



Published in final edited form as:

*Med Care*. 2017 January ; 55(1): 57–63. doi:10.1097/MLR.0000000000000621.

## The Effects of Medicaid Home and Community-Based Services Waivers on Unmet Needs among Children with Autism Spectrum Disorder

Douglas L. Leslie, Ph.D.<sup>1</sup>, Khaled Iskandarani<sup>1</sup>, Andrew W. Dick, Ph.D.<sup>2</sup>, David S. Mandell, Sc.D.<sup>3</sup>, Hao Yu, Ph.D.<sup>2</sup>, Diana Velott, M.P.A.<sup>1</sup>, Edeanya Agbese, M.P.H.<sup>1</sup>, and Bradley D. Stein, M.D., Ph.D.<sup>2</sup>

<sup>1</sup> Penn State College of Medicine, Hershey, PA

<sup>2</sup> RAND Corporation, Pittsburgh, PA

<sup>3</sup> University of Pennsylvania, Philadelphia, PA

### Abstract

**Background**—Several states have passed Medicaid Home and Community Based Services (HCBS) waivers that expand eligibility criteria and available services for children with autism spectrum disorder (ASD). Previous research has shown considerable variation in these waivers, but little is known about the extent to which they address the healthcare needs of children with ASD.

**Objective**—To determine the effects of Medicaid HCBS waivers, and their characteristics, on unmet healthcare needs among children with ASD.

**Methods**—We used data from the 2003, 2007 and 2011 waves of the National Survey of Children's Health with detailed information on the Medicaid HCBS waiver programs of 35 states. Quasi-difference-in-difference-in-differences models were used to determine the effects of waivers and their characteristics on parent report of unmet healthcare needs of children with ASD compared with children without ASD.

**Results**—Greater waiver cost limits per child, estimated costs of services, and enrollment limits were associated with significant decreases in the adjusted rate of unmet healthcare needs, with considerable variation by household income level.

**Conclusions**—These findings suggest that Medicaid HCBS waivers significantly decrease the unmet need for healthcare among children with ASD, most substantially among those who would not otherwise qualify for Medicaid. The findings regarding the effects of specific aspects of these waivers can inform the development of insurance policies in other states to address the needs of children with ASD.

## Introduction

Autism spectrum disorder (ASD) is a complex developmental disorder characterized by repetitive behavior and delayed social interaction and communication.<sup>1-3</sup> Autism affects approximately 1 in 68 children,<sup>4,5</sup> with symptoms usually appearing in infancy or toddlerhood, and usually continuing throughout the individual's life. Effective early intervention can enhance cognition, adaptive functioning and early educational attainment in children with ASD,<sup>6-11</sup> but individuals with ASD generally need additional services, even after intensive early intervention. There is great debate, however, about how best to finance these labor-intensive and expensive interventions, and financing for these services currently varies greatly across the United States. Until recently, most private health insurers excluded ASD services from benefit plans, requiring many families to pay out-of-pocket.<sup>12</sup> As a result, families of children with ASD often have greater challenges accessing services than families of children with many other special health care needs.<sup>13,14</sup> The challenges in identifying, accessing, navigating and paying for ASD services can place a substantial burden on the families of children with ASD.

Many states have turned to Medicaid to help finance autism services. At Medicaid's inception in 1965, Medicaid eligibility was limited to individuals with specific disabilities or in low-income households, who could receive only those services listed in their state's Medicaid plan.<sup>15,16</sup> Since 1981, the federal government has allowed states to use Medicaid Home and Community-Based Services (HCBS) waivers both to expand eligibility for Medicaid-reimbursed services and to provide services not covered by their Medicaid plans to individuals at high risk of institutionalization. Many states have since taken advantage of HCBS waivers to enhance services for children with ASD, and there are 50 current or former HCBS waivers in 29 states that explicitly include children with ASD in their target population.<sup>17</sup> Medicaid is now the single largest payer of healthcare for children with ASD, serving as much as 45% of US children with ASD.<sup>18</sup>

