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Medicaid Personal Care in New York City: Service Use and Spending Patterns

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Contents

EXECUTIVE SUMMARY iii

INTRODUCTION 1

PERSONAL CARE USE IN NEW YORK CITY: A SNAPSHOT 3

THE 2003 COHORT OF PERSONAL CARE RECIPIENTS 5
- Major Characteristics 6
- Personal Care Service Use and Spending 8
- Other Health Care Service Use and Spending 12
  - Before Personal Care 13
  - During Personal Care 16
  - After Personal Care 19

IMPLICATIONS FOR POLICY 21

ACKNOWLEDGMENT 22

Executive Summary

New York's Medicaid personal care program provides a number of services for New Yorkers receiving long-term care. It includes assistance with eating, bathing, and dressing, as well as activities associated with independent living (such as shopping and meal preparation). In New York State about 80,000 Medicaid beneficiaries receive personal care assistance each year, and in 2009 Medicaid spending on personal care totaled $2.7 billion. Personal care is a particularly substantial and important component of long-term care service delivery in New York City, which accounts for 84 percent of Medicaid personal care spending statewide.

In this report we analyzed Medicaid paid claims for elderly dual Medicare-Medicaid beneficiaries receiving personal care services in New York City. Our goal was to compile a comprehensive profile of personal care recipients' characteristics, including their Medicaid enrollment patterns, personal care service use, and overall Medicaid service use and spending.

The analysis presents a brief examination of elderly duals who received personal care during December 2008. It then profiles in depth a cohort of new personal care users—elderly duals whose first personal care claim occurred during 2003—and follows them in Medicaid for the seven years from 2002 through 2008, in order to analyze their characteristics and their Medicaid service use and spending before, during, and after their reliance on personal care. Lastly, the analysis examines service use and spending by New York City neighborhood, using the nine Community Alternative Systems Agency (CASA) areas to show neighborhood trends.

Enrollment Patterns

Personal care recipients tended to be long-term Medicaid enrollees, suggesting that elderly New Yorkers are not enrolling in Medicaid principally to receive personal care.

- In December 2008, over 84 percent of beneficiaries receiving personal care had been enrolled in Medicaid for seven years or longer.
- Over two-thirds of the 2003 cohort was enrolled in Medicaid in January 2002, and the average time on Medicaid before a personal care episode began was 13 months.

Duration of Personal Care Service

Personal care recipients tended to use personal care services over very long periods of time. Since longer-term recipients ultimately accounted for the bulk of program costs, gaining a better understanding of which beneficiaries are likely to use personal care over long periods could support increased opportunities to manage service use.

- In December 2008, over 40 percent of personal care recipients had received personal care services for at least seven years, with an average of 57 months, or 4.75 years.
- For the 2003 cohort, beneficiaries clustered around two poles in terms of the average length of time during which they received personal care: either shorter-term, for two years or less, or longer-term, for six years or more.

Amount of Personal Care Received

Personal care recipients fell along a continuum of average monthly service use, from lower intensity (less than $1,500 per month in personal care costs) to higher intensity ($4,000 or more per month in personal care costs). Recipients' diagnostic characteristics and Medicaid spending in the year prior to a personal care episode were related to both average monthly personal care costs and the number of months using personal care services. The question of whether and how certain key diagnoses, particularly in the behavioral health realm, drive personal care utilization warrants particular attention from policymakers.

- High-intensity users had higher rates of mental illness or cognitive impairment, as well as higher Medicaid spending on other long-term care services, before they started to receive personal care.
- High-intensity users also tended to receive personal care for an average of 1.5 years longer than low-intensity recipients.

Personal Care Recipients' Overall Medicaid Service Use and Costs

On average, when a beneficiary began a personal care episode, Medicaid spending on acute and other long-term care services decreased dramatically; however, total Medicaid costs increased due to new spending on personal care. When beneficiaries stopped receiving personal care, their Medicaid costs did not fall, due mainly to their increased reliance on other long-term care services. This trajectory of overall spending indicates that once Medicaid beneficiaries become personal care recipients, they typically will not revert to lower levels of service use or cost. This finding highlights the magnitude and complexity of the care management and cost containment challenges faced by policymakers as they address the needs of elderly dual beneficiaries who rely heavily on long-term care.

- Before a personal care episode, 32 percent of annualized Medicaid spending was for acute care ($8,098) and 68 percent was for long-term care ($17,170).
- During a personal care episode, acute care costs fell to an average of only 8 percent ($5,015) of annualized Medicaid spending, with 92 percent going toward long-term care. Personal care constituted the bulk—86 percent, or $37,338—of this long-term care spending.
- After a personal care episode, acute care costs increased to an average of 18 percent of annualized Medicaid spending ($7,956), and long-term care costs remained higher than they were before the episode, at 82 percent of total annualized Medicaid cost ($36,779).

Rates of Personal Care Service Use Across New York City

Among personal care recipients in New York City, some patterns of service use and spending were uniform, while others varied by neighborhood. This combination of variation and uniformity in personal care service use and spending underscores the need for clear data and robust data management systems. More complete utilization information will help policymakers determine whether variation supports or undermines effective management of the personal care program.

- There was substantial variation in the rates of personal care utilization across New York City by neighborhood. Elderly duals in two neighborhoods, Brooklyn Central and Brooklyn Southwest, were twice as likely to receive personal care as their counterparts in five of the other seven neighborhoods.
- There was also some uniformity throughout New York City, primarily in the volume of personal care services delivered per episode. Both average annualized personal care costs and the average number of months that beneficiaries received personal care were almost identical across the nine neighborhoods.

Conclusion / Policy Implications

A better understanding of personal care can play a role in addressing three major challenges New York Medicaid now faces. The first major policy challenge is managing the care of complex and high-cost Medicaid beneficiaries, including those who rely on long-term care, to ensure the delivery of appropriate and cost-effective services in the most appropriate setting. The findings in this analysis about the intensity and duration of personal care service use suggest that, in the case of personal care, appropriateness of service use may be difficult to determine and define. A second key policy challenge is containing Medicaid spending in the context of a severe state budget deficit—an imperative that spans the Medicaid program as a whole. The finding in this analysis that Medicaid personal care recipients tend to have higher total Medicaid spending, even after their personal care episodes end, implies that containing Medicaid spending is a highly complex issue, requiring thorough examination across a broad spectrum of health care services. A third important policy challenge is ensuring that Medicaid has an administrative structure that supports the design and implementation of coherent and effective policy and purchasing decisions, and that the program uses scarce administrative resources efficiently. This analysis found both variation and uniformity in personal care use patterns, which suggests a need for better data to help policymakers determine whether variation supports or undermines effective management of the personal care program.

Introduction

New York's Medicaid personal care program provides a number of services for New Yorkers receiving long-term care. It includes assistance with eating, bathing, and dressing, as well as activities associated with independent living (such as shopping and meal preparation). In New York State about 80,000 Medicaid beneficiaries receive personal care assistance each year,[1] and in 2009 Medicaid spending on personal care totaled $2.7 billion.[2]

Personal care spending in New York State represents 5 percent of total Medicaid spending on services. Personal care accounts for 50 percent more costs than Medicaid home health services ($1.8 billion)—including short-term home health care and services provided under the Long-Term Home Health Care Program (LTHHCP). However, Medicaid spending on personal care is less than half as much as Medicaid spending on skilled nursing facilities ($7.2 billion). It also accounts for far less than Medicaid spending on home- and community-based services for beneficiaries with developmental disabilities ($5.6 billion). In New York City, personal care is a particularly substantial and important component of Medicaid long-term care service delivery and spending; 84 percent of Medicaid personal care spending statewide takes place in the city.[3]

Personal care sits at the intersection of three major challenges for Medicaid. The first key challenge is how to manage the care of complex and high-cost Medicaid beneficiaries, many of whom depend on long-term care services, to ensure the delivery of appropriate and cost-effective services in the appropriate setting. A second challenge is containing Medicaid spending in the context of a severe state budget deficit. A third challenge is ensuring that Medicaid has an administrative structure that supports the design and implementation of coherent and effective policy and purchasing decisions, and that the program uses scarce administrative resources efficiently.

