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# Public vs. private insurance: Cost, use, accessibility, and outcomes of services for children with autism spectrum disorders

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### ABSTRACT

Very little research has been conducted on insurance type (private vs. public funded) and costs, accessibility, and use of services of children with autism. Analysis of five parent reported outcomes: (a) out-of-pocket expenditures, (b) variety of services used, (c) access to services, (d) child and family service outcomes, and (e) satisfaction with payer of services against private and public insurance was completed. Parents/caregivers completed a survey regarding recent usage of nine specific services—inpatient care, medication management, counseling or training, individual therapy, in-home behavior therapy, speech and language therapy, occupational therapy, case management, and respite care. Across all respondents ( $n = 107$ ), 73.5% were privately insured; 21.2% were publicly insured. Based on insurance type, no statistically significant differences in outcome variables were found, findings that were not consistent with previous research. However, an indirect association was found between out-of-pocket expense and parent satisfaction with the payer of services, access to care, and family outcomes. Further, a significantly higher percentage of total out-of-pocket expenditures were allocated to speech language therapy among publicly insured children than among privately insured children ( $p = .03$ ) and parent stress was a moderating variable between access to care and variety of services used.

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Recent surveillance data from the Centers for Disease Control and Prevention indicates that as many as one in 150 children in the United States have an autism spectrum disorder (ASD) (Centers for Disease Control and Prevention [CDC], 2007). The prevalence and complexity of ASD has placed extraordinary demands on agencies that provide therapeutic services (Ruble & McGrew, 2007). In comparison to the general population and to other children with special health care needs (SHCN), children with ASD use services at a significantly higher rate (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). Treatment approaches have often included a combination of medical subspecialty care, such as psychopharmacologic and behavioral intervention, educational and rehabilitative therapy, and complementary or alternative medicine (Brachlow, Ness, McPheeters, & Gurney, 2007). Research suggests that children with ASD have twice as many inpatient and outpatient hospitalizations (Croen et al., 2006) and have significantly more pediatric, psychiatric, and medication management visits compared to children without ASD (Croen et al., 2006). When compared to other children receiving psychotherapeutic agents, children with ASD received a greater variety of and nearly twice the average total number of prescriptions (Croen et al., 2006). The high rate of service utilization combined with the multifaceted approach to treatment sought by parents of children with autism has created an extremely complex environment for medical care.

The Academy of Pediatrics' (AAP) medical home model of care (The Medical Home, 2002) lists the following essential features of care—accessibility, comprehensiveness, family centeredness, compassion, coordination, and affordability. The medical home model has become recognized as the standard for quality care in pediatrics; children with SHCN with medical home model care are less likely to forgo or delay care or have unmet health care needs (Strickland et al., 2004). According to an analysis of a national survey by Strickland et al. (2004), nearly 90% of children with SHCN met the medical home requirement of having a usual place for sick/well care and a personal doctor or nurse. Similarly, the vast majority reported having no difficulty in obtaining needed referrals (78%) or receiving family centered care (67%) (Strickland et al., 2004). In total, over 52% of children with SHCN reported receiving care that meets all requirements of the medical home model (Strickland et al., 2004).

Unfortunately, the positive outcomes anticipated by the creation of the medical home model and experienced by many children with SHCN have been largely missing in the realm of care for children with autism. When compared to parents of other children with SHCN, parents of children with autism were only half as likely to report care consistent with the medical home model, especially in regards to accessibility, care coordination, and family centeredness of care (Brachlow et al., 2007). Three times as many parents of children with ASD reported problems with coordination of care between specialty doctors and other providers than have parents of children with SHCN. Similarly, parents of children with autism reported less satisfaction with and less access to care (Krauss, Gulley, Sciegaj, & Wells, 2003; Liptak, Orlando, et al., 2006; Liptak, Stuart, & Auinger, 2006).