A systematic review of the Medicaid HCBS waivers that target children with ASD found considerable variation both within and between states in waiver characteristics, including waivers' eligibility criteria, services covered, and enrollment and spending limits.<sup>17</sup> Although a previous study found that children participating in Medicaid HCBS waivers were less likely to be hospitalized or placed in long-term care than Medicaid-enrolled children not receiving services through the waiver,<sup>19</sup> there is a paucity of information about the effects of these waivers on service use and costs for children with ASD, and whether these effects vary across subgroups, such as household income level. To specifically address how well these waivers meet the needs of this vulnerable population, and to better understand whether specific waiver features are more effective in meeting these needs, we used nationally representative survey data to examine the impact of waivers on unmet needs for healthcare among children with ASD from 2003-2011 from 35 states.

## Study Data and Methods

### Data

Data from the 2003, 2007, and 2011 waves of the National Survey of Children's Health (NSCH) were used to assess unmet need for healthcare among children with ASD. The NSCH is a nationally representative cross-sectional, random-digit-dialed telephone survey that collects information about the physical and emotional health of US children 17 years and younger.<sup>20,21</sup> Children were categorized as having ASD if their caregiver answered “yes” to the question “To the best of your knowledge, does [child's name] currently have any of the following conditions ... autism or autism spectrum disorder (ASD)?” To increase the specificity of this question, we limited the sample to children with ASD aged 2 years, for whom diagnostic accuracy is greater.

Questions regarding healthcare access were used to construct a dichotomous (Yes/No) measure indicating whether the child had an unmet need for healthcare. The unmet need variable was defined across the three survey years by combining questions that probe for difficulties or delays in receiving needed medical care, including dental care, mental health services, or prescription medications. In the 2003 survey, there were separate questions for medical care (“During the past 12 months, did [child name] receive all of the medical care he/she needed?”), dental care (“During the past 12 months, did [child name] receive all of the routine preventive dental care he/she needed?”), and prescription medications (“During the past 12 months, did [child name] receive all of the prescription medication he/she needed?”). However, in the 2007 and 2011 surveys, the question was phrased: “Sometimes people have difficulty getting health care when they need it. By health care, I mean medical care, as well as other kinds of care like dental care and mental health services. During the past 12 months, was there any time when [child name] needed health care but it was delayed or not received?”, with follow-up questions for whether it was medical care, dental care, mental health services, or something else. If the respondent answered “yes” to any of these questions about unmet needs, then they were classified as having an unmet need for the purposes of our study.

Data describing state Medicaid HCBS waiver programs were collected from source materials that were submitted in support of waiver applications by each state and for each waiver from 2000 through 2014, and are described in more detail elsewhere.<sup>17</sup> The following measures that characterized waiver features were generated from the data: 1) Estimated cost, which each state calculates for its own waiver, and is defined as the total annual estimated costs of waiver services per individual expected to participate in the waiver; 2) Cost limit, which is defined as the maximum cost of services that each state allowed for individuals enrolled under the waiver; and 3) Enrollment limit, which is defined as the maximum number of participants that the waiver will serve, expressed as a proportion of the total number of children in the state.

Thirty-five states were included in the study sample. Between 2003 and 2011, 11 states had a Medicaid HCBS waiver that targeted children with autism (Colorado, Idaho, Illinois, Massachusetts, Maryland, Maine, Michigan, Montana, North Dakota, South Carolina, and Wisconsin); 24 control states did not have a child-specific Medicaid HCBS waiver during

the study period (Alabama, Arizona, Connecticut, District of Columbia, Georgia, Hawaii, Iowa, Kentucky, Minnesota, Missouri, North Carolina, Nebraska, Nevada, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Washington, West Virginia, and Wyoming). We excluded the remaining 16 states (Alaska, Arkansas, California, Delaware, Florida, Indiana, Kansas, Louisiana, Mississippi, New Hampshire, New Jersey, New Mexico, New York, Ohio, Utah and Virginia) because they had waivers that included both children and adults, and it was impossible to determine the level of services available for children under such waivers. States that passed a child-specific waiver later in the study period (such as Montana) as well as those that passed a waiver later in the study period that included both children and adults (such as Missouri) were included among the control states in earlier years prior to passage of the waiver.

