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Expenses and Burden, 1996-2004**

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## ABSTRACT

**Objective:** This paper estimates the healthcare expenditures associated with a disability and their recent trends.

**Design:** Retrospective analysis of survey data

**Participants:** Data from multiple years (1996 through 2004) of the Medical Expenditure Panel Survey (MEPS) for a nationally representative sample of civilian, non-institutionalized US population.

**Interventions:** Not applicable

**Main Outcome Measures:** Healthcare expenditures consisted of: total healthcare expenditures, total out-of-pocket spending (OOP), and burden (the ratio of OOP to family income). All the analyses accounted for the complex survey design of the MEPS.

**Results:** Between 1996 and 2004, 6% to 9% of individuals in the working age group (21-61 years) were identified as having a disability. Persons with disabilities consistently had higher total health expenditures, OOP and burden compared to their counterparts without disabilities. In 2004, the average total expenditures were estimated at \$10,508 for persons with disabilities and at \$2,256 for those without disabilities. In a multiple regression framework, persons with disabilities were consistently found to have higher expenditures, OOP and burden between 1996 and 2004. Although expenditures, OOP and burden increased over time, after controlling for demographic, socio-economic, and health status, these three healthcare costs were not found to change disproportionately for individuals with disability.

**Conclusions:** Over the 1996-2004 period, persons with disabilities were consistently found to have significantly higher health expenditures, OOP and burden compared to their counterparts without disabilities, which may adversely affect their health and standard of living.

**Key Words:** Disability, Health Expenditures, Out of Pocket Expenditures, Burden.

## INTRODUCTION

It is estimated that, in the United States, between 40 and 50 million people have a disability.<sup>1</sup> For working age individuals, recent estimates range between 20 and 23 million.<sup>2</sup> During the 1990s, the disability prevalence rate among the working age population increased.<sup>3</sup> At the same time, among all adults younger than 65 years, healthcare costs have been rising and an increasing proportion of family budgets have been for out-of-pocket (OOP) spending<sup>4</sup>, particularly if the individuals have chronic health conditions, i.e. medical conditions that require ongoing treatment.<sup>5</sup> For those under 65 with chronic conditions, the highest OOP expense has been reported to be physician office visits, and if they are uninsured, they are five times less likely to see a medical provider than those with insurance in a given year.<sup>6</sup> There have been studies of trends in expenditures for specific chronic conditions.<sup>7</sup> However, such studies do not cover the expenditures associated with disability because disability is not a medical attribute of the individual. Indeed, disability has increasingly been considered as taking place at the interface of the individual and the physical and social environment. Having a disability does not require having a medical chronic condition, and in reverse, a medical chronic condition does not necessarily lead to a disability. Among persons with disabilities, several studies have demonstrated that persons with disabilities face, compared to those without disability, higher cost-of-living in general,<sup>8</sup> and higher healthcare expenditures in particular.<sup>9</sup> It has also been noted that activity limitations alone increase the cost of care.<sup>10</sup> The financial burden of OOP spending as a proportion of total family income was 2.5 times greater for a family with a person with disability compared to families without a person with a disability in 1987,<sup>11</sup> even after controlling for availability of healthcare insurance.

It is essential to understand how the increasing trend in healthcare expenditures, OOP, and burden for the general population is affecting persons with disabilities for several reasons. It has been shown that poor families with a member with a disability resort to healthcare rationing.<sup>11</sup> Recent trends in health expenditures for working age persons with disabilities may also have implications for future healthcare spending as this population becomes older and eligible for Medicare.<sup>12</sup> A major policy concern has been that the rising cost of healthcare has contributed to the decline in the employment of persons with disabilities of the 1990s, but evidence of an impact on health insurance is unclear.<sup>13</sup> Finally, several policy initiatives over the 1990s and early 2000s were expected to affect persons with disabilities' access to healthcare services and insurance (e.g., Medicaid Buy-in programs for persons with disabilities). Past research has shown that persons with disabilities overall have greater healthcare expenditures than their counterparts without disabilities but estimates of the magnitude of extra healthcare expenditures are outdated. For example, using 1997 Medical Expenditure Panel Survey (MEPS) data, Yelin, Cisternas and Trupin<sup>9</sup> find that a person with a disability faces an increment in medical care expenditures of \$2,953 beyond what would be expected of similar persons without disabilities. Persons with disabilities often, but not always, need substantial healthcare services and support.<sup>14</sup> For example, a person who loses a limb may experience a high demand for healthcare in the short term, but not after the condition has stabilized.<sup>13</sup> It is also possible that persons with disabilities underutilize healthcare services due to their limited access to healthcare providers and facilities,<sup>15, 16</sup> which may result in lower healthcare expenditures.