Currently, there is little information available about who uses personal care, how long it is used, or how much is used. The goal of this analysis is to compile a comprehensive profile of personal care recipients' characteristics, including their Medicaid enrollment patterns, personal care service use, and overall Medicaid service use and spending. This analysis examines Medicaid personal care within New York City because it accounts for 84 percent of all Medicaid personal care spending statewide. It focuses on traditional Medicaid personal care—whereby services are provided by a licensed agency paid directly by Medicaid, as opposed to consumer-directed personal care services provided by a direct care worker who is hired and supervised directly by the Medicaid beneficiary or a surrogate—because traditional personal care claims represent 94 percent of Medicaid personal care costs in the city.[4]

[1] United Hospital Fund analysis of New York State Department of Health data.

[2] United Hospital Fund analysis of CMS 64 data for FFY 2009.

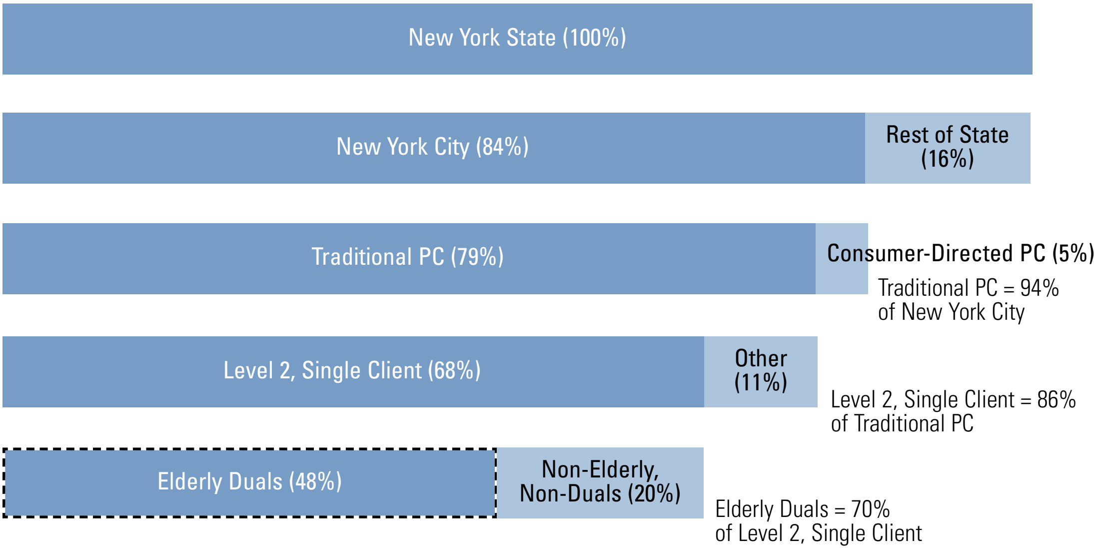
[3] United Hospital Fund analysis of CMS MSIS data for FFY 2005.

[4] New York City personal care claims, 2007.

To ensure uniformity in the discussion and consistency in all comparisons, we examined paid claims for personal care Level 2 services—assistance with activities of daily living, such as dressing and bathing—delivered to a single client, which account for an estimated 86 percent of traditional personal care spending in the city. We excluded Level 1 personal care, which provides assistance only with instrumental activities of daily living, such as shopping and meal preparation. Personal care can also be delivered to two clients simultaneously; in our analysis we focused on single-client claims to more accurately analyze recipients' characteristics, including their patterns of enrollment, service use, and spending.

Within the subset of Level 2 personal care recipients in New York City, we focused on elderly dual Medicare-Medicaid enrollees (elderly duals) because this subset represents 70 percent of these recipients. All told, this analysis included an estimated 48 percent of Medicaid personal care spending statewide (and an estimated 60 percent of Medicaid personal care spending within New York City), as shown in Figure 1.

Figure 1.
The Sample as a Share of All Medicaid Personal Care Spending in New York State



The analysis begins with a brief examination of elderly duals who received personal care during December 2008, the most recent month for which the complete Medicaid paid claims file was available. These beneficiaries' Medicaid enrollment and service use patterns provide a snapshot of recent personal care utilization in New York City.

Since beneficiaries tend to use personal care services over extended periods, this analysis followed a cohort of new personal care users—Medicaid beneficiaries whose first personal care claim occurred during 2003 (the "2003 cohort")—over seven years from 2002 through 2008. The cohort analysis details the cohort's demographic and health characteristics, as well as their Medicaid service use and annualized spending before, during, and after their reliance on personal care, creating a profile of personal care users over time. Throughout this analysis, average spending is annualized to reflect less than full years of service use.

This profile of new personal care users analyzes the characteristics and enrollment patterns of beneficiaries who receive personal care. In addition, the cohort analysis reveals how much personal care beneficiaries receive and for how long. Finally, it examines how personal care utilization and costs fit into the totality of Medicaid service use and spending over time by elderly duals.

In addition to examining these patterns for New York City as a whole, we compared findings by neighborhood, using mapping software that approximates the catchment areas for the nine Community Alternative Systems Agency (CASA) offices situated throughout the city by aggregating beneficiaries' zip codes. CASA offices process applications for personal care assistance, administer authorizations for services, and monitor the cases of recipients.

Personal Care Use in New York City: A Snapshot

In December 2008, there were over 29,000 elderly duals receiving personal care in New York City. In general, they were long-term Medicaid enrollees. Citywide, over 84 percent of beneficiaries receiving personal care had been enrolled in Medicaid for seven years or longer. Even beneficiaries using personal care for one month or less, those who began personal care during December 2008, had been enrolled in Medicaid for an average of over four and a half years. For eight out of nine CASAs, there was little variation in enrollment patterns: the average length of time beneficiaries were enrolled in Medicaid and the proportion of beneficiaries on Medicaid for at least seven years were very similar (Table 1).

Personal care recipients tended to use personal care services over very long periods of time. More than 40 percent of elderly dual personal care recipients had been receiving personal care for at least seven years. Twenty-one percent used personal care between four and seven years, and twenty-seven percent used personal care between one and four years. Only 10 percent received a year or less of personal care. Beneficiaries in most CASAs spent similar amounts of time receiving personal care. For the majority of CASAs, the average number of months a beneficiary received personal care varied from the citywide average by six months or less.

Table 1.
Recipients' Duration of Medicaid Enrollment and Personal Care Use

	Bronx	Manhattan North	Manhattan South	Queens West	Queens East	Brooklyn East	Brooklyn Central	Brooklyn Southwest	Staten Island	NYC
Average months on Medicaid	77	79	76	75	75	79	80	80	65	78
On Medicaid 7 years	84%	87%	79%	79%	78%	86%	89%	90%	61%	84%
Average months receiving PC	55	56	55	51	51	55	61	60	42	57
12 months or less of PC	11%	11%	9%	14%	12%	11%	8%	9%	19%	10%
13–24 months of PC	10%	7%	10%	12%	11%	9%	7%	8%	17%	9%
25–36 months of PC	9%	8%	10%	9%	11%	10%	7%	8%	11%	9%
37–48 months of PC	10%	10%	11%	10%	9%	10%	8%	7%	10%	9%
49–60 months of PC	8%	10%	9%	10%	10%	8%	8%	7%	10%	8%
61–72 months of PC	7%	9%	9%	6%	7%	8%	6%	6%	5%	7%
73–83 months of PC	5%	8%	8%	6%	6%	6%	6%	6%	6%	6%
84 months of PC	40%	37%	34%	33%	33%	39%	50%	49%	21%	42%

Distributions may not sum to 100% due to rounding.