In addition to being underserved (Ruble, Heflinger, Renfrew, & Saunders, 2005), data also suggest children with autism are underinsured (Krauss et al., 2003; Ruble et al., 2005). Compared to families of children with SHCN, families of children with ASD were twice as likely to report problems acquiring appropriate service referrals and obtaining an adequate number of service visits (Krauss et al., 2003). Behavioral health care data from a state-wide Medicaid managed care program indicated service utilization rates as low as 10% for children with ASD based on estimated prevalence rates as well as a significant reduction in service use over a 6-year period (Ruble et al., 2005). Families of children with ASD are also twice as likely to report problems with their health plan refusing to pay and with affording the amount of out-of-pocket expense remaining (Krauss et al., 2003). In fact, children with autism have medical expenditures that are extraordinarily high in comparison to expenditures of children without ASD diagnoses (Ganz, 2007; Liptak, Orlando, et al., 2006; Liptak, Stuart, et al., 2006; Mandell, Cao, Ittenbach, & Pinto-Martin, 2006; Shimabukuro, Grosse, & Rice, 2008). The mean annual expenditures can be 9 times greater than those of non-ASD children among the publicly insured (Mandell et al., 2006) and 3–6.2 times greater among the privately insured (Croen et al., 2006; Shimabukuro et al., 2008). Privately insured children with ASD can incur 2 times the outpatient and hospital care costs, 7.6 times the medication costs, and 1.3 times the emergency department costs compared to the non-ASD children (Croen et al., 2006). When compared to costs for age-matched non-ASD children, the cost of medication was double for 2–4-year olds with ASD and 8 times higher for 5–9,

10–14, and 15–18-year olds with ASD. Even in comparison to a subgroup of children with other psychiatric conditions, the total annual average health care costs were 45% higher for those with an ASD. Thus, the presence of ASD seems to raise costs above and beyond what is usually incurred to treat non-ASD psychiatric conditions (Croen et al., 2006).

Analysis of indirect costs paints a complex and somewhat more mixed picture. Indirect costs include out-of-pocket expenses, loss of parent productivity, and payment for interventions excluded from coverage. Most studies based on parental report find that the out-of-pocket costs are unreasonable (Honberg, McPherson, Strickland, Gage, & Newacheck, 2005; Kogan, Newacheck, Honberg, & Strickland, 2005), while a minority report costs as manageable (McPherson et al., 2004). Data, which include out-of-pocket expenses, copays, and deductibles, suggest that the average caregiver of a child with ASD incurs an 8.4–9.5 times greater cost than does a caregiver of a child without an ASD (Shimabukuro et al., 2008). Annual mean out-of-pocket expenditures for children with ASD have been reported to be between \$500 and \$600 (Liptak, Orlando, et al., 2006; Liptak, Stuart, et al., 2006), which is much higher than the \$150–200 reported by parents of non-ASD children (Shimabukuro et al., 2008). According to the 2000 Medical Expenditure Panel Survey, out-of-pocket costs were twice as high for children with SHCN, including those with ASD compared to children without special health care needs. Families of children with SHCN were 2–3 times more likely to have annual out-of-pocket expenses exceeding \$1000 or exceeding 5% of family income than those of other children (Newacheck & Kim, 2005).

Indirect costs, access, and satisfaction with care may be experienced differentially by families of children with autism and other SHCN depending on their type of insurance coverage. Some studies suggest that private insurance plans are superior to public plans in providing children with SHCN with a usual source of care, ensuring a regular clinician, meeting medical care needs, and ensuring parental satisfaction (Newacheck, McManus, Fox, Hung, & Halfon, 2000; Newacheck, Pearl, Hughes, & Halfon, 1998). In contrast, other studies report that Medicaid or public secondary coverage provides children with SHCN better access to preventative care and prescription drugs (Liptak, Benzoni, Mruzek, Nolan & Thingvoll, 2008), use of a greater variety of services (Liptak et al., 2008; Weller, Minkovitz, & Anderson, 2003; Witt, Kasper, & Riley, 2003), and decreased likelihood of experiencing a health-plan related access problem (Krauss et al., 2003). For many aspects of care, however, there is no difference in the reported provision of services for children with SHCN by private vs. public insurance. For example, no significant difference was found between public and private insurance in their associations with use of physician services or in delayed or missed care (Newacheck et al., 2000; Smaldone, Honig, & Byrne, 2005). In addition, Medicaid and private insurance have been found to be similar in ensuring access to care from a specialist (Kuhlthau, Nyman, Ferris, Beal, & Perrin, 2004; Liptak et al., 2008), providing timely acute care (Liptak et al., 2008), and supplying continuous and adequate coverage (Honberg et al., 2005).

