. In addition, the study highlighted more negative effects on caregivers who reside with the care recipient, as opposed to those who do not. The results of these studies highlight the need for ongoing data collection for the entire population of caregivers, regardless of age.

Few instruments describe the care recipients’ perspectives on the role of the caregiver. While caregivers report how their role impacts them, there is limited data on the care recipients’

perspectives on the role of the caregiver. Only one ongoing survey, the NLTCs, captures detailed information from both the care recipient as well as the caregiver; and that survey was administered only to care recipients over age 65. The care recipient's perspective may be useful in understanding situations in which caregiving interventions would be welcomed. For example, the care recipient may note that the caregiver has no support system, but a caregiver may be reluctant to admit this in a survey. Given that a downturn in either the caregiver's or the care recipient's health can negatively affect the other, it is important to include both dimensions in a public health surveillance system designed to assess the caregiving burden.

## **5. The Need for State-Level Data**

Another limitation with existing caregiver data is the lack of systematic collection of state-level data on the broader population of caregivers and care recipients. State-level estimates are particularly important, given the findings from implementing the National Family Caregiver Support Program, which showed substantial variation in services and service options for caregivers across states (Feinberg and Newman 2006).

Efforts to collect state-level data have been made in the past. In 2000, two questions that asked respondents whether they had the role of caregiver for an elderly relative or friend were included in the BRFSS core module. The respondent was asked if he/she had provided regular care or assistance in the past month to a family member or friend who was 60 years of age or older or had a long-term illness or disability. The second caregiving question asked who the respondent would call to arrange care in the home (short- or long-term) for an elderly relative or friend who was no longer able to care for him/herself (CDC 2007a). Other questions related to caregiving were included in the 2000 and 2001 modules, but were posed to the care recipient, and focused on the quality of care and who provided it (CDC 2007a).

The CDC has recognized the need for state-level data, as well as a variety of caregiving situations, and currently is developing a caregiver module for the 2009 BRFSS (CDC 2007b). The module was pilot-tested in North Carolina in 2005. If all states opt to use the caregiving module in 2009, it will be the first time that caregiver health status could be reported by state as well as nationally (CDC 2007b). The caregiver module will collect information on the age, sex, diagnosis, and functional limitations of the care recipient, the relationship of the care recipient and caregiver, the travel time to reach the care recipient, the duration of and weekly time spent providing care, and the difficulties experienced by the caregiver as a result of providing care.

## **6. Need for Cross-Agency Collaboration**

Individual federal agencies have undertaken efforts to develop caregiver surveys and research programs; however, there may be opportunities for agencies to realize synergies through collaboration. Some examples of current agency-specific caregiver research efforts include (1) the AHRQ research on the inclusion of a caregiver module for a national health survey; (2) the Administration on Aging development of the Performance Outcome Measures Project Caregiver Support and Assessment Survey; (3) the National Institutes of Health (NIH)-funded NLTCs, Resources for Enhancing Alzheimer's Caregivers Health (REACH), and the Health and Retirement Study (HRS); (4) the Centers for Medicare & Medicaid Services (CMS)

demonstrations, including the Money follows the Person Demonstration (MFP); and (5) the Assistant Secretary for Planning and Evaluation (ASPE) Long Term Care research portfolio.

One way to facilitate interagency collaboration is through the development of an Interagency Committee on Caregiver Research, which would follow the model established by the Interagency Committee on Disability Research (ICDR). The ICDR facilitates the exchange of information on disability research activities among its 70-plus member agencies. The committee meets regularly and holds a conference each year that summarizes the recent results from disability research projects and identifies future research priorities. Establishing a similar committee that focuses on caregiving research, would help to facilitate the exchange of information on caregiver research, and provide a platform for building a more coordinated effort aimed at improving the lives of both caregivers and care recipients.

### **C. AREAS FOR FUTURE RESEARCH**

We have identified several areas for future research, such as the inclusion of caregiver questions in the BRFSS, which will provide the annual state level data. The areas include (1) collaboration with AHRQ efforts to develop and test questions for a caregiver module to be included in a national health survey; (2) the inclusion of a caregiver module in the 2010 HRS; and (3) monitoring new intervention efforts, such as the MFP demonstration, that may provide new insights into the public health effects of caregiving and interventions with the potential to improve the health of caregivers and care recipients.