While personal care recipients spent similar amounts of time receiving Medicaid and personal care services across CASAs, the share of elderly duals receiving personal care varied widely (Table 2). By focusing on elderly duals, this analysis used a clear denominator for calculating personal care recipient rates: the number of elderly dual Medicaid enrollees. None of the CASAs had rates close to the citywide average rate of 107 personal care recipients for every 1,000 elderly dual Medicaid beneficiaries—or one recipient for every ten beneficiaries. CASAs clustered closely either above or below the city average. Five CASAs had relatively low personal care beneficiary concentrations, with rates between 71 and 83 users per 1,000. In contrast, four CASAs had relatively high concentrations, with rates between 126 and 169 per 1,000. Elderly duals in two of these high-concentration CASAs,

Table 2.
Personal Care Recipients per 1,000 Elderly Dual Beneficiaries

CASA	Rate /1,000	Ratio to NYC	Rate New Recipients/1,000
Queens East	71	0.7	9
Bronx	71	0.7	8
Queens West	77	0.7	11
Manhattan North	83	0.8	9
Staten Island	83	0.8	16
NYC Average	**107**	**1.0**	**11**
Brooklyn East	126	1.2	13
Manhattan South	127	1.2	12
Brooklyn Southwest	158	1.5	14
Brooklyn Central	169	1.6	14

Brooklyn Central and Brooklyn Southwest, were roughly twice as likely to receive personal care as their counterparts in the five low-concentration CASAs. The large variation in rates of personal care utilization by CASA raises questions about differences in the supply and availability of personal care services and about variation in local administration of the personal care program across New York City.

Of the New York City CASAs, Staten Island was an outlier with regard to personal care utilization. Personal care recipients on Staten Island had been enrolled in Medicaid for shorter periods (Table 1). The average recipient on Staten Island had been on Medicaid for about five and a half years, 13 months less than the citywide average. This lower average reflects the fact that Staten Island had more new Medicaid beneficiaries who quickly began to receive personal care. The share of new Staten Island personal care recipients who were enrolled in Medicaid for one year or less was close to four times the citywide share, and more than two times that of the next highest CASA. Half of new personal care recipients in Staten Island had six months or less of prior Medicaid enrollment.

The December 2008 snapshot of personal care use among elderly duals in New York City reveals several key characteristics of Medicaid personal care recipients. First, personal care recipients, even those just starting to receive personal care, tended to be long-term Medicaid enrollees. Second, beneficiaries used personal care for a significant amount of time—typically several years. Third, while personal care recipients throughout New York City tended to spend similar amounts of time enrolled in Medicaid and receiving personal care, the share of elderly duals receiving personal care varied widely across the city.

The 2003 Cohort of Personal Care Recipients

Since the overwhelming majority of recipients at any given time had been receiving personal care for several years, the bulk of this analysis focused on a cohort of over 5,300 new personal care recipients, each of whom first received personal care in 2003, to provide a comprehensive picture of Medicaid beneficiaries' enrollment, service use, and spending patterns. This analysis followed the 2003 cohort over a period of seven years, from January 2002 through December 2008. The analysis considered recipients' experience at three distinct phases: before receiving personal care; during their personal care episodes, which spanned the period from the first month with a personal care claim to the last month with a personal care claim; and after their reliance on personal care.

Tracing the trajectories of this cohort entails a discussion of pathways onto and off personal care. By definition, the analysis separates beneficiaries who were still receiving personal care in December 2008 from beneficiaries who stopped receiving personal care before that month. While the majority of this cohort stopped receiving personal care, close to one-third were still receiving it as of December 2008 (Table 3).

Table 3.
Distribution of Personal Care Recipients

	Stopped Receiving PC Before 12/08	Still Receiving PC in 12/08	Total
Number of recipients in 2003 cohort	3,665	1,641	5,306
Percentage of 2003 cohort	69%	31%	100%

Both groups used substantial amounts of personal care over an extended period of time, but they demonstrated different Medicaid coverage patterns, demographic profiles, and diagnostic histories.

Major Characteristics

Consistent with the December 2008 snapshot, over two-thirds of personal care recipients in this cohort were enrolled in Medicaid well before they started using personal care. This cohort of personal care recipients was similarly composed of relatively long-term Medicaid enrollees. On average, beneficiaries were on Medicaid for over a year before they started to use personal care services.

However, Medicaid enrollment patterns differed between beneficiaries who continued receiving personal care and those who stopped; those continuing were enrolled in Medicaid longer than those who stopped. The share of beneficiaries enrolled in Medicaid at the start of the study period was higher for those who continued receiving personal care, 78 percent, than for those who stopped, 62 percent (Table 4). People who left personal care also tended to leave Medicaid. Nearly one-third of beneficiaries who terminated personal care services before the end of the study period (December 2008) left Medicaid within one month of ending personal care; we assume—though we cannot confirm it through the Medicaid claims data—that a large share of those who lost Medicaid enrollment did so upon death. The remaining two-thirds of beneficiaries who stopped receiving personal care were enrolled in Medicaid for an average of 21 months afterward. Only one in four beneficiaries who stopped receiving personal care was enrolled in Medicaid in December 2008. By definition, all of those still receiving personal care were Medicaid enrollees at the end of the study period.

Table 4.
Recipients' Duration of Medicaid Enrollment and Personal Care Use

	Stopped Receiving PC Before 12/08	Still Receiving PC in 12/08	Total
Average number of months on Medicaid before PC	13	15	13
Percentage on Medicaid in 1/02	62%	78%	67%
Percentage on Medicaid <1 month prior to PC	7%	3%	6%
Percentage on Medicaid in 12/08	24%	100%	48%
Average number of months on Medicaid after PC	14	NA	NA
Average number of months receiving PC	24	64	37

Personal care recipients in the 2003 cohort tended to be age 75 or above (in 2003), nonwhite, and female (Table 5). An older cohort likely reflects the fact that older adults tend to have more limited functional ability and thus require the assistance provided by personal care aides. That more women than men received personal care is consistent with women's longer life expectancy. Despite some broad similarities, however, there were demographic differences between those who continued receiving personal care and those who stopped. More beneficiaries who left personal care were older. Over 30 percent of people who ended personal care were age 85 or older, while only 16 percent of people still receiving personal care were in this age group. Instead, close to 85 percent of those still receiving personal care were between 65 and 84 years old. In addition, 70 percent of those still receiving personal care were nonwhite, compared to 57 percent of those who ended personal care.

Table 5.
Demographic Characteristics of Personal Care Recipients

	Stopped Receiving PC Before 12/08	Still Receiving PC in 12/08	Total
Ages 65–74	23%	31%	26%
Ages 75–84	45%	53%	47%
Ages 85+	32%	16%	27%
Female	75%	80%	77%
Male	25%	20%	23%
White	43%	30%	39%
Nonwhite	57%	70%	61%

Based on cumulative diagnoses during the year before starting personal care, chronic disease was widespread among the entire 2003 cohort of personal care recipients.[5] Their health status, however, was similar to that of the average elderly dual beneficiary in New York City. Over 70 percent of personal care recipients in this cohort had at least one chronic disease, and over half had multiple chronic diseases (Table 6). Cardiovascular chronic diseases were prevalent. Close to 60 percent of personal care recipients had hypertension, 30 percent had ischemic heart disease, and over 20 percent had congestive heart failure. The rates for cardiovascular chronic disease and diabetes are consistent with previous United Hospital Fund research on elderly duals.[6] Mental illness was also fairly prevalent among this cohort of personal care recipients; one in four had at least one mental health diagnosis.

