

**Access, quality & financial implications of transitions of children with autism  
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**Final Report**

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## **I. Introduction**

A growing foundation of evidence indicates that families of children with autism experience problems of access, financial burden and difficulties paying for health care and autism services, but little evidence positions these experiences in time as they relate to critical childhood milestones (Parish et al., 2011a; Thomas et al., 2011; Kogan, 2008; Liptak et al., 2008; Krauss et al., 2003). There is some evidence that childhood transitions, into, through and out of school, are associated with increased family and child turmoil (Griffith et al., 2010; Lounds et al., 2007). Pinning down when episodes of difficulties with access and financial burden are likely to occur over the trajectory of childhood may inform development of policies that effectively improve access to care for these children. This study examined the implications of transitions and financial burden among families raising children with autism through the following aims:

- 1. To compile a rich source of data on children with autism and their families (n=337) by pooling national panel data over time that describe service use, expenditures and family finances, and that the investigators have used extensively;**
- 2. To conduct multivariate analyses to examine the child and family factors that are associated with service expenditures and financial burden; and**
- 3. To describe variation in expenditures and resulting financial burden for families with a child with autism over the course of childhood in order to inform development of interventions that improve access to care for these children by targeting interventions to times of greatest need.**

The study used pooled data from the Medical Expenditure Panel Survey 2000-2009 on children under 21 years of age with autism (n=337) to describe expenditures for services, their composition, and resulting family financial burden. Two-part models were used to estimate the association of child transition age (5,6,11,14) and expenditures and the child and family characteristics associated with financial burden. Findings provide a map of the trajectory of difficulties in access and financial burden for families with a child with autism over the course of childhood in order to inform policies that promote access to care for these children. These findings have particular relevance for underserved populations whose networks of support maybe more tenuous and susceptible to limited access and burden. Findings address Healthy People 2020 objectives regarding access to care (AHS6), the quality of care received (AHS7), and children's receipt of mental health services (MHMD6) in particular (USDHHS, 2011).

## **II. Background**

There is significant evidence that families of children with autism experience problems accessing services, but little evidence positions these experiences in time as they relate to critical childhood milestones (Parish et al., 2012a; Thomas et al., 2012; Kogan, 2008; Liptak et al., 2008; Krauss et al., 2003). Experiences of symptoms and recommendations for treatment planning suggest that health care expenditures for children with autism will vary over the trajectory of childhood. Longitudinal studies have found that children with autism experience improved symptoms and problem behaviors over time, but improvements typically plateau after children leave high school (Taylor & Seltzer, 2010; McGovern & Sigman, 2005; Sigman & McGovern, 2005). Treatment guidelines recommend shifts in critical services, focusing greater attention on community involvement as children reach adolescence (Meyers & Johnson, 2007;

Aman, 2005). National data indicate that the mix of services shifts and expenditures and unmet needs increase as children age (Wang, Mandell et al, 2012; Cidav, Lawer et al, 2012; Thomas, Parish et al, 2012). There is also evidence that transition in and of itself is difficult for children with autism and impacts family functioning. A defining feature of autism is inflexible adherence to specific, nonfunctional routines or rituals (American Psychiatric Association [*DSM-IV-TR*], 2000). School changes that occur as children age require challenging new routines that often are associated with increasing problem behaviors (Joosten, Bundy et al, 2012; Griffith, 2010; Lounds, 2007). The impact of school transition on service use among children with autism remains a pertinent but unanswered question.

Families raising children with autism report greater financial burden due to their children's health care expenses than other children with special health care needs (Parish et al., 2011a; Kogan et al., 2008). Family financial burden in turn leads to poor child and family outcomes. Our recent findings show that greater family financial burden for children with autism is associated with the stability and severity of the child's condition; and poverty as well as state public and private insurance policy (Parish et al., 2011a; Parish et al., 2011b). However, the relationship between families' financial burden and children's health insurance coverage has not been examined.

This study explores the association between school transition age for children with autism and their healthcare expenditures in order to develop an understanding of how school transitions affect children and their families, particularly those facing health or socioeconomic disadvantage. Following the analysis of transition age, the study examines the impact of health insurance status on family financial burden in an effort to discover which insurance strategies work best to protect families from the financial challenges of transition and family financial burden.

### **III. Study design and methods**

#### *Data*

The Medical Expenditure Panel Survey (MEPS) provides nationally representative data on the civilian noninstitutionalized population, including family and individual-level data, with detailed information on health service use and expenditures, finances, and need for care (Ezzati-Rice et al., 2008). Cross-sectional data from 2000 through 2009 were pooled to compile an adequately powered sample of children under 21 years of age with autism (n=337; AHRQ, 2010). Pooled two-year panel data (n=155) were also constructed. Children with autism are identified as having a condition of pervasive developmental disorder, which describes autism and rarer variations including childhood disintegrative disorder, Rhett's disorder and pervasive developmental disorder not otherwise specified. Conditions in the MEPS are assigned through a process of professional review of parent-reported conditions (MEPS, 2011). Health care expenditure data are compiled from both families and their medical providers (Machlin & Dougherty, 2007). Missing values in the MEPS are imputed according to an algorithm that makes use of public and restricted panel data on each individual and family (Machlin &

Dougherty, 2007). Use of these data was exempt from Office of Human Research Ethics oversight because the data were already existing public use data.