The information gained from research regarding the similarities and differences in public and private coverage for children with SHCN cannot necessarily be applied to children with ASD. The differences between private and public coverage may be more significant for ASD because many private insurance plans deem autism a diagnostic exclusion (Peele, Lave, & Kelleher, 2002). Moreover, many of the services commonly used by children with ASD such as educational testing, rehabilitation, coursework, respite care, and educational counseling are often excluded under private plans as “social and human services.” Medicaid, on the other hand, has been found to be far more comprehensive than most private insurance plans in provision of autism-related services such as case management, rehabilitative services, personal care, psychological counseling, and recuperative and long-term residential care (Newacheck, Hughes, Stoddard, & Halfon, 1994).

Despite evidence of atypical cost, problems with access, and poor satisfaction in care for children with autism, no study to date has reported on the association between all of these factors and insurance type within the ASD subgroup of children with SHCN. Due to the complexity and costliness of ASD care, a multidimensional approach to research in this area is critical. To better understand the correlations between financing and outcomes of services among children with ASD, a community-based survey was developed and administered that allowed for a preliminary examination of the associations between several interdependent variables: (a) out-of-pocket expenditures, (b) variety of services used, (c) access to services, (d) child and family outcomes of services, and (e) satisfaction with

the financier of services. The differences between these variables were evaluated by type of insurance (public vs. private). Due to the scarcity of previous research comparing insurance plans in outcomes for children with ASD, no directional hypotheses were proposed.

1. Method

This study is part of a secondary analysis of an examination of parent and caregiver experiences with the service system in one state. Further details on methods are given in the original report (Ruble & McGrew, 2007). To help reduce selection bias, the survey was distributed using multiple methods including direct dissemination at parent support groups, at a special educator meeting, via mail using state databases from community mental health centers, via the internet from autism listservs for persons living in the state of Kentucky, and via internet with a web-based version of the survey. Data from 113 parents/caregivers of children (ages 2.5–21) with ASD were analyzed. The mean age of the children was 9.9 years (*SD* = 4.4 years). Respondents came from 46 counties distributed across Kentucky. Demographic comparisons between the participants and the population of the state were similar. However, education and income levels were somewhat higher than typical for the state (see Table 1).

The survey consisted of a 43-item questionnaire regarding services received in the prior 6 months. The questionnaire targeted nine specific services—inpatient care, medication management, counseling or training, individual therapy, in-home behavior therapy, speech and language therapy, occupational therapy, case management, respite care, and contained one set of questions for “other service.” Due to the diversity of “other services” reported and to the range of out-of-pocket costs involved (\$0–140,000), the “other service” category was excluded from all analyses. Items from the questionnaire were used to construct the five variables evaluated against type of insurance: (a) out-of-pocket expenditures, (b) variety of services used, (c) access to services, (d) child and family outcomes of services, and (e) satisfaction with the financier of services. *Total out-of-pocket expense* was determined by computing the items endorsed by the caregivers as self-pay (“I paid for the services. How much in total \$\_\_\_”). The dollar amounts were then summed for each of the nine services. *Variety*

**Table 1**  
Descriptive characteristics of the sample.

Respondent characteristics	N (percent)
Education	
Graduate/professionals	28 (24.8)
College graduate	40 (35.4)
Some college	21 (18.6)
High school graduate	22 (19.5)
Some high school	1 (0.9)
Junior high	1 (0.9)
Marital status	
Never married	5 (4.4)
Spouse is parent of child with ASD	82 (72.6)
Spouse not parent of child with ASD	8 (7.1)
Widowed	1 (0.9)
Divorced	14 (12.4)
Separated	2 (1.8)
Income	
<\$10,000	7 (6.2)
10,000–24,999	14 (12.4)
25,000–49,999	32 (28.3)
50,000–100,000	38 (33.6)
100,000+	17 (15)
Race of child	
Caucasian	106 (93.8)
African American	1 (0.9)
Multiracial	4 (3.5)
Native American	1 (0.9)