Table 6.
Health Characteristics of Personal Care Recipients

	Stopped Receiving PC Before 12/08	Still Receiving PC in 12/08	Total
At least one chronic disease	69%	80%	72%
Two or more chronic diseases	50%	58%	52%
Hypertension	54%	69%	59%
Ischemic heart disease	29%	34%	31%
Congestive heart failure	25%	20%	23%
Diabetes	30%	31%	30%
Any mental health diagnosis	24%	28%	25%
Bipolar disorder	5%	10%	7%
Dementia	7%	5%	7%
Alzheimer's	5%	5%	5%

Within the cohort of personal care recipients, those who continued receiving personal care and those who did not had fairly similar diagnostic profiles. Beneficiaries still receiving personal care in December 2008 had slightly higher rates of chronic disease and mental illness, including more than twice the rate of bipolar disorder of their counterparts who stopped receiving personal care services. Health conditions in the year prior to personal care did not appear to be strongly related to whether or not a beneficiary continued receiving personal care at the end of the study period.

Personal Care Service Use and Spending

For beneficiaries in the 2003 cohort, 62 percent of personal care episodes lasted for more than two years. About 31 percent of this cohort was still receiving personal care in December 2008; a further 31 percent received personal care for less than six years but more than two; and 38 percent received it for two years or less (Table 7).

[5] Reliance on Medicaid claims for diagnostic profiles has limitations. There may be underreporting of health conditions when multiple diagnoses do not result in additional payments to providers.

[6] Birnbaum M and L Powell. 2008. *Managing Care for High-Cost Elderly Duals: A Challenge for Medicaid*. New York: United Hospital Fund. Page 6.

Table 7.
Recipients' Duration of Medicaid Enrollment and Personal Care Use, by CASA

	Bronx	Manhattan North	Manhattan South	Queens West	Queens East	Brooklyn East	Brooklyn Central	Brooklyn Southwest	Staten Island	NYC
Stopped PC in 2 years or less	43%	42%	34%	39%	44%	35%	34%	32%	57%	38%
Stopped PC after 2–6 years	30%	26%	31%	34%	31%	33%	32%	31%	28%	31%
Still receiving PC in 12/08	27%	32%	35%	27%	25%	32%	34%	37%	15%	31%
Average number of months receiving PC	34	36	39	36	33	38	39	40	27	37
Annualized PC cost	$32,034	$35,609	$37,972	$36,583	$37,684	$35,317	$34,788	$35,220	$36,942	$35,623
Percentage of total Medicaid cost	79%	84%	87%	87%	85%	82%	85%	82%	88%	84%

Personal care accounted for 84 percent of average annualized Medicaid spending on all services—roughly $36,000 annually per recipient in the 2003 cohort. Since personal care use generally occurs over several years, annualized spending does not tell the whole story. Although those still receiving personal care in December 2008 constituted less than one-third of the 2003 cohort, they accounted for more than half of aggregate personal care expenditures over the years because the average time they received personal care was much longer—over six years, compared to two years for those who had stopped receiving personal care.

Annualized personal care expenditures and personal care as a share of total Medicaid cost did not vary significantly across New York City by CASA (Tables 7 and 13). Beneficiaries across the city received similar amounts of personal care as measured by both average annualized spending for personal care services and average time receiving personal care. There was consistency in the amount of personal care used, despite some variation in health conditions across CASAs. A contributing factor in this consistency is that personal care workers are often assigned in blocks of time, such as four-hour increments. This occurs because, regardless of the severity of a recipient's case, personal care aides must be engaged for a minimum number of hours, and in increments that add up to full daily shifts, for employers to attract and retain them.

Personal care recipients fell along a continuum of average monthly service use over the course of a personal care episode, from lower to higher intensity. Close to one in four beneficiaries was a high-intensity personal care recipient, accounting for an average of $4,000 or more per month in Medicaid spending on personal care. Twenty-eight percent of beneficiaries were low-intensity personal care recipients, accounting for $1,500 or less in average monthly personal care expenditures. Roughly half of personal care recipients fell in the middle, consuming between $1,500 and $3,999 per month of personal care services (Table 8).

Table 8.
Distribution of Personal Care Recipients, by Intensity of Spending

Average monthly spending	Low <$1,500		Medium $1,500–$2,499		Medium $2,500–$3,999		High $4,000+		Total	
Total	1,472	28%	1,293	24%	1,282	24%	1,259	24%	5,306	100%
Stopped receiving PC before 12/08	1,148	31%	892	24%	845	23%	780	21%	3,665	100%
Still receiving PC in 12/08	324	20%	401	24%	437	27%	479	29%	1,641	100%

Columns and rows may not sum to totals due to rounding.

The higher the intensity of service use, the more likely a beneficiary was to continue receiving personal care at the end of the study period. Close to four in ten high-intensity recipients were still receiving personal care in December 2008, compared to about two in ten low-intensity recipients (Table 9).

Table 9.
Recipients' Duration of Medicaid Enrollment and Personal Care Use, by Intensity of Spending

Average monthly spending	Low <$1,500	Medium $1,500–$2,499	Medium $2,500–$3,999	High $4,000+	NYC
Average number of months on Medicaid before PC	14	14	13	12	13
Percentage on Medicaid in 1/02	73%	73%	67%	53%	67%
Percentage on Medicaid in 12/08	47%	49%	48%	47%	48%
Average number of months on Medicaid after PC	21	15	11	7	14
Stopped PC in 2 years or less	55%	40%	32%	23%	38%
Stopped PC after 2-6 years	37%	45%	48%	53%	45%
Still receiving PC in 12/08	22%	31%	34%	38%	31%
Average number of months receiving PC	27	36	40	44	37
Annualized PC cost	$11,940	$23,153	$37,105	$62,544	$35,623
Percentage of total Medicaid cost	64%	77%	85%	91%	84%

Distributions may not sum to 100% due to rounding.

The higher the intensity of monthly personal care use and costs, the longer a beneficiary continued to receive personal care. On average, high-intensity personal care recipients received personal care 17 months longer than low-intensity personal care beneficiaries. This pattern was consistent with higher-intensity personal care recipients being more functionally impaired and requiring personal care services for a longer duration.

Naturally, high monthly intensity translates into higher annualized personal care costs, which in turn leads to personal care accounting for a greater share of total Medicaid cost during personal care episodes, since other Medicaid spending does not increase significantly with monthly personal care intensity. The average annualized personal care expenditure for high-intensity recipients ($62,544) was more than five times that for low-intensity recipients ($11,940). For high-intensity beneficiaries, personal care accounted for over 90 percent of annualized total Medicaid cost during personal care episodes, compared to 64 percent for low-intensity recipients.

High-intensity personal care recipients were significantly different from low-intensity personal care recipients in their Medicaid enrollment patterns, demographic profiles, and diagnostic histories.

The higher the intensity of personal care use, the less likely a beneficiary was to be enrolled in Medicaid at the beginning of the study period. High-intensity personal care recipients also included the highest share of beneficiaries on Medicaid less than one month before starting personal care. This pattern was consistent with personal care being the most immediate service need as this cohort was enrolled in Medicaid.

More than twice as many high-intensity personal care recipients were age 85 or older, and a greater share of high-intensity recipients were white, although the majority of personal care users at any intensity level were people of color (Table 10).

Table 10.
Demographic Characteristics of Personal Care Recipients, by Intensity of Spending

Average monthly spending	Low <$1,500	Medium $1,500–$2,499	Medium $2,500–$3,999	High $4,000+	NYC
Ages 65-74	33%	30%	23%	15%	26%
Ages 75-84	48%	51%	48%	43%	47%
Ages 85+	20%	19%	29%	42%	27%
Female	74%	74%	75%	83%	77%
Male	26%	26%	25%	17%	23%
White	37%	35%	37%	48%	39%
Nonwhite	63%	65%	63%	52%	61%

Distributions may not sum to 100% due to rounding.