However, for total health expenditures, we expect to find an increase for persons with disabilities that is disproportionate compared to persons without disabilities due to several key

developments in federal policies, the 1990 American with Disabilities Act (ADA) and the 1999 Olmstead decision in particular. One may expect greater access to healthcare services for persons with disabilities made possible by the ADA. Title II of the ADA protects qualified individuals with disabilities from discrimination on the basis of disability in accessing services, programs, or activities provided by state and local governments. Title III prohibits discrimination against individuals with disabilities by places of public accommodation and private healthcare providers are considered places of public accommodation. However, the ADA did not specifically prohibit private insurance companies from discriminating on the basis of actuarial risk. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 did attempt to extend coverage to individuals with pre-existing conditions, but this protection, together with that of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986, is hardly sufficient.<sup>17, 18</sup> In addition, the Supreme Court's Olmstead decision of 1999 may have also put some upward pressure on health expenditures for persons with disabilities. This decision challenged states to provide community placements and develop more accessible services for persons with disabilities, and continued a move toward deinstitutionalization started in the early 1980s. Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981 (Public Law 97-35), added section 1915(c) to the Social Security Act for the Medicaid program to create Home and Community-Based Services Waivers, states were allowed to waive or set aside some of the Medicaid provisions to allow long-term care services to be delivered in community settings outside of institutional settings for those with disabilities. Being in the community may generate expenditures to the individual which were previously covered through an institution.

While total health expenditures are expected to have increased disproportionately more for persons with disabilities, OOP and burden on the contrary may have increased

disproportionately less for persons with disabilities compared to their counterparts without disabilities. Indeed, several policy initiatives developed at the federal and state level in the 1990s and 2000s may have placed a downward pressure on OOP and burden among persons with disabilities. There have been several initiatives to make public health insurance benefits more widely available among persons with disabilities, and in particular to break the link between public health insurance benefits (Medicaid and Medicare) and income support benefits, i.e. Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Most notably, Section 4733 of the Balanced Budget Act of 1997 and provisions of the Ticket to Work and Work Incentives Improvement Act of 1999 (Ticket to Work Act thereafter) encouraged, but did not require, states to implement Medicaid buy-in programs, under which workers with disabilities that would qualify for SSI or SSDI but earn more than the allowable limits for regular Medicaid, can purchase Medicaid benefits at a heavily subsidized premium. Thirty-two states have implemented the Medicaid Buy in Program. Finally, OOP and burden may have been influenced by general developments related to disability benefits for persons with disabilities. Disability benefit programs such as SSDI and SSI have grown very rapidly through the 1990s and early 2000s,<sup>19</sup> which may have had an effect on the personal income of persons with disabilities and reduced OOP through access to Medicare and Medicaid respectively. Overall, the expected increase in public health insurance coverage leads us to expect that OOP and burden for persons with disabilities would have increased disproportionately less than for their counterparts without disabilities.

Despite increased disability prevalence among working age individuals, very little is known about healthcare expenditures, OOP and burden among persons with disabilities and their recent trends. To the best of our knowledge, no study has so far assessed, based on recent data



the disparity and trends in healthcare expenditures, OOP, and burden across disability status. The objective of this study is to compare healthcare expenditures, OOP, and burden for individuals with and without disabilities aged between 21 and 61 years and their trends between 1996 and 2004 using nationally representative household data from the Medical Expenditure Panel Survey (MEPS). This study takes the perspective of the individual living with the disability rather than the perspective of insurers or society-at-large coping with the costs, as so frequently reported.<sup>20</sup> Our hypotheses are that, for persons with disabilities compared to persons without disabilities, (i) expenditures, OOP and burden are consistently higher, (ii) total health expenditures have disproportionately increased while (iii) OOP and burden have increased relatively less over the 1996-2004 period.

## **METHODS**

### **Data Source**

We used data from the household component of the MEPS. The MEPS, which began in 1996, is a nationally representative household data set on healthcare use, expenditures, sources of payment, and insurance coverage for the non-institutionalized civilian population. The MEPS also collects detailed information on activity and functional limitations, which are used in our paper to define disability. The MEPS has an overlapping panel design: for each panel, six rounds of interviews are conducted over a period of two and a half years. We used data from selected years only (1996, 1998, 2000, 2002 and 2004) to avoid repeated observations.

### **Participants**

We restricted our study sample to individuals in the working age group (i.e. between 21 and 61 years). We used 61 years as the cut-off point instead of 64 to avoid including persons who have transitioned to early retirement under the Social Security Administration Old Age

program. We also excluded part year observations (e.g., individuals who died during the calendar year\*, individuals who could not be located). Thus, our final study sample consisted of 10,987 individuals in 1996, 11,407 in 1998, 12,082 in 2000, 18,854 in 2002 and 16,459 in 2004.