#### **1. Collaboration with AHRQ for Development and Testing of Caregiver Surveillance Questions**

There is relatively little research on the development and testing of questions that identify caregiving activities and the caregiving environment. In addition, the emergence of the ICF as a primary tool for describing disabilities, and the fact that caregivers play an important role in the lives of people with disabilities and chronic diseases, indicates a need to develop caregiver surveillance questions consistent with the ICF. Most of the survey questions we identified in the database were developed before the ICF, and so are not consistent with it.

One way to address these limitations is to build on the AHRQ-sponsored research to pretest a caregiver module for a national health care survey covering caregivers of either adults or children with disabilities (Schwartz and Marton 2006). The findings from the pretest reveal a number of important insights into the problems that caregivers encounter in describing their caregiver role based on a limited set of survey questions. In particular, the pretest concluded that a small number of questions cannot capture the complexity of most caregiving situations, and that the variations in the type of assistance needed by persons of different ages and with different types of disabilities can be addressed only with a more detailed set of questions tailored to the characteristics of the person with a disability. It also identified potential biases that arise with the use of one question to identify the amount of time spent providing informal care. Finally, it identified problems with the interpretation of certain types of caregiving activities questions. For example, the pre-test revealed that respondents were not including non-medical therapies, such as physical therapy or play therapy for children with disabilities, in answering the question identifying “obtaining, managing or administering medications or medical treatments.” It will be

important to build on these initial findings using a set of questions designed to capture ICF concepts and a larger test sample; this will enable researchers to understand whether survey questions are adequately describing the characteristics of caregivers necessary for monitoring the public health effects of caregiving.

## **2. Inclusion of a Caregiver Module in the Health and Retirement Study (HRS)**

The inclusion of a caregiver module in the HRS has the potential to provide new evidence on the health effects of caregiving by following caregivers into, and potentially out of, their caregiving roles. Most of the caregiving survey instruments we encountered were cross-sectional or prospective studies, and were limited to describing the health of caregivers after taking on their caregiving role. They measure the health effects of caregiving by comparing the health of caregivers to a group of people who are not caregivers. It is possible, however, that caregivers are in worse health prior to taking on the caregiving role, and cross-sectional and prospective studies are unable to adequately capture these pre-caregiving differences in health. These studies thus capture differences in health that occur regardless of the caregiving role, rather than differences in health associated with caregiving, and may not represent the health effects of providing unpaid care to persons with disabilities or chronic diseases.

The HRS surveys more than 22,000 Americans over the age of 50 every two years. It is designed to describe an aging America's physical and mental health, insurance coverage, financial status, family support systems, labor market status, and retirement planning. It began in 1992 collecting data on a cohort born between 1931 and 1941, and has re-interviewed the cohort every two years since then. By 2006, the original HRS cohort had been interviewed eight times, covering a 14-year period. HRS has added cohorts to the study over time, and is now representative of the U.S. population over the age of 50. In addition to an extensive core survey that contains a large set of health measures, HRS accepts proposals to conduct experimental modules covering topics not included in the core survey instrument.

The inclusion of a caregiver module in the HRS 2010 interview could be used to identify individuals who provide, or have provided, unpaid care to family members, and capture retrospective information on when they provided unpaid care, the type of care provided, the burden of care, and the caregiving environment. By collecting retrospective information, the module could be used to create a caregiver event history file. More important, it could be linked to the HRS core instrument, which has collected up to eight data points on a large set of health measures covering a fourteen-year period. For family caregivers who started to provide unpaid care after they began participating in the HRS interviews, the interviews could be used to examine health before entering the caregiver role and describe how health evolves over the course of the transition into and potentially out of caregiving. Comparisons could be made with those who have not taken on a caregiving role, and properly account for pre-caregiving differences in health through the use of the detailed HRS health measures. Such a data collection effort has the potential to overcome the usual limitations with cross-sectional or prospective studies of being unable to control in its sample for pre-caregiving differences between caregivers and non-caregivers.

