U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

DISABILITY AND CARE NEEDS OF OLDER AMERICANS:

AN ANALYSIS OF THE 2011 NATIONAL HEALTH AND AGING TRENDS STUDY

April 2014

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TABLE OF CONTENTS

ACRONYMS iii

EXECUTIVE SUMMARY iv

INTRODUCTION 1

DATA OVERVIEW: THE NATIONAL HEALTH AND AGING TRENDS STUDY 3
- Activity Limitations and Assistance 6
- Care Resources Available to Older Adults with Activity Limitations 10

SUMMARY AND IMPLICATIONS 16

REFERENCES 19

APPENDICES
- APPENDIX I. Construction of Activity Limitation Measures 22
- APPENDIX II. Imputation of Paid and Unpaid Hours 23

LIST OF TABLES

TABLE 1. Percentage and Number of the 65 and Older Population with Self-Care, Mobility, and Household Activity Limitations 7

TABLE 2. Percentage of the 65 and Older Population with Self-Care, Mobility, and Household Activity Limitations: By Five-Year Age Groups 7

TABLE 3. Types of Assistance Received by Older Americans 8

TABLE 4. Characteristics of the Population Ages 65 and Older, by Level of Assistance 9

TABLE 5. Potential and Actual Care Networks for the Non-Nursing Home Population Ages 65 and Older, by Level of Assistance 10

TABLE 6. Percentage of Older Adults Receiving Paid and Unpaid Help in the Last Month and Mean Non-Staff Hours Among those Receiving Assistance: By Level of Assistance 11

TABLE 7. Support Services Available and Used by Older Adults in Supportive Care Settings 12

TABLE 8. Potential and Actual Care Networks for the Non-Nursing Home Population Ages 65 and Older Receiving Assistance, by Residential Setting 13

TABLE 9. Percentage of Older Adults Receiving Non-Staff Paid and Unpaid Help in the Last Month and Mean Hours Among those Receiving Assistance: By Residential Setting 13

TABLE 10. Percentage of the 65 and Older Non-Nursing Home Population with Adverse Consequences in the Last Month Related to Unmet Need 14

TABLE 11. Percentage of Older Adults with Difficulty or Receiving Help Who Report an Adverse Consequence Related to Unmet Need: By Level and Type of Assistance 15

ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ADL	Activity of Daily Living
IADL	Instrumental Activity of Daily Living
MCBS	Medicare Current Beneficiary Survey
NHATS	National Health and Aging Trends Study
NLTCS	National Long-Term Care Survey

EXECUTIVE SUMMARY

The economic cost of dependency at older ages is large and projected to grow rapidly as the number of older adults increases in the coming decades, and reduced well-being for individuals facing loss of functioning and their families, who provide the bulk of uncompensated care, also is an important societal concern. The purpose of this report is to describe disability and care needs of the United States population over the age of 65 using baseline (2011) measures from the National Health and Aging Trends Study, a new study designed to support understanding of both trends and trajectories in health and disability in later life. To provide a context for framing policy discussions of disability and care needs of older adults, we investigate two overarching topics: (a) the extent of activity limitations and use of assistance by older adults; and (b) care resources available to and used by older adults and the extent of unmet need in the population with care needs.

This report shows that late-life care needs are significant--nearly one-half of all adults in the United States over age 65, or 18 million people, have difficulty or receive help with daily activities. (This is for the total population over age 65, but disability increases with age. The percentage is lower for those aged 65-75 and higher for those over age 85.) At the same time, potential care networks among those receiving help are substantial--nearly 98% of older adults receiving help with daily activities have at least one close family member, household member, or close friend--and on average most older adults have four potential informal network members. Moreover, levels of informal assistance, primarily from family caregivers, are substantial not only for older adults in the community but also for those living in assisted living and other supportive care settings. Nearly all of those receiving help (irrespective of setting) receive informal care, and about three in ten receive some paid care. Those receiving assistance from paid, non-staff caregivers have especially high risk for adverse consequences related to unmet needs--nearly 60% had an adverse consequence in the last month.

We also find a substantial proportion of the population--7% or nearly 3 million--receiving assistance with three or more self-care or mobility activities in settings other than nursing homes, exceeding the level of need typically associated with eligibility for benefits under either private insurance or public program eligibility. A disproportionate share of older persons at this level of assistance is in the lowest income quartile. Although publicly and privately paid care continues to be an important source of assistance to older adults with extensive needs, the higher level of adverse consequences linked to unmet need among those receiving paid care warrants further investigation. As individual preferences and public programs continue to support the shift of the locus of long-term care from nursing homes to the community and alternative residential care settings, a better understanding of unmet need can inform policies to promote safety and maximized functioning in the community and the well-being of older adults and their families.

INTRODUCTION

The economic cost of dependency and underlying medical conditions at older ages are large and projected to grow rapidly as the number of older adults continues to increase in the coming decades (Johnson & Wiener 2006). In addition, reduced well-being for individuals facing loss of functioning and for their families, who provide the bulk of uncompensated care, are important societal concerns. A number of ongoing trends make in-depth study of disability and care arrangements critically important.

First, disability trends continue to change. Previous national studies yield a wide range of activity limitation estimates for the older population, ranging from 13%-32% depending on definition and source (Freedman et al. 2013). For most definitions, during the 1980s and 1990s, the percentage of older adults with activity limitations fell (Freedman et al. 2004; Spillman 2012; Wolf & Knickman 2005), although recent studies suggest the trend has leveled off and may reverse as the Baby Boom generation continues to age (Freedman et al. 2013, Lin et al. 2012, Kaye et al. 2013). Some have suggested increases in obesity and a slowdown of gains from education as reasons to be pessimistic about a continued downward trajectory (Sturm et al. 2004; Freedman & Martin 1999). On the other hand, studies suggest the use of assistive devices has increased among older adults (Freedman et al. 2006; Spillman 2005), potentially alleviating the need for assistance for some older adults (Agree et al. 2005; Allen et al. 2001).