### *Dependent variables*

Total health care expenditures of the child with autism, associated family out-of-pocket expenditures, and relative financial burden (out-of-pocket expenditures incurred for the child with autism, as a percentage of per capita family income) were used as dependent variables. Dollar values are adjusted for inflation to reflect 2009 dollars. Access to care was measured through three dichotomous measures of perceived problems getting care: no usual source of care, delays in care, and unable to get needed care, however, these data were too sparse by transition status to support further analyses.

### *Independent variables of interest*

Transition age children are identified by typical age of entry into a new level of school: 5 or 6 years of age (typical age of entry into elementary school), 11 years of age (typical age of entry into middle school), or 14 years of age (typical age of entry into high school). The insurance status of the child with autism was categorized as coverage during the past year, with the following four categories: (1) ever covered by Medicaid or the State Children's Health Insurance Program (SCHIP), (2) no Medicaid/SCHIP but some other type of public insurance, (3) covered only by private insurance, or (4) uninsured for the entire year.

### *Control variables*

Control variables capture predisposing, enabling and need variables of the child and family. Predisposing variables measure male gender, minority race, Hispanic or Latino ethnicity and household structure (family is headed by a single mother, whether the household included one or more other children with special health care needs). An estimate of the available time for childcare was computed as the number of adults in the household times 40 hours less the total number of hours worked by the adults in the household; this was then divided by the number of dependent children in the household (including the child with autism). Two items measured the health status of adults living in the household: any adult reported fair or poor physical health and any adult reporting fair or poor mental health. Enabling variables measure child health insurance status (continuous private insurance only, continuous coverage with any public insurance or ever uninsured), parent education (college or higher), total family income (2009 dollars), low family income (a dichotomous measure identifying families living below 200 percent of the federal poverty level), and language as a barrier (responding parent not comfortable with English). Need for services by the child with autism was captured by four measures. Severity of impairment was included as a dichotomous measure identifying children aged 5-17 with high impairment measured as scoring in the top quartile, 27 or more, on the Columbia Impairment Scale and youth 18-20 who are reported to experience confusion, problems making decisions, or who require supervision (Steinhausen & Metzke, 2001; Mayes et al, 2001; Harris et al, 1996). Parent report of child health status and mental health status were included in addition to a binary indicator of whether the child had any hospitalizations in the past year. Context was captured by rural residence.

### *Analytic Methods*

Descriptive statistics characterize the sample of children with autism, their family context, and the composition of their total and out-of-pocket health care expenditures. Two-part models were used to model factors associated with total and out-of-pocket expenditures and financial burden: a logit was used to estimate the binary outcome of any expenditures or burden (yes/no) and ordinary least squares regression was used to estimate level of expenditure or burden among those families that reported having any expenditures. Linear regressions modeling change in expenditures over time were estimated using the two-year panel data.

### **IV. Findings**

Table 1 describes the sample of children with autism (n=337). Eighteen percent of children were of transition age (weighted analysis, not shown). One-third of children were living in families whose income was below twice the federal poverty level, and nearly 10 percent experienced a period without health insurance in the past year. Ten percent of children were in fair or poor health.

Median total expenditures for health care among children with autism were \$2,400 with an upper quartile of \$5,900 in 2009 dollars. Eighty-two percent of the sample reported having any out-of-pocket spending for the child's health care in the past year. In inflation-adjusted (to 2009 dollars) terms, mean and median out-of-pocket spending for the year was \$729 and \$215, respectively. Relative financial burden, or the percent of family income per person in the household that was spent on the health care needs of the child with autism, had a mean of 4.1% and a median of 1.35% (data not shown). Table 2 shows the composition of total and out-of-pocket expenditures for children with autism overall and by transition status. The majority of expenditures were made for outpatient medical visits and prescription medication. A larger share of out-of-pocket expenditures were devoted to prescription medication expenses. When children were transition age, a larger proportion of expenditures went toward ambulatory therapy, overall and out-of-pocket while a smaller proportion of out-of-pocket expenditures were devoted to prescription medications compared to children of other ages.

Table 3 describes prevalence and median out-of-pocket spending for types of spending that at least 20% of all families reported, and these are stratified by family income relative to twice the federal poverty level and child's health insurance status. Families of children with ASD who have Medicaid/SCHIP are less likely to pay out-of-pocket. Notably, 96% of families of privately-insured children reported having any out-of-pocket spending compared to 69% of those with Medicaid/SCHIP. However, among families with income above twice the federal poverty threshold, median out-of-pocket spending (\$623) was more than twice as high for families of privately-insured children compared to those with Medicaid/SCHIP (\$287). The most prevalent types of health care expenditures varied somewhat by the child's health insurance coverage and family income level. Among children with Medicaid/SCHIP coverage, the greatest proportion of families reported having spending for prescription medications and outpatient services. Among children with private insurance, the three most prevalent types of out-of-pocket expenditures were for outpatient services, prescription medications and dental care, respectively. The overall trend of greater prevalence of out-of-pocket spending was also

evident in the amount of out-of-pocket expenditures. Median out-of-pocket spending for prescription drugs for privately-insured children living in families with income above twice the federal poverty level (\$242) was more than twice the level spent by same-income children with Medicaid/SCHIP (\$89). Across all categories, this trend persisted.