## Analysis

We first re-examined the probability weights after developing the analytic sample and dropping observations with missing data to ensure they were producing consistent representations of the ASD and non-ASD populations across the independent samples. We then estimated standard multivariable logistic regression models in which the unit of analysis was the child-year. Combining across the three waves of the NSCH, our sample consisted of a total of 154,060 observations on children ages 2 to 17, including 1,824 children with ASD. We normalized the waiver policy measures that were continuous (Expected cost, Cost limit, and Enrollment limit) across states so that each had mean of zero and standard deviation of one among states with active waivers. This allows us to interpret estimated odds ratios as the effect of a 1-standard deviation change in the measure, based on the observed variation in policies across states. We specified the multivariable logistic regression models as quasi-difference-in-difference-in-differences (QDDD) models. The triple-difference in our study arises from changes in waiver policies (the 1<sup>st</sup> difference) across states with and without waivers (the 2<sup>nd</sup> difference) for children with ASD relative to children without ASD (the 3<sup>rd</sup> difference). Ours is a *quasi*-DDD design because in addition to dichotomous indicators for the waivers, characteristics of the waivers (e.g., estimated costs and cost and enrollment limits) are continuous measures. We specify a latent value formulation of the logistic regression model as follows:

$$Y_{ist}^* = \beta_0 + \beta_1 X_{ist} + \beta_2 P_{st} + \beta_3 T + v_s + ASD_{ist} * (\alpha_0 + \alpha_1 X_{ist} + \alpha_2 P_{st} + \alpha_3 T + v_s) + \varepsilon_{ist},$$

$$Y_{ist}^* = 1 \text{ if } Y_{ist}^* > 0, 0 \text{ otherwise,}$$

where  $i$ ,  $s$ , and  $t$  index child, state and time, respectively;  $X$  is a vector of child characteristics (age, sex, race, health status, and insurance status) and family characteristics (number of children in the household, whether English was the primary language spoken, and household income),  $P$  is a vector of waiver policy variables (estimated cost, cost limit, and maximum enrollment limit),  $T$  is a vector of dummy variables indicating year of the survey,  $v$  is a vector of state-level fixed effects, and  $\varepsilon$  is a logistically distributed error term. We included an indicator for current ASD status; interactions between the ASD indicator, waiver policies, and household income; and interactions between the ASD indicator and the state fixed effects. The interactions of ASD status, waiver policies, and state fixed-effects allow us to produce estimates of the effects of waivers based on their changes within state

over time, compared to changes in other states, and compared to the effects for children without ASD. The interactions with household income allow us to examine whether the effects of the waiver policies on unmet needs for children with ASD vary by household income level. We estimated the models using the probability weights and cluster robust standard errors (clustered at the state level).<sup>22,23</sup> The use of cluster robust standard errors provides consistent estimates of the standard errors even in the presence of serial correlation within states over time (cites).<sup>24-26</sup>

We then generated adjusted rates of unmet need that show the substantive effect sizes of implementing an “average” waiver (i.e., a waiver in which the estimated cost, cost limit and enrollment limit are set at the means of these values across all waivers), as well as 1-standard deviation increases in each of the waiver characteristics above its respective mean.<sup>27</sup> The adjusted rates of unmet need are based on the weighted NSCH samples so that they are representative of the national ASD population. The changes (with and without policies) that we display for the ASD population are relative to the changes for the population without ASD, and therefore, reflect the QDDD of the analytic model.

Stata® 12.1 software was used to conduct all the data management and analyses. The study was approved by the Institutional Review Board of the Pennsylvania State University College of Medicine.

## Results

The number of states with a Medicaid HCBS waiver targeting children with ASD increased from two states (Maryland and Wisconsin) in 2003 to 11 states in 2011. Characteristics of these waivers are described in Table 1. The mean estimated cost of services across all waivers fell from \$49,044 in 2003 to \$38,246 in 2011. The mean waiver cost limit increased over the same period, from \$81,138 in 2003 to \$121,204 in 2011, and the mean maximum number of children who could be served under the waivers fell from 969 in 2003 to 907 in 2011. There was considerable variation in these waiver characteristics across states, but no linear time trend for any of the waiver characteristics.