A second major set of trends relate to families of older adults. The family has long been the major provider of care to older adults, but the number of potential family caregivers has been declining. In addition, societal trends toward delayed childbearing and increased female labor-force participation continue to place competing demands on potential family caregivers' time. Spillman & Pezzin (2000), for instance, found that increasing demands confronting family caregivers and higher disability levels among those receiving care contributed to growing reliance on paid caregivers between 1984 and 1994. A subsequent analysis found, however, that use of paid care declined dramatically between 1994 and 1999, after the transition to prospective payment for Medicare home health, while family caregiving remained stable (Spillman & Black 2005). As a result, the proportion relying only on informal caregivers increased. Certainly, the potential and actual caregiving landscape, how paid arrangements are evolving, and how families complement residential care arrangements are important to investigate as the Baby Boom enters late life.

A third important development relates to shifts in residential care settings for older adults, which continue to increase as long-term nursing home use continues to decline (Spillman, Liu & McGuilliard 2002; Spillman & Black 2006). The 2010 National Survey of Residential Care Facilities, a provider-based survey of state-regulated residential care facilities with four or more beds and primarily serving adults indicates nearly

1 million beds serving about 650,000 residents age 65 or older (Park-Lee et al. 2011; Caffrey et al. 2012). Using a more inclusive definition of places confirmed by a facility respondent, National Health and Aging Trends Study (NHATS) identified 2 million older adults living in either assisted or independent living within a residential care setting in 2011 (Freedman & Spillman 2013). Relatively little is known about the service profile available to and used by older adults in these settings or the extent to which informal and formal caregivers from outside the place provide assistance (in addition to services provided by paid staff).

Finally, concerns about whether the needs of older adults with limitations are being appropriately met are not new, but as settings diversify and concern about availability of family caregivers increase, interest in this topic has re-emerged. About one in five older people with activity of daily living (ADL) limitations report that they need more help than they receive (Desai et al. 2001; Spillman 2013). Among the adverse consequences of reported unmet need are falls, burns, inadequate nutrition, incontinence, missing physician appointments, depression, hospitalization, and emergency room use (Allen & Mor 1997; Desai et al. 2001; LaPlante et al. 2004; Komisar et al. 2005; Sands et al. 2006). As disability and care availability continue to shift, it is important to track how older adults' care needs are currently being met.

Much of what we understand about disability at the national level is from the 1982-2004 National Long-Term Care Survey (NLTCS). The NLTCS screened older adults who were eligible for Medicare to identify those with suspected disability and followed up with an in-depth in-person interview, with a focus on ADLs and instrumental activities of daily living (IADLs). In 2011, the National Institute on Aging launched the successor to the NLTCS, which was NHATS. Like NLTCS, NHATS includes older individuals irrespective of where they live (i.e., in the community, residential care settings, or nursing homes) and follows sample members over time. However, NHATS eliminated screening, updated content areas, and re-engineered how functional information is collected with the goal of capturing a more nuanced picture of late-life functioning and disability.

The purpose of this report is to describe disability and care needs of the older population using NHATS' baseline (2011) measures. To provide a context for framing policy discussions of disability and care needs of older adults, we investigate two overarching topics. (1) ***Activity Limitations and Assistance***. We begin by estimating the number of older adults with activity limitations and the distribution of the population by level of assistance and the demographic profile of older adults who receive assistance with activities. (2) ***Care Resources for Older Adults with Limitations and Unmet Needs***. Next, we describe the size and composition of the potential and actual care networks of older adults and the number of hours of care received by level of assistance. For older adults living in residential care settings, we present estimates of the availability and use of various services, including non-staff paid and unpaid help. Finally, we provide estimates of unmet need, overall and by levels of assistance, composition of the care network, and residential setting.

DATA OVERVIEW: THE NATIONAL HEALTH AND AGING TRENDS STUDY

NHATS has been designed to capture a detailed picture of how functioning in daily life changes with age (Freedman 2009). The validated protocol (Freedman et al. 2011) probes whether and how activities are performed in the prior month along with information on types of help received with personal assistance, household help, and other common tasks such as transportation assistance or being accompanied to doctor appointments. NHATS also offers detail on the service environments in which older adults live and measures of unmet needs, defined as having experienced specific adverse consequences associated with particular activities for lack of help.

Sample. The first round of NHATS took place in 2011 with a national sample of older adults drawn from the Medicare enrollment file (Montaquila et al. 2012a). African Americans and respondents at older ages were oversampled. In all, 8245 interviews were completed. Respondents living in the community and residential care settings other than nursing homes received a two-hour in-person interview that included self-reports and performance-based measures of disability. For respondents in residential care settings including nursing homes a facility respondent provided information about services available and the type of place. For the prevalence of disability and characteristics of the population with and without disabilities, we draw upon the 8077 respondents who either had a completed sample person interview (N=7609) or were residing in a nursing home (N=468). Because only facility interviews were conducted for those living in nursing homes, they are assumed to be dependent in at least one activity for the purpose of disability prevalence estimates and excluded from analyses of care arrangements and unmet needs.

Key Measures for this Report. We constructed several key measures for this report reflecting activity limitations, assistance, the potential and actual care network, hours of care, and residential care and services.

- *Activity limitations*. We constructed a three-category measure reflecting limitations in self-care, mobility, or household-related activities. Self-care activities include bathing, dressing, eating, and toileting. Mobility-related activities include getting out of bed, getting around inside one's home or building, and leaving one's home or building. Taken together, self-care and mobility activities correspond to ADLs. Household activities include laundry, hot meals, shopping for personal items, paying bills/banking, handling medications, corresponding to IADLs. Three hierarchical categories were created summarizing how activities are carried out: (1) without difficulty and without assistance from another person; (2) with difficulty when carried out alone and with whatever accommodations the individual has made; and (3) with assistance

from another person, which for household activities must be for health-related or functioning-related reasons. See Appendix I for further details.