***Disability definitions.*** Defining and measuring disability is challenging. Disability has been defined through different conceptual models that lead to different measures.<sup>†</sup> For instance, in the medical model, disability is caused by a disease, an injury or other health conditions and requires medical care in the form of treatment and rehabilitation. Under this model, an individual with any impairment is considered disabled, regardless of whether the person experiences limitations in his or her life activities due to the impairment. An impairment is an anatomical or physiological loss (deaf, blind) caused by a pathology. On the other hand, in the social model, disability is understood as a social construct; “disability is not the attribute of an individual, instead it is created by the social environment and requires social change.”<sup>21</sup> A third model of interest is the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization. ICF is conceptually an integration of the medical and the social models.<sup>22</sup> In the ICF, disability is an umbrella term, which covers impairments, functional limitations (e.g. limitation in walking) and participation restrictions (e.g. restrictions in employment). In addition to the conceptual challenge of defining disability, several researchers have empirically demonstrated the importance of using multiple disability measures.<sup>23</sup> Therefore, we use two measures of disability that can be understood as part of the ICF model. Our first measure of disability is based on major activity limitations, which is typically used in disability research for the working age population<sup>‡</sup>. For each panel, in rounds three and five, individuals were queried as to whether they had any limitation in work, housework or school. Persons who answered positively in either round were recorded as disabled. It is important to note that this

activity limitation measure may lead to an overestimate of the burden since persons with work limitations are likely to have lower earnings compared to persons without work limitations. This might affect our estimates of burdens for given years, but is not expected to affect the trend analysis. This limitation makes it important to use other measures of disability. Our second measure of disability was derived using functional limitations. In two rounds of the MEPS, respondents were queried if they had a walking limitation or a cognitive limitation (individuals are asked if they experienced confusion or memory loss, had problems making decisions, or required supervision for their own safety). In addition, in one round of the survey, functional limitations questions related to seeing and hearing were asked. For each of the functional limitation questions described above, the person can only answer “yes” or “no.” In our second measure of disability, a person who reported at least one functional limitation in one round was considered as having a disability.

### **Dependent Variables**

***Annual Total Healthcare Expenditure.*** Within the MEPS, healthcare services that were paid for by third party payors and/or individuals themselves are defined as “health expenditures” and reported for each year. We used individual’s annual total expenditures that were summed across inpatient, emergency room, outpatient (e.g., clinic and office-based visits), pharmacy, and other (e.g., home health services, vision care services, dental care, ambulance services, and medical equipment). All expenditures were adjusted for inflation and converted to constant 2004 dollars with the use of the consumer price index for medical care services.

***Out-of-pocket Spending on Healthcare.*** In the MEPS, total expenditures were also categorized by 12 major sources of payment<sup>§</sup>, including out of pocket expenditures paid by the individual or the family. Our measure of OOP expenditures did not include expenditures for healthcare

insurance premiums because data on premiums paid is not available in the Public Use files of the MEPS.

***Out-of-Pocket Spending Burden.*** We measured the burden of out-of-pocket spending as the percent of family income spent out-of-pocket because the ability to pay for healthcare costs not covered by third party payers is an important determinant of the use of healthcare services.

### **Statistical Methods**

Differences in levels and trends in total health expenditures, OOP, and OOP burden across disability status were examined using linear regression models. Due to the highly skewed nature of the data, we transformed total health expenditures, OOP expenditures and burden into logarithmic terms using  $\ln(\text{outcome}+1)$ . Many studies use generalized linear models (GLM) with log link to examine the relationship between expenditures and other variables.<sup>24</sup> We compared the deviance and kurtosis to assess the fitness of the GLM log-normal model as an alternative to the OLS log-normal model. We found in all years, the total healthcare expenditures were right-skewed and had kurtosis value greater than 3, which suggested that the OLS log-normal model is preferable to the GLM model.<sup>25</sup> All analyses controlled for the complex sampling design<sup>||</sup>.

The linear model described above does not distinguish between group composition changes and differences in regression coefficients across disability status. To understand the factors that contribute to the difference in health expenditures between persons with and without disabilities, we follow the Oaxaca decomposition method (e.g., Oaxaca and Ransom<sup>26</sup>). Oaxaca decomposes the gap in the mean of outcome between two groups: it allows for the possibility that the gap in outcome (log health expenditures, log of OOPS or burden) is caused in part by differences in the effects of determinants (regression coefficients). For example, the health expenditures of persons with disabilities may be less responsive to changes in insurance

coverage. The Oaxaca decomposition starts with a multiple regression analysis of the outcome variable as follows:

$$\ln E_{i,j} = \alpha_j + \beta_j X_{i,j} + \varepsilon_{i,j} \quad (j=D \text{ or } ND) \quad (1)$$

where  $\ln E_{i,j}$  is the log of health expenditures of individual  $i$ ,  $D$  and  $ND$  denote persons with and without disability respectively,  $X_{i,j}$  a set of characteristics, which include demographic, socioeconomic, health variables and a time variable.  $\beta_{i,j}$  are the coefficients on those characteristic variables. The difference in mean health expenditures between persons with and without disabilities can be decomposed as:

$$\ln \bar{E}_{ND} - \ln \bar{E}_D = (\bar{X}_{ND} - \bar{X}_D) \hat{\beta}_D + \bar{X}_D (\hat{\beta}_{ND} - \hat{\beta}_D) \quad (2)$$

On the right-hand side of equation (2), the first term is the difference in health expenditures which is attributable to differences in characteristics, while the second term represents the part of the expenditure difference which is unexplained. The second term may result from differences in unobservables and in returns to characteristics between the two groups.