Figure 1 presents the unadjusted, weighted median out-of-pocket spending among children with Medicaid/SCHIP or private insurance, stratified by family income in relationship to 200% of the federal poverty level. Figure 1 represents the entire sample, including those families without any out-of-pocket expenditures in the prior year. Median out-of-pocket spending for low-income families of Medicaid/SCHIP-insured children with autism in the prior year was \$7, markedly lower than the \$160 median for low-income children with private insurance. Among families with income at or above twice the federal poverty level, median expenditures were \$100 for children with Medicaid/SCHIP and \$598 for children with private insurance.

Figure 2 reports the median out-of-pocket spending among those families that reported any out-of-pocket expenditures in the previous year (families that reported no out-of-pocket spending are excluded in Figure 2). Among low-income families, median spending was essentially the same: \$171 for children insured with Medicaid/SCHIP and \$169 for privately-insured children. Among families with income at or above twice the federal poverty level, however, median spending for children with Medicaid/SCHIP coverage was \$287 and 54% below the \$623 median for privately-insured children with autism spectrum disorders.

#### *Transition and expenditures for autism services*

Table 4 presents models of any expenditures and level of expenditures among those with any expenditures. After controlling for predisposing, enabling and need characteristics, transition by itself was not significantly associated with the likelihood or amount of expenditures (not shown). However, the experience of transition was different for some families. Four sets of models are presented, each focusing on an interaction between transition-age of the child with autism and a measure of vulnerability: high child impairment, minority race, low income, and living in a household headed by a single woman. Each set of findings delineates models for total and out-of-pocket expenditures.

Children with autism who were highly impaired and of transition age had lower total expenditures than others. In contrast, children who were not highly impaired and in transition had higher out-of-pocket expenditures than others. Children with autism who had low income and were in transition had lower total expenditures than others. Again, children who did not have low income and were in transition had higher out-of-pocket expenditures than others. In addition, children with low income *but not* in transition had lower odds of having out-of-pocket costs than others, and when children did have out-of-pocket expenditures, this same group had lower expenditures than others. There were no significant differences in total expenditures for minority children compared to others whether or not they were in transition. However, as before, nonminority children in transition had greater odds of having out-of-pocket expenditures than others, and when they did, they were higher than others. Children living in households headed by single women and who were not in transition had higher odds of having

any expenditures than others, but total expenditures for these children were the same whether or not they were in transition. They also had greater odds of having out-of-pocket expenditures than children in transition, but among children in transition, the pattern was switched. Children in transition living in households headed by single women had lower odds of any out-of-pocket expenditures than all others. Among children with out-of-pocket expenditures, those who lived in single women households had lower out-of-pocket expenditures than others: among children in transition, those who lived in single women households had lower expenditures than those living in other types of families; and among children not in transition those living in single women household had lower expenditures than those living in other types of families as well.

Analyses of pooled two-year panel data were conducted to model the association of time variant and invariant child and family characteristics with changes in expenditures experienced between the two years of the panel. These analyses failed to yield meaningful findings. Change in expenditures, total, out-of-pocket, and financial burden, was strongly associated with initial year expenditures only. Sensitivity analyses with alternative measures did not change these findings.

#### *Health insurance and family financial burden*

Table 5 presents multivariate regression results, controlling for income and other indicators of socioeconomic status as well as a range of child and household characteristics including severity of the child's impairments (n=316). In part 1, we found that families raising children with autism spectrum disorders who had private insurance were more than five times as likely to have any out-of-pocket expenditures as families raising children who were publicly-insured (OR=5.33;  $p<.05$ ). Several covariates emerged as statistically-significant predictors of the likelihood of having any out-of-pocket spending: the number of weekly hours available to care for each dependent (OR=0.97,  $p<.05$ ); if an adult in the household reported being in fair or poor health (OR=2.63;  $p<.05$ ); and log of total family income (OR=1.98;  $p=.05$ ). In part 2, among those families reporting any out-of-pocket spending, families of privately insured children had approximately 2% ( $p<.05$ ) higher relative burden compared to children with Medicaid/SCHIP (greater burden transformed by exponentiating the coefficient of 0.68), after controlling for all model covariates. In other words, out-of-pocket spending for children with ASD was increased by 2.0% of per-person family income for those ASD who had private insurance, compared to children with Medicaid. In the second regression model, two covariates emerged as statistically-significant predictors increased relative financial burden: whether a parent had a bachelor's degree or higher (Beta=0.75; 2.1% greater relative burden;  $p<.05$ ) and whether the child had any hospitalizations in the previous year (Beta=1.43; 4.2% greater relative burden;  $p<.01$ ).