- *Assistance*. We define four levels of assistance. All respondents living in a nursing home (confirmed by a staff person at the place) are assumed to be receiving assistance and are treated as a distinct category. Individuals receiving assistance with 3+ self-care or mobility activities are considered separately from those receiving assistance with 1-2 self-care or mobility activities. A fourth category consists of individuals who receive assistance with household activities for health or functioning reasons. We sum these first four groups to form the population receiving help with any self-care, mobility or household activities (analogous to any ADL or IADL assistance).

- *Potential care network*. We counted as potential informal network members all living children (in and outside the household), spouses/partners, other household members, and social network members (up to five people the sample person feels he/she can talk to about important things) identified by the respondent. There is no way to definitively identify an individual's potential informal care network, but our measure captures the types of individuals most commonly involved in care. Our approach may overstate actual availability of informal care if needed because it does not take into account willingness or ability to provide care or geographic proximity. On the other hand, the approach is conservative in its exclusion of non-resident siblings and step-children (the latter group less likely to be involved in care of their step-parents than biologic children; Pezzin & Schone 1999).

- *Actual care network*. Actual networks include those who helped in the last month with self-care or mobility tasks, household tasks, or selected other tasks (driving, seeing the doctor, less common money matters, and health insurance matters). If the respondent lived in a residential care setting, staff members were not counted, but were considered a source of paid help. Other non-staff paid and unpaid persons assisting respondents in residential care were counted individually. In this report we focus on actual networks for sample persons who received help in the last month with any self-care or mobility task or any household task for health or functioning reasons.

- *Supportive care environments and services*. NHATS distinguishes among care settings that are nursing homes, supportive care settings other than nursing homes, and all other community settings. Nursing home and other supportive care places were confirmed through an interview with a facility staff member. Such an interview was triggered by questions in the sample person interview about whether the place they lived offered group meals, bathing and dressing care, or had different levels of care the sample person could move to if he/she

needed care.[1] In cases where an interviewer conducted the facility interview first, the type of setting was first confirmed through the facility interview, and a sample person interview attempted if the respondent was found to be in a residential care setting other than a nursing home. Supportive care included the following place types (as reported by the facility respondent): adult family care homes, group homes, board and care homes, personal care homes, assisted living, the assisted living section of a multi-level place, independent living or an independent part of a multi-level place, and enriched housing (housing with services).

The sample person interview asked about whether particular services were available and, if so, if they were used in the last month. In addition, facility respondents were asked to indicate whether each service was offered at the sample person's level of care. Services included: meals, help with medications, help with bathing and dressing, laundry services, housekeeping services, transportation to medical care providers, transportation for shopping or leisure activities, recreational facilities, organized social events/activities. In this report we use facility reports of services available and sample person interview reports of services used.[2]

- *Hours of unpaid and paid care*. For older adults living outside the nursing home, NHATS provides estimates of hours of unpaid and paid care in the last month provided by each caregiver, excepting hours provided by staff at residential care settings.

  Hours were missing for one or more caregivers for 12% of sample persons receiving help. For these sample persons receiving help who were missing hours we imputed paid and/or unpaid hours for each caregiver based on the NHATS respondent's age, sex, level of assistance, and for informal caregivers their relationship to the sample person and, then summed across caregivers to create total hours. See Appendix II for details.

  We include all hours provided by an individual identified as a (non-staff) caregiver for the activities identified earlier, including self-care, mobility, household tasks, driving, seeing the doctor, and help with insurance matters and other less common financial tasks. NHATS respondents report only total hours provided by each caregiver identified, so that hours cannot be parsed into those devoted to particular activities.

[1] The services trigger was used for people living in multi-unit buildings; people living in other structures (e.g., free standing or attached homes or mobile homes) were instead handed a list of places and asked if the place they lived was a private residence or one of the other places on the card (e.g., board and care facility, assisted living facility or continuing care retirement community, or religious group quarters).

[2] In cases where a facility questionnaire was not completed (N=59) or information on specific services missing (N=9 to N=11 cases, depending on the service), respondent reports on services available were used to fill in missing information.

- *Adverse consequences associated with unmet need*. Finally, among the older population who report difficulty or getting help, NHATS asked about adverse consequences linked to unmet need for assistance with self-care, mobility, and household activities (Allen & Mor 2007; Komisar et al. 2005). For each activity, sample persons who reported difficulty doing the activity by themselves were asked, whether there was ever a time in the last month when they had a particular consequence because it was too difficult to do the activity by themselves. Respondents who reported receiving help all the time or not doing the activity in the last month were asked whether the consequence occurred because there was no one there to help. Consequences included: having to stay in bed, not being able to go places in their home or building, not being able to leave their home or building, going without eating, going without showering/bathing/washing up, accidentally wetting or soiling their clothes, going without getting dressed, going without clean clothes, going without groceries or personal items, going without a hot meal, going without handling bills and banking matters, and making a mistake in taking their medications. We created three summary measures indicating: an adverse consequence for mobility/self-care, for household care, and for either type of activity.

Weighted Percentages and Population Estimates. For all estimates we use analytic weights that take into account differential probabilities of selection and non-response (Montaquila et al. 2012b). For population estimates, we further adjust totals to the age distribution of the sample frame.

Activity Limitations and Assistance

Activity Limitations. Table 1 shows the percentage and number of older adults with self-care or mobility limitations, household activity limitations, and either type of limitation. Altogether, 18% report difficulty but not receiving assistance with self-care and mobility limitations and another one in five (20.1%) receives assistance from another person. With respect to household activities, 12% report difficulty but not receiving assistance, and one in four (24.8%) have received assistance related to their health or functioning in the last month.