## RESULTS

Disability prevalence as measured by the percentage of working age persons with a major activity limitation has increased from 6.7% in 1996 to 9.4% in 2004 ( $.01 \leq p < .05$ ). Persons with disabilities are significantly more likely to be older, less educated, less likely to be employed, to have public insurance, and more likely to be poor than the nondisabled (Table 1).

Table 2 displays the levels and changes over time in all three measures of healthcare expenditures between 1996 and 2004 by disability status. In 2004, median total health expenditures were estimated at \$649 for those without disabilities, and \$4,449 for persons with

disabilities, and median OOP were \$280 and \$703 for those without disabilities and persons with disabilities respectively. The median burden of OOP on family income was 1% for persons without disabilities but 4.4% for persons with disabilities. The descriptive evidence in Table 2 thus provides support to our first hypothesis that persons with disabilities have substantially higher total health expenditures, OOP and burden compared to persons without disabilities.

Over the 1996-2004 period, the gaps in mean and median total health expenditures across disability status have increased. As shown in the ratio column, the median health expenditures for persons with disabilities were six times higher than those without disabilities in 1996, but seven times higher in 2004. This result supports our second hypothesis that health expenditures have disproportionately increased for persons with disabilities. OOPs have increased for both groups of interest, but increased more for persons with disabilities. Median OOPs grew by 124% for persons with disabilities and by 62% for persons without disabilities. The median burden has increased by 25% from 0.8 to 1 for those without disability, and increased by 22% from 3.6 to 4.4 for those with disabilities. Our third hypothesis that OOP and burden have increased less for persons with disabilities is only partly supported by the data in Table 2. For persons with disabilities, the burden has increased less than for persons without disabilities, but OOPs have increased more.

The first column of Table 3 shows unadjusted trends in total healthcare expenditures, OOP spending and burden. In this model, only time (0 to 8), disability status, and a time disability interaction term were included as independent variables. The estimated parameters of the time and disability variables are positive in all three models, which indicate that health expenditures, OOP and burden have increased over the period of interest and that there are significant differences in health expenditures, OOP and burden over time and across disability

status. The coefficient of the disability time interaction term is positive and significantly different from zero in the regression of health expenditures and burden, but imprecisely estimated for OOP. This suggests that health expenditures and burden may have disproportionately increased for persons with disabilities compared to those without disability.

In the second and third columns of Table 3, we control for demographic and socioeconomic characteristics. Given that perceived health status and mental health status are highly correlated with disability status (as shown in Table 1), we first leave out health characteristics in Model 1, and then include them in Model 2. After the health covariates are introduced, the regression coefficient of the disability binary variable is reduced but remains positive and significantly different from zero for health expenditures (from 1.895 to 0.988), OOP (from 0.988 to 0.498) and burden (from 0.828 to 0.432). In Model 2, having a disability is associated with an increase in total health expenditures by 168%, in OOP by 65% and in burden by 54%. The models with and without the health covariates suggest that disability status is an independent and significant predictor of expenditures, OOP, and the burden. These results provide support to our first hypothesis that persons with disabilities have higher total health expenditures, OOPs and burden.

Finally, in Models 1 and 2, we find that, after characteristics of individuals are controlled for, disability time interaction terms become close to zero and insignificant for the three outcomes, which suggests that there has not been any disability specific trend in outcomes over the 1996-2004 period. This result stands against our second and third hypotheses that there have been disproportionate trends in total health expenditures, OOPs and burden.

We next turn to the decomposition of the gap in healthcare expenditures. Over the 1996-2004 period, we observe a gap in the mean log of total healthcare expenditures of -2.31 between

persons with and without disability (7.69 versus 5.38). After adjusting for characteristics, the estimated gap is -1.88 (7.28 versus 5.40), or 35 percentage points. This negative difference reflects the fact that individuals with disability have greater expenditures than those without disability. Of this gap, we find that -0.913 (or 48.4% of the gap) is explained by differences in characteristics between the two groups. The negative sign of the explained portion suggests that if individuals with disability had the characteristics of individuals without disability (e.g., in terms of age, health status), the total expenditures of individuals with disability would be lower. When we examine in Table 4 the total explained difference by domains such as demographics, socio-economic status, access to care and health status, we find that 40.3% of the gap is due to differences in health. Time contributed only 0.2% of the gap, so there are no significant trends associated with having a disability. This result is consistent with the result reached earlier in the regression analysis (Table 3) where the interaction term between time and disability status is not statistically different from zero. The same result was reached with the decompositions in the gaps in OOP and burden across disability status and is available from the authors.