### **3. Intervention Studies**

A third area of future scientific inquiry is to examine interventions aimed at improving the health and quality of life of caregivers and care recipients. One such intervention is the MFP Rebalancing Demonstration. Building on the successes of the Cash and Counseling project, MFP is authorized by the Deficit Reduction Act of 2005, and is the latest federal initiative to help states reduce their reliance on institutional care for people needing long-term care, and expand community-based options for elderly people, individuals with developmental disabilities, children with extensive health and medical needs, and those with mental illness. With appropriations of \$1.75 billion over five years, it is the largest demonstration program in the history of Medicaid.

States are expected to use these new funds to achieve two objectives. First, state Medicaid agencies will develop systems and services to help people living in nursing facilities and intermediate care facilities for the mentally retarded (ICFs-MR) who want to move back to home or community-based settings. Settings include not only nursing homes, but also acute and chronic disease hospitals, mental health facilities, assisted living residences, and residential care homes. States will use the money that would have been spent on an individual's institutional care to cover costs associated with transitioning back to the community over a one-year period. Second, states will increase efforts to shift Medicaid long-term care spending permanently toward community-based care and services.

In conjunction with formal supports, a huge emphasis of MFP is the inclusion of informal caregivers who will serve in both paid (when allowed by state regulations) and unpaid roles (typical). Transition and reentry into the community are difficult, and prior research demonstrates that the most successful transitions occur when there are one or more informal caregivers present to share and assist with care coordination. However, often it is caregiver burnout that initially results in institutional placement.

States that have developed nursing facility transition programs have found lack of affordable housing with supportive services to be one of their biggest challenges. In addition, some people enter nursing homes, or fail to leave them, because they do not know about available community-based supports, or because programs to support them in the community are insufficient. For example, capacity is limited and waiting lists are long in many state Medicaid home and community-based waiver programs. In some states, Medicaid eligibility rules remain biased in favor of nursing facility care, and Medicaid budgeting practices make it hard to shift funds to community-based options.

CMS contracted with MPR to conduct a comprehensive five-year evaluation. The research will address how state long-term care systems change to support the transition of people from institutions to the community, whether the changes are successful and sustainable, and to what extent MFP helps change state long-term care spending. MPR's evaluation also will assess the effects of MFP on Medicaid beneficiaries' health and quality of life, and identify those characteristics of individuals and state programs strongly associated with success. As in the Cash and Counseling demonstration, the impact of MFP on family caregivers also will be assessed. There may be opportunities for CDC to collaborate on this effort, and to improve the state of the science on the public health effects of providing care to individuals with disabilities and chronic diseases.



## V. SUMMARY AND CONCLUSION

The health effects of providing unpaid care to people with a disability or chronic disease is an important public health issue, and the need for a public health surveillance system for caregivers has been recognized by *Healthy People 2010*, a comprehensive, nationwide health promotion and disease prevention agenda managed by the HHS. CDC is playing an important role in developing effective surveillance strategies for monitoring caregiver health and its complex relationship to recipient well-being. As part of its effort, the CDC awarded a contract to MPR to (1) develop a database that identifies survey and research instruments that describe the caregiving experience, and (2) complete a report that documents the current state of knowledge on the health effects of caregiving. In this report, we summarize the process used to develop the caregiver database by describing: the key elements of a public health surveillance system for caregivers, the design and organization of the caregiver surveillance database we developed, the strengths and limitations of existing surveillance instruments, and areas for future scientific inquiry.

The next report will describe the current state of knowledge on the health effects of caregiving. To date, the majority of caregiving studies appear in the gerontology literature base and focus heavily on dementia care. While this domain does encompass the majority of caregiving scenarios, it fails to acknowledge and document the vast caregiving world that includes, children, adults, grandparents, physical and intellectual disabilities, heart disease and cancer, ventilator and diabetes care, along with a host of other situations. The intent of the second report is to provide a targeted overview of key literature addressing the impact of caregiving on health across different caregiving experiences. Together with the caregiver surveillance database, the project as a whole will provide the CDC with a strong foundation to build a state-of-the-art surveillance system and develop public health interventions that improve the lives of caregivers and the persons with disabilities and chronic diseases that rely on them.