The bottom panel combines self-care/mobility and household activity limitations. Nearly 20%--7.5 million--report difficulty with at least one activity but no assistance, and another 28.7%--nearly 11 million--received assistance with at least one activity in the last month.

TABLE 1. Percentage and Number of the 65 and Older Population with Self-Care, Mobility, and Household Activity Limitations		
	%	Number (millions)
Self-care and mobility limitations[a]		
No difficulty and no help	61.5	23.4
Difficulty, but no help	18.3	7.0
Help	20.1	7.7
Household activity limitations[b]		
No difficulty and no help	62.8	23.9
Difficulty, but no help	12.4	4.7
Help for health or functioning reasons	24.8	9.5
Any limitations		
No difficulty and no help	51.7	19.8
Difficulty, but no help	19.6	7.5
Help	28.7	10.9

SOURCE: 2011 NHATS; N=8077.
NOTES:
a. Bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.
b. Laundry, hot meals, shopping for personal items, paying bills/banking, or handling medications.

Table 2 shows these prevalences by five-year age groups. The percentage reporting difficulty with self-care or mobility activities increase from 65-69 to 80-84 and then declines through ages 90+ whereas the percentage getting help with such activities increases from 11% of 65-69 year olds to nearly 62% of 90+ year olds. With respect to household activities, reports of difficulty but no help increase through age 70-79 (peaking at 13.6%) before declining to under 6% for those 90+, as the proportion receiving help increases.

TABLE 2. Percentage of the 65 and Older Population with Self-Care, Mobility, and Household Activity Limitations: By Five-Year Age Groups						
	65-69	70-74	75-79	80-84	85-89	90+
Self-care and mobility limitations[a,b]						
Difficulty, but no help	17.1	17.7	19.1	21.8	19.1	14.6
Help	11.0	12.9	18.1	26.1	41.8	61.7
Household activity limitations[c]						
Difficulty, but no help	12.2	13.6	13.6	12.5	10.8	5.7
Help for health or functioning reasons	12.3	14.6	23.9	34.2	54.1	73.1
Any limitations						
Difficulty, but no help	19.6	20.7	21.0	21.2	16.5	9.3
Help	15.8	18.8	27.5	38.2	58.5	76.0
Population (in millions)	11.6	8.9	6.9	5.4	3.4	1.9
Unweighted n	1417	1610	1569	1590	1067	824

SOURCE: 2011 NHATS; N=8077.
NOTES:
a. Bathing, dressing, eating, toileting.
b. Getting out of bed, getting around inside one's home or building, or leaving one's home or building.
c. Laundry, hot meals, shopping for personal items, paying bills/banking, handling medications.

When all activities are considered (bottom panel), the proportion with difficulty but receiving no help is fairly stable at about 20% until age 85, at which point the proportion

receiving help begins to rise more rapidly. The percentage receiving help with at least one activity rises from less than 16% of adults ages 65-69 to more than 75% of those age 90 and older.

Assistance with Activities. Table 3 presents a more detailed hierarchical measure that further describes the distribution of the population by type of assistance received. Overall, 28.7% or about 11 million older adults received help in the last month. The majority of this group received assistance with self-care or mobility-related activities or resided in a nursing home (7.7 million) and the remaining 3.3 million receive assistance only with household activities.

TABLE 3. Types of Assistance Received by Older Americans

Assistance Level	%	Number (millions)
Nursing home	2.9	1.1
3+ Self-care or mobility activities[a]	7.0	2.7
1-2 Self-care or mobility activities[a]	10.3	3.9
Household activities[b]	8.5	3.3
Any self-care, mobility, or household activity	**28.7**	**10.9**
No assistance	**71.3**	**27.2**

SOURCE: 2011 NHATS; N=8077.

NOTES:

a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.

b. Assistance for health or functioning reasons only with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care or mobility activities).

Table 4 shows the characteristics of the population receiving assistance, by level of assistance. The first column shows percentages for the nursing home population (representing 2.9% of the population) and all other columns include only those living outside of nursing homes (the remaining 97.1%).

Women are a disproportionate share of the nursing home population and of those receiving assistance with self-care or household activities. Blacks and Hispanics are over-represented in self-care assistance categories, and Blacks are also over-represented among nursing home residents. Widowed individuals and those with low incomes are over-represented among those receiving assistance. Less than 2% of individuals receiving no assistance are living in supportive care settings other than nursing homes, compared with 13% of those receiving assistance with 1-2 self-care or mobility activities and nearly 17% of those receiving assistance with three or more such activities.

TABLE 4. Characteristics of the Population Ages 65 and Older, by Level of Assistance (%)

	Nursing Home Population	Non-Nursing Home Population					
		3+ Self-Care or Mobility Activities[a]	1-2 Self-Care or Mobility Activities[a]	Household Activities[b]	Any Self-Care, Mobility, or Household Activity[c]	No Assistance	Total, Non-Nursing Home
Gender							
Male	27.0	31.1	31.9	32.3	31.8	47.7	43.4
Female	73.0	68.9	68.1	67.7	68.2	52.3	56.6
Race							
White, non-Hispanic	79.6	71.0	74.9	78.4	75.0	82.6	80.5
Black, non-Hispanic	12.0	11.6	10.2	8.7	10.1	7.4	8.1
Other, non-Hispanic	4.0	5.0	3.9	4.0	4.2	4.8	4.6
Hispanic	4.4	12.4	11.1	8.9	10.7	5.3	6.7
Marital status							
Married/living with partner	---	42.1	47.0	40.7	43.6	61.9	57.0
Separated/divorced	---	8.7	11.4	12.9	11.1	12.7	12.2
Widowed	---	44.0	37.1	41.3	40.3	22.1	27.1
Never married	---	5.2	4.6	5.1	4.9	3.3	3.7
Income quartiles							
1st (lowest)	---	43.6	37.1	36.2	38.6	18.4	23.8
2nd	---	29.6	28.7	28.3	28.8	22.6	24.3
3rd	---	17.1	20.3	21.2	19.7	29.3	26.7
4th (highest)	---	9.7	13.9	14.3	12.9	29.7	25.2
Residence type							
Community	0.0	83.2	86.6	81.0	83.8	98.4	94.5
Supportive care setting other than nursing home	0.0	16.8	13.4	19.0	16.2	1.6	5.5
Nursing home	100.0	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Unweighted n	468	749	968	782	2499	5110	7609

SOURCE: 2011 NHATS.