of services used was computed by summing the number of affirmative responses to “In the past 6 months, has your child received X service?” for each of the nine services. Thus, the maximum *variety of services* possible was nine (including “other service”). *Access to care* was measured by responses to three items, each rated on a 5-point Likert scale (1 “strongly disagree” to 5 “strongly agree”). The items included, “I am able to access the services my child needs within my community,” “I am able to access the services my child needs within 30 miles,” and “Finding physicians or professionals in my area of the state who are trained in treating ASDs has not been a problem for me.” The mean across the three items was calculated. The *access to care* scale had a coefficient alpha of 0.70. *Outcomes of the services* for the child and for the family were rated separately. Respondents used a 5-point Likert scale (1 “strongly disagree” to 5 “strongly agree”) to rate outcomes for each service they had received during the past six months (e.g., “As a direct result of this service my child is doing better at home”). An overall mean score was calculated separately for parent and for child outcomes. *Parent satisfaction* was measured by responses to the question, “Overall, what is your rating of the program that provides funding for this service?” (0 “As bad as a program can be”, 10 “As helpful as a program can be”). Satisfaction with payer was assessed for each service received in the last 6 months. The mean score was used for this variable. *Parent stress* was measured by responses to the question, “On a scale of 1–10, how would you rate your level of stress caused by issues having to do with your child who has an autism spectrum disorder?” (1 “No problem”, 10 “Big problem”).

## 2. Results

### 2.1. Out-of-pocket expense and insurance type

The vast majority (85.7%,  $n = 84$ ) of participants reported out-of-pocket expenditures less than \$500. In fact, 60.2% ( $n = 59$ ) reported out-of-pocket expenditures of \$0. On the other hand, out-of-pocket expenses exceeded \$1000 for 14.3% ( $n = 15$ ) of the sample. Because the data were skewed, nonparametric statistics were used for this variable. Overall, caregivers reported a mean out-of-pocket expense of \$705.39 ( $SD = 2280.60$ ). The median expense was \$0. A Mann–Whitney  $U$ -test revealed no significant difference in the out-of-pocket expenditures of privately ( $Mdn = 0.00$ ,  $n = 75$ ) and publicly ( $Mdn = 0.00$ ,  $n = 23$ ) insured children,  $U = 859$ ,  $z = -0.03$ ,  $p = .97$  (see Table 2).

A series of independent-sample  $t$ -tests were used to compare participants with out-of-pocket expenses of \$0 to those with expenses greater than \$0 on key outcomes (see Table 3). No significant differences were found between the two groups in the variety of services used, parent stress, or child outcomes. However, parents with \$0 out-of-pocket expenses had significantly higher satisfaction with the payer of services ( $t = 4.74$ ,  $p < .001$ ), better access to care ( $t = 2.54$ ,  $p = .013$ ), and better family outcomes ( $t = 1.98$ ,  $p = .05$ ) than did parents with some out-of-pocket expense.

**Table 2**  
Association of insurance type and key outcomes.

Outcome	Insurance type <sup>a</sup>		Test statistic	<i>p</i> -Value
	Private	Public		
	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )		
Total OOP expense <sup>b</sup>	<i>Mdn</i> = 0.00	<i>Mdn</i> = 0.00	$U = 859.0$	0.974
Satisfaction with payer (per service used)	6.14 ( <i>SD</i> : 2.57)	5.89 ( <i>SD</i> : 2.76)	$t = -0.383$	0.703
Variety of services used	3.58 ( <i>SD</i> : 2.055)	3.25 ( <i>SD</i> : 1.75)	$t = -0.711$	0.479
Parent stress <sup>b</sup>	<i>Mdn</i> = 7	<i>Mdn</i> = 7.5	$U = 800.0$	0.409
Access to care	2.41 ( <i>SD</i> : 1.013)	2.68 ( <i>SD</i> : 0.990)	$t = 1.177$	0.242
Outcomes of services used				
Family outcomes	3.07 ( <i>SD</i> : 0.94)	3.42 ( <i>SD</i> : 1.01)	$t = 1.519$	0.132
Child outcomes	3.554 ( <i>SD</i> : 0.696)	3.72 ( <i>SD</i> : 0.82)	$t = 1.056$	0.294

<sup>a</sup> 83 respondents reported having private insurance; 24 respondents reported having public insurance.

<sup>b</sup> Assessed using Mann–Whitney  $U$ -test due to skew in data.

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

**Table 3**  
Comparison of participants with no out-of-pocket expense to those with some out-of-pocket expense on key outcomes.

