

Examination of Parent Insurance Ratings, Child Expenditures, and Financial Burden Among Children With Autism: A Mismatch Suggests New Hypotheses to Test

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abstract

OBJECTIVE: Families raising children with autism contribute significant amounts to the cost of care. In this era of health care reform, families have more insurance choices, but people are unfamiliar with health insurance terms. This study uses 2 national data sets to examine health insurance ratings from parents raising children with autism and child expenditures to explore how these measures align.

METHODS: Children with autism who met criteria for special health care needs and were continuously insured were examined. Data from the National Survey of Children With Special Health Care Needs 2009–2010 were used to examine parent report of adequate insurance ($n = 3702$). Pooled data from the Medical Expenditure Panel Survey 2002–2011 were used to examine expenditures ($n = 346$). Types of health insurance included private alone, Medicaid alone, and combined private and wrap-around Medicaid.

RESULTS: Having Medicaid doubled the odds of reporting adequate insurance compared with private insurance alone ($P < .0001$), and children on Medicaid had the lowest out-of-pocket costs (\$150, $P < .0001$). Children covered by combined private and wrap-around Medicaid had the highest total expenditures (\$11 596, $P < .05$) and the highest expenditures paid by their insurance (\$10 638, $P < .05$).

CONCLUSIONS: These findings highlight a mismatch between parent ratings of insurance adequacy, child expenditures, and relative financial burden. Findings generate a number of questions to address within single sources of data. By elaborating the frameworks families use to judge the adequacy of their insurance, future research can develop policy strategies to improve both their satisfaction with their insurance coverage and the service use of children with autism.

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Historically, children with autism have faced insurance deficits.¹⁻³ Although nearly all (97%) children with autism and other special health care needs in the United States have health insurance, families raising children with autism contribute significant amounts out of pocket to the cost of care. This pay-as-you-go strategy is associated with disparities in use for vulnerable families,⁴ unmet needs for care,⁵ and financial difficulties.^{6,7} In fact, mental disorders (a set of conditions that include autism) have been identified as the most costly set of childhood conditions.⁸

To better address these needs, there has been an effort to examine, improve, and extend insurance coverage for children with autism. Although Medicaid confers extensive benefits, a shortage of providers who accept Medicaid,^{9,10} combined with limited family resources for navigating the system,¹¹ pose barriers to care for Medicaid-eligible children with autism. Historically, private health insurance has tended to exclude coverage for autism services.¹²

To address this gap, the majority of states have implemented insurance mandates regarding benefits for autism and mental health, but the evidence of their impact remains mixed.¹³ Although living in a state with an autism mandate has been found to be associated with a lower probability of families' spending more than \$500 on the costs of their child's care and lower rates of shifting to Medicaid,^{6,14} other work suggests that living in a state with a mental health mandate (examined separately for mention of autism) is not beneficial. Bilaver et al¹⁵ found that living in a mandate state was not associated with spending more than \$1000 or reporting unmet needs.

Some children with autism and other special health care needs benefit from a combination of private insurance and Medicaid coverage. States can

extend Medicaid coverage to children with private insurance through provisions of the Family Opportunity Act (part of the 2005 Deficit Reduction Act, PL 109-171), a Medicaid waiver, and eligibility rules that exclude parent income.^{16,17} Children may also have combined private and Medicaid coverage if they receive Supplemental Security Income (SSI) and are also covered through private insurance. Private insurance serves as the primary payer and Medicaid as the secondary payer, providing wrap-around coverage for services not paid for by private insurance and required copayments. However, there is no good evidence about the impact of combined coverage on children's access to care.¹⁸

The Patient Protection and Affordable Care Act (PL 111-148) brings 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 health care treatment and rehabilitative care as essential benefits. In addition, the health insurance marketplaces offer more choices between plans and a format for comparing them.