Compared to low-intensity recipients, high-intensity recipients had lower rates of most chronic diseases, and half the rate of cancer. But they had over four times the rate of Parkinson's/Huntington's, almost five times the rate of Alzheimer's, and three times the rate of dementia as low-intensity recipients; they also had higher rates of mental illness other than bipolar disorder (Table 11). Medium-intensity recipients closely resembled low-intensity recipients, with slightly higher rates of mental illness.

Table 11.
Health Characteristics of Personal Care Recipients, by Intensity of Spending

Average monthly spending	Low <$1,500	Medium $1,500–$2,499	Medium $2,500–$3,999	High $4,000+	NYC
At least one chronic disease	75%	77%	73%	62%	72%
Two or more chronic diseases	55%	57%	55%	44%	52%
Hypertension	62%	65%	59%	49%	59%
Cardiovascular disease	9%	12%	15%	18%	13%
Ischemic heart disease	33%	35%	32%	23%	31%
Congestive heart failure	23%	25%	25%	20%	23%
Asthma	9%	10%	10%	5%	9%
Chronic obstructive pulmonary disease	14%	17%	13%	9%	13%
Diabetes	31%	32%	34%	24%	30%
Renal disease	6%	6%	6%	3%	5%
Cancer	21%	22%	18%	10%	18%
Parkinson's or Huntington's	1%	2%	3%	5%	3%
Any mental health diagnosis	22%	25%	25%	31%	25%
Bipolar disorder	9%	8%	6%	5%	7%
Incontinence	4%	3%	5%	7%	5%
Dementia	4%	5%	6%	12%	7%
Alzheimer's	2%	3%	6%	10%	5%

Personal care utilization can be defined by two key factors—how long beneficiaries receive personal care, and the amount of personal care used. Beneficiaries with shorter personal care episodes tended to use less personal care, measured by both annualized expenditures and monthly intensity. Beneficiaries with longer personal care episodes tended to have higher annualized personal care spending and higher monthly intensity.

Other Health Care Service Use and Spending

In addition to focusing on personal care service use and spending, our analysis also considered utilization and annualized costs across the full spectrum of Medicaid covered services. This included service use before, during, and (where applicable) after personal care episodes ended. These broad service use patterns also varied by the monthly intensity of personal care use, and by whether a beneficiary ended personal care or continued receiving it.

For this analysis, acute care spending included primary and specialty care, mental health treatment, emergency department services, durable medical equipment, transportation, and dental services; it did not include outpatient prescription drug costs for the study period because implementation of Medicare Part D in 2006 shifted responsibility for this service to Medicare. Because Medicaid claims do not capture Medicare payments, they contain incomplete information on duals' acute care—and, therefore, total—service use and spending. Long-term care spending consists of personal care, home health services (including those provided by certified home health agencies and those provided under the Long-Term Home Health Care program), adult day care, managed long-term care, and other community-based long-term care services and supports. Because Medicare has very limited coverage for long-term care services, however, Medicaid claims likely represent a close approximation for long-term care service use and spending.

Before Personal Care. Medicaid beneficiaries received substantial long-term care services through Medicaid before they began to receive personal care. Over two-thirds of personal care recipients' prior annualized Medicaid costs consisted of mainstream long-term care services, including short-term home health services, the LTHHCP, skilled nursing facilities, adult day care, and managed long-term care (Table 12). Hospital inpatient services and other acute care accounted for 32 percent of annualized total Medicaid spending.

The intensity of a beneficiary's Medicaid service use and spending before starting to receive personal care, particularly for long-term care, correlated with monthly personal care use intensity and, therefore, on aggregate appeared to be a sound predictor of personal care costs. This pattern held whether a beneficiary continued receiving personal care or not. Greater total Medicaid costs before personal care—driven entirely by greater long-term care spending—corresponded with higher monthly personal care use intensity. High-intensity personal care recipients had almost five times the

Table 12.
Average Annual Medicaid Spending Before Personal Care Use, by Intensity of Spending

Average monthly spending	Low <$1,500		Medium $1,500–$2,499		Medium $2,500–$3,999		High $4,000+		NYC	
Inpatient	4,646	32%	5,780	28%	7,725	26%	5,111	13%	5,786	23%
Other acute	2,496	17%	2,452	12%	2,299	8%	1,906	5%	2,312	9%
Acute subtotal	**7,143**	**50%**	**8,232**	**40%**	**10,024**	**33%**	**7,017**	**17%**	**8,098**	**32%**
Home health	3,515	24%	8,569	41%	13,892	46%	23,826	59%	11,645	46%
Skilled nursing facility	1,495	10%	1,375	7%	2,804	9%	5,246	13%	2,578	10%
LTHHC	547	4%	988	5%	1,587	5%	2,504	6%	1,328	5%
Adult day care	1,285	9%	964	5%	633	2%	594	1%	897	4%
Managed care	379	3%	537	3%	983	3%	889	2%	675	3%
Other LTC	58	0%	41	0%	8	0%	80	0%	46	0%
LTC subtotal	**7,279**	**50%**	**12,475**	**60%**	**19,906**	**67%**	**33,140**	**83%**	**17,170**	**68%**
Total	**14,422**	**100%**	**20,707**	**100%**	**29,931**	**100%**	**40,158**	**100%**	**25,268**	**100%**

Columns may not sum to totals due to rounding.

amount of annualized long-term care expenditures before personal care as low-intensity personal care recipients, yet their acute care subtotal was almost identical (Table 12). This relationship likely reflects the fact that beneficiaries with lower health and functional status require more long-term care across the full spectrum of services covered by Medicaid.

Before personal care episodes began, recipients' annualized total Medicaid expenditures and total long-term care costs varied little across New York City by CASA. However, annualized expenditures for the component long-term care services varied significantly by CASA, particularly for home health, skilled nursing facilities, and LTHHCP (Table 13). For example, the average annualized skilled nursing facility cost before personal care was three times higher in Staten Island than the citywide average

Table 13.

Average Annual Medicaid Spending Before, During, and After Personal Care, by CASA