Outcome	Out-of-pocket expense		Test statistic	p-Value
	\$0 M (SD)	>\$0 M (SD)		
Satisfaction with payer (per service used)	7.10 (SD: 2.39)	4.76 (SD: 2.49)	$t = 4.736$	<.001 <sup>a</sup>
Variety of services used	3.92 (SD: 1.94)	3.64 (SD: 1.51)	$t = 0.800$	0.425
Parent stress	7.30 (SD: 2.10)	7.16 (SD: 2.08)	$t = 0.331$	0.741
Access to care	2.60 (SD: 0.98)	2.12 (SD: 0.92)	$t = 2.538$	0.013 <sup>a</sup>
Outcomes of services used				
Family outcomes	3.33 (SD: 1.11)	2.95 (SD: 0.80)	$t = 1.982$	0.050 <sup>a</sup>
Child outcomes	3.59 (SD: 0.81)	3.54 (SD: 0.66)	$t = 0.343$	0.732

<sup>a</sup> 59 respondents reported having \$0 out-of-pocket expense; 45 respondents reported having greater than \$0 out-of-pocket expense.

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

**Table 4**  
Use and out-of-pocket expense for individual services among privately and publicly insured children with ASD.

Service	Insurance type <sup>a</sup>		Test statistic	p-Value
	Private	Public		
Inpatient care (n, %)	4 (5.0)	3 (12.5)	$\chi^2 = 1.654$	.198
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 6.00$	1.00
Medication management (n, %)	34 (41.5)	11 (45.8)	$\chi^2 = 0.145$	.703
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 143.00$	.290
Counseling (n, %)	30 (37.0)	9 (37.5)	$\chi^2 = 0.002$	.967
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 103.00$	.450
Individual therapy (n, %)	38 (45.8)	8 (33.3)	$\chi^2 = 1.177$	.278
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 135.00$	.734
In-home behavior therapy (n, %)	21 (25.3)	2 (8.3)	$\chi^2 = 3.176$	.075
Out-of-pocket expense (Mdn)	\$0.00	\$432.00	$U = 20.00$	1.00
Speech language therapy (n, %)	64 (78.0)	17 (70.8)	$\chi^2 = 0.536$	.464
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 422.00$	.026 <sup>a</sup>
Occupational therapy (n, %)	60 (72.3)	13 (54.2)	$\chi^2 = 2.820$	.093
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 378.00$	.661
Case management (n, %)	22 (26.5)	7 (29.2)	$\chi^2 = 0.067$	.796
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 73.5$	.573
Respite care (n, %)	24 (29.3)	8 (33.3)	$\chi^2 = 0.146$	.703
Out-of-pocket expense (Mdn)	\$0.00	\$0.00	$U = 73.5$	.427

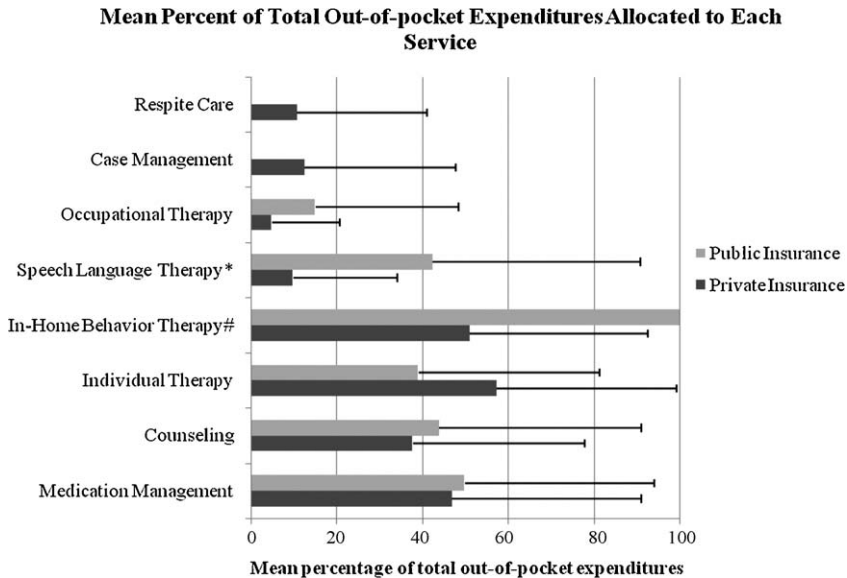
<sup>a</sup> 83 respondents reported having private insurance; 24 respondents reported having public insurance.