But a critical concern is that people do not understand health insurance benefits and are not good at picking plans that meet their needs. People find it difficult to understand cost-sharing provisions.¹⁹⁻²¹ Low literacy and numeracy impede choice.^{22,23} Simulated exercises of insurance exchange choices show that people's efforts to choose a cost-effective plan are no better than chance.²⁴ Moreover, simulations illustrate that although the actuarial value of a plan provides some information about its value, out-of-pocket spending can vary between plans of equal actuarial value.²⁵ This means that choosing the best plan requires anticipating service use while understanding plan benefits and the resulting actuarial value, a complex task. Indeed, on the

Massachusetts exchange, families with someone in poor health, with more children, or those with low income are more likely to experience unanticipated out-of-pocket costs after picking a plan.²⁶

This study uses 2 national data sets to examine health insurance ratings from parents raising children with autism and child expenditures to explore how these measures align. This work expands existing evidence on variation in family report of underinsurance² by providing an objective assessment of the benefits of insurance for high-need families with autism to compare with families' subjective ratings of how well their plans work. These data, collected before implementation of Affordable Care Act reforms, can highlight issues needing attention. Health service use is understood through the classic public health conceptual framework, the Andersen Behavioral Model of Health Care Use, in which predisposing, enabling, and need characteristics of a child with autism and family determine the child's use of health services.²⁷ Good health insurance is a critical enabling feature of this model. On the basis of these considerations, the hypothesis examined in this study is that children with autism covered by combined private and wrap-around Medicaid insurance will report more adequate insurance because private coverage maintains access to a broad array of providers while Medicaid expands the types of covered services, lower out-of-pocket contributions because they are largely covered by Medicaid, and greater total expenditures because better coverage provides an incentive to use more services compared with children with other types of health insurance coverage.^{16,28}

METHODS

Children with autism who met criteria for special health care needs

and were continuously insured over a year were examined in 2 nationally representative data sets. Data from the National Survey of Children With Special Health Care Needs (NSCSHCN) 2009 to 2010 were used to examine parent report of adequate insurance by type of insurance ($n = 3702$). The NSCSHCN provides data from a complex sample design with clustering of children within households, stratification of households within states, and separate landline and cell phone sampling frames.²⁹ The interview completion rate among households known to contain a child with special needs was 80.8%. The survey provides nationally representative data on children <18 years of age with special health care needs in the civilian noninstitutionalized population, including family- and individual-level data, with detailed information on parent report of the Health Resources and Services Administration's Maternal and Child Health Bureau core outcomes for these children, including adequate insurance. The data are weighted to reflect the population of noninstitutionalized children with special health care needs in each state. Autism is identified by parent self-report, defined as answering yes to the question, "Has a doctor or other health care provider ever told you that [child] had Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?" Weighted statistics provide estimates of the prevalence of child characteristics and relationships between them.

Pooled data from the Medical Expenditure Panel Survey (MEPS) 2002 to 2011 were used to examine total and out-of-pocket health care expenditures by type of insurance ($n = 346$). The MEPS provides data from a complex national probability sample, with clustering of respondents within households

and oversampling of low-income and minority households. The overall full-year response rate since 2002 has been about 60%. The survey provides nationally representative data on the civilian noninstitutionalized population, including family- and individual-level data, with detailed information on health service use and expenditures.^{30,31} Weighted statistics provide estimates of the prevalence of respondent characteristics and relationships between them. The MEPS has been used to provide national estimates of the characteristics of children with autism and relationships between them.^{4,32,33}

The Office of Human Research Ethics of the University of North Carolina at Chapel Hill reviewed this research and deemed it was not human subjects research because it uses deidentified secondary data and exempted it from additional oversight.

Children with autism are identified as having a condition of pervasive developmental disorder (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] code 299) that describes autism and rarer variations including childhood disintegrative disorder, Rett's disorder, and pervasive developmental disorder not otherwise specified. Conditions in the MEPS are assigned via ICD-9-CM codes through a process of professional review of parent-reported conditions. To provide a sample comparable to that in the NSCSHCN, children with autism in the MEPS also had to meet criteria for special needs, determined by a positive answer to 1 of the 5 questions in the Children With Special Health Care Needs Screener.³⁴

Parent report of the adequacy of their health insurance coverage captures their subjective evaluation of the quality of their insurance. Adequate health insurance coverage is a core

outcome of the Maternal and Child Health Bureau of HRSA, defined as insurance that usually or always meets needs, that leaves uncovered costs that are usually or always reasonable, and that usually or always permits a child to see needed providers.^{3,35} In the NSCSHCN, it is measured with a binary measure that identifies families who report that their insurance meets all 3 criteria.