Average Annual Spending

	Bronx	Manhattan North	Manhattan South	Queens West	Queens East	Brooklyn East	Brooklyn Central	Brooklyn Southwest	Staten Island	NYC
Before PC										
Inpatient	$5,750	$6,097	$3,761	$6,516	$6,845	$7,012	$5,623	$6,228	$4,158	$5,786
Other acute	2,633	2,385	1,604	2,004	2,594	2,361	2,323	3,137	1,175	2,312
Acute subtotal	**8,382**	**8,483**	**5,364**	**8,521**	**9,439**	**9,373**	**7,946**	**9,366**	**5,333**	**8,098**
Home health	8,015	13,865	10,612	10,523	14,079	12,251	12,353	13,232	10,604	11,645
Skilled nursing facility	3,025	3,471	1,679	2,580	2,739	3,931	1,535	1,166	7,259	2,578
LTHHC	2,322	2,211	784	1,313	1,571	809	778	1,013	1,951	1,328
Adult day care	1,399	173	485	561	920	1,681	735	1,832	175	897
Managed care	1,443	377	1,005	380	23	358	595	882	424	675
Other LTC	39	31	152	6	22	11	41	67	0	46
LTC subtotal	**$16,243**	**$20,127**	**$14,716**	**$15,363**	**$19,354**	**$19,041**	**$16,037**	**$18,191**	**$20,413**	**$17,170**
Total	**$24,625**	**$28,610**	**$20,081**	**$23,883**	**$28,793**	**$28,415**	**$23,983**	**$27,557**	**$25,745**	**$25,268**
During PC										
Inpatient	$2,212	$1,905	$1,125	$1,361	$1,413	$2,054	$1,600	$1,711	$1,105	$1,628
Other acute	2,951	2,370	1,746	2,158	2,672	2,835	2,497	2,915	1,200	2,444
Acute subtotal	**5,163**	**4,275**	**2,871**	**3,518**	**4,084**	**4,889**	**4,098**	**4,626**	**2,306**	**4,072**
Personal care	32,034	35,609	37,972	36,583	37,684	35,317	34,788	35,220	36,942	35,623
Home health	754	1,250	1,567	969	803	655	805	579	1,412	955
Skilled nursing facility	245	579	307	173	240	208	165	237	508	260
LTHHC	105	176	0	35	67	0	37	0	0	56
Adult day care	2,269	571	1,085	661	1,259	2,074	1,117	2,037	808	1,348
Managed care	18	72	26	52	6	60	47	13	75	39
Other LTC	9	27	39	0	7	10	0	0	0	14
LTC subtotal	**$35,433**	**$38,284**	**$40,996**	**$38,473**	**$40,067**	**$38,323**	**$36,959**	**$38,086**	**$39,746**	**$38,294**
Total	**$40,596**	**$42,560**	**$43,867**	**$41,992**	**$44,151**	**$43,212**	**$41,057**	**$42,712**	**$42,051**	**$42,366**
After PC (among those who stopped receiving PC)										
Inpatient	$5,601	$3,727	$6,864	$6,210	$5,115	$7,883	$5,760	$4,132	$4,403	$5,568
Other acute	2,629	1,992	1,779	2,301	2,544	2,283	2,722	2,525	2,767	2,388
Acute subtotal	**8,230**	**5,719**	**8,643**	**8,511**	**7,659**	**10,166**	**8,482**	**6,657**	**7,171**	**7,956**
Home health	5,786	6,858	5,352	7,827	6,115	11,309	12,038	22,499	6,505	9,101
Skilled nursing facility	19,240	19,469	29,582	25,031	22,845	19,949	23,421	23,764	31,086	23,248
LTHHC	2,519	1,091	829	418	1,366	677	195	11	0	883
Adult day care	729	49	197	299	241	655	125	577	26	318
Managed care	4,868	6,672	2,653	2,213	2,344	2,701	1,693	1,070	4,685	3,158
Other LTC	0	0	476	0	28	0	49	0	0	70
LTC subtotal	**$33,142**	**$34,138**	**$39,090**	**$35,788**	**$32,939**	**$35,290**	**$37,521**	**$47,921**	**$42,303**	**$36,779**
Total	**$41,372**	**$39,858**	**$47,732**	**$44,299**	**$40,598**	**$45,456**	**$46,003**	**$54,578**	**$49,474**	**$44,735**

Note: Columns may not sum to totals due to rounding.

cost, while in Brooklyn Southwest it was half the city average. This variation in individual long-term care services may be due to supply factors, particularly differences in the availability of each type of service by CASA.

For the majority of CASAs, acute care expenditures varied less than long-term care spending, and were mostly comparable across CASAs. In seven of the CASAs, personal care recipients' average annualized Medicaid costs for acute care were between $8,000 and $9,000; in Manhattan South and Staten Island, the average was much lower, about $5,000 in annualized expenditures.

Table 13.

Average Annual Medicaid Spending Before, During, and After Personal Care, by CASA (continued)

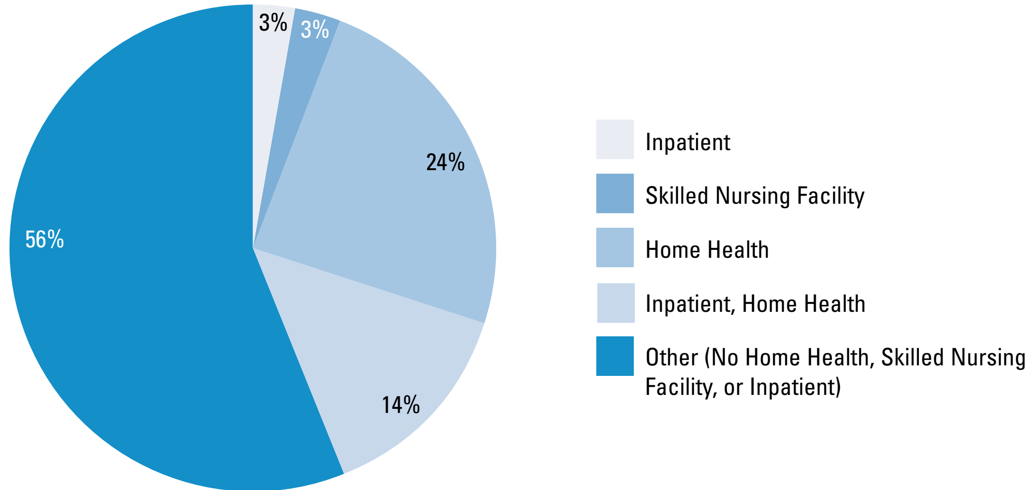
Percentages

	Bronx	Manhattan North	Manhattan South	Queens West	Queens East	Brooklyn East	Brooklyn Central	Brooklyn Southwest	Staten Island	NYC
Before PC										
Inpatient	23%	21%	19%	27%	24%	25%	23%	23%	16%	23%
Other acute	11%	8%	8%	8%	9%	8%	10%	11%	5%	9%
Acute subtotal	**34%**	**30%**	**27%**	**36%**	**33%**	**33%**	**33%**	**34%**	**21%**	**32%**
Home health	33%	48%	53%	44%	49%	43%	52%	48%	41%	46%
Skilled nursing facility	12%	12%	8%	11%	10%	14%	6%	4%	28%	10%
LTHHC	9%	8%	4%	5%	5%	3%	3%	4%	8%	5%
Adult day care	6%	1%	2%	2%	3%	6%	3%	7%	1%	4%
Managed care	6%	1%	5%	2%	0%	1%	2%	3%	2%	3%
Other LTC	0%	0%	1%	0%	0%	0%	0%	0%	0%	0%
LTC subtotal	**66%**	**70%**	**73%**	**64%**	**67%**	**67%**	**67%**	**66%**	**79%**	**68%**
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
During PC										
Inpatient	5%	4%	3%	3%	3%	5%	4%	4%	3%	4%
Other acute	7%	6%	4%	5%	6%	7%	6%	7%	3%	6%
Acute subtotal	**13%**	**10%**	**7%**	**8%**	**9%**	**11%**	**10%**	**11%**	**5%**	**10%**
Personal care	79%	84%	87%	87%	85%	82%	85%	82%	88%	84%
Home health	2%	3%	4%	2%	2%	2%	2%	1%	3%	2%
Skilled nursing facility	1%	1%	1%	0%	1%	0%	0%	1%	1%	1%
LTHHC	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Adult day care	6%	1%	2%	2%	3%	5%	3%	5%	2%	3%
Managed care	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Other LTC	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
LTC subtotal	**87%**	**90%**	**93%**	**92%**	**91%**	**89%**	**90%**	**89%**	**95%**	**90%**
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
After PC (among those who stopped receiving PC)										
Inpatient	14%	9%	14%	14%	13%	17%	13%	8%	9%	12%
Other acute	6%	5%	4%	5%	6%	5%	6%	5%	6%	5%
Acute subtotal	**20%**	**14%**	**18%**	**19%**	**19%**	**22%**	**18%**	**12%**	**14%**	**18%**
Home health	14%	17%	11%	18%	15%	25%	26%	41%	13%	20%
Skilled nursing facility	47%	49%	62%	57%	56%	44%	51%	44%	63%	52%
LTHHC	6%	3%	2%	1%	3%	1%	0%	0%	0%	2%
Adult day care	2%	0%	0%	1%	1%	1%	0%	1%	0%	1%
Managed care	12%	17%	6%	5%	6%	6%	4%	2%	9%	7%
Other LTC	0%	0%	1%	0%	0%	0%	0%	0%	0%	0%
LTC subtotal	**80%**	**86%**	**82%**	**81%**	**81%**	**78%**	**82%**	**88%**	**86%**	**82%**
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

Note: Columns may not sum to totals due to rounding.