## **V. Discussion**

### *Conclusions*

The findings from this study suggest that when children with autism transition between schools, children from vulnerable families experience a drop in expenditures that is made up with out-of-pocket spending in families with more resources. Families raising children with ASD

who had private insurance coverage were much more likely to have any out-of-pocket medical care spending for their child, and also reported having significantly greater out-of-pocket spending for their children's health care. Among middle- and upper-income families, financial burden was markedly higher for privately-insured children in contrast to those with public insurance, both across the entire sample and among just those with any out-of-pocket spending. While further study is necessary, this investigation indicates that Medicaid appears to buffer the financial costs of raising children with ASD in ways that private insurance does not.

### *Limitations*

Although the MEPS data provide uniquely detailed evidence about the amount and sources of expenditures for autism services, limitations of the data are important to keep in mind. First, the pooled data used for this analysis cover a period of time, 2000-2009, when the evidence base and treatment patterns for autism have been changing (Warren et al, 2011). For example, during this period of time, evidence has been generated that some antipsychotics can reduce challenging behaviors in children with autism. Since the findings reported here indicate that families contribute a significant amount to cover the cost of prescription medications, all kinds of families may have fewer resources today to address transition needs. It will be important to monitor parent report of unmet needs during times of transition in the future. Second, the MEPS asks families to report on their expenditures for medical care for their child. While many autism-related services clearly fall under the umbrella of medical care, such as outpatient pediatric visits and prescription drugs, other services may be more difficult to categorize or clearly different (Thomas et al, 2007). For example, community integration services provided by a high school graduate may contribute to the cost of care for autism, but not be considered medical services by a family. Complementary and alternative medicines are more clearly different. To the extent that these other autism-related services are excluded, the findings reported here are conservative; they underestimate total expenditures and particularly underestimate out-of-pocket expenditures. Third, these data capture child age, but they do not identify explicitly when a child has experienced a change of school. To the extent that child age is an imprecise measure of school transition, the significance of the associations of transition and expenditures may be underreported. Finally, these data do not support analysis of family spending variation by state of residence or state Medicaid policy characteristics. Previous research has found significant state variability in family burden for CSHCN (Parish et al, 2009) and reduced burden for families living in states with autism parity legislation (Parish, Thomas et al, 2012a) and for families living in states with greater per capita Medicaid spending (Parish, Thomas et al, 2012b).

### *Implications*

These findings raise questions about the opportunities and challenges inherent in transitioning to a new school for a child with autism. Schools and families may see transition into a new school as an opportunity to leave behind outgrown supports. Later adjustments may bring back some supports or add new ones that raise the level of expenditures again. In this sense, although transition to a new school may be associated with a disruption of services for children with autism, it is not necessarily unplanned or unreasonable. The concern is that the present findings suggest vulnerable families are most likely to experience this disruption. It appears that

families that are more likely to be disconnected from the system of care or less likely to have abundant resources for help-seeking or additional care appear to receive fewer services for their children while more advantaged families make up for disruptions with increased out-of-pocket spending. It is also possible that families of less impaired children bear the burden for documenting continued need for school-based services while services for children with high impairment remain elevated during transitions.

This study adds to the growing body of evidence that families raising children with ASD incur substantial financial burdens. In previous research, the limited coverage provided for ASD by private insurers has been amply discussed<sup>17-19</sup> (Busch & Barry, 2009; Kraus et al, 2003; Peele et al, 2002) and these gaps have prompted advocates to secure passage of so-called autism parity legislation in 32 states (Autism Speaks, 2013) to date. The present study bolsters claims that the out-of-pocket spending incurred by families of children with ASD are higher for children who lack public insurance, even after controlling for socio-economic status and family income.

It is evident from these findings that insurance does not fully cover autism services; families incur significant out-of-pocket costs to meet their child's medical care needs. Moreover, reliance on a pay-as-you-go system leads to racial, ethnic and economic disparities in care among children with autism (Magana et al, 2012). The Patient Protection and Affordable Care Act (PL 111-148) promises to bring important improvements to insurance for children with autism, such as elimination of preexisting condition exclusions, extension of dependent coverage to age 26, and explicit inclusion of behavioral healthcare treatment and habilitative care as essential benefits. There still remain, however, areas of uncertainty in the coverage of autism services. First, after a state benchmark plan is chosen, states are no longer allowed to reduce the *actuarial value* of a plan below the benchmark, but this leaves uncertainty about the depth and breadth of specific covered services (CCIIO, 2012; Weiner, 2012; Spielman, 2011). Second, because habilitative services are rarely included in current plans, the guidance leaves room for significant variation and uncertainty over the scope of these services in particular that will be required (CCIIO, 2012; Spielman, 2011; CCIIO, 2011). Third, since the definition of behavioral healthcare treatment is open to interpretation, insurance plans may or may not (except in states with mandates to cover it) include autism (Sarata, 2011).

These findings raise important new questions about the dimensions of care for children with autism. Health insurance may not be the best tool to ensure continuity of care over the span of childhood. Schools could include goals for continuity of health care services in the individualized education plans for transition-aged children with autism. Healthcare providers could anticipate and work to avoid service disruptions during school transitions, particularly for vulnerable families, through careful monitoring and coordination of care. Care collaboration and medical home models are promising strategies to address these disparities although barriers to access must be overcome there as well (Sheldrick et al, 2010; Brachlow et al, 2007).