Annual total and out-of-pocket expenditures provide an objective measure of the quality of the insurance for 3 reasons. First, these expenditures reflect the breadth and depth of services used.³⁶ Second, the majority of expenditures are covered by insurance.⁴ Third, insurance coverage provides an incentive for greater service use.²⁸ Four elements of a child's health care expenditures are examined in the MEPS: total expenditures for all medical services, out-of-pocket expenditures for all medical services, total expenditures for mental health services, and out-of-pocket expenditures for mental health services. Expenditures divided into comprise 11 categories: outpatient medical care (including speech therapy), chiropractor visits, vision care, ambulatory therapy (physical or occupational therapy), emergency department visits, inpatient stays, prescription medication, dental visits, home health care, equipment (vision and durable medical), and other (unknown). Mental health expenditures are identified by the involvement of a possible mental health provider (physician, nurse, nurse practitioner, psychologist, social worker, or other) and 1 of the following: psychotherapy, a psychotherapeutic drug, or diagnosis of a mental disorder. Psychotherapeutic drugs were identified by membership in class 242 of the Multum classification system, which MEPS uses to organize prescription drugs.³⁷ Dollar values were adjusted for inflation to reflect 2011 dollars. The relative burden

of out-of-pocket expenditures on family income was measured as the percentage of family income devoted to out-of-pocket costs adjusted by level of income (low, mid-low, mid-high, and high).³⁸

The policy variable of interest is type of health insurance. Both surveys provide binary indicators of private insurance, Medicaid or State Children's Health Insurance Program, or other insurance. Type of health insurance was measured as private alone, Medicaid alone, combined private and wrap-around Medicaid, or other source.

Control variables capture predisposing, enabling, and need characteristics of the Andersen Behavioral Model of Health Care Use.²⁷ Predisposing variables include male gender, age, minority race, Hispanic or Latino ethnicity, and household structure (family headed by a single adult, presence of other children). Enabling variables measure, in addition to child's health insurance type, parent education (more than high school), low family income (2 dichotomous measures identifying families living below 200% of the federal poverty level and above 200% but below 400% of the federal poverty level), and language as a barrier (in the NSCSHCN English is not the primary language at home, in the MEPS the responding parent is not comfortable with English). Need for services by the child with autism was captured by 3 measures. Complexity was included as a dichotomous measure identifying children who met ≥ 4 items on the Children With Special Health Care Needs (CSHCN) Screener.³⁴ Severity of impairment was included in the NSCSHCN as parent report that the child's condition affects his or her ability to do things a great deal or some and that the child's health care needs change all the time. Severity was measured in the MEPS as a dichotomous measure identifying children aged 5 to 17 years, with

high impairment measured as scoring in the top quartile on the Columbia Impairment Scale. The Columbia Impairment Scale assesses impairment of functioning based on mood, behavior, interpersonal relationships, and functioning at school and during leisure time as reported by a parent. It has good concurrent and discriminant validity in samples of chronically ill and community-dwelling children.³⁹⁻⁴¹ Having a comorbid mental health condition was included based on parent report, similar to the protocols described earlier for report of autism. In the MEPS, comorbid mental health conditions were identified with the assigned ICD-9-CM codes 294-298 (bipolar disorder, schizophrenia, and psychoses), 300 (anxiety), 301 (personality disorders), 311 (depression), 312-313 (conduct and emotional disorders), and 314 (attention deficit disorder).

Data from the NSCSHCN 2009 to 2010 ($n = 3702$) were used to estimate a logit model of the association between parent report of adequate insurance and type of insurance controlling for predisposing, enabling, and need characteristics. Data from the MEPS ($n = 346$) were used to estimate least squares means of total and out-of-pocket health care expenditures by type of insurance. Means and proportions with 95% confidence intervals show expenditures and relative burden by type of insurance by using untransformed expenditures and including zeros. Differences in expenditures based on type of insurance were assessed based on analysis of variance, regressing log-transformed expenditures on insurance type; families with 0 expenditures were excluded from these analyses. χ^2 tests were used to assess the difference in burden by insurance type. All analyses were weighted to be representative of the target population and account for the complex sample design using

the SAS (SAS Institute, Inc, Cary, NC) SURVEY procedures. We used the DOMAIN statement to provide accurate estimates for the population subgroup of interest (children with autism and special health care needs and continuously insured) while maintaining the full study design.