### **Alternative Specifications:**

We specified several alternative models to ensure the robustness of our findings with regard to disability and healthcare costs. These are summarized below.

*Second Definition of Disability:* We repeated the analysis above using the second disability definition based on functional limitations. Disability prevalence based on functional limitations is higher compared to that based on activity limitation but shows a similar increasing trend over the 1996-2004 period, from 17.2% to 19.4% ( $p < .01$ ). Findings from the analysis using the



second definition of disability did not substantially differ from those with our primary definition<sup>¶</sup>.

*Two-part model:* We found that nearly 20% of adults in the age group 21 – 61 had zero total healthcare expenditures. Therefore, we also estimated a two-part model for total expenditures. In the first part, the probability of nonzero health expenditures is estimated, while in the second part, the amount of healthcare expenditures is estimated for all individuals with positive expenditures. This approach has been used in many studies (e.g., Steinman, Telser, & Zweifel 2007<sup>27</sup>) and has been found to be superior to those that simultaneously estimate use and expenditures through Heckman type selection models.<sup>28</sup>

In the first part, findings from the logistic regression to predict the likelihood among working age adults to have positive total healthcare expenditures revealed that those persons with disabilities were nearly three times more likely than those without disability to incur healthcare expenditures during the study period. The adjusted odds ratio was 2.75 with 95% confidence interval [2.00, 3.77]. In the second part of the model, among working age adults with positive healthcare expenditures, persons with disabilities had greater expenditures. The OLS parameter estimate for disability status was 0.73 (p = 0.000). Again, after controlling for demographic and socioeconomic characteristics, the interaction term between disability and time did not reveal any significant difference in the trend of total expenditures across disability status<sup>\*\*</sup>.

## DISCUSSION

Across all years, persons with disabilities had greater total health expenditures, OOP and burden compared to adults without disability, suggesting there are additional healthcare costs associated with disability. Higher OOP associated with disability, has implications for the

measurement and estimation of the prevalence of poverty among persons with disabilities. As shown in Fujiura, Yamaki and Czechowicz,<sup>29</sup> the percentage of households living below the poverty line is significantly higher when the household has a person with a disability (28%) compared to a household without a person with a disability (8.3%). These estimates of poverty prevalence among households with and without a person with a disability were estimated applying the standard poverty threshold, assuming that the minimum standard of resources encapsulated in the poverty threshold is sufficient to meet the needs of persons with disabilities. The estimate of poverty among households with members with a disability would be even higher if the poverty line was adjusted to reflect the extra health costs of living with a disability. In fact, She and Livermore found that the conventional income-based measures of poverty do not adequately measure poverty among those with disabilities who require additional resources just to meet basic material needs, particularly medical needs and food security.<sup>30</sup>

Although further research is needed to estimate the extent to which OOP leads to poverty among persons with disabilities and assess the adequacy of disability benefits such as SSDI, SSI and of mainstream benefits such as TANF (Temporary Assistance for Needy Families), one could speculate that the benefit amounts should be higher for persons with disabilities to reach a standard of living similar to persons without disabilities. In addition, researchers and policy makers need to assess whether the Health Savings Accounts created in 2003 to enable individuals to pay for current health expenses and save for future expenses on a tax-free basis have helped persons with disabilities cover their extra health care costs. Another policy that might alleviate the burden of extra-costs of living with disability is to provide allowances to persons with disabilities as part of standalone programs that compensate for disability related expenditures. Such programs are available in other developed countries. For example, in

Sweden, special allowances are provided for a wide range of disability related costs, including durable medical equipment and attendant care.<sup>31</sup> In Great Britain, the so-called “disability living allowance” compensates for the extra costs incurred due to the effects of a disability.<sup>32</sup> The allowance has two components, a care component and a mobility component and is provided on a temporary or a permanent basis, irrespective of the work status of the person.

Our hypotheses regarding disability specific trends in expenditures, OOP and burden were not confirmed by the analysis. Between 1996 and 2004, we found significant increases in total healthcare expenditures, OOP and burden for all working age individuals. However, there was not any evidence of a disproportionate increase in total expenditures among persons with disabilities over the study period. This finding suggests that there might not have been an improvement in access to healthcare services, as expected following the ADA of 1990 and the Olmstead decision of 1999, which would have resulted in higher total health expenditures. Of course, this paper does not provide any direct evidence on the effects of the ADA and the Olmstead decision, but certainly points toward the need for more research in this area.