NOTES:

a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.

b. Assistance for health or functioning reasons with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care, mobility, or household activities.

c. Assistance only with transportation, seeing the doctor, less frequent money matters, or health insurance matters, not necessarily related to health or functioning.

Care Resources Available to Older Adults with Activity Limitations

Potential informal networks and actual care networks of older adults living outside nursing homes are shown in Table 5. Only 2.5% of those receiving assistance and about 1.2% of those receiving no assistance had no informal network members. The mean size of the potential network is relatively stable across levels of care, approximately 4.0-4.1 across groups.

TABLE 5. Potential and Actual Care Networks for the Non-Nursing Home Population Ages 65 and Older, by Level of Assistance

	3+ Self-Care or Mobility Activities[a]	1-2 Self-Care or Mobility Activities[a]	Household Activities[b]	Any Self-Care, Mobility, or Household Activity	No Self-Care, Mobility, or Household Activity[c]
Potential informal care network					
Mean	4.1	4.1	4.0	4.0	4.0
% with none	2.7	2.9	1.9	2.5	1.2
1	7.9	5.8	7.5	6.9	6.7
2	13.4	16.7	15.7	15.5	12.2
3	19.6	19.5	20.4	19.8	22.2
4+	56.4	55.1	54.5	55.3	57.7
Actual network[d]					
Mean	2.6	2.1	1.8	2.2	1.1
0	1.7	1.7	3.9	2.4	20.6
1	24.2	35.8	39.1	33.7	53.9
2	30.1	30.3	35.9	32.1	18.9
3	20.9	18.5	15.3	18.1	5.0
4+	23.2	13.8	5.8	13.7	1.7
Unweighted n	749	968	782	2499	5110

SOURCE: 2011 NHATS; N=7609.

NOTES:

a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.

b. Assistance related to health or functioning with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care or mobility activities).

c. This group may be receiving paid or unpaid assistance with household and other tasks (e.g., transportation, getting to the doctor, less frequent money management tasks, and choosing health insurance) not necessarily related to health and functioning. Helpers for these tasks are shown in the lower panel under actual network.

d. Actual network in residential care counts only non-staff paid helpers and unpaid helpers. Staff in residential care are excluded from the counts.

Whereas 75% to more than 80% of all groups have three or more potential informal network members, about two-thirds of all who received assistance rely on only one or two actual caregivers. The size of the actual care network, including paid (non-staff) caregivers, also increases with the level of assistance. For instance, those who receive assistance with only household activities have 1.8 caregivers on average whereas those who received assistance with 3+ self-care or mobility activities have 2.6. (Note that nearly 80% of older adults with no activity limitations also report receiving assistance with household and other activities (for non-health or functioning reasons); persons who fall into this group receive help from on average one person.)

The majority of actual helpers to adults receiving assistance with any self-care, mobility, or household activity are members of the potential informal network, typically near relatives (not shown): children in and outside the household (42%),

spouses/partners (18%), other household members (8%) and other social network members (6%). The remaining 26% of helpers come from outside the potential network: 10% are paid and 16% unpaid. The most common type of "other" unpaid helpers are friends, followed by granddaughters, other non-relatives, and daughters-in-law.

Composition of Actual Network and Hours Received. Table 6 provides information on network composition and hours of non-staff care received by the older population outside of nursing homes, including those in supportive care settings. Among those receiving any help in the last month, 34.5% received paid help (including help from staff), 95.0% received unpaid help, and 29.5% received both types of assistance (Table 6).

TABLE 6. Percentage of Older Adults Receiving Paid and Unpaid Help in the Last Month and Mean Non-Staff Hours Among those Receiving Assistance: By Level of Assistance

	3+ Self-Care or Mobility Activities[a]	1-2 Self-Care or Mobility Activities[a]	Household Activities[b]	Any Self-Care, Mobility, or Household Activity
Any paid help	50.0	28.0	29.4	34.5
Any unpaid help	94.7	95.6	94.6	95.0
Paid help only	5.3	4.4	5.3	5.0
Unpaid help only	50.0	72.0	70.5	65.5
Both	44.7	23.6	24.1	29.5
Paid non-staff hours (mean)	69.9	13.7	4.5	25.9
Unpaid hours (mean)	252.8	118.1	85.0	143.8
Total hours (mean)	322.6	131.8	89.6	169.7
Unweighted n	749	968	782	2499

SOURCE: 2011 NHATS; N=2499.
NOTES:
a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.
b. Assistance related to health or functioning with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care or mobility activities).

The percentage receiving paid help varies by level of assistance, with those receiving assistance in three or more self-care or mobility activities receiving substantially more paid help than other groups receiving assistance (50.0% vs. 28%-29%). The receipt of unpaid help is nearly universal (94%-96%) across all levels of assistance, but the percentage relying solely on unpaid help is much higher for those receiving assistance only with household activities (70.5%) or 1-2 self-care (72.0%) activities than for those receiving assistance with three or more self-care or mobility activities (50.0%). Correspondingly, the percentage receiving a combination of paid and informal is highest (44.7%) for those at the most intense levels of assistance and is about one in four for other assistance groups.