## REFERENCES

- Arno, Peter S., Carol Levine, and Margaret M. Memmott. "The Economic Value of Informal Caregiving." *Health Affairs*, vol. 18, no. 2, 1999, pp. 182–188.
- Arno, Peter S. "Economic Value of Caregiving: 2004." Paper presented at the Care Coordination & the Caregiver Forum, Department of Veteran Affairs, National Institutes of Health, Bethesda MD, January 25-27, 2006.
- Benjamin, A.E., and Ruth Matthias. "Work-Life Differences and Outcomes for Agency and Consumer-Directed Home-Care Workers." *The Gerontologist*, vol. 44, no. 4, August 2004, pp. 479-488.
- Centers for Disease Control and Prevention. BRFSS Historical Question Results (related to Care Giving). <http://apps.nccd.cdc.gov/brfssQuest/ResultsV.asp?StartPg=1&EndPg=10&TopicID=44&fromyr=Any&toyr=Any&Text=&Join=AND&SUBMIT1=+Go+>. Accessed on November 4, 2007.
- Centers for Disease Control and Prevention. "Characteristics and Health of Caregivers and Care Recipients – North Carolina, 2005." *MMWR*, vol. 56, no. 21, June 1 2007, pp. 529-32.
- Centers for Disease Control and Prevention. "Updated Guidelines for Evaluating Public Health Surveillance Systems: Recommendations from the Guidelines Working Group." *MMWR*, vol. 50, no. RR-13, 2001, pp. 1-35.
- Chandler, M.A. "When a Kid Becomes the Caregiver." *The Washington Post*, August 25, 2007.
- Holtz-Eakin, Douglas. "The Cost and Financing of Long-Term Care Services." Testimony before the Subcommittee on Health, Committee on Energy and Commerce, U.S. House of Representatives, Washington, DC, April 27, 2005. Washington, DC: Congressional Budget Office, 2005.
- Crews, John E. "Neither Prepared Nor Rehearsed: Discovering the Health Effects of Caregiving." <http://www.va.gov/occ/Conferences/Docs/Crews-Handout.pdf>. Accessed on July 13, 2006.
- Davis, Kenneth L., Deborah B. Marin, Robert Kane, Donald Patrick, Elaine R. Peskind, Murray A. Raskind, Katherine L. Puder. "The Caregiver Activity Survey (CAS): Development and Validation of a New Measure for Caregivers of Persons with Alzheimer's Disease." *International Journal of Geriatric Psychiatry*, vol. 12, no.10, 1997, pp. 978-988.
- DesRoches, David and Susan Sprachman. "MEPS Caregiver Module Design: Literature Review." Princeton, NJ: Mathematica Policy Research, Inc., August 2003.
- Fedeyko, Holly J and Donald J. Lollar. "Classifying Disability Data: A Fresh Integrative Perspective." In *Research in Social Sciences and Disability: Using Survey Data to Study Disability*, edited by Altman, B.M., S.N. Barnartt, G.E. Hendershot, and S.A. Larson, vol. 3. Oxford: Elsevier, 2003, pp. 55-72.

