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## Living at the thin margin of health: Out-of-pocket health care spending by Medicaid beneficiaries with disabilities

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### Abstract

When considering the plight of community-dwelling adults with disabilities who are Medicaid beneficiaries – a population with a thin margin of health – cost-related barriers to care with potential adverse consequences are a real, yet largely unexplored, matter of concern. Using national survey data, we find that the Medicaid program effectively limits out-of-pocket health care spending for the majority of these individuals. However, for 10 percent of them, annual out-of-pocket spending is \$1200 or higher. As state policymakers contemplate benefit reductions that could increase cost-shifting to Medicaid beneficiaries, careful consideration must be given to potential impacts on this particularly vulnerable “high spender” group.

### Introduction

The disproportionately high cost and complexity of offering health care to adult Medicaid beneficiaries with disabilities has long-captured the attention of Medicaid policymakers.(1) Medicaid, a joint federal-state health insurance program for low income individuals, shoulders substantial responsibility for the payment and provision of their health care. Beneficiaries with disabilities represent 16% of the Medicaid population but account for 43% of its health care expenditures.(2) Moreover, their Medicaid enrollment is likely to be of long duration.(3) Thus, states are redesigning health care delivery for this population to simultaneously contain Medicaid spending and improve health care quality. To inform these evolving care models, Medicaid programs and their research partners have studied health care utilization patterns and program-borne expenditures for adults with disabilities (AWDs), particularly among the highest cost beneficiaries.(4) Less attention has been given, thus far, to the health care expenditures borne by the beneficiaries themselves. Yet, out-of-pocket spending levels may signal cost-related barriers to care and unmet health care needs that are relevant to the redesign of care for non-institutionalized AWDs.

High out-of-pocket spending burden is associated with forgoing needed medical treatment to pay for basic goods. In turn, cost-related treatment non-adherence is associated with an increase in cost-ineffective care -- including increased nursing home admissions, emergency department

visits, non-elective hospitalization, and poor clinical outcomes -- for a variety of health conditions.(5–7) Recent estimates of out-of-pocket spending among publicly insured individuals are not specific to adults with disabilities; however, they reveal that substantial spending is common. Among non-elderly, poor individuals with public insurance, about 16%, or 6.4 million individuals, live in families that spend more than 10% of their total after-tax family income on health care.(8)

The negative consequences of burdensome out-of-pocket health care spending may be magnified for AWDs, a population that has been described as having a thin margin of health. (9) Their disabling physical or mental health impairment places them at increased risk of secondary conditions and co-morbidities.(10) The health of Medicaid beneficiaries with disabilities may be particularly precarious as they possess few financial resources to apply to health maintenance. The vulnerability created by the combination of compromised health and socioeconomic status increases the importance of adequate health insurance and care delivery in order to maintain health and function.

Importantly for policymakers, factors within their control can substantially influence out-of-pocket health care spending levels. Such spending is sensitive to insurance benefit design, and to the types of utilization and cost-management strategies that state Medicaid programs deploy, such as co-payments, prior authorization policies, preferred drug lists, etc. Thus, to the extent that adults with disabilities experience high out-of-pocket spending with possible adverse effects, policy-makers can respond by redesigning health benefits, care delivery and management policies.

In this study, the first to estimate out-of-pocket expenditures among adult Medicaid beneficiaries with disabilities, we find that such spending, although prevalent, is generally modest and concentrated on prescription medications. However, 10% of these beneficiaries spend more than \$1200 annually. We argue that as states modify covered benefits to contain Medicaid spending growth, it will be particularly important to consider the impact for this “high-spender” sub-group.(11)

## Study data and methods

We pool data from the Medical Expenditure Panel Survey, 2001–2004, for this study.(12) This representative survey of the U.S. civilian non-institutionalized population consists of five in-person interviews over thirty months to yield health care use and expenditure data for two calendar years per household member. Household members report their use of health care services and supplies for inpatient visits, prescription medication use, ambulatory care, emergency department, home health, dental and other (e.g., durable medical equipment). We construct a dataset in which each observation is a person-year; each individual may contribute up to two observations in the dataset.