Children with and without ASD differed substantially on a variety of characteristics (Table 2). Children with ASD were much more likely to have an unmet need than children without ASD (19.5% versus 5.9%,  $p<0.001$ ). Children with ASD were also more likely to speak English at home (96.5% versus 89.5%,  $p<0.001$ ), to be ages 6 to 12 (53.7% versus 43.5%,  $p<0.001$ ) and white non-Hispanic (67.1% versus 61.1%,  $p<0.001$ ), and to be Medicaid-enrolled (42.8% versus 28.9%,  $p<0.001$ ) than children without ASD. Children with ASD were less likely than children without ASD to be female (19.1% versus 49.4%,  $p<0.001$ ), aged 2 to 5 (17.1% versus 24.8%,  $p<0.001$ ), to be black non-Hispanic (9.4% versus 13.8%,  $p=0.006$ ) or other Hispanic (4.1% versus 7.7%,  $p=0.005$ ), and to have excellent health (32.4% versus 61.0%,  $p<0.001$ ). Children with ASD did not differ from children without ASD in family composition (one child household and one adult household), household income, or whether they lived in a state with a HCBS waiver. Among all children, unmet needs increased with poverty level and decreased with child age (both  $p<0.001$  for trend).

In a multivariable logistic regression examining unmet needs (Table 3), waiver characteristics were strongly associated with unmet needs for children with ASD after controlling for child and family characteristics, with the effects varying considerably by household income. A 1-standard deviation increase in enrollment limit was associated with significantly reduced odds of having an unmet need for children with ASD, compared with children without ASD, living in households with incomes greater than 400% FPL (OR 0.68, 95% CI 0.51 – 0.90), but not in lower income households. A 1-standard deviation increase in the waiver cost limit was associated with significantly reduced odds of having an unmet need for children with ASD relative to children without ASD living in households with incomes 150% to 400% FPL (OR 0.80, 95% CI 0.72 – 0.89), but no statistically significant effects in the other income categories. For each of the waiver characteristics, there was a tendency for the effects to be stronger as household income increased, but it was not always statistically significant. Relative to children without ASD, children with ASD living in states without waivers were not statistically more likely to have unmet healthcare needs than children living in states with an average waiver; the estimated effect was in that direction, but it did not reach statistical significance. In addition to the waiver characteristics, several other factors were significantly associated with unmet need, such as child age, race/ethnicity, insurance status, and other child and household characteristics (Table 3).

Table 4 shows the adjusted rates of unmet need without a waiver, and how these rates change when waivers were implemented and characteristics of the waivers were increased. Among all children, the adjusted rate of unmet healthcare need among children with ASD was 18.5% when there was no waiver. Implementing an average waiver decreased the rate of unmet need by 4.2%, although the decrease was not statistically significant. However, increasing the cost limit and enrollment limit by 1 standard deviation led to additional decreases in rates of unmet need of 16.6% and 16.5%, respectively. These effects were limited to the higher household income groups, with a 1-standard deviation increase in estimated cost leading to a 19.5% decrease in the adjusted rate of unmet need for children with ASD in households with incomes 150% to 400% of FPL and a 1-standard deviation increase in the enrollment limit leading to 17.2% reduction in the adjusted rate of unmet need among children with ASD living in households with incomes greater than 400% of FPL; the policies had no statistically significant effects on adjusted rates of unmet needs for children living in households with incomes below 150% of FPL.

## Discussion

**This study examined** the effects of state policies on parent-reported outcomes for children with ASD. We found that HCBS waivers are associated with significant decreases in rates of unmet need among children with ASD, most prominently among children living in households with higher incomes. The effects of 1-standard deviation increases in the estimated cost, cost limit, and enrollment limit in reducing unmet need increased as household income increased, although the effects were not always statistically significant, likely due to small sample sizes. That waivers appear to disproportionately benefit higher income children may be because children living in lower income households may already qualify for Medicaid coverage, and Medicaid coverage for ASD unrelated to HCBS waivers is often generous relative to commercial insurance.<sup>28</sup> It also may be that families with higher

incomes have the resources to successfully navigate the often-cumbersome process of enrolling in the waiver, and policymakers and advocates should consider the role for enhancing the resources and supports available to families in lower income groups with children with ASD to enhance their opportunities to benefit from the waivers.