- Feinberg, L. F., and S. L. Newman. "Preliminary Experiences of the States in Implementing the National Family Caregiver Support Program: A 50-State Study." *Journal of Aging Social Policy*, vol. 18, no. 3-4, 2006, pp. 95-113.
- Flanagan, Susan. "An Inventory of Consumer-Directed Support Service Programs: Overview of Key Program Characteristics." Paper presented at the Annual Meeting of the Cash and Counseling Demonstration and Evaluation, Arlington, VA, October 24, 2001.
- Foster, L., S.B. Dale, and R. Brown. "How Caregivers and Workers Fared in Cash and Counseling." *Health Services Research*, vol. 42, no. 1. pt. 2, 2007, pp.510-532.
- Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "The Effects of Cash and Counseling on the Primary Informal Caregivers of Children with Developmental Disabilities." Princeton, NJ: Mathematica Policy Research, Inc., April 2005.
- Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus. "How Cash and Counseling Affects Informal Caregivers: Findings from Arkansas, Florida, and New Jersey." Princeton, NJ: Mathematica Policy Research, Inc., July 2005.
- Lefley, Harriet P. "Synthesizing the Family Caregiving Studies: Implications for Service Planning, Social Policy, and Further Research." *Family Relations*, vol. 46, no. 4: Family Caregiving for Persons with Disabilities, October 1997, pp. 443-450.
- Lee, Sunghee, Nancy A. Mathiwetz, and Roger Tourangeau. "Measuring Disability in Surveys: Consistency over Time and Across Respondents." *Journal of Official Statistics*, vol. 23, no. 2, 2007, pp. 163-184.
- Lewin Group. *The National Family Caregiver Support Program: Resource Guide*. Falls Church, VA: The Lewin Group, 2002. [http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/resources/nfcsp\\_resources\\_guide.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/resources/nfcsp_resources_guide.asp). Accessed on November 4, 2007.
- Lyons, K.S., H.S. Zarit, A.G. Sayer, and C.J. Whitlatch. "Caregiving as a Dyadic Process: Perspectives from Caregiver and Care Receiver." *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, vol. 57, no. 3, 2002, pp. 195-204.
- McCarron, M., M. Gill, B. Lawlor, and C. Beagly. "A Pilot Study of the Reliability and Validity of the Caregiver Activity Survey - Intellectual Disability (CAS-ID)." *Journal of Intellectual Disability Research*, vol. 46, no. 8, 2002, pp. 605-612.
- National Alliance for Caregiving and AARP. "Caregiving in the U.S. 2004. " [www.caregiving.org/data/04finalreport.pdf](http://www.caregiving.org/data/04finalreport.pdf). Accessed July 7, 2006.
- National Family Caregivers Association (NFCA). *Caregiver Survey-2000*. Kensington, MD: NFCA, 2000.
- Pinquart, M., and S. Sorensen. "Correlates of Physical Health of Informal Caregivers: A Meta-Analysis." *Journals of Gerontology: Series B, Psychological Sciences and Social Sciences*, vol. 62, no. 2, 2007, p.126-137.

- Schultz, Richard J., Jason Newson, Maurice Mittelmark, Lynda Burton, C. Hirsch, and S. Jackson. "Health Effects of Caregiving: The Caregiver Health Effects Study." *Annals of Behavioral Medicine*, vol. 19, 1997, pp.101-109.
- Schulz, Richard J., and Scott R. Beach. "Caregiving as a Risk Factor for Mortality The Caregiver Health Effects Study." *Journal of the American Medical Association*, vol. 282, 1999, pp. 2215-2219.
- Schultz, Richard. "Health Effects of Caregiving." PowerPoint presentation presented at CDC Advancing the Public Health of Caregiving Conference, October 4, 2007.
- Schwartz, Lisa, and Krisztina Marton. "Measuring Informal Caregiver Time." Princeton, NJ: Mathematica Policy Research, Inc., 2006.
- Spillman, Brenda C., and Sharon K. Long. "Does High Caregiver Stress Lead to Nursing Home Entry?" Washington, DC: U.S. Department of Health and Human Services, Assistant Secretary of Planning and Evaluation, 2007.
- Talley, Ronda C., and John E. Crews. "Framing the Public Health of Caregiving." *American Journal Public Health*, vol. 97, 2007, pp. 224-228.
- U.S. Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. Washington, DC: U.S. Government Printing Office, November 2000.
- Vitaliano, Peter P., James M. Scanlon, and Jianging Zhang. "Is Caregiving Hazardous to One's Physical Health? A Meta-Analysis." *Psychological Bulletin*, vol. 129, no. 6, 2003.
- Vitaliano, Peter P., Heather M. Young, and Jianping Zhang. "Is Caregiving a Risk Factor for Illness?" *Current Directions in Psychological Science*, vol. 13, no. 1, 2004, pp. 13-16.
- Wolf, D.A., K. Hunt, J. Knickman. "Perspectives on the Recent Decline in Disability at Older Ages." *Milbank Quarterly*, vol. 83, no. 3, 2005, pp. 365-95.
- Wolf, Douglas. "Population Change: Friend or Foe of the Chronic-Care System?" *Health Affairs*, vol. 20, 2001, pp. 28-42.
- World Health Organization. *International Classification of Disability, Health and Functioning*. World Health Organization: Geneva, 2001.
- Yaffe, Kristine, Patrick Fox, Robert Newcomer, Laura Sands, Karla Lindquist, Kyle Dane, and Kenneth E. Covinsky. "Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia." *Journal of the American Medical Association*, vol. 287, 2002, pp. 2090-2097.
- Zarit S.H., K.E. Reever, J. Bach-Peterson. 1980. "Relatives of the Impaired Elderly: Correlates of Feelings of Burden." *Gerontologist*, vol. 20, 1980, pp. 649-55.