Average paid, unpaid, and total non-staff hours all rise sharply with level of assistance. Older adults receiving assistance with 3+ self-care or mobility activities received an average 323 hours of help provided by non-staff caregivers over the last month: 70 hours of paid care and 253 hours of unpaid care. Older adults receiving assistance with 1-2 self-care or mobility activities received less than half that number of

hours--132 hours of care, 14 paid and 118 unpaid, and those adults receiving assistance only with household activities received on average 90 hours of help, nearly all unpaid.

In addition to non-staff assistance, those living in settings where supportive services are available (other than nursing homes) received staff-provided help with an array of activities, depending on the place. Table 7 shows the services available (for those in multi-level places, at the current level of care) and used in the last month. The most commonly *available* services were social activities (92%), meals (87%), and housekeeping services (79%). The services most commonly used by residents were meals (77%) and housekeeping (68%). Although other services were available to the majority of residents, fewer than 50% used transportation, laundry, medication, or personal care services or recreational facilities.

TABLE 7. Support Services Available and Used by Older Adults in Supportive Care Settings

Support Services	% with Service Available	% Used Service in the Last Month
Social activities	91.6	61.7
Meals	86.5	76.7
Housekeeping services	79.1	68.0
Van to shopping	75.4	26.0
Van service to the doctor	72.8	27.9
Laundry services	72.3	47.8
Help with medications	64.3	41.6
Recreation facilities	64.0	29.5
Help with bathing or dressing	62.6	30.2
SOURCE: 2011 NHATS; N=412.		

Potential and Actual Networks and Unmet Need: Supportive Care Settings versus Community. Table 8 shows the size of the potential and actual care networks of individuals receiving assistance with self-care, mobility, and household activities in supportive care settings (other than nursing homes) and community settings. The potential informal care network is slightly smaller in supportive settings than in the community, and a larger percentage of those in supportive care settings have no potential informal caregivers (8.7% vs. 1.3%). Excluding residential care staff, average actual network sizes are similar for those in supportive care settings and the community (1.7 vs. 2.3), but 12.5% of those in supportive care settings have only staff helpers (no non-staff helpers) in their networks.

TABLE 8. Potential and Actual Care Networks for the Non-Nursing Home Population Ages 65 and Older Receiving Assistance, by Residential Setting		
	Supportive Care Settings	**Community**
Potential informal care network		
Mean	2.9	4.2
% with none	8.7	1.3
1	12.4	5.9
2	22.7	14.1
3	20.5	19.7
4+	35.7	59.0
Actual Network[a]		
Mean	1.7	2.3
% with none	12.5	0.5
1	37.7	32.1
2	31.2	33.1
3	9.9	19.9
4+	8.7	14.9
Unweighted n	316	2183

SOURCE: 2011 NHATS; N=2499.
NOTE:
a. Actual network in supportive care settings counts only non-staff paid helpers and unpaid helpers. Staff in supportive care settings are excluded from the counts.

Table 9 shows the distribution of older adults receiving assistance by whether help received is paid or unpaid and mean hours in the last month, by setting.[3] The percentage receiving any non-staff paid help is only slightly smaller in supportive care settings than in the community (14.5% vs. 21.2%). The percentage receiving unpaid help is similar: 96.1% in care settings vs. 97.6% in the community. Only about one in ten in supportive care settings vs. nearly one in five in the community receives both paid and unpaid help. Average hours of non-staff paid help in the community are also twice those in supportive care settings (28.7 vs. 14.2 hours) and average unpaid hours are more than three times those in supportive settings (164.0 vs. 49.6 hours).

TABLE 9. Percentage of Older Adults Receiving Non-Staff Paid and Unpaid Help in the Last Month and Mean Hours Among those Receiving Assistance: By Residential Setting[a]		
	Supportive Care Settings	**Community**
Any non-staff paid help	14.5	21.2
Any unpaid help	96.1	97.6
Non-staff paid help only	3.9	2.4
Unpaid help only	85.5	78.8
Both	10.6	18.8
Paid non-staff hours (mean)	14.2	28.7
Unpaid hours (mean)	49.6	164.0
Total hours (mean)	63.7	192.6
Unweighted n	283	2174

SOURCE: 2011 NHATS; N=2457.
NOTE:
a. Excludes 42 cases receiving only staff care.

[3] Unlike Table 6, which included staff in the definition of paid help, here we exclude staff in order to highlight paid help from outside the facility.

Overall, 15% of the 65 and older population reported one or more adverse consequences related to unmet need (see Table 10). Focusing on the subset of older adults with care needs (either having difficulty with or receiving help with a self-care, mobility, or household activity), the figure increases to 32%. In other words, one out of every three older adults with basic needs experienced an adverse consequence in the last month linked to unmet need. The most common consequences were wetting or soiling clothes, staying inside, not going places inside one's home or building, and making mistakes with medicine.

TABLE 10. Percentage of the 65 and Older Non-Nursing Home Population with Adverse Consequences in the Last Month Related to Unmet Need

Activity	% with Adverse Consequence (N=7609)	% with Adverse Consequence Among Those with Difficulty or Receiving Help with Activity (N)
Wet or soiled clothes	3.8	43.4 (820)
Stayed inside	5.8	29.6 (1834)
Did not go places in home/building	4.8	26.0 (1680)
Made mistake taking medicine	3.3	19.9 (1482)
Went without bathing/showering/cleaning	2.0	12.9 (1473)
Had to stay in bed	2.3	11.5 (1698)
Went without a hot meal	1.9	9.5 (1844)
Went without getting dressed	1.3	7.5 (1625)
Went without groceries	1.4	6.3 (2138)
Went without paying bills	0.9	5.7 (1549)
Went without clean laundry	0.9	4.9 (1637)
Went without eating	0.3	3.7 (671)
Any consequence	**15.0**	**31.8 (4026)**

SOURCE: 2011 NHATS.