RESULTS

Table 1 provides descriptive statistics of the NSCSHCN and MEPS samples of children with autism and special health care needs who were continuously insured. The children in the NSCSHCN have higher rates of minority race, Hispanic ethnicity, a comorbid mental health condition, and parents with more than a high school degree, and the children in the MEPS have higher rates of CSHCN screener items met. Just over half (54.5%) of families reported that their child with autism was covered by adequate insurance. Mean annual total expenditures for all medical services were \$6316 and for mental health services were \$1154. Out-of-pocket costs were 13% and 14% of total costs, respectively.

Families with children covered by Medicaid have more than twice the odds of reporting adequate insurance compared with those with private insurance alone ($P < .001$, Table 2). Families with children covered by combined private and wrap-around Medicaid have 45% higher odds of reporting adequate insurance compared with those with private insurance alone ($P < .05$). This pattern was consistent across the 3 elements of adequate insurance (meets needs, costs reasonable, permits access to needed providers; not shown). Controlling for child and family characteristics did not improve the fit of the model or highlight variations in the outcome (not shown).

Consistent with the goals of Medicaid, out-of-pocket costs were significantly different by

TABLE 1 Characteristics of Children With Autism and Their Families

Characteristic	NSCSHCN ^a (N = 3702)		MEPS ^b (N = 346)	
	N	Percentage or Mean (SE)	N	Percentage or Mean (SE)
Male	2914	77.1	301	88.1
Age		9.8 (0.1)		9.6 (0.3)
Minority race	861	31.2	53	12.1
Hispanic or Latino ethnicity	410	16.8	73	12.3
Single head of household	870	23.3	77	21.2
Other children in the household	2579	75.0	273	75.0
Type of insurance				
Medicaid and private	591	17.5	34	9.9
Private only	1950	46.6	131	46.6
Medicaid only	1075	33.9	154	36.9
Other insurance	69	2.0	27	6.6
Parent education beyond high school	3013	72.0	175	59.1
Income as a percentage of poverty line				
≥400%	1146	26.2	67	26.7
200%–399%	1139	29.1	119	38.1
<200%	1417	44.6	160	35.3
Primary language not/not comfortable with English	126	7.0	24	3.1
Complex needs (4+ CSHCN screener items)	1995	54.3	237	67.4
Severity of impairment				
Severity (parent report/CIS)	3012	82.5	72	20.8
Stability (care needs change all the time)	455	14.4		
Comorbid mental health condition	2427	65.0	131	42.5
Insurance meets criteria for adequate insurance	2008	54.5		
Health care expenditures ^c				
Total expenditures for all medical services			346	6316 (912)
Out-of-pocket expenditures for all medical services			346	844 (255)
Total expenditures for mental health services			346	1154 (163)
Out-of-pocket expenditures for mental health services			346	166 (30)

^a NSCSHCN, National Survey of Children with Special Health Care Needs.

^b MEPS: Medical Expenditure Panel Survey 3 Values are adjusted for inflation to reflect 2011 dollars.

^c Values are adjusted for inflation to reflect 2011 dollars.

type of insurance: They were greatest for children covered by private insurance and smallest for those covered by Medicaid (Table 3, Fig 1). Children covered by combined private and wrap-around Medicaid have the highest total expenditures (\$11 596, $P < .05$) and the highest expenditures paid by their insurance (\$10 638, $P < .05$). Children covered by Medicaid alone fall in the middle (\$7238 and \$7088, $P < .0001$). Children covered by private insurance have the lowest total expenditures and the lowest expenditures paid by insurance (\$4486 and \$3151, reference category). In addition, 95% confidence intervals for out-of-pocket expenditures for private

insured were wider than those with combined insurance for all medical service expenditures but not mental health expenditures. Tests of the significance of the association between plan type and expenditures were not different when logged expenditures were used.