The sample includes full-year Medicaid beneficiaries ages 18–64 who participate in the federal cash assistance program for persons with disabilities, Supplemental Security Income, the primary path to Medicaid eligibility for adults with disabilities. It is a federal means-tested program for persons with physical or mental health impairments that substantially limit their capacity to work. Generally, an individual may not possess more than \$2000 in assets (excluding home, car, and personal effects) nor have an income that exceeds 75% of the federal poverty level to qualify for Supplemental Social Security cash assistance (e.g., \$6,983 in 2004). (13) Disabled Medicare beneficiaries also enrolled in Medicaid (“dual eligibles”) are excluded from this study as states have limited authority over the design of their benefits and care delivery. The unweighted sample includes 1175 person-years.

Evaluations of out-of-pocket health care spending typically take one of two approaches: analyzing the actual level of spending, or examining spending as a portion of disposable income.(8;14;15) We adopt the former approach as our primary aim is to describe the prevalence, amount, and allocation of out-of-pocket spending to inform Medicaid benefit and health care delivery design. Our initial analyses describe aggregate annual Medicaid and out-of-pocket spending for the beneficiary population. We follow these analyses with beneficiary-level estimates of out-of-pocket spending, its prevalence, magnitude, and allocation across service categories. Finally, we conduct bivariate and multivariable logistic regression analyses comparing the characteristics of beneficiaries with high and low annual out-of-pocket expenditures, to identify potential risk factors at the high end.

We define high and low annual out-of-pocket expenses as those above and below \$350, respectively. This spending level represents approximately 5% of the maximum income allowed for Supplemental Social Security program participation, an expense-to-income ratio considered burdensome for low-income populations.(14) As potential risk factors for high out-of-pocket spending, we examine the socioeconomic, health status, and health care delivery factors that research has consistently found associated with out-of-pocket spending, such as age, sex, and health status.(14;16) All analyses are weighted to represent the non-institutionalized adult Medicaid population with disabilities. Standard errors account for the complex survey design of the Medical Expenditure Panel Survey. Dollars are converted to constant 2004 dollars using the consumer price index for urban households.

## Results

Aggregate annual Medicaid health care expenditures for the program's 1.8 million community-dwelling AWDs are approximately \$11.6 billion as shown in Exhibit 1. Total annual out-of-pocket expenditures for this population are \$873 million. At the population level, prescription medicines command the largest amount of this spending, \$637 million, followed by ambulatory care, at \$151 million.

Annual outcomes per beneficiary are summarized in Exhibit 2. Most beneficiaries, 82% on average, report incurring an out-of-pocket health care expense during the year. Approximately 79% state they do so for prescription medications, while only 5% report doing so for hospital care. The distribution of total annual per beneficiary out-of-pocket spending is highly skewed. At the median, beneficiaries spend \$87. This amount increases to \$406 at the 75<sup>th</sup> percentile and over \$1200 at the 90<sup>th</sup> percentile of the spending distribution. Consistent with the aggregate results, prescription medications command the largest share, 80% on average, of out-of-pocket spending per beneficiary. Ambulatory care accounts for the second largest share, approximately 11%.

As shown in Exhibit 3, high out-of-pocket spenders (over \$350 per year) tend to be older, female, and in fair or poor physical health. They are also more likely to report having at least one limitation in activities of daily living (such as bathing, toileting, or dressing). In our regression adjusted findings, these factors persist in their association with high total out-of-pocket spending, though point estimates are imprecise. Men had lower odds of being in the high-spending group (OR = .58,  $p < .01$ ). Self-reported fair or poor physical health status significantly raised the odds of being in the high-expense group, as did the presence of a limitation in activities of daily living. The characteristics associated with high out-of-pocket spending level for prescription drugs mirror these results.

## Discussion

The budgetary impact of adult Medicaid beneficiaries with disabilities places them at the center of ongoing health care redesign efforts across the country.(17) However, evaluations of these reforms often lack an examination of cost-related barriers to care despite the sensitivity of AWDs to the accessibility of their health systems.(18;19) In this study, we examine one potential measure of cost-related barriers to care, out-of-pocket health care spending. We find that such spending is prevalent among AWDs, although the annual level is modest for most beneficiaries and concentrated on prescription medications. However, it is also highly skewed, with 10% of beneficiaries, approximately 182,000 beneficiaries spending more than \$1200 annually.