In addition, we could not find evidence of a smaller increase in OOP and burden for persons with disabilities, which may point toward the inability of recent policy attempts to facilitate persons with disabilities’ access to health insurance. Programs such as the Medicaid Buy In programs do not appear to have curbed the increase in OOP for persons with disabilities relative to persons without disabilities. Again, more research is needed to assess the specific impact of such policy initiatives on OOP and generally on access to healthcare among persons with disabilities.

This study has several limitations. This study does not cover the institutionalized population with disabilities, and is therefore not representative of the entire working age

population with disabilities. This study is focused on health related expenditures and it therefore does not capture other potential additional expenditures associated with disability such as transportation which has been shown to be significant based on data for other countries.<sup>33</sup> The MEPS dataset did not capture the complete expenditure for personal attendant care, care that has both a formal and an informal component, and can represent a significant portion of community-based expenditures for persons with disabilities.<sup>34, 35</sup> The primary level of analysis for this paper is the individual. Further research on expenditures across disability status is required at the household level and at the insurer level, whether public or private. Furthermore, our study did not include insurance premiums, which changed over the study period in Medicare and in private health insurance plans, and might have affected persons with and without disabilities differentially.

## CONCLUSIONS

Despite these limitations, this paper fills an important knowledge gap. It uses a nationally representative dataset of the non-institutionalized population to analyze levels and recent trends in healthcare expenditures, OOP, and OOP burden across disability status. The paper finds that substantial direct healthcare expenditures, OOP and burden are associated with disability. Although expenditures, OOP and burden increased over time, after controlling for demographic, socio-economic, and health status, these three healthcare costs were not found to change disproportionately for individuals with disability. Our findings suggest that insurance coverage expansions as they have been put in place over the last decade or so may alone not be enough to reduce OOP and burden among persons with disabilities. Further research is needed on expenditures, OOP and burden associated with a disability at the household level and on the

effectiveness of specific policy initiatives in reducing OOP and burden on persons with disabilities.

## NOTES

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\* By removing persons who die during the year, we avoid the challenge of comparing part year expenditures to full year expenditures and we reduce the skew in the data. However, health expenditures in the last year of life are known to be high, so removing persons who died during the year is likely to lead to an underestimate of actual expenditures and might bias our estimates if mortality occurs differentially across disability status.

† A detailed coverage of these models is available in Altman (2001) and Mitra (2006).

‡ We could not use definitions of disability based on limitations in Activities of Daily Living (ADL) and in self care tasks (Instrumental Activities of Daily Living) due to small sample sizes. Such definitions are usually used for the elderly.

§ These sources were: 1) Out of pocket by user or family; 2) Medicare; 3) Medicaid; 4. Private Insurance; 5) Veterans Administration, excluding CHAMPVA (VA); 6) Tricare; 7) Other Federal Sources--includes Indian Health Service, Military Treatment Facilities, and other care provided by the Federal government; 8. Other State and Local Source--includes community and neighborhood clinics, State and local health departments, and State programs other than Medicaid; 9) Worker's Compensation; 10) Other Unclassified Sources--includes sources such as automobile, homeowner's, and 11) Other Private - any type of private insurance payments reported for persons.

|| The MEPS has a complex sample design with stratification, clustering, multiple stages of selection, and disproportionate sampling.<sup>36, 37</sup> This complex survey design requires special adjustments with regard to variance estimation and analysis for results to be nationally representative. Appropriate commands in the SAS software were used to have such an adjustment done in the analysis.

¶ Results are available from the authors.

\*\* Results of the two-part model are available from the authors.

**Table 1**  
**Description of Sample by Disability (Activity Limitation) Status**  
**Medical Expenditure Panel Survey – 1996, 1998, 2000, 2002, 2004**