Waiver policies vary substantially across states, as policymakers seek to balance the waiver benefits with the waiver's costs and reach, as well as other constraints on the state Medicaid program. Merely implementing a waiver did not decrease unmet need; the waiver's impact on unmet need was associated with its specific features and relative generosity. Greater waiver estimated cost, which can be considered a measure of the generosity of benefits under the waiver, appears to have a greater impact on reducing unmet need than higher cost and enrollment limits, although the confidence intervals around waiver features were quite broad.

Our finding that the waiver characteristics' effects were largest among children with ASD living in higher income households likely reflects the lack of adequate private health insurance coverage for ASD services during the study period.<sup>29</sup> Although 22 states passed an autism insurance mandate between 2007 and 2010 requiring private insurers to cover autism services,<sup>30</sup> the limited research in this area suggests that these mandates have not been effective in improving access to care for children with ASD.<sup>31</sup> State Medicaid HCBS waivers appear to continue to play an important role in reducing unmet healthcare needs among this vulnerable population.

Although one must always use caution when drawing causal inference from retrospective data analyses, ours is a particularly strong research design. The quasi-difference-in-difference-in-differences design allows us to identify changes in rates of unmet needs among children with ASD before and after policy changes within a state and compare them to changes among children without ASD over the same period. It also allows us to compare rates of unmet needs among children with ASD in states with policy changes to rates of unmet need among children with ASD in states without policy changes, allowing us to control for secular changes in the care of children with ASD. Still, correlation between unobserved factors associated with both the changes in the policy variables within states and rates of unmet needs among children with ASD (such as any state or local programs that improved access to ASD services that became effective at the same time as the state HCBS waiver policy) may exist and limit causal interpretation.

Other study limitations also deserve mention. First, we limited our analysis to HCBS waivers that target children only; state-years in which there was also a waiver targeting adults were excluded. Our rationale was that adults and children with ASD have very different service needs, and we were not able to construct child-specific policy characteristics for waivers that also target adults, potentially limiting generalizability of our results to states with waivers targeting children only. Second, the NSCH survey data were only available through 2011, so we were not able to include the two HCBS waivers that were implemented after 2011 (Arkansas and Utah), nor other renewals, amendments or terminations that occurred since 2011. Third, the diagnosis of ASD relies on parent self-report and has not been validated in these survey data, and there is the potential for both

false positives and false negatives. False negatives likely do not influence the results, given the large sample of children with ASD. False positives may affect the results, although parent report of current autism status has generally been found to be specific.<sup>32</sup> In addition, parental respondents in the NSCH with a child with ASD may not be aware of or access services that are available under the HCBS waiver. Hence, we are not able to directly observe whether enrollment in the waiver directly reduced unmet needs; we can only observe the relationship between the existence of a waiver (and waiver characteristics) and rates of unmet needs for all children in the state with ASD. Finally, our information is limited to parents' perceptions of whether there was a healthcare need that was not met in a timely manner, and we have no information on the severity of illness, underlying level of need or services received. Further research is needed to examine the effects of HCBS waivers on ASD service use and outcomes.

Despite these limitations, our study demonstrates that Medicaid HCBS waivers that target children with ASD effectively reduce unmet need among these children, especially those in higher income households. **These waivers may have had** more of an impact than private health insurance mandates in reducing unmet need for healthcare among children with ASD, even among families likely to have commercial insurance. In the era of the Affordable Care Act and Medicaid expansion, states should consider waivers as an effective strategy to improve care and reduce unmet needs for all families of children with autism.