The substantial out-of-pocket expenditures that we observe for prescription drugs is not altogether surprising. While all Medicaid programs provide coverage for prescription medications, they also commonly implement co-payments, limits on the number of prescriptions, and utilization management strategies (e.g., prior authorization practices and preferred drug lists) to contain costs.(20) Co-payments alone are unlikely to explain substantial out-of-pocket spending, as they typically do not exceed \$3 per prescription (even after the Deficit Reduction Act's authorization of higher and enforceable co-payments(21)). The prescription limits, prior authorization policies and/or preferred drug lists that operate in 42 state Medicaid programs(21) may offer a more plausible explanation for personal spending on prescription drugs. These cost-containment policies are relatively effective at reducing the payer's, and increasing the individual's, spending on prescription medications.(22) However, within the Medicaid population, they are also associated with treatment discontinuity, unfavorable clinical outcomes and increased expenditures for other health care services.(23–25) Given the magnitude of out-of-pocket spending on prescription medications, comparative state policy evaluation is a necessary next step in understanding how policymakers may mitigate this burden among AWDs.

We observe a strong association between poor physical health and functional status and high out-of-pocket spending. The cross-sectional design of our study prevents us from determining whether poor health precipitates, or results from, the high spending. Nor are we able to observe how OOP spending influences subsequent health care outcomes, such as access to needed medical care and medications. Longitudinal research that dually considers the predictors and effects of out-of-pocket spending on health, care access and resource use in Medicaid's AWD population is needed, so that programs can evaluate the costs and benefits of their beneficiary cost-sharing policies.

Our results should be interpreted in light of the study's strengths and weaknesses. While we observe the presence or absence of out-of-pocket spending, we do not observe the extent to which community-dwelling beneficiaries with disabilities can or do substitute medical care for other basic goods and services, such as food and utilities. Thus, low (or no) OOP spending may reflect an individual's limited resources, rather than indicate that medical needs are satisfied at little or no cost to the individual.(8) Similarly, high OOP spending may indicate that needed medical care is obtained, but basic goods are forgone in the process. A growing body of research examines such trade-offs between medical and other goods for the older Medicare and Medicaid enrollees.(26;27) Parallel research specific to Medicaid-only disabled beneficiaries has not yet emerged.

The causes and consequences of high out-of-pocket spending among community-dwelling AWDs merit particular attention in light of the severe budget constraints that states face and the limited options at their disposal to reduce Medicaid spending. Recent federal legislation, both the American Recovery and Reinvestment Act and the Patient Protection and Affordable

Care, require states to maintain Medicaid eligibility criteria for most populations.(28;29) Thus, to combat growth in Medicaid spending, states are reducing covered benefits and provider payments.(11;30) In late 2009, almost 30 state Medicaid programs expected to make cuts in benefits or provider payments within the fiscal year.(31) The unique health and socioeconomic profile of community-dwelling Medicaid AWDs calls for examination of how these programmatic changes may impact their personal spending burden and potential downstream consequences.

## Conclusion

Our findings suggest that for most community-dwelling adult beneficiaries with disabilities, the Medicaid program effectively limits personal spending on health care -- as intended. However, for at least 10% of this population, out-of-pocket spending is substantial relative to programmatic income eligibility thresholds. While state Medicaid programs consider implementing benefit reductions to meet balanced budget requirements, careful consideration of this small, yet highly vulnerable, beneficiary group should not be overlooked.