	1996				Sig	2004				
	N	wt %	N	wt %		N	wt %	N	wt %	Sig
	Disabled		Not Disabled			Disabled		Not Disabled		
<b>ALL</b>	<b>769</b>	<b>100.0</b>	<b>10,218</b>	<b>100.0</b>		<b>1,782</b>	<b>100.0</b>	<b>14,677</b>	<b>100.0</b>	
<b>Gender</b>					*					***
Women	446	55.1	5,334	50.4		1,053	55.6	7,827	50.3	
Men	323	44.9	4,884	49.6		729	44.4	6,850	49.7	
<b>Age</b>					***					***
21 - 39	249	32.8	5,250	52.1		453	24.9	7,238	47.4	
40 - 49	215	28.8	2,879	28.4		536	29.7	4,028	28.1	
50 - 61	305	38.4	2,089	19.6		793	45.4	3,411	24.6	
<b>Race/Ethnicity</b>					**					***
White	520	73.4	6,575	73.2		1,023	68.8	7,694	67.2	
African American	124	15.4	1,215	11.4		350	14.6	1,990	11.4	
Latino	108	8.3	2,025	10.8		286	9.3	3,982	14.4	
Other	17	3.0	403	4.6		123	7.3	1,011	6.9	
<b>Living with Spouse</b>					***					***
Yes	399	50.2	6,597	62.2		727	44.5	8,923	60.5	
No	370	49.8	3,621	37.8		1,055	55.5	5,754	39.5	
<b>Metro Area</b>					**					***
Yes	559	76.1	8,141	81.8		1,322	77.0	12,231	84.1	
No	210	23.9	2,077	18.2		460	23.0	2,445	15.9	
<b>Region</b>					NS					NS
Northeast	124	16.9	2,033	19.6		274	18.0	2,170	18.6	
Midwest	168	20.8	2,229	23.0		323	21.2	2,806	22.3	
South	292	38.4	3,582	35.0		767	38.0	5,833	35.7	
West	185	23.9	2,374	22.4		418	22.9	3,867	23.5	
<b>Education</b>					***					***
Less than High School	263	29.8	1,826	13.4		601	25.2	3,165	13.1	
High School	273	35.8	3,454	33.5		654	40.1	4,554	30.9	
Above High School	232	34.4	4,927	53.1		515	34.6	6,833	56.0	
<b>Employed</b>					***					***
Yes	247	34.8	8,644	86.6		534	36.6	12,291	87.1	
No	521	65.2	1,570	13.4		1,248	63.4	2,383	12.9	
<b>Poverty Status</b>					***					***
Poor	274	29.2	1,265	9.2		705	30.4	2,063	8.3	
Near Poor	166	22.8	1,743	15.4		455	23.4	2,978	14.1	
Middle Income	189	27.0	3,365	33.5		362	24.9	4,475	32.8	
High Income	140	21.0	3,845	41.9		260	21.2	5,161	44.9	

**Health Insurance**

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**Table 1**  
**Description of Sample by Disability (Activity Limitation) Status**  
**Medical Expenditure Panel Survey – 1996, 1998, 2000, 2002, 2004**

	1996					2004				
	N	wt %	N	wt %	Sig	N	wt %	N	wt %	Sig
			<b>Not Disabled</b>					<b>Not Disabled</b>		
	<b>Disabled</b>					<b>Disabled</b>				
Private	343	48.8	7,775	79.8		646	47.3	10,049	78.2	
Public	327	38.3	684	5.1		874	38.4	1,259	5.2	
Uninsured	99	12.9	1,759	15.1		262	14.3	3,369	16.5	
<b>Usual Source of Care</b>					***					***
Yes	676	88.4	7,580	75.9		1,524	86.1	10,053	72.5	
No USC	92	11.6	2,586	24.1		245	13.9	4,451	27.5	
<b>Perceived Health</b>					***					***
Excellent/Very Good	76	10.9	5,551	57.2		79	5.3	6,104	47.0	
Good	158	22.9	3,309	31.4		311	19.4	6,080	39.1	
Fair/Poor	535	66.2	1,358	11.4		1,392	75.2	2,492	13.9	
<b>Chronic Conditions</b>					***					***
None	301	42.5	7,617	75.0		613	35.8	10,601	71.0	
One	244	29.4	2,006	19.3		476	27.4	2,929	20.9	
Two	131	17.0	475	4.6		359	19.3	878	6.1	
Three	60	7.3	99	0.9		214	11.3	217	1.5	
Four or more	33	3.9	21	0.2		120	6.2	52	0.4	
<b>Mental Health</b>					***					***
Excellent/Very Good	191	26.4	6,583	66.6		219	14.5	7,608	55.8	
Good	276	35.4	3,015	27.8		561	33.2	5,768	36.2	
Fair/Poor	302	38.2	620	5.6		1,002	52.3	1,300	7.9	
<b>Any Mental Illness</b>					***					***
Yes	265	34.3	1,093	10.9		851	48.2	1,948	14.3	
No	504	65.7	9,125	89.1		931	51.8	12,729	85.7	

## Notes:

i) Based on individuals aged between 21 and 61. Asterisks represent significant differences in sample composition by disability status based on chi-square statistic.

ii) Perceived health and mental health questions are inquired in each round of MEPS. Individuals were categorized as having fair-poor health if they reported being in fair/poor health in any of the three rounds.

\*\*\*  $p < .001$ ; \*\*  $.001 \leq p < .01$ ; \*  $.01 \leq p < .05$ ; NS stands for not statistically significant.