## **VI. List of Products**

Following is the list of manuscripts that have been prepared from this study. The analyses of access to care measures and those based on pooled panel data did not yield findings adequate to support manuscript publication.

1. Thomas KC, Parish SL, Williams CS (2013) Healthcare expenditures for autism during times of transition: Some vulnerable families fall behind, under review.
2. Parish SL, Thomas KC, Williams CS, Crossman M (2013) Autism and Families' Financial Burden: The Association with Health Insurance Coverage, under review.

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**Table 1. Characteristics of children with autism and their families**

	<b>Transition<sup>1</sup></b> (N=67)	<b>Not Transition</b> (N=270)	
Variables	Percent	Percent	p-value <sup>2</sup>
Male gender	89.2	86.4	0.552
Minority race or Hispanic ethnicity	30.1	23.8	0.301
Health insurance status			
Ever any public, never uninsured	48.5	46.3	0.331
Private only, never uninsured	47.2	43.6	
Ever uninsured	4.3	10.1	
Education of parents BA or higher	54.9	63.1	0.286
Low income <sup>1</sup>	35.3	30.4	0.484
Single woman head of household	10.3	12.2	0.654
Parent not comfortable with English <sup>2</sup>	1.3	2.4	0.472
High impairment <sup>3</sup>	14.1	25.7	0.048
Health status fair or poor	9.8	10.6	0.854
Rural residence	5.0	16.8	0.018

<sup>1</sup>Transition age based on age in November – 5,6,11, 14

<sup>2</sup>Two-tailed t-test comparing children in a transition age vs. other ages

<sup>1</sup>Defined as  $\leq 200\%$  of the federal poverty line

<sup>2</sup>Refers to the household reference person, usually a parent

<sup>3</sup>A dichotomous measure identifying children aged 5-17 scoring in the top quartile on the Columbia Impairment Scale and youth 18-20 reported to experience confusion, problems making decisions, or who require supervision

**Table 2. Composition of Total and Out-of-Pocket Expenditures for Children with Autism, Overall and by Transition Age**

	Overall			Transition Age <sup>1</sup>			Other Ages			p-value <sup>2</sup>
	Mean	Median	Max	Mean	Median	Max	Mean	Median	Max	
<b>Types of Expenditures as Percent of Total Expenditures</b>										
	<i>N=317</i> <sup>3</sup>			<i>N=63</i>			<i>N=254</i>			
Outpatient Medical	27.7	17.0	100.0	21.8	11.7	100.0	29.1	18.3	100.0	0.076
Chiropractor	0.1	0.0	22.7	0.0	0.0	1.4	0.1	0.0	22.7	0.536
Vision Care	1.4	0.0	52.5	1.6	0.0	27.8	1.3	0.0	52.5	0.730
Ambulatory										0.034
Therapy	3.8	0.0	90.1	9.5	0.0	90.1	2.6	0.0	79.8	
Emergency Room	1.6	0.0	96.6	1.2	0.0	96.6	1.7	0.0	89.0	0.579
Inpatient	2.4	0.0	95.0	1.2	0.0	88.0	2.7	0.0	95.0	0.351
Prescription										0.204
Medications	31.1	18.0	100.0	25.9	13.0	96.1	32.2	20.4	100.0	
Dental	12.8	0.8	100.0	19.0	2.7	100.0	11.4	0.1	100.0	0.091
Home Health	9.3	0.0	100.0	5.7	0.0	100.0	10.1	0.0	99.8	0.182
Other	0.7	0.0	67.4	0.5	0.0	27.1	0.7	0.0	67.4	0.680
Unknown	9.0	0.0	100.0	13.5	0.0	78.1	8.0	0.0	100.0	0.138
<b>Types of Expenditures as Percent of Out-of-Pocket Expenditures</b>										
	<i>N=254</i> <sup>4</sup>			<i>N=48</i>			<i>N=206</i>			
Outpatient Medical	26.1	10.8	100.0	28.2	7.1	100.0	25.7	11.8	100.0	0.733
Chiropractor	0.3	0.0	67.4	0.1	0.0	3.4	0.3	0.0	67.4	0.465
Vision Care	3.8	0.0	100.0	4.1	0.0	100.0	3.7	0.0	100.0	0.903
Ambulatory										0.036
Therapy	2.5	0.0	100.0	7.2	0.0	75.4	1.4	0.0	100.0	
Emergency Room	1.2	0.0	100.0	0.1	0.0	4.4	1.4	0.0	100.0	0.143
Inpatient	0.5	0.0	84.9	0.0	0.0	0.0	0.6	0.0	84.9	0.197
Prescription										0.026
Medications	45.7	37.7	100.0	33.8	10.5	100.0	48.3	41.1	100.0	
Dental	9.2	0.0	100.0	11.9	0.0	100.0	8.6	0.0	100.0	0.436
Home Health	0.5	0.0	100.0	0.0	0.0	0.0	0.7	0.0	100.0	0.189
Other	1.6	0.0	100.0	1.9	0.0	97.8	1.5	0.0	100.0	0.848
Unknown	8.6	0.0	100.0	12.8	0.0	83.2	7.7	0.0	100.0	0.251