Examination of relative burden indicates that private and combined insurance protect families best from financial burden (Table 4). Among children covered by private and combined insurance, most (50% and 40%, respectively) have low relative burden, and decreasing proportions are exposed to higher levels of burden. In contrast, children covered by Medicaid are most likely to

TABLE 2 Logistic Regression of Adequate Insurance Ratings by Type of Insurance Among Families Raising Children With Autism

Type of Health Insurance	Adequate Insurance	
	OR (95% CI)	P
Private only—reference		
Medicaid only	2.38 (1.66–3.42)	<.001
Private and Medicaid	1.45 (1.00–2.10)	.048
Other	4.49 (1.69–11.91)	.003
C-statistic	0.615	

Source: NSCSHCN (N = 3702). Estimates are adjusted for male gender, age, minority race, Hispanic ethnicity, single head of household, presence of other children, parent education, low family income, language as a barrier, complexity of child's condition, severity and stability of child's impairment, and comorbid mental health condition.

experience mid-low relative burden (56%).

DISCUSSION

Ratings of insurance adequacy from families raising children with autism show that families prefer Medicaid alone to combined private insurance and Medicaid, which they prefer to private insurance alone. Out-of-pocket costs for all medical and mental health expenditures align inversely with adequacy ratings: private over combined over Medicaid. In contrast, total expenditures are higher for combined, then Medicaid, then private coverage. Examination of relative burden suggests that families with Medicaid are most likely to experience burden, followed by private, followed by combined insurance. When considered together, these findings highlight some mismatch between insurance adequacy, expenditures, and relative burden.

The findings that families prefer Medicaid are consistent with recent evidence that families with children report higher satisfaction on cost-related measures when covered by Medicaid compared with private insurance and that low-income

TABLE 3 Least Squares Means of All Medical and Mental Health Expenditures, Total and Out of Pocket, by Type of Insurance for Children With Autism

Type of insurance	All Medical Services								Mental Health Services							
	Total Expenditures				OOP Expenditures				Total Expenditures				OOP Expenditures			
	Mean ^a	95% CI	P ^b	P ^c	Mean ^a	95% CI	P ^b	P ^c	Mean ^a	95% CI	P ^b	P ^c	Mean ^a	95% CI	P ^b	P ^c
Medicaid and private	11 596	5191–18 000	.035	.208	957	350–1564	.046	<.001	1904	624–3184	.242	.418	206	18–394	.281	.009
Medicaid only	7238	3970–10 506	.583	—	150	36–264	<.001	—	1284	633–1935	.461	—	74	2–147	.012	—
Other insurance	6127	3216–9037	.420	—	1092	–405–2589	.430	—	1174	250–2099	.157	—	80	29–130	.015	—
Private only	4486	2649–6324	—	—	1335	432–2238	—	—	888	598–1177	—	—	242	139–344	—	—

Source: MEPS (N = 346). OOP, out-of-pocket.

^a Means and 95% confidence intervals (CIs) are based on untransformed 2011 dollars and include 0s for those with no expenditures. P values for the association between insurance type and expenditures are based on analysis of variance comparisons of log expenditures, excluding those with no expenditures.

^b Compared with private only (t test on least squares means; 1 df).

^c Overall P value (F test; 3 df).

adults report that the quality and affordability of Medicaid are better than private insurance.^{42,43} It may be that families feel a sense of social obligation to rate Medicaid highly because they do not pay a premium for it.⁴⁴ It is also possible that Medicaid families, who typically have lower levels of education than others, may have lower expectations for their insurance.⁴⁵ Additionally, families may not attribute the met needs, out-of-pocket expenditures, and access to needed providers they experience to their insurance coverage but instead attribute it to other factors such as the power of relationships and individual efforts.⁴⁶ Even though combined insurance pays the most, it may be difficult to navigate, leading families to lower their ratings. Alternatively, families may rate their insurance relative to their out-of-pocket expenditures because the out-of-pocket costs of care are the insurance feature clearest to them. Fundamentally, families may use out-of-pocket expenditures as a yardstick to measure the benefit of their health insurance because that is the measurement they have at hand.

The NSCSHCN and the MEPS together provide a rich source of detail on families raising children with autism and their insurance preferences and experiences. However, several limitations are important to note.

Comparisons across data sets such as those presented here may reflect spurious relationships resulting from unmeasured differences in the samples. Although use of the NSCSHCN and MEPS data sets is insightful, it is only a first step to illustrate the mismatch between ratings of adequate insurance and expenditures. Further research is needed to explore the relationship between ratings, expenditures, and burden at an individual level. The MEPS may not capture all of family spending for autism, if families consider some autism-related

services as outside the realm of medical care. For example, education services, social support services, and disability-centered community activities may or may not be considered autism-related medical services.³² Families with large expenditures outside their reported medical expenditures may be more likely to have difficulty covering copayments and be less likely to report adequate insurance.