## References

1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed.. American Psychiatric Publishing; Arlington, VA: 2013.
2. Kulage KM, Smaldone AM, Cohn EG. How will DSM-5 affect autism diagnosis? A systematic literature review and meta-analysis. *J Autism Dev Disord*. 2014; 44(8):1918–1932. [PubMed: 24531932]
3. Maenner MJ, Rice CE, Arneson CL, et al. Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry*. 2014; 71(3):292–300. [PubMed: 24452504]
4. Centers for Disease Control and Prevention. [April 18, 2012] Autism and Developmental Disabilities Monitoring (ADDM) Network. <http://www.cdc.gov/ncbddd/autism/addm.html>.
5. Christensen DL, Baio J, Braun KV, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C. : 2002). 2016; 65(3):1–23.
6. Cohen H, Amerine-Dickens M, Smith T. Early intensive behavioral treatment: replication of the UCLA model in a community setting. *J Dev Behav Pediatr*. 2006; 27(2 Suppl):S145–155. [PubMed: 16685181]
7. Dawson G, Rogers S, Munson J, et al. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*. 2010; 125(1):e17–23. [PubMed: 19948568]
8. Harris SL, Handleman JS. Age and IQ at intake as predictors of placement for young children with autism: a four- to six-year follow-up. *J Autism Dev Disord*. 2000; 30(2):137–142. [PubMed: 10832778]
9. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol*. 1987; 55(1):3–9. [PubMed: 3571656]
10. Remington B, Hastings RP, Kovshoff H, et al. Early intensive behavioral intervention: outcomes for children with autism and their parents after two years. *Am J Ment Retard*. 2007; 112(6):418–438. [PubMed: 17963434]



11. Smith T, Groen AD, Wynn JW. Randomized trial of intensive early intervention for children with pervasive developmental disorder. *Am J Ment Retard.* 2000; 105(4):269–285. [PubMed: 10934569]
12. Montes G, Halterman JS. Association of childhood autism spectrum disorders and loss of family income. *Pediatrics.* 2008; 121(4):e821–826. [PubMed: 18381511]
13. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics.* 2008; 122(6):e1149–1158. [PubMed: 19047216]
14. Sheldrick RC, Perrin EC. Medical home services for children with behavioral health conditions. *J Dev Behav Pediatr.* 2010; 31(2):92–99. [PubMed: 20110825]
15. Zaharia, R., Moseley, C. State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants. Rutgers Center for State Health Policy; New Brunswick, NJ: 2008.
16. LeBlanc AJ, Tonner MC, Harrington C. Medicaid 1915(c) home and community-based services waivers across the states. *Health Care Financ Rev.* 2000; 22(2):159–174. [PubMed: 12500326]
17. Velott DL, Agbese E, Mandell D, et al. Medicaid 1915(c) Home- and Community-Based Services waivers for children with autism spectrum disorder. *Autism.* 2015
18. Semansky RM, Xie M, Mandell DS. Medicaid's increasing role in treating youths with autism spectrum disorders. *Psychiatr Serv.* 2011; 62(6):588. [PubMed: 21632723]
19. Cidav Z, Marcus SC, Mandell DS. Home- and community-based waivers for children with autism: effects on service use and costs. *Intellect Dev Disabil.* 2014; 52(4):239–248. [PubMed: 25061768]
20. Blumberg SJ, Foster EB, Frasier AM, et al. Design and operation of the National Survey of Children's Health, 2007. *Vital Health Stat 1.* 2012(55):1–149.
21. Child and Adolescent Health Measurement Initiative. [May 29, 2015] National Survey of Children's Health. <http://childhealthdata.org/learn/NSCH>.
22. Huber, PJ. Proceedings of the Fifth Berkeley Symposium on Mathematical Statistics and Probability. Vol. 1. University of California Press; Berkeley, California: 1967. The behavior of maximum likelihood estimates under nonstandard conditions.; p. 221-233.
23. White H. A heteroskedasticity-consistent covariance matrix estimator and a direct test for heteroskedasticity. *Econometrica.* 1980; 48(4):817–838.
24. Bell RM, McCaffery DF. Bias reduction in standard errors for linear regression with multi-stage samples. *Survey Methodology.* 2002; 28(2):169–182.
25. Bertrand M, Duflo E, Mullainathan S. How much should we trust differences-in-differences estimates? *Quarterly Journal of Economics.* 2004; 119(1):249–275.
26. Kezdi G. Robust standard error estimation in fixed-effects panel models. 2003 Available at SSRN 596988.
27. Newhouse, JP. Insurance Experiment Group. Free for All? Lessons from the RAND Health Insurance Experiment. Harvard University Press; Cambridge, MA: 1993.
28. Wang L, Mandell DS, Lawer L, Cidav Z, Leslie DL. Healthcare Service Use and Costs for Autism Spectrum Disorder: A Comparison Between Medicaid and Private Insurance. *J Autism Dev Disord.* 2012
29. Peele P, Lave J, Kelleher K. Exclusions and Limitations in Children's Behavioral Health Care Coverage. *Psychiatric Services.* 2002; 53(5):591–594. [PubMed: 11986509]
30. [August 29, 2015] Autism Speaks. <https://www.autismspeaks.org/state-initiatives>.
31. Chatterji P, Decker SL, Markowitz S. The effects of mandated health insurance benefits for autism on out-of-pocket costs and access to treatment. *J Policy Anal Manage.* 2015; 34(2):328–353. [PubMed: 25893237]
32. Mental health in the United States: parental report of diagnosed autism in children aged 4-17 years--United States, 2003-2004. *MMWR Morb Mortal Wkly Rep.* 2006; 55(17):481–486. [PubMed: 16675944]