<sup>1</sup>Transition age based on age in November – 5,6,11, 14

<sup>2</sup>Two-tailed t-test comparing children in a transition age vs. other ages

<sup>3</sup>Excludes those reporting no expenditures

<sup>4</sup>Excludes those reporting no out-of-pocket expenditures

**Table 3. Level of out-of-pocket expenditures by insurance<sup>a</sup> & income, for types of health care expenditure with at least 20% of families reporting spending (weighted)**

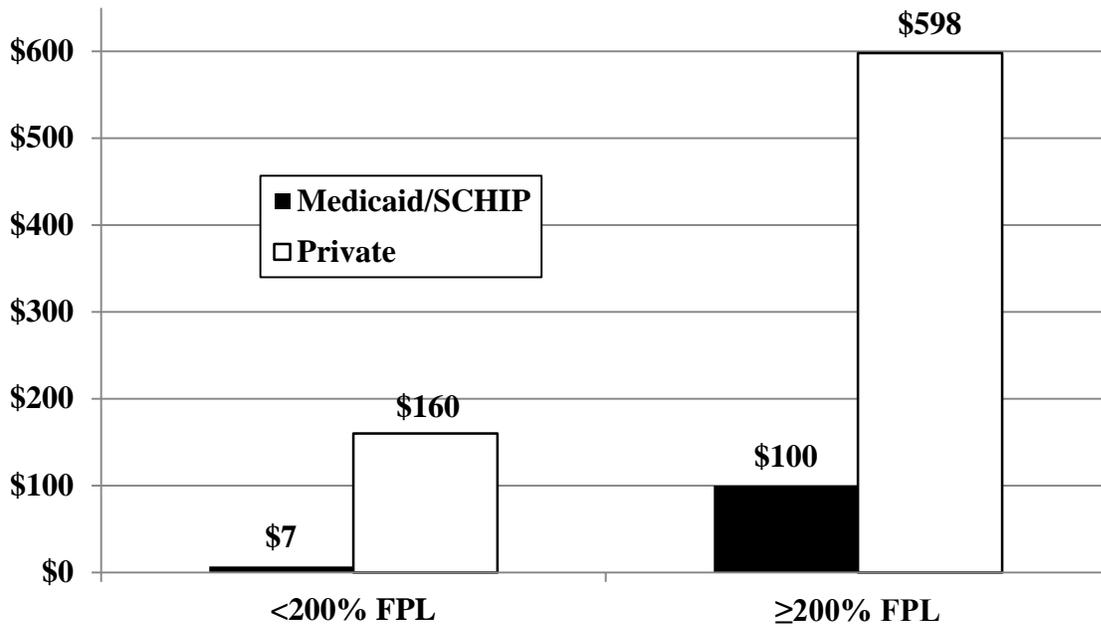
Type of Out-of-Pocket Expenditure		Overall			Insurance Status <sup>a</sup>					
					Medicaid/SCHIP			Private Only		
		All	Percent of FPL		All	Percent of FPL		All	Percent of FPL	
			200% +	<200%		200% +	<200%		200% +	<200%
<b>Total n →</b>		<b>293</b>	<b>166</b>	<b>127</b>	<b>173</b>	<b>67</b>	<b>106</b>	<b>120</b>	<b>99</b>	<b>21</b>
Total	% with Any expenditure <sup>b</sup>	82.0%	89.9%	65.6%	68.8%	80.5%	57.3%	95.9%	95.6%	97.5%
	Median \$ <sup>c</sup>	351	501	169	235	287	171	560	623	169
Prescription Drug	% with Any expenditure <sup>b</sup>	64.0%	70.7%	50.0%	50.6%	56.6%	44.8%	78.0%	79.3%	70.1%
	Median \$ <sup>c</sup>	175	209	81	89	89	93	198	242	81
Outpatient Medical	% with Any expenditure <sup>b</sup>	55.9%	69.6%	27.8%	26.9%	40.6%	13.5%	86.5%	87.2%	82.2%
	Median \$ <sup>c</sup>	99	102	57	120	120	101	85	99	57
Dental	% with Any expenditure <sup>b</sup>	23.6%	31.2%	7.9%	1.6%	2.4%	0.8%	46.8%	48.7%	35.1%
	Median \$ <sup>c</sup>	147	160	60	117	117	84	150	163	60

<sup>a</sup> Children with Other Public Insurance (N=12) or No Insurance (N=11) are excluded from this table.

<sup>b</sup> This is the percentage of sample families who had any out-of-pocket expenditures in the specified category for the child with autism.