The percentage reporting adverse consequences increases markedly with levels of need (Table 11). Less than 15% of those with difficulty (but not receiving help) with self-care, mobility or household activities and nearly 25% of those receiving help with only household activities reported a consequence. Among those receiving assistance with self-care or mobility, rates were far higher. More than four in ten of those receiving help with 1-2 self-care or mobility activities and about seven in ten of those receiving help with three or more self-care or mobility activities reported at least one consequence in the last month. Adverse consequences were substantially higher among those receiving paid, non-staff help (58.2%) compared with those receiving any unpaid help (44.7%). Estimates for living in supportive care settings indicate only slightly higher rates of unmet than among community residents (35.0% vs. 31.4%).

TABLE 11. Percentage of Older Adults with Difficulty or Receiving Help Who Report an Adverse Consequence Related to Unmet Need: By Level and Type of Assistance			
	Adverse Consequence with:		
	Self-Care or Mobility	Household Activities	Either
Assistance with any self-care, mobility, or household activity	38.4	16.0	44.4
3+ Self-care or mobility activities[a]	71.7	18.9	73.7
1-2 Self-care or mobility activities[a]	34.8	15.7	40.7
Household activities only[b]	15.2	13.9	24.8
Difficulty but no help	7.0	9.9	14.8
Any paid non-staff help[c]	50.3	22.7	58.2
Any unpaid help[c]	38.1	16.0	44.7
Supportive care settings	28.2	11.1	35.0
Community	24.6	13.6	31.4
Total[c]	24.9	13.4	31.8

SOURCE: 2011 NHATS; N=4026.

NOTES:

a. Assistance with bathing, dressing, eating, toileting, getting out of bed, getting around inside one's home or building, or leaving one's home or building.

b. Assistance related to health or functioning with laundry, hot meals, shopping for personal items, paying bills/banking, handling medications (but not self-care or mobility activities).

c. Among those who have received help with self-care or mobility activities or household activities for health-related reasons.

SUMMARY AND IMPLICATIONS

Using the new NHATS, this report describes late-life disability and care needs for older adults (over age 65). We find that 18 million older adults--nearly half--have received help related to their health or functioning or had difficulty carrying out self-care, mobility, or household activities alone with whatever supports they have put into place during the last month.

The group receiving help with the most basic self-care and mobility activities represents over 7 million people. This figure corresponds to 20% of the population, which is substantially larger than previous estimates (Spillman 2011; Freedman et al. 2013). Indeed, the percentage reporting help with self-care or mobility is twice the size of the estimate from the 2004 NLTCS (10%) and the 2008 Medicare Current Beneficiary Survey (MCBS) (11%) (Freedman et al. 2013). Several measurement-related issues likely contribute to the higher estimates. For instance, we include going outside, which is not consistently included with self-care and mobility measures in other studies. Excluding going outside, the NHATS estimate would be 17.4%. NHATS's captures help received over a longer reference period--the last month rather than the one week used in the NLTCS. Finally, NHATS asks all sample members (except nursing home residents) whether they ever perform self-care and mobility activities, how they are carried out, and if they ever did them by themselves in the last month, and only then ask about whether they have difficulty when they perform each activity independently with whatever assistive devices they use. Other surveys use screening or skips that exclude some sample members from questions about assistance based on whether they acknowledge or perceive difficulty. For example, the NLTCS pre-screens and excludes sample members who do not perceive a "problem" with self-care or mobility activities, and the MCBS skips respondents around assistance questions if they report no difficulty with activities. Similar issues also pertain to household activities, but they are even more stark in the case of the NLTCS, which asks the reason for receiving help *only* if a respondent receives help and reports inability to do an activity. It is also possible that disability rates actually have increased since 2004 in the case of the NLTCS or 2008 in the case of the MCBS, but the numbers presented in this report should not be interpreted as trends given the distinct measurement approaches.

Very few older adults have no potential informal network members. The mean size of the potential network is approximately four per person (including spouses/partners, children, household members, and close friends)--the latter group has not typically been included in such potential network counts. Actual networks increase in size in proportion to intensity of assistance and are varied. This study confirmed that caregivers often are children and spouses/partners (60%), but also identified a role for other household members (8%) and other social network members (6%). The remaining helpers come from outside the potential network and include paid and other kinds of informal helpers (e.g., friends outside the social network, granddaughters, other

non-relatives, and daughters-in-law). About three in ten older adults who receive assistance have both paid and unpaid help; the percentage is even higher--45%--among those at the most intense levels of assistance (3+ self-care or mobility activities). Average paid, unpaid, and total hours also all rise sharply with level of assistance.

For the 2 million older adults living in supportive care settings (broadly defined), the most commonly used services were meals (77%) and housekeeping (68%). Hours of non-staff paid help are higher in community settings than residential settings with supportive services (29 vs. 14 hours per month) as are unpaid hours (164 vs. 50 hours per month). This latter finding suggests that residential care may substitute for both paid and unpaid sources of help.

Levels of adverse consequences suggestive of unmet need are high, particularly among those with greater levels of care. Overall, 32% of the 65 and older population with difficulty or receiving help with a self-care, mobility or household activities reported having at least one unmet need in the last month. The chances of having an adverse consequence because an activity was too difficult or no one was available to help increase markedly with level of assistance. Among those who have difficulty or receive help, those in supportive care settings have only a slightly higher risk of unmet need relative to those in the community. Those receiving paid care from persons other than staff, however, have especially high levels of unmet need: nearly 60% had a negative consequence in the last month. This finding warrants further investigation to better understand who is in this group, particularly in light of the focus on expanding public benefits in the community to avoid or reduce the need for nursing home care.

There are several limitations to this analysis. At baseline, NHATS did not interview respondents in nursing homes and therefore we could not explore disability, care, and unmet need among this population. However, older adults living in nursing homes are a small and shrinking group--now about only half the size of the supportive care population broadly defined. Moreover, NHATS purposefully included older adults in all supportive care settings and interviewed not only the sampled person in these settings but also a facility respondent as well so that services could be accurately captured. A second limitation is that this initial description is by design cross-sectional. Future research is needed that examines how older adults transition from one stage of disability to the next. Finally, this report presents details on informal care from only recipients' point of view; a separate report (forthcoming) will detail care from the informal providers' viewpoint.