**Table 1**

Summary of Medicaid HCBS waivers targeting children with ASD \*

	2003	2007	2011
Number of states	2	6	11
States included **	MD, WI	CO, IL, MA, MD, MI, WI	CO, ID, IL, MA, MD, ME, MI, MT, ND, SC, WI
Estimated cost, mean (SD)	\$49,044 (\$35,329)	\$18,946 (\$5,246)	\$38,246 (\$39,375)
Cost limit, mean (SD)	\$81,138 (\$14,174)	\$91,474 (\$92,652)	\$121,204 (\$101,389)
Max children served, mean (SD)	969 (851)	828 (1,242)	907 (1,412)

\* Characteristics refer to the state waiver policies, and were gathered during a systematic review of waiver applications, renewals and amendments. Only states with at least 1 active 1915(c) Home and Community Based Services (HCBS) waiver targeting children with Autism Spectrum Disorder (ASD) during the year with known waiver policy information are included.

\*\* Sample also includes 24 control states that did not have a waiver targeting children with ASD during the period of study. These states were AL, AZ, CT, DC, GA, HI, IA, KY, MN, MO, NC, NE, NV, OK, OR, PA, RI, SD, TN, TX, VT, WA, WV, and WY

**Table 2**

## Characteristics of the sample

Measure	All Children (N=154,060) <sup>*</sup>		No ASD Sample (N=152,236) <sup>*</sup>		ASD Sample (N=1,824) <sup>*</sup>		P-value
	Mean	SD	Mean	SD	Mean	SD	
Unmet need	0.061	0.239	0.059	0.236	0.195	0.396	<.0001
State waiver status <sup>†</sup>							
No waiver	0.777	0.416	0.777	0.416	0.745	0.436	0.107
One waiver	0.167	0.373	0.167	0.373	0.170	0.375	0.832
Two waivers	0.056	0.231	0.056	0.230	0.086	0.280	0.054
Family characteristics	0.012	0.108	0.000	0.000	1.000	0.000	
One child in household	0.212	0.408	0.211	0.408	0.227	0.419	0.379
One adult in household	0.143	0.350	0.142	0.350	0.182	0.386	0.054
Household not English speaking	0.104	0.306	0.105	0.307	0.035	0.184	<.0001
Child characteristics							
Special health care needs	0.215	0.411	0.207	0.405	0.937	0.242	<.0001
Excellent health	0.607	0.488	0.610	0.488	0.324	0.468	<.0001
Female sex	0.491	0.500	0.494	0.500	0.191	0.394	<.0001
Child age <sup>**</sup>							
2 to 5	0.247	0.431	0.248	0.432	0.171	0.376	<.0001
6 to 12	0.437	0.496	0.435	0.496	0.537	0.499	<.0001
13 to 17	0.317	0.465	0.317	0.465	0.292	0.455	0.279
Child race/ethnicity							
White non-Hispanic	0.612	0.487	0.611	0.488	0.671	0.470	<b>0.019</b>
White Hispanic	0.087	0.282	0.087	0.282	0.091	0.288	0.819
Black non-Hispanic	0.138	0.345	0.138	0.345	0.094	0.292	<b>0.006</b>
Black Hispanic	0.006	0.076	0.006	0.076	0.004	0.062	0.268
Other non-Hispanic	0.081	0.273	0.081	0.273	0.099	0.299	0.130
Other Hispanic	0.077	0.266	0.077	0.267	0.041	0.199	<b>0.005</b>
Household income <sup>†***</sup>							
<100% FPL	0.185	0.388	0.185	0.389	0.177	0.382	0.703
100% to 150% FPL	0.114	0.318	0.114	0.318	0.124	0.329	0.528
150% to 200% FPL	0.104	0.305	0.104	0.305	0.102	0.303	0.920
200% to 300% FPL	0.180	0.384	0.179	0.384	0.205	0.404	0.279
300% to 400% FPL	0.142	0.349	0.142	0.349	0.134	0.341	0.680
> 400% FPL	0.275	0.447	0.275	0.447	0.257	0.437	0.360
Insurance status							
Medicaid	0.290	0.454	0.289	0.453	0.428	0.495	<.0001
Private	0.628	0.483	0.629	0.483	0.547	0.498	<b>0.002</b>
Uninsured	0.082	0.274	0.083	0.275	0.025	0.156	<.0001