**APPENDIX A**

**INSTRUMENTS IDENTIFIED FOR INCLUSION INTO  
THE CAREGIVER DATABASE**



## **2007**

The Division of Developmental Disabilities Assessment. Washington State Department of Social and Health Services.

Canadian National Population Health Survey, Household Component. Statistics Canada.

## **2006**

Evercare Study of Caregivers in Decline. Mathew Greenwald & Associates, Evercare, National Alliance for Caregiving.

Informal Caregivers Survey. U.S. Department of Health and Human Services (HHS), Montana Aging Services Bureau.

Caregiver Self-Assessment Questionnaire. American Medical Association.

Minnesota Long Term Care Consultation Services Assessment Form. American Medical Association.

## **2005**

Young Caregivers in the U.S. and Child Caregivers: A First Look at an Unstudied Population. U.S. Administration on Aging, National Alliance for Caregiving, United Hospital Fund, Mathew Greenwald & Associates.

2005 North Carolina Behavioral Risk Factor Surveillance System Questionnaire. Centers for Disease Control and Prevention, North Carolina Department of Health and Human Services.

American Time Use Survey. Bureau of Labor Statistics.

Wisconsin Longitudinal Survey. National Science Foundation, National Institute on Aging.

Massachusetts Real Choice Functional Needs Assessment. Massachusetts Alzheimer's Disease Research Center, University of Massachusetts Center for Health Policy and Research.

## **2004**

National Long Term Care Survey, Informal Caregiver Survey. Duke University, National Institute on Aging.

The National Survey of Participants in Older American Act Programs. U.S. Administration on Aging.

Miles Away: The MetLife Study of Long-Distance Caregiving. Zogby International, MetLife Mature Market Institute, National Alliance for Caregiving.

Medicare Current Beneficiary Survey. Centers for Medicare & Medicaid Services, Westat.

Health and Retirement Study. University of Michigan, National Institute on Aging.

Health and Retirement Study: Aging Demographics and Memory Supplement. University of Michigan, National Institute on Aging.

POMP 5 Caregiver Program Support and Assessment Survey. U.S. Administration on Aging, Westat.

## **2003**

National Alliance for Caregiving - AARP National Caregiving Survey. MetLife Foundation, National Alliance for Caregiving, AARP.

National Survey of Child and Adolescent Well-Being (NSCAW) Current Caregiver Instrument Module. Office of Planning, Research & Evaluation, Administration for Children & Families, HHS, Research Triangle Institute, Walter R. MacDonald Associates, Caliber Associates.

POMP Survey of DOEA Caregivers 2003. HHS, Administration on Aging, Florida Department of Elder Affairs (DOEA).

## **2002**

The California Statewide Survey of Caregivers. Center for the Advanced Study of Aging Services, University of California Berkeley; Inland Empire Research Consortium, California State University.

Informal Caregivers: 2002 Outreach Survey. North Dakota State Data Center (NDSDC) at North Dakota State University (NDSU), the Child Development and Family Science Department at NDSU, the North Dakota Center for Rural Health at the University of North Dakota (UND), the North Dakota Department of Human Services (NDDHS) Aging Services Division.

## **2001**

Family Strain Questionnaire. S. Maugeri Foundation, Istituto Di Ricovero E Cura A Carattere Scientifico.

Survey of Self-Identified Family Caregivers. The National Family Caregivers Association, The Caregivers Advisory Panel.

Survey of Income and Program Participation: Wave 7 - Informal Caregiving Topical Module. U.S. Census Bureau

Resources for Enhancing Alzheimer's Caregiver Health. HHS, National Institutes of Health, National Institute on Aging, University of Pittsburgh Center for Social and Urban Research.

## **2000**

Cash and Counseling Caregiver Survey. HHS, Office of Disability, Aging and Long-Term Care Policy (DALTCP), University of Maryland, Mathematica Policy Research, Inc.

AARP Caregiver Identification Study. AARP, IRC Inc.