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

Chi-square tests comparing frequency of service use for each of the nine services revealed no significant difference between publicly and privately insured groups (see Table 4). Also, with the exception of speech language therapy, Mann–Whitney *U*-tests revealed that individual services involved similar out-of-pocket expense (Table 4) and accounted for similar proportions of total out-of-pocket expense for private and publicly insured children (see Fig. 1). A significantly higher percentage of total out-of-pocket expenditures were allocated to speech language therapy among publicly insured children ( $Mdn = 19.4\%$ ,  $n = 8$ ) than among privately insured children ( $Mdn = 0\%$ ,  $n = 26$ ),  $U = 58.5$ ,  $z = -2.225$ ,  $p = .03$ .

Among privately insured children, in-home behavior therapy accounted for the highest mean percentage of user's total out-of-pocket expenses, while respite care and case management accounted for the smallest. In contrast, among publicly insured children, individual therapy accounted for the largest mean percentage of user's total out-of-pocket expenses, while occupational therapy and speech-language therapy accounted for the smallest percentage.



**Fig. 1.** Mean percent of total out-of-pocket expenditures used on each service (+SD) for privately and publicly insured groups. \*A significant difference ( $p < .05$ ). No other comparisons were significantly different. #Only two publicly insured children used in-home behavior therapy, and though they used other services, in-home behavior therapy accounted for 100% of their total out-of-pocket expense.

## 2.2. Use of services and type of insurance

On average, families used 3.5 ( $SD = 1.98$ ) different services. An independent-samples  $t$ -test revealed no significant difference in the number of services used by parents with privately ( $M = 3.58$ ,  $SD = 2.06$ ) and publicly ( $M = 3.25$ ,  $SD = 1.75$ ) insured children,  $t = -.71$ ,  $p = .48$ .

## 2.3. Parent satisfaction, stress, and type of insurance

Parents reported an overall mean rating of 6.11 ( $SD = \pm 2.68$ ) in satisfaction with payers of services (1 = as bad as a program can be; 10 = as helpful as a program can be). An independent-samples  $t$ -test found no statistically significant differences in satisfaction ratings between children who were privately ( $M = 6.14$ ,  $SD = 2.52$ ) and publicly insured ( $M = 5.89$ ,  $SD = 2.76$ ,  $t = -0.383$ ,  $p = .703$ ).

Parents reported a mean stress rating of 7.04 (10 = very much) ( $SD = 2.16$ ) "caused by issues having to do with your child who has an ASD." A Mann–Whitney  $U$ -test revealed no significant difference in self-reported stress of parents with privately ( $Mdn = 7.00$ ,  $n = 82$ ) and publicly ( $Mdn = 7.50$ ,  $n = 22$ ) insured children,  $U = 800.0$ ,  $z = -0.83$ ,  $p = .41$ .

## 2.4. Access to care and type of insurance

A mean access to care rating of 2.44 ( $SD = 1.0$ ) was calculated out of a possible of 5 for the total sample. An independent-samples  $t$ -test was conducted to compare the access ratings for publicly and privately insured children. Access ratings were not significantly different between the privately insured ( $M = 2.41$ ,  $SD = 1.01$ ) and publicly insured ( $M = 2.68$ ,  $SD = 0.99$ ),  $t = 1.18$ ,  $p = .24$ .

## 2.5. Child and family outcomes and insurance type

An independent-samples  $t$ -test was conducted to compare the family and child outcome ratings for publicly and privately insured children. The difference in mean ratings of child outcomes among those



**Table 5**

Means, standard deviations, and zero-order correlations for variables in the study.