There are several Medicaid services that can be thought of as pathways to personal care: home health services (either short-term or through the LTHHCP), nursing home care, and inpatient hospital admissions. However, 56 percent of personal care recipients in the 2003 cohort began receiving personal care without receiving any of these "pathway" services in the month immediately before (Figure 2). Among the major long-term care services that recipients used prior to their personal care episodes, home health services (not including the LTHHCP) were the leading pathway to personal care for elderly duals. More than one-third of personal care recipients started personal care after receiving home health services.

Figure 2.
Selected Medicaid Long-Term Care Services Received in Month Before Personal Care



These findings imply that beneficiaries are not following common pathways to personal care under Medicaid, such as other long-term care services or hospital inpatient stays. However, it is possible that—were this analysis able to consider experience under both Medicare and Medicaid—personal care recipients would have been seen to follow a more consistent set of pathways.

During Personal Care. Once beneficiaries began using personal care, total annualized Medicaid costs increased—with personal care becoming the largest component of spending. The greater the average monthly personal care usage, the larger the increase in total Medicaid cost. High-intensity recipients' annualized total Medicaid spending was more than twice as high during personal care than before it.

During a personal care episode, average annualized total long-term care expenditures accounted for 90 percent of total Medicaid expenditures, compared to 68 percent before personal care. The higher the average monthly personal care intensity, the greater the share of total Medicaid spending accounted for by long-term care. This increase in long-term care spending was due to personal care services, which constituted 93 percent of total long-term care costs.

During personal care episodes, use of other forms of long-term care substantially declined. Medicaid expenditures for home health, skilled nursing facility, and LTHHCP almost disappeared, leaving personal care as the near-exclusive mode of long-term care (Table 14).

Table 14.
Average Annual Medicaid Spending During Personal Care Use, by Intensity of Spending

Average monthly spending	Low <$1,500		Medium $1,500–$2,499		Medium $2,500–$3,999		High $4,000+		NYC	
Still Receiving PC in 12/08										
Inpatient	467	3%	688	2%	1,145	3%	1,077	2%	878	2%
Other acute	2,633	14%	2,292	8%	2,287	5%	2,425	3%	2,397	6%
Acute subtotal	**3,100**	**17%**	**2,980**	**10%**	**3,432**	**8%**	**3,502**	**5%**	**3,275**	**8%**
Personal care	12,425	67%	23,265	81%	36,995	87%	64,331	91%	36,578	86%
Home health	281	2%	597	2%	910	2%	1,302	2%	820	2%
Skilled nursing facility	90	0%	144	1%	167	0%	327	0%	192	0%
LTHHC	0	0%	117	0%	58	0%	73	0%	66	0%
Adult day care	2,580	14%	1,467	5%	748	2%	1,103	2%	1,392	3%
Managed care	26	0%	66	0%	32	0%	21	0%	36	0%
Other LTC	0	0%	18	0%	9	0%	28	0%	15	0%
LTC subtotal	**15,402**	**83%**	**25,676**	**90%**	**38,920**	**92%**	**67,186**	**95%**	**39,098**	**92%**
Total	**18,508**	**100%**	**28,659**	**100%**	**42,352**	**100%**	**70,688**	**100%**	**42,376**	**100%**
Stopped Receiving PC Before 12/08										
Inpatient	1,891	10%	3,354	10%	3,089	7%	1,800	3%	2,516	6%
Other acute	2,532	13%	2,693	8%	2,583	6%	2,233	3%	2,499	6%
Acute subtotal	**4,423**	**23%**	**6,047**	**19%**	**5,672**	**12%**	**4,034**	**6%**	**5,015**	**12%**
Personal care	11,440	60%	23,014	72%	37,240	82%	60,378	90%	34,492	81%
Home health	733	4%	953	3%	1,261	3%	1,427	2%	1,115	3%
Skilled nursing facility	196	1%	305	1%	464	1%	375	1%	340	1%
LTHHC	63	0%	24	0%	71	0%	23	0%	45	0%
Adult day care	2,219	12%	1,574	5%	777	2%	782	1%	1,295	3%
Managed care	16	0%	28	0%	41	0%	74	0%	41	0%
Other LTC	0	0%	8	0%	0	0%	27	0%	10	0%
LTC subtotal	**14,667**	**77%**	**25,907**	**81%**	**39,855**	**88%**	**63,085**	**94%**	**37,338**	**88%**
Total	**19,091**	**100%**	**31,955**	**100%**	**45,526**	**100%**	**67,119**	**100%**	**42,354**	**100%**

Columns may not sum to totals due to rounding.

Annualized costs for home health, skilled nursing facility, and long-term home health care each fell by at least 90 percent during personal care episodes. The higher the monthly personal care use intensity, the greater the decrease in costs among other long-term care services. Moreover, since greater long-term care service use before personal care was correlated with more intense personal care utilization, these trends suggest that personal care was substituting for the range of long-term care services delivered before personal care.

Adult day care was the one long-term care service for which utilization and annualized Medicaid costs substantially increased during personal care episodes. Lower-intensity personal care beneficiaries used more adult day care, indicating that at the lower intensity levels, adult day care and personal care at least complement each other, with personal care aides providing the necessary support for beneficiaries to travel from home in order to receive services. Lower-intensity personal care recipients may be able to use more adult day care because they may have higher functional status; mental illness was less prevalent among lower-intensity personal care beneficiaries.

At every intensity level, the dollar amount of annualized personal care expenditures was similar regardless of whether a beneficiary continued receiving personal care or not. However, personal care costs constituted a higher share of average total Medicaid expenditures for those whose episodes continued, because those who terminated their personal care episodes before the end of the study period had substantially more acute care spending during their personal care episodes.

While annualized total acute costs for both groups decreased significantly compared to costs before personal care (by 54 percent for those who continued receiving personal care and by 41 percent for those who did not), total acute costs during personal care episodes on average were 1.5 times greater for those who stopped receiving personal care: $5,015 compared to $3,275 for those who kept receiving it. Since other acute spending was roughly equivalent for the two groups, beneficiaries who terminated personal care services before the end of the study period had higher inpatient costs during personal care episodes. For those who stopped receiving personal care, annualized inpatient costs declined by an average of 60 percent, from $6,222 to $2,516. For those who kept receiving personal care, annualized inpatient costs decreased by an average of 80 percent, from $4,936 before personal care to $878 during personal care. The divergent declines in acute expenditures, particularly for inpatient hospital costs, suggest that those who stopped receiving personal care had greater acute care needs, which in turn may have caused them to move from personal care to more intensive settings.

While there was some variation in other service use during personal care, all personal care recipients had remarkably similar annualized total Medicaid costs during personal care episodes, regardless of CASA and variation in other services (Table 13, and the discussion of personal care use above). Overall Medicaid costs were relatively uniform across the city during personal care episodes because personal care accounted for the vast majority of total Medicaid expenditures.

After Personal Care. This section focuses on the two-thirds of the sample cohort who terminated a personal care episode before the end of the study period. Since this analysis relies on Medicaid paid claims data, there is no way to know what happened to former personal care recipients who left Medicaid. We assume that some of these beneficiaries died, but the claims data do not indicate which ones. Half of this group were not enrolled in Medicaid at the end of the study period, and there is no information on Medicare service use, which plays a central role in end-of-life care. Within these limitations, this section thus considers service use and spending for former personal care recipients who remained on Medicaid.

For those beneficiaries who remained enrolled in Medicaid after their personal care episodes ended, annualized total Medicaid costs were higher after personal care than during personal care for all but the formerly high-intensity personal care recipients. Moreover, total Medicaid costs after personal care were higher than costs before personal care for all recipients. Medicaid spending on acute care remained roughly equivalent before and after personal care. Thus, the increase in total Medicaid expenditures post-personal care resulted primarily from an increase in long-term care service use and spending. During personal care, annualized total long-term care expenditures doubled, compared to before personal care, and long-term care costs remained at this level after personal care episodes ended. After personal care, long-term care spending constituted 82 percent of annualized total Medicaid expenditures per year, close to the 88 percent share of total Medicaid cost during personal care (Tables 14, 15). The sustained increase in long-term care costs is not surprising, given that an aging cohort of personal care recipients will decline in health and functional status over time. Nevertheless, it is notable that the end of personal care episodes was not marked by a decline in Medicaid long-term care spending for those still on Medicaid.