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**EXHIBIT 1**

Annual aggregate Medicaid and out-of-pocket spending for adult beneficiaries with disabilities (\$2004)

<b>Population</b>	1,823,450
<b>Total Medicaid expenditures</b>	\$11,570 million
<b>Total out-of-pocket spending</b>	\$873 million
<b>Out-of-pocket spending by service category</b>	
<b>Prescription medications</b>	\$637 million
<b>Ambulatory care</b>	\$151 million
<b>Other medical<sup>a</sup></b>	\$65 million
<b>Hospital care (inpatient &amp; emergency)</b>	\$21million

Source: Authors' calculation using pooled data from the MEPS, 2001–2004

<sup>a</sup>Other medical includes home health, durable medical supplies/equipment, and dental



Annual per beneficiary out-of-pocket spending among adult Medicaid beneficiaries with disabilities

EXHIBIT 2

	Total	Prescription Medications	Ambulatory Care	Other Medical	Hospital (Inpatient & Emergency)
<b>Population with out-of-pocket spending</b>					
Mean share of population with any out-of-pocket spending [95% C.I.]	.82 [.79, .86]	.79 [.75, .82]	.31 [.27, .34]	.15 [.12, .17]	.05 [.03, .07]
<b>Out-of-pocket expenditures (\$2004)</b>					
Expenditures at select percentiles (\$2004)					
25 <sup>th</sup> Percentile	9	2	0	0	0
Median	87	53	0	0	0
75 <sup>th</sup> Percentile	406	300	3	0	0
90 <sup>th</sup> Percentile	1272	1001	58	20	1
Mean share of out-of-pocket spending allocated to each service <sup>b</sup> [95% C.I.]	1 [.77, .83]	.80 [.77, .83]	.11 [.09, .13]	.08 [.06, .10]	.02 [.01, .03]

Source: Authors' calculation using pooled data from the MEPS, 2001–2004

<sup>a</sup>Other medical includes home health, durable medical supplies/equipment, and dental

<sup>b</sup>Among beneficiaries with any out-of-pocket spending in the year.



**EXHIBIT 3**

Beneficiary characteristics by annual level of out-of-pocket expenses, adult Medicaid beneficiaries with disabilities

<b>Total Out-of-pocket Spending</b>			
	<b>Low (&lt; \$350)</b>	<b>High (≥ \$350)</b>	<b>Regression-adjusted difference between high and low spenders Odds Ratio, [95% CI]</b>
Age (mean)	43	47*	<b>1.02 [1.01, 1.04]</b> *
Female (%)	.58	.74*	<b>1.73 [1.18, 2.55]</b> *
Non-White (%)	.44	.44	1.13 [.79, 1.64]
Education above high school/GED (%)	.46	.53	1.40 [.97, 2.00]
Fair/poor physical health (%)	.49	.73*	<b>2.31 [1.53, 3.48]</b> *
Fair/poor mental health (%)	.38	.44	.99 [.70, 1.39]
Any limitation in activities of daily living (ADL) (%)	.09	.18*	<b>2.61 [1.40, 4.88]</b> *
Any limitation in instrumental activities of daily living (IADL) (%)	.22	.31^	1.06 [.66, 1.71]
Residence in metropolitan statistical area (%)	.73	.70	.77 [.53, 1.13]
Managed care (%)	.44	.41	.83 [.57, 1.19]
<b>Prescription Medications Out-of-pocket Spending</b>			
Age (mean)	43	48*	<b>1.03 [1.01, 1.05]</b> *
Male (%)	.60	.74*	<b>1.66 [1.10, 2.50]</b> ^
Non-White (%)	.44	.44	1.16 [.78, 1.74]
Education above high school/GED (%)	.46	.53^	1.23 [.83, 1.84]
Fair/poor physical health (%)	.50	.75*	<b>2.39 [1.54, 3.71]</b> *
Fair/poor mental health (%)	.39	.43	.87 [.62, 1.23]
Any limitation in activities of daily living (ADL) (%)	.09	.19*	<b>2.84 [1.53, 5.25]</b> *
Any limitation in instrumental activities of daily living (IADL) (%)	.23	.29	.95 [.61, 1.48]
Residence in metropolitan statistical area (%)	.74	.67	.67 [.45, 1.00]^
Managed care (%)	.43	.44	1.08 [.75, 1.55]

Source: Authors' calculation using pooled data from the MEPS, 2001–2004 Regression models additionally adjust for census region and survey year.

\* statistically different from low group,  $p < .01$

^ statistically different from low group,  $p < .05$