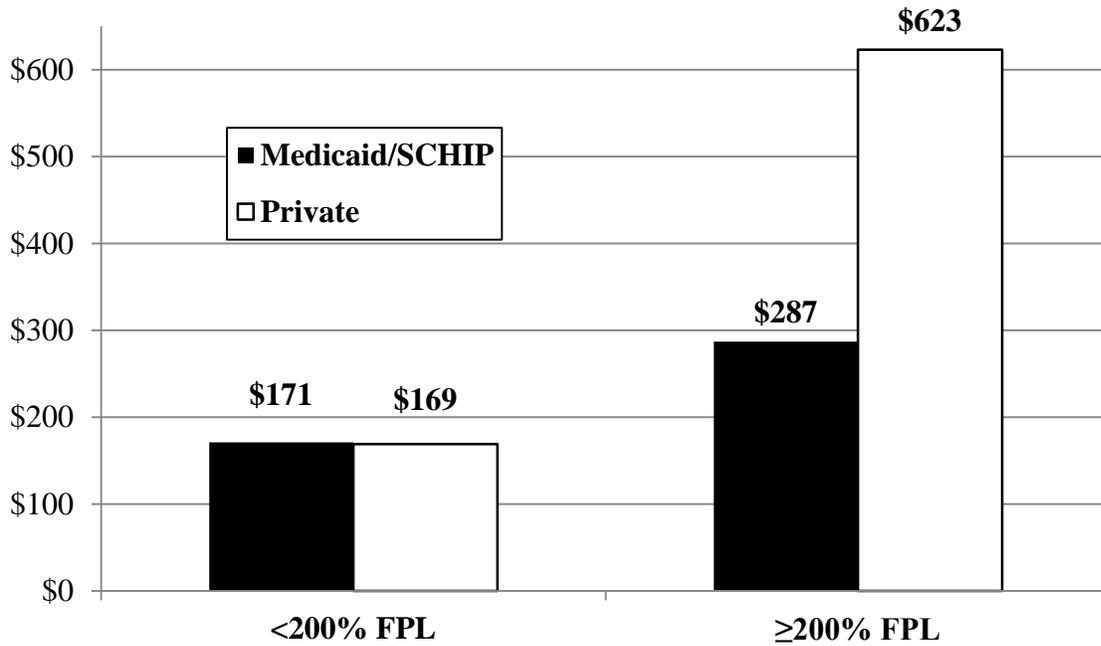
<sup>c</sup> The median spending amounts are the median for those with > \$0 out-of-pocket spending in the specified category.

**Figure 1. Median annual out-of-pocket spending by family income and child's private or public insurance status (full sample)**



<sup>a</sup>FPL = federal poverty level; in 2009, for example, the federal poverty level for a family of three was \$18,310; twice the FPL for a family of three was \$36,620

**Figure 2. Median annual out-of-pocket expenditures by family income and child's private or public insurance status (among those with any expenditures)**



<sup>a</sup>FPL = federal poverty level; in 2009, for example, the federal poverty level for a family of three was \$18,310; twice the FPL for a family of three was \$36,620

**Table 4. Logit models of any expenditures and linear regressions of level of expenditures among children with expenditures**