**Table 2**  
**Trends in Total Healthcare Expenditures, Out-of-Pocket Spending (2004\$)**  
**and Burden by Disability Status**  
**Medical Expenditure Panel Survey, 1996 through 2004**

	Mean			Median		
	Disabled	Not Disabled	Ratio	Disabled	Not Disabled	Ratio
<b>Total Expenditures</b>						
1996	\$8,442 (18,344)	\$1,844 (5,094)	4.58	2,345	385	6.1
1998	\$8,388 (16,922)	\$1,750 (4,202)	4.79	2,153	415	5.2
2000	\$9,300 (24,180)	\$1,887 (5,888)	4.93	3,243	461	7.0
2002	\$9,701 (18,608)	\$2,067 (5,446)	4.69	4,048	610	6.6
2004	\$10,508 (36,216)	\$2,256 (11,101)	4.66	4,449	649	6.9
<b>Out-Of-Pocket (OOP)</b>						
1996	\$1,061 (2,189)	\$442 (1,134)	2.40	314	173	1.8
1998	\$1,037 (2,323)	\$451 (1,237)	2.30	377	178	2.1
2000	1,263 (2,482)	441 (1,122)	2.86	513	207	2.5
2002	\$1,367 (3,161)	\$500 (1,304)	2.74	613	250	2.5
2004	\$1,458 (3,030)	\$504 (1,330)	2.89	703	280	2.5
<b>OOP-Burden as percent of Family Income</b>						
1996	9.50 (27)	1.82 (11)	5.22	3.6	0.8	4.5
1998	5.53 (16)	2.01 (11)	2.75	3.1	0.7	4.4
2000	8.18 (22)	1.53 (7)	5.35	3.7	0.8	4.6
2002	9.71 (26)	2.11 (12)	4.60	4.1	0.9	4.6
2004	10.61 (29)	2.08 (12)	5.10	4.4	1	4.4

Note: Based on individuals who were alive as of the end of calendar year and aged between 21 and 61. The standard deviation of the mean is between parentheses. Total expenditures and Out-of-pocket spending are expressed in 2004 dollars based on consumer price index for medical services. Asterisks represent significant differences in average expenditures by disability based on t-tests. The ratio is, for each indicator of interest (e.g., mean total expenditures), that of persons with disabilities divided by that of persons without disabilities.



**Table 3**  
**Unadjusted and Adjusted Trends in**  
**Total and Out-of-Pocket Expenditures and Burden By disability Status**  
**Medical Expenditure Panel Survey, 1996, 1998, 2000, 2002, 2004**

	Unadjusted			Model 1			Model 2		
	Beta	SE	Sig	Beta	SE	Sig	Beta	SE	Sig
<b>Total Expenditures</b>									
Intercept	5.467	0.030	***	1.888	0.077	***	0.660	0.077	***
Year	0.014	0.006	*	0.026	0.004	***	0.010	0.004	*
Disabled	2.164	0.072	***	1.895	0.069	***	0.988	0.068	***
Disability * Year	0.034	0.013	**	0.014	0.012		-0.014	0.012	
<b>Out-of-Pocket Expenditures</b>									
Intercept	5.138	0.021	***	4.451	0.063	***	3.667	0.064	***
Year	0.022	0.004	***	0.017	0.004	***	0.007	0.003	*
Disabled	0.673	0.063	***	0.988	0.057	***	0.498	0.058	***
Disability * Year	0.020	0.012		0.015	0.011		-0.002	0.011	
<b>OOP Burden Family Income</b>									
Intercept	-5.548	0.020	***	-3.310	0.076	***	-3.936	0.077	***
Year	0.030	0.004	***	0.033	0.003	***	0.024	0.003	***
Disabled	1.417	0.075	***	0.828	0.066	***	0.432	0.065	***
Disability * Year	0.038	0.014	**	0.014	0.012		0.000	0.012	

Note: Based on individuals who were aged between 21 and 61. Adjusted trend is based on ordinary least squares regression on logged expenditures for total and out-of-pocket spending. Model 1 adjusted for gender, race/ethnicity, age, marital status, region of residence, education, employment, and poverty status. Model 2 additionally included controls for physical illness, mental illness, perceived physical and mental health status.

\*\*\*  $p < .001$ ; \*\*  $.001 \leq p < .01$ ; \*  $.01 \leq p < .05$ ; + \*  $.05 \leq p < .1$

**Table 4: Decomposition of Total Healthcare Expenditures  
by Disability Status,  
Medical Expenditure Panel Survey, 1996, 1998,2000,2002, 2004**

	<b>Total Gap</b>	<b>Explained Gap</b>	<b>%</b>
Total	<b>-1.886</b>	<b>-0.913</b>	<b>48.43%</b>
Variables:			
Year	-0.038	-0.003	0.15%
Demographics	0.115	-0.070	3.69%
Socioeconomic	0.557	0.174	-9.25%
Access to care	0.006	-0.256	13.58%
Health status	0.188	-0.759	40.26%

Note: Based on individuals aged between 21 and 61. Decomposition is based on parameter estimates derived from 3 regressions (non-disabled, disabled, pooled regression without controlling for disability status). The model adjusted for gender, race/ethnicity, age, marital status, region of residence, education, employment, poverty status, physical illness, mental illness, perceived physical, and perceived mental health status.

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