There is evidence that state-level policies are associated with access to care and financial burden for children

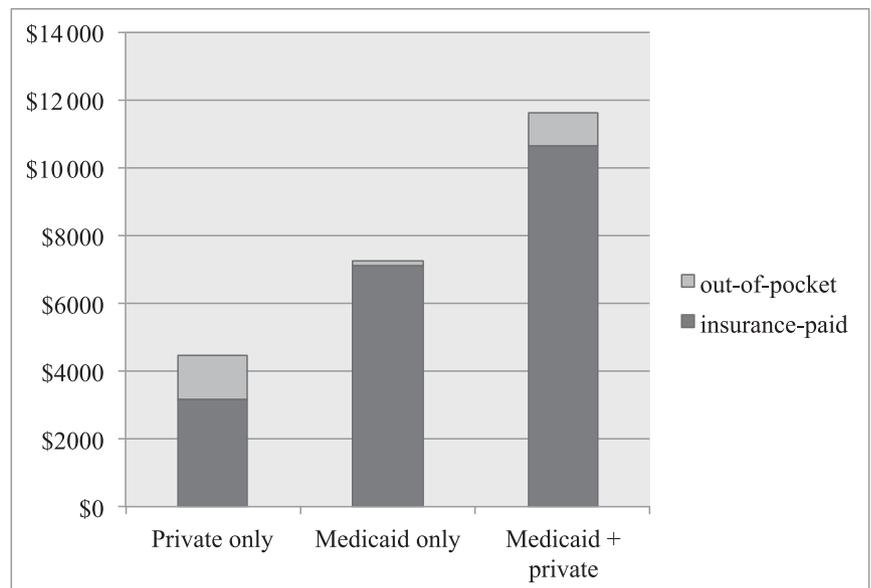


FIGURE 1

Out-of-pocket and insurance-paid expenditures for all medical services by insurance type for children with autism. Source: MEPS (N = 346) least squares models of untransformed total and mental health expenditures, overall and out-of-pocket.

TABLE 4 Association of Child Insurance Type With Relative Financial Burden Among Families Raising Children With Autism

Type of Insurance	Low Burden			Mid-Low Burden			Mid-High or High Burden		
	<i>N</i>	%	95% CI	<i>N</i>	%	95% CI	<i>N</i>	%	95% CI
Medicaid and private	14	40.1	23.4–56.8	14	34.8	14.0–55.6	6	25.1	8.0–42.2
Private only	64	50.0	39.4–60.5	43	32.9	23.2–42.6	24	17.1	9.6–24.6
Medicaid only	44	29.9	19.5–40.3	92	56.0	45.0–66.9	18	14.1	6.4–21.9
Other insurance	10	37.9	11.8–64.1	9	40.7	12.0–69.3	8	21.4	4.0–38.8
Overall	132	40.8	33.8–47.7	158	42.1	34.9–49.3	56	17.1	11.6–22.6

Source: MEPS (*N* = 346). *P* < .048 for the association between insurance type and burden (Rao–Scott χ^2 combining mid-high and high burden).

with autism.^{6,14,47} Living in a state with generous insurance policies may also affect the relationships between type of insurance and plan ratings and expenditures. However, in the NSCSHCN logit presented here, an interaction term between insurance type and living in a state with an autism insurance mandate was not significant (*P* = .157) and did not meaningfully change the odds ratios on insurance types. The analyses presented here omit state-level factors because the public use MEPS files do not provide state identifiers, and the goal was to present parallel analyses of the NSCSHCN and MEPS to support comparisons between them. Future research should examine the roles of state legislation, rule making, and culture on family insurance ratings and child expenditures.

The predisposing, enabling, and need characteristics of the Andersen Behavioral Model of Health Care Use did not improve the fit of the logit model of insurance rating after inclusion of insurance type. It is possible that the model estimates are biased because of collinearity (eg, between insurance type and poverty status), but we have used these measures in other models successfully.^{4,48} It is also possible that they are biased because of misspecification (eg, rating may be a result of experiences navigating the system of care). Future work using mixed methods should seek to elucidate and test a conceptual model of satisfaction with health insurance.