	N	M	SD	1	2	3	4	5	6
1. Total out-of-pocket expenditures	104	705.39	2280.60						
2. Total number of services used	104	3.495	1.98	.16					
3. Access to care	104	2.44	1.00	-.14	-.19*				
4. Total satisfaction with payer	99	6.11	2.68	-.32**	-.05	.32**			
5. Family outcomes	100	3.16	1.00	-.10	.16	.15	.28**		
6. Child outcomes	103	3.57	0.75	.05	.05	.15	.24*	.80**	
7. Parent stress	101	7.04	2.16	.12	.33**	-.37**	-.10	-.13	-.19

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

with private insurance ( $M = 3.54$ ,  $SD = 0.70$ ) and those with public insurance ( $M = 3.72$ ,  $SD = 0.82$ ) were not significant ( $t = 1.06$ ,  $p = .29$ ). Similarly, the comparison of mean ratings of family outcomes between privately and publicly insured respondents were non-significant ( $M = 3.07$ ,  $SD = 0.94$  and  $M = 3.42$ ,  $SD = 1.01$ , respectively;  $t = 1.52$ ,  $p = .13$ ).

### 2.6. Intercorrelations among variables

Because of the need to begin to consider a multidimensional approach to understanding service issues, the intercorrelations of the variables studied are presented (see Table 5). *Access to care* had a significant positive correlation with *satisfaction with payer* ( $r = .32$ ,  $p < .01$ ) and significant negative correlations with *parent stress* ( $r = -.37$ ,  $p < .01$ ) and with *variety of services used* ( $r = -.19$ ,  $p < .05$ ). *Parent stress* was also positively correlated with *variety of services used* ( $r = .33$ ,  $p < .01$ ). *Satisfaction with payer* was significantly negatively correlated with total out-of-pocket expense ( $r = -.32$ ,  $p < .01$ ) and positively correlated with family and child outcomes ( $r = .28$ ,  $p < .01$  and  $r = .24$ ,  $p < .05$ , respectively). As expected, the highest intercorrelation was between family and child outcomes ( $r = .80$ ,  $p < .01$ ).

## 3. Discussion

Although there are many studies available on the associations between insurance type and costs, accessibility and use of services among children with SHCN, information on these relationships for children with ASD is largely lacking. The information gained from research regarding the similarities and differences in public and private coverage for children with SHCN cannot necessarily be applied to children with ASD. In light of the escalating prevalence rates of ASD (CDC, 2007), very high medical expenses (Shimabukuro et al., 2008), and threats of diagnostic exclusion under coverage (Peele et al., 2002), research into the associations of insurance type and service characteristics and outcomes among children with ASD is imperative. Accordingly, this study sought to begin to fill this gap in the research literature and provide preliminary data on differences that may exist between public and private insurance coverage for children with ASD.

### 3.1. Out-of-pocket expense, service use, and access

Although some findings were consistent with prior research, there also were unexpected results. For parents of children with ASD residing in the state of Kentucky, private and public insurance were notably similar in terms of out-of-pocket expense, individual service use, overall variety of services used, and accessibility of services. These findings are consistent with those of Newacheck and Kim (2005) who found that among children with SHCN, insurance status was not associated with out-of-pocket expenses that exceed 5% of the family income. Also similar to prior studies of children with SHCN (Croen et al., 2006; Newacheck, Inkelas, & Kim, 2004; Newacheck & Kim, 2005), the out-of-pocket expenditure data was skewed. Moreover, the mean out-of-pocket expense (\$705) was comparable to other studies, which have generally found annual mean out-of-pocket expenditures for children with autism to vary around \$600 (Liptak, Orlando, et al., 2006; Liptak, Stuart, et al., 2006; Shimabukuro et al., 2008).



In contrast, and surprisingly, except for speech language therapy, there were no significant differences between insurance types in the mean percentages of out-of-pocket expense allocated to each service. That parents of children with Medicaid and private insurance pay similar amounts of out-of-pocket expenses is unexpected. Even more surprising, and inconsistent with previous research, parents of children with Medicaid in Kentucky paid significantly *more* out-of-pocket for speech and language therapy services. A survey of families of children with autism in North Carolina found that Medicaid was an enabling factor for the use of speech and language therapy and that Medicaid-covered children had 2–11 times the odds of using this service than did children with private insurance (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Our findings suggest that Medicaid may be operating differently in Kentucky for speech and language therapy use. Clearly, further information is needed to understand why Medicaid families are paying more out-of-pocket costs.