Nevertheless, findings in this report suggest several potentially important avenues for future research. First, a large share of the older population--over 70%--is managing independently. Many older adults are fully able to carry out daily activities, but others are using assistive devices, environmental modifications, or limiting their activities (Freedman et al. in press). Understanding the role of behavioral accommodations in delaying assistance and mitigating difficulty would be beneficial.

Second, findings regarding the interplay of non-staff paid care and informal care with care provided in supportive settings are new and warrant further study. It may be that residential care compensates for smaller effective potential networks; we did not take into account willingness and ability to provide care among potential network members or proximity. Alternatively, residence in supportive care settings may be a way of making caregiving more sustainable, particularly as care needs or the need for oversight increase. As future rounds of NHATS become available, researchers will be able to analyze the interplay between supportive care settings and care networks outside the residence and investigate whether involvement of supplemental care in this setting helps keep unmet need levels on a par with the community.

Third, the prominent level of adverse consequences linked to unmet need in the older population with limitations in daily activities, particularly among those receiving formal care in the community, is noteworthy. Although past research has established that unmet need has negative outcomes including increased falls, hospitalizations, and emergency room use (Allen & Mor 1997; Desai et al. 2001; LaPlante et al. 2004; Komisar et al. 2005; Sands et al. 2006), less is known about which care networks give rise to unmet need and what policy solutions might be proposed to address it.

In conclusion, this report paints an up-to-date picture of late-life disability and care needs for older adults. New measures in NHATS suggest that needs are higher than previous data have suggested, but care networks are also substantial, and levels of informal assistance are high, not only for older adults in the community but also for those in residential care. Particularly notable is that we find a much larger proportion of the population receiving assistance with three or more self-care or mobility activities, a level of need associated with a high rate of unmet need, high risk of institutionalization, and with eligibility for private insurance or public program benefits. A disproportionate share of older persons at this level of assistance is in the lowest income quartile. Although publicly and privately paid care continues to be an important source of assistance to older adults with extensive needs, the higher level of unmet need for care among those receiving paid care is cause for concern and warrants further investigation. As individual preferences and public programs continue to support the shift of the locus of long-term care from nursing homes to the community and alternative residential care settings, a better understanding of unmet need can inform policies to promote safety and maximized functioning in the community and the well-being of older adults and their families.

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APPENDIX I. CONSTRUCTION OF ACTIVITY LIMITATION MEASURES

For self-care and mobility limitations (eating, dressing, bathing, toileting, getting out of bed, getting around inside, getting outside; corresponding to ADLs), respondents are asked if and how often they used specific devices for the task, how often they received help, and how difficult the task was for them to carry out by themselves (if relevant, when they used devices previously named). We created a three-category summary variable: no difficulty or help, difficulty but no help, and any help. NHATS respondents living in nursing home settings are assumed to be helped with self-care or mobility activities.

For household activities (laundry, hot meals, shopping for personal items, paying bills/banking, handling medications; corresponding to IADLs), respondents are asked whether anyone does the activity with them or for them for health or functioning-related reasons, whether they ever do the activity on their own, and if they do the activity on their own whether they have difficulty carrying out the activity by themselves. We created a three-category summary variable: no difficulty or help, difficulty for health-related or functioning-related reasons but no help, and any help. NHATS respondents living in nursing home settings are assumed to be helped with household activities for health/functioning-related reasons.

Finally, we summarized across the self-care or mobility and household activities as follows: no difficulty or help with any activities, difficulty but no help, and any help. NHATS respondents living in nursing home settings are assumed to be helped.

APPENDIX II. IMPUTATION OF PAID AND UNPAID HOURS

Paid and unpaid hours for helpers assisting sample members with mobility, self-care or household tasks were constructed at the caregiver level and then summed to the sample person level.

Of the 6411 sample persons receiving any help with any activity for any reason, 738 sample persons were missing information on either paid or unpaid hours for all or part of their care network (12%). Among the 2499 sample persons defined as receiving assistance with self-care or mobility or with household activities related to health or functioning, 311 were missing information on either paid or unpaid hours for all or part of their care network (12%).

For the caregiver(s) with missing information we imputed mean hours of care, based on the sample person's age group, sex, a hierarchal measure of care (mobility/self-care/household activities/other activities) and for unpaid caregivers their relationship to the recipient (spouse/partner or child, other relative, other non-relative). Altogether 43 (4%) of paid and 1041 (10%) of unpaid caregivers were filled in this way; six additional caregivers with no relationship information had informal hours imputed based on respondent characteristics alone.

Among sample persons receiving unpaid assistance, the weighted mean for unpaid hours was 98.6 before and 100.4 after imputation. Among those receiving non-staff paid assistance, the weighted mean for paid hours was 81.7 before and 82.9 after imputation. Among those receiving either non-staff paid or unpaid assistance, the weighted mean for total hours was 105.7 before and 107.6 after imputation.

ANALYSES OF THE 2011 NATIONAL HEALTH AND AGING TRENDS STUDY AND NATIONAL STUDY ON CAREGIVING

Reports Available

Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study

Executive Summary	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DSes.cfm
HTML	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DS.cfm
PDF	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DS.pdf

Disability and Care Needs of Older Americans: An Analysis of the 2011 National Health and Aging Trends Study

Executive Summary	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DCNes.cfm
HTML	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DCN.cfm
PDF	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DCN.pdf

Informal Caregiving for Older Americans: An Analysis of the 2011 National Health and Aging Trends Study

Executive Summary	http://aspe.hhs.gov/daltcp/reports/2014/NHATS-ICes.cfm
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Email: webmaster.DALTCP@hhs.gov

NOTE: All requests must be in writing.

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