National Family Caregivers Association Caregiver Survey. National Family Caregivers Association, Bruskin Research.

Caregiver Well-Being Scale. School of Social Service, St. Louis University.

The C.A.R.E. Tool. Health Transition Fund, Health Canada, Mount St. Vincent University Institute of Family Studies and Gerontology.

United Kingdom Time Use Survey. Economic and Social Research Council; the Department of Culture, Media and Sport; the Department for Education and Skills; the Department of Health; the Department of Transport, Local Government and the Regions; and the Office for National Statistics.

Harvard School of Public Health/Robert Wood Johnson Foundation Caregivers Study. ICR, Inc., Harvard School of Public Health, Robert Wood Johnson Foundation.

The National Informal Caregiver Survey Research Study. Center for Home Care and Policy Research, Visiting Nurse Service of New York, the United Hospital Fund, Harvard School of Public Health, and The Henry J. Kaiser Family Foundation.

## **1999**

Caregiver Activity Survey-Intellectual Disability (CAS-ID). Health Research Board, Trinity Centre for Health Science at St. James Hospital.

The Metlife Juggling Act. The National Alliance for Caregiving (NAC), The National Center on Women and Aging at Brandeis University, Metlife Mature Market Institute.

Caregiver Quality of Life Index Cancer (CQOLC) Scale. University of South Florida. H. Lee Moffitt Cancer Center.

New Zealand Time Use Survey. Statistics New Zealand, Ministry of Women's Affairs.

## **1998**

Medical Expenditure Panel Survey (MEPS): 1997 and 1998 Caregiver Supplements. Westat, National Opinion Research Center, Agency for Healthcare Research and Quality.

Caregiving Across the Life Cycle: Caregiver Member Survey. National Family Caregivers Association, Fortis Long Term Care.

The Commonwealth Fund 1998 Survey of Women's Health. The Commonwealth Fund, Louis Harris and Associates, Inc.

Long Term Care from the Caregiver's Perspective. Harvard School of Public Health, National Opinion Research Center, Henry J. Kaiser Family Foundation, Visiting Nurse Service of New York, the United Hospital Fund.

National Longitudinal Caregiver Study. Department of Veterans Affairs, Duke University.

Caregiver Health Effects Study. National Institute for Mental Health.

Canadian General Social Survey (Cycle 12 -Time Use Survey). Statistics Canada.

Survey of Income and Program Participation, Wave 7, Home Health Care Topic Module. U.S. Census Bureau.

## **1997**

Comprehensive Options Assessment Form. Pennsylvania Department of Aging.

Caregiver Activity Survey (CAS). Mount Sinai School of Medicine.

Australian Time Use Survey. Australian Bureau of Statistics.

National Family Caregiver Survey. National Alliance for Caregiving, AARP.

## **1996**

Canadian Study of Health and Aging, Caregiver Health Interview. Health Canada.

Canadian General Social Survey, Cycle 11, Social and Community Support. Statistics Canada.

## **1995**

National Health Interview Survey 1995 Disability Followback Survey, Adult's Questionnaire, Phase II. National Center for Health Statistics.

National Health Interview Survey 1995 Disability Followback Survey, Child's Questionnaire, Phase II. National Center for Health Statistics.

National Health Interview Survey 1995 Disability Followback Survey, Supplement on Aging (SOA) Questionnaire, Phase II. National Center for Health Statistics.

## **1994**

National Health Interview Survey 1994 Supplement Disability, Phase I. National Center for Health Statistics.

National Survey of Families and Households. University of Wisconsin-Madison, National Institute of Child Health and Human Development, National Institute on Aging.

**1993**

Panel Study of Income Dynamics, Health Care Burden Supplement. National Institute of Child Health and Human Development, University of Michigan.

**1991**

New Beneficiary Survey. Social Security Administration, Temple University.

Screen for Caregiver Burden. University of Washington.

**1990**

Longitudinal Survey of Aging. National Center for Health Statistics, National Institute on Aging.

Caregiver Activities Time Survey. Hoechst Marion Roussel Pharmaceuticals.

**1983**

National Long Term Care Channeling Demonstration, Caregiver Instrument. Mathematica Policy Research, Inc., HHS.