Under the Affordable Care Act, parents face new insurance choices

for their child with autism. The value of the health insurance marketplace derives from the notion that families have the best knowledge of their health and can choose plans that best meet their health and financial needs. The findings reported here, that family insurance ratings are aligned with out-of-pocket expenditures without regard to the breadth and depth of services covered, are consistent with the growing evidence that families may not understand how to identify the best insurance for their needs.^{26,49} This evidence is troubling from a policy perspective because low-deductible and low-copayment plans are expensive, reduce resources and thereby constrain use of uncovered services, and may even require families to trade off coverage of mental health and habilitative services. Additionally, families raising children with autism and other special health care needs should be aware of public insurance options, such as those available through the Family Opportunity Act, Medicaid waivers, and SSI disability determination.¹⁶ Strategies should be developed to teach people about insurance benefits and coverage options and how to pick a plan that best meets their needs.⁵⁰

To elucidate insurance plan choice strategies by families raising a child with autism, rigorous testing is needed within a single data set to assess how insurance plan features and child service use are associated with family ratings of insurance adequacy, out-of-pocket spending, relative burden, and plan

choices. Furthermore, exploration of the distribution of out-of-pocket spending for a given insurance plan and relative burden experienced by families with and without a child with autism would provide valuable information about the extent to which that plan could provide protection against the risk of financial outlays in the event a child is diagnosed with autism.

Policy changes could also be made to simplify the choices families face. For example, standards might be set to limit plan variation to low, medium, and high levels of deductibles, copayment structures, and allowable loss limits that are the same levels across plans. This change would limit the number of offered plans and make comparisons simpler. Currently, states are offering a mean of 71 plans on their exchanges; Wisconsin offers the highest number, at 452 plans.⁵¹ Setting a limit on the number of plans offered would make the job of shopping easier. People have been surprised and dismayed at the extent of change happening to plans within a year and from 1 year to the next.⁵² For example, changes in practice ownership and acceptance of insurance can alter coverage for desired providers. Changes in plan features and offerings from year to year can change their value to families. Limiting midyear change and establishing rules for grandfathering existing commitments in the face of change could reduce the need for annual shopping.

These findings suggest that families with private insurance

alone would value the opportunity to obtain wrap-around Medicaid coverage, and children would have expanded service use. Expanding Medicaid eligibility under the Family Opportunity Act, raising income limits, excluding assets from assessment, and excluding parent resources from the assessment are potential ways states could expand combined private and Medicaid coverage to a targeted group of children with intensive health care needs. Updates to federal and state protocols for assessment of SSI determination in children may be warranted as new evidence emerges about the trajectory of autism and co-occurring conditions as children age.^{53–55} Future research that sheds light on how combined insurance works for families, their understanding of their child's coverage features, the time they devote to seeking services and obtaining coverage for them, and challenges experienced will be important to elucidate the full set of factors that influence parents' satisfaction with their child's coverage.

Future research also is needed to explore the combined impacts of insurance reforms for families across states. New data with child, family, and state-level characteristics are needed to examine the impacts of Affordable Care Act insurance reforms, autism-specific legislation, and the variety of Medicaid expansion options for children with autism and their families. Data that contain sufficient numbers of children with autism to support analyses, include children with public and with private insurance, and provide detail on both expenditures and child and family characteristics are not available and would be extremely expensive to collect. Instead, researchers need to be creative about combining and comparing existing data sources and building on them to find efficient ways to address these critical issues.

CONCLUSIONS

Examination of data from families raising children with autism across 2 national data sets highlights some mismatch between parent ratings of insurance adequacy,

child expenditures, and the relative financial burden experienced by families. These findings generate a number of questions to address within single sources of data. By elaborating the frameworks families use to judge the adequacy of their insurance, future research can develop policy strategies to improve both their satisfaction with their insurance coverage and the service use of children with autism.

ABBREVIATIONS

CIS: CIS Columbia Impairment Scale
CSHCN: Children With Special Health Care Needs
ICD-9-CM: International Classification of Diseases, Ninth Revision, Clinical Modification
MEPS: Medical Expenditure Panel Survey
NSCSHCN: National Survey of Children With Special Health Care Needs
SSI: Supplemental Security Income

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