Expenditures	Model set 1: Children with high impairment		Model set 2: Children with low income		Model set 3: Minority children		Model set 4: Children in a single wo hh	
	Total	Out of pocket	Total	Out of pocket	Total	Out of pocket	Total	Out of pocket
<b>Logistic Regression for Any Expenditure<sup>1</sup></b>	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)	Odds Ratio (95% CI)
<b>Transition X High Impairment</b>	NA	0.46 (0.15,1.42)						
Transition x not high impairment		1.57 (0.70,3.52)						
Not transition x high impairment		1.56 (0.56,4.32)						
Not transition x not high impairment		reference						
<b>Transition X Low Income</b>			1.21 (0.21,7.04)	0.97 (0.49,1.93)				
Transition x not low income			0.91 (0.24,3.40)	0.99 (0.46,2.12)				
Not transition x low income			1.51 (0.48,4.78)	0.39 (0.19,0.83)**				
Not transition x not low income			reference	reference				
<b>Transition X Minority</b>					NA	0.46 (0.20,1.09)*		
transition x not minority						1.92 (0.89,4.12)*		
Not transition x minority						0.56 (0.24,1.28)		
Not transition x not minority						reference		
<b>Transition X Single Woman Household</b>							0.17 (0.02,1.34)*	0.16 (0.05,0.49)**
Transition x not single wo hh							2.89 (0.77,10.85)	3.03 (1.42,6.45)**
Not transition x single wo hh							7.51 (1.02,55.08)**	3.66 (1.32,10.18)**
Not transition x not single wo hh							reference	reference
<b>Linear Regression for Expenditures, Among those with Any Expenditures</b>	Coefficient (SE)	Coefficient	Coefficient	Coefficient	Coefficient	Coefficient	Coefficient	Coefficient
<b>Intercept</b>	7488.52 (1957.72)**	384.02 (196.43)*	7532.58 (1945.84)**	391.34 (196.54)**	7599.56 (1959.84)**	392.57 (163.63)**	7536.26 (1950.56)**	382.34 (200.61)*
<b>Transition X High Impairment</b>	4007.03 (1562.15)**	-25.24 (232.74)						
Transition x not high impairment	955.07*(1384.29)	1159.41 (408.4)**						
Not transition x high impairment	107.01 (1949.59)	363.36 (221.35)						
Not transition x not high impairment	reference	reference						
<b>Transition X Low Income</b>			-2859.72 (1276.21)**	586.57 (492.53)				
Transition x not low income			-708.33 (1595.89)	1130.57 (461.5)**				
Not transition x low income			-1998.42 (1459.39)	-295.43 (127.82)**				
Not transition x not low income			reference	reference				
<b>Transition X Minority</b>					-603.1 (1552.37)	1032.34 (1263.03)		
Transition x not minority					-1766.09 (1439.65)	962.87 (342.83)**		
Not transition x minority					-1144.79 (1602.47)	290.24 (307.12)		
Not transition x not minority					reference	reference		
<b>Transition X Single Woman Household</b>							-2649.21 (1952.65)	410.59 (278.68)
Transition x not single wo hh							-1319.68 (1305.01)	1015.75 (384.7)**
Not transition x single wo hh							-956.46(1891.8)	-557.33 (219.65)**
Not transition x not single wo hh							reference	reference
<b>High impairment</b>			-328.46 (1750.44)	212.75 (214.06)	-284.3 (1755.99)	235 (206.92)	-252.68 (1762.96)	244.3 (212.78)
<b>Low income</b>	-2461.36 (1269.71)*	-453.24 (138.97)**			-2335.33 (1288.31)*	-395.51 (157.55)**	-2379.69 (1284.8)*	401.06 (141.83)**
<b>Minority race</b>	905.55 (1331.07)	287.74 (335.63)	-1062.69 (1337.55)	265.13 (341.01)			-918.08 (1335.44)	292.34 (343.02)
<b>Single woman household</b>	-1030.45 (1584.09)	-541.38 (208.75)**	-1084.91 (1593.32)	-622.87 (217.66)**	-1094.55 (1572.80)	-608.61 (216.5)**		
<b>Uninsured at least 1 month</b>	-464.42 (2266.39)	438.56 (525.07)	-310.88 (2263.15)	501.71 (534.89)	-371.43 (2257.02)	468.72 (537.49)	-382.07 (2262.08)	480.08 (537.59)
<b>Bachelor's degree or higher</b>	-1187.8 (1671.29)	420.19 (175.64)**	-1239.01 (1703.89)	433.05 (169.08)**	-1151.11 (1668.38)	453.11 (179.39)**	-1161.88 (1687.2)	454.22 (184.77)**
<b>Rural</b>	2809.41 (2450.88)	183.41 (262.46)	2779.46 (2460.02)	161.12 (264.44)	2717.67 (2454.66)	154.79 (262.86)	2772.21 (2459.12)	156.27 (264.82)
<i>transition*disadvantage interaction</i>	0.15	0.009	0.272	0.42	0.555	0.959	0.577	0.199
<b>R2</b>	0.025	0.15	0.024	0.143	0.024	0.139	0.023	0.14

<sup>1</sup>These estimates are adjusted for the other variables shown in the linear regression below. NA: Inestimable because there are no high impairment or non-minority children in a transition age with no expenditures. \* p<0.10, \*\* p<0.05

**Table 5. Two-Part Regression Models for Financial Burden**

	<b>Part 1: Full sample, Logistic Regression for Any Financial Burden</b>		<b>Part 2: Among those with Any Burden, Linear Regression for log (burden)</b>	
<b>Effect</b>	<b>OR</b>	<b>(95% CI)</b>	<b>Est</b>	<b>SE</b>
Insurance status of child <sup>a</sup>				
Private only	5.33	(1.50,18.93) <sup>c</sup>	0.68 <sup>c</sup>	(0.33)
Uninsured	0.80	(0.18,3.60)	0.88	(0.56)
Other public	1.97	(0.20,19.42)	0.53	(0.50)
Age 14-17	0.98	(0.34,2.84)	0.21	(0.29)
Minority race	0.36	(0.12,1.05) <sup>b</sup>	-0.03	(0.37)
Hispanic ethnicity	0.64	(0.25,1.65)	-0.12	(0.50)
Available weekly hours per dependent	0.97	(0.94,0.99) <sup>c</sup>	-0.01	(0.01)
Single woman household	2.01	(0.67,5.99)	-0.42	(0.39)
Bachelor's degree or higher	1.46	(0.60,3.53)	0.75 <sup>c</sup>	(0.26)
Adult in household reports fair/poor health	2.63	(1.09,6.33) <sup>c</sup>	0.07	(0.37)
Adult in household reports fair/poor mental health	1.12	(0.42,3.00)	-0.07	(0.30)
High Impairment of child	1.41	(0.59,3.36)	0.23	(0.35)
Other child in household with special health care needs	1.46	(0.57,3.75)	0.23	(0.33)
Any Hospitalizations	2.24	(0.67,7.51)	1.43 <sup>d</sup>	(0.44)
Rural (non-MSA)	0.87	(0.20,3.70)	0.41	(0.33)
Log (total family income)	1.98	(1.00,3.93) <sup>c</sup>	-0.35	(0.23)

<sup>a</sup> Referent condition: child had Medicaid/SCHIP insurance

<sup>b</sup> p<.10; <sup>c</sup>p<.05; <sup>d</sup>p<.001