Although several studies suggest that service utilization and access are experienced differentially by families of children with autism and of children with SHCN depending on type of insurance coverage, findings have been inconsistent; some suggest that private insurance plans are superior to public plans (Newacheck et al., 2000, 1998) whereas others indicate that Medicaid is superior (Liptak et al., 2008; Krauss et al., 2003; Weller et al., 2003; Witt et al., 2003), and still others report no differences (Honberg et al., 2005; Kuhlthau et al., 2004; Liptak et al., 2008; Newacheck et al., 2000; Smaldone et al., 2005). Some of the explanations offered to explain these inconsistencies in findings across studies may be important for interpretation of our findings. First, the different measurement systems or approaches used across studies make direct comparison of results confusing if not impossible. In this study, *access to care* was measured by parents' ability to access services or knowledgeable physicians within their community, within 30 miles of their home, and within their area of the state. Therefore, findings in terms of access from this study may not generalize to accessibility issues in other states or studies, where access has been defined, for example, as ability to acquire appropriate service referrals (Krauss et al., 2003), having access to preventative and specialist care (Kuhlthau et al., 2004), or having a usual source of care and regular physician (Newacheck et al., 2000). Second, states may vary in their implementation of public funded insurance programs for children. In Kentucky, for example, we found no differences in access to a variety of services. However, this may not necessarily mean that both private and public insurance are equally good. According to Kentucky Administrative Regulations (907 KAR 1:044), the only approved vendors for Medicaid behavioral health are community mental health centers (CMHC) (Kentucky Legislative Research Commission, 2007). Thus in order for licensed psychologists to be able to provide behavioral health care to children with ASD, they must be employed or affiliated with a CMHC. In addition, Kentucky law stipulates that all treatment plans generated by a licensed psychologist receive approval by a child psychiatrist. Therefore, it is quite possible that parents of children with Medicaid might be less able to access autism specialists because they are less likely to be located within CMHCs and more likely to be located in tertiary or subspecialty pediatric care centers. That is, the apparent similarity in access may reflect differences in regulations governing availability rather than equivalence in private and public coverage of services. Future research should include an examination of the differences in state's laws regarding Medicaid, the provider network and requirements, as well as implementation of public funded programs.

### 3.2. *Satisfaction and outcomes*

There were no significant differences in child and family outcomes or in satisfaction with payer among insurance types. Although previous research has investigated parent satisfaction with care (Newacheck et al., 2000), no study to our knowledge has explored insurance type in relation to the payer of services. Also, no study to date has explored insurance type in relation to service outcomes as defined in this study for children with ASD, specifically. Given the small samples size and the relative uniqueness of this data, the results should be viewed as preliminary

### 3.3. *Intercorrelation among outcome variables*

The intercorrelations among outcome variables were fairly consistent with expectations. Increased satisfaction with the payer of services, was related to reports of increased access to care, improved

family and child outcomes, and decreased out-of-pocket expense. Moreover, as access to care increased, parent stress decreased. Somewhat less intuitive is the relationship between variety of services used, access to care, and parent stress. Use of a greater variety of services was associated with lower ratings of access to care and greater report of parent stress. One explanation for the seemingly odd inverse relationship between variety of services used and access to care is their joint relationship with parent stress. After controlling for parent stress, the negative correlation between access to care and variety of services was reduced to insignificance ( $r = -.093, p = .336$ ). It is important to recall that all of these variables are self-reported by the parent. Thus, parent stress may be acting as a third variable in the apparent relationship between service use and access to care. That is, the association of increased parent stress with both a need for a greater variety of services and poorer access to those services is likely producing an artifactual correlation between service use and access to care.

This study suffers from several limitations. The small sample size may have limited the power to detect differences in outcomes among insurance types. However, it is unclear if a larger sample size would have led to findings of significant difference given that the effect sizes also tended to be small. Moreover, the ability to detect differences in variety of services used by publicly and privately insured groups may have been limited by the inclusion of only nine services on the survey, and a more fine grained analysis of individual services may have revealed differences. Finally, the *access to care* outcome was measured by only three items which were primarily evaluated in terms of proximity to service providers. In future research, access to care should be defined more comprehensively and/or include constructs from the medical home model of care (The Medical Home, 2002).

In conclusion, understanding how to improve the health care access, quality, and outcomes for children with ASD is extremely complex. Comparing data across studies is difficult if not impossible given differences in constructs studied, measurement systems used, data sets available, samples represented, and intra-state variability. Nevertheless, the study of services research in ASD is no longer a choice but a necessity.

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