Table 15.
Average Annual Medicaid Spending After Personal Care Use, by Intensity of Spending

Average monthly spending	Low <$1,500		Medium $1,500–$2,499		$2,500–$3,999		High $4,000+		NYC	
Inpatient	5,639	15%	4,915	11%	7,380	14%	3,944	8%	5,568	12%
Other acute	2,372	7%	2,708	6%	1,950	4%	2,477	5%	2,388	5%
Acute subtotal	**8,011**	**22%**	**7,623**	**17%**	**9,330**	**17%**	**6,422**	**12%**	**7,956**	**18%**
Home health	7,908	22%	8,317	18%	10,441	19%	12,080	23%	9,101	20%
Skilled nursing facility	14,521	40%	25,259	55%	32,436	59%	31,671	60%	23,248	52%
LTHHC	1,648	5%	656	1%	162	0%	120	0%	883	2%
Adult day care	512	1%	226	0%	85	0%	259	0%	318	1%
Managed care	3,803	10%	3,802	8%	2,105	4%	1,620	3%	3,158	7%
Other LTC	25	0%	25	0%	0	0%	386	1%	70	0%
LTC subtotal	**28,416**	**78%**	**38,284**	**83%**	**45,229**	**83%**	**46,136**	**88%**	**36,779**	**82%**
Total	**36,427**	**100%**	**45,907**	**100%**	**54,559**	**100%**	**52,557**	**100%**	**44,735**	**100%**

Columns may not sum to totals due to rounding.

Beneficiaries who stopped using personal care tended to transition to other long-term care services; the most common were skilled nursing facilities and home health services. On average, nursing home care accounted for over half of annualized total Medicaid spending after personal care, roughly seven times the amount and five times the share spent on nursing homes before personal care. The more personal care a beneficiary used, the greater the annualized Medicaid expenditures for skilled nursing care after personal care. This relationship is consistent with beneficiaries experiencing declines in health and functional status and requiring more intense services.

After skilled nursing facilities, home health was the next greatest source of long-term care costs when personal care episodes ended. Unlike skilled nursing facility services, home health spending after personal care tended to be equal to or less than home health costs before personal care. For low- and low-medium intensity personal care recipients, costs for home health returned to roughly the same share of annualized total cost as before personal care. High-medium and high-intensity personal care beneficiaries spent markedly less on home health after personal care, and home health's shares declined by one-third and one-half, respectively. Personal care intensity was not strongly correlated with home health costs after personal care episodes ended; all groups of former personal care recipients had similar annualized home health costs.

Notably, inpatient costs rebounded after personal care. This pattern is consistent with the continued decline in health status and functional ability of an elderly population. For those who stopped receiving personal care, annualized inpatient costs after personal care were approximately the same as before personal care for low-intensity personal care beneficiaries, and were lower than before personal care for all other intensity levels. The continued decline in inpatient costs at higher personal care intensity levels, combined with the greater nursing care uptake at these levels, suggests that beneficiaries left personal care because of declines in functional ability, and not necessarily due to acute health care needs. The rebound in inpatient costs and the significant and continuing long-term care spending suggest that elderly dual beneficiaries who received personal care services continued to experience declining health and functional status.

As noted earlier, there was a slight variation in total Medicaid service use and spending by CASA before personal care episodes began, primarily driven by variation in long-term care service use and spending. This variation essentially disappeared during personal care episodes because personal care costs, which were almost identical across CASAs, made up most of total Medicaid spending. After personal care episodes ended, significant variation in total Medicaid spending by CASA returned, again driven primarily by variation in long-term care costs (Table 13). After personal care episodes, annualized Medicaid spending on acute care services varied only slightly by CASA.

Implications for Policy

Because personal care is part and parcel of three major challenges for Medicaid, it can play a role in addressing each one. The first major policy challenge is managing the care of complex and high-cost Medicaid beneficiaries, including those reliant on long-term care, to ensure the delivery of appropriate and cost-effective services in the appropriate setting. Personal care occupies a unique space in this discussion. While in many cases it can reduce reliance on other, more costly services covered by Medicaid, personal care is not a health care service per se. Compared to health care services, there is less certainty about when personal care is indicated; when it is indicated, there is much less certainty about how much personal care is appropriate. Often, the level of support available from family caregivers will determine a beneficiary's level of service. And distinct from many other Medicaid services, there may be no such thing as too many personal care hours from the perspectives of recipients and their advocates.

The findings in this analysis about the intensity and duration of personal care service use support the notion that appropriate personal care use may be difficult to determine and define, especially because patient characteristics and health service spending before personal care do not appear to predict the length of a personal care episode. Both shorter-term recipients, those receiving personal care for an average of two years, and longer-term recipients, those receiving personal care for an average of six years, were diagnosed with key health conditions at similar rates, and had comparable Medicaid spending on other health care services in the year prior to a personal care episode. However, personal care recipients' diagnostic history and Medicaid spending before receiving personal care were more closely related to average monthly personal care use. More detailed data on key diagnoses, including the severity of illness and functional status, would help inform further analysis of personal care recipients and their Medicaid service use and spending.

A second key policy challenge is containing Medicaid spending in the context of a severe state budget deficit—an imperative that spans the Medicaid program as a whole. The long-term patterns of service use and spending by personal care recipients revealed by this analysis pose implications for Medicaid cost containment. In general, elderly New Yorkers were not enrolling in Medicaid principally to receive personal care. Moreover, when a beneficiary began a personal care episode, total Medicaid costs increased due to new spending on personal care, despite a dramatic drop in Medicaid spending on acute and other long-term care services. When beneficiaries stopped receiving personal care, spending remained elevated, mainly as a result of increased reliance on other long-term care services. This trajectory of overall spending indicates that once Medicaid beneficiaries become personal care recipients they typically will not revert to lower levels of service use or cost. This finding highlights the magnitude and complexity of the care management and cost containment challenges faced by policymakers.

A third important policy challenge is ensuring that Medicaid has an administrative structure that supports the design and implementation of coherent and effective policy and purchasing decisions, and that the program uses scarce administrative resources efficiently. Personal care is one of the few services for which local governments—the state's 57 counties and New York City—play key roles in Medicaid administration. In New York City, the Human Resources Administration (HRA)—the city's local district social services (LDSS) office—uses nine CASA offices situated throughout the city to process applications for personal care assistance, administer authorizations for services, and monitor the cases of recipients. While these CASAs are bound by the same state policies, subject to the same city administrative rules, and accountable to a central office within HRA, there is in practice a decentralized decision-making process governing which Medicaid beneficiaries receive personal care, and how much they receive. This model raises questions of consistency.

This analysis found that some patterns of personal care service use and spending varied by CASA, while others were uniform. There was substantial variation in the rates of personal care utilization across New York City by CASA. For instance, elderly duals in two CASAs, Brooklyn Central and Brooklyn Southwest, were twice as likely to receive personal care as their counterparts in five of the other seven CASAs. However, despite variation in rates of personal care uptake, there is uniformity throughout New York City in the volume of personal care services delivered per episode. Both the average annualized personal care cost and the average number of months that beneficiaries received personal care were almost identical across the nine CASAs. This uniformity was somewhat surprising, given the variation by CASA in personal care recipients' underlying health status. The combination of variation and uniformity in personal care use patterns points to a need for clear data and robust data management systems. More complete information will help policymakers determine whether variation supports or undermines effective management of the personal care program.

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