<sup>†</sup>Whether the child lives in a state with no waiver, one waiver or two waivers

<sup>†</sup>FPL = Federal poverty level

\* Unweighted N's to indicate sample size. The rest of the statistics presented in the table are from weighted data.

\*\* P<0.001 for trend

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 3**

Multivariable weighted logistic regression results: Factors associated with unmet healthcare needs

	OR	95% CI	p-value
<b>QDDD * estimates (Policy effects among children with ASD), by household income</b>			
Estimated cost			
<150% FPL	1.61	0.61 4.25	0.33
150 to 400% FPL	0.70	0.44 1.12	0.13
>400% FPL	0.12	0.02 1.02	0.05
Cost limit			
<150% FPL	0.82	0.39 1.75	0.61
150 to 400% FPL	<b>0.80</b>	<b>0.72 0.89</b>	<b>&lt;0.01</b>
>400% FPL	0.69	0.44 1.07	0.10
Maximum enrollment limit			
<150% FPL	0.90	0.55 1.45	0.65
150 to 400% FPL	0.75	0.50 1.13	0.17
>400% FPL	<b>0.68</b>	<b>0.51 0.90</b>	<b>0.01</b>
No Waiver			
<150% FPL	0.78	0.43 1.44	0.43
150 to 400% FPL	1.39	0.76 2.54	0.28
>400% FPL	1.39	0.76 2.56	0.29
<b>State Waiver Characteristics, main effects</b>			
Estimated cost	0.98	0.90 1.07	0.64
Cost limit	0.96	0.91 1.01	0.11
Maximum enrollment limit	0.95	0.88 1.03	0.22
No Waiver			
<150% FPL	0.93	0.72 1.21	0.59
150 to 400% FPL	0.85	0.68 1.07	0.17
>400% FPL	1.07	0.81 1.43	0.62
<b>Family characteristics</b>			
One child in household	<b>1.11</b>	<b>1.03 1.19</b>	<b>0.01</b>
One adult in household	1.12	0.99 1.27	0.08
Household not English speaking	<b>0.66</b>	<b>0.56 0.78</b>	<b>&lt;0.01</b>
Household income			
<100% FPL	<b>3.31</b>	<b>2.66 4.12</b>	<b>&lt;0.01</b>
100 to 150% FPL	<b>3.71</b>	<b>3.11 4.43</b>	<b>&lt;0.01</b>
150 to 200% FPL	<b>3.15</b>	<b>2.60 3.82</b>	<b>&lt;0.01</b>
200 to 300% FPL	<b>2.61</b>	<b>2.15 3.15</b>	<b>&lt;0.01</b>
300 to 400% FPL	<b>1.57</b>	<b>1.33 1.87</b>	<b>&lt;0.01</b>
> 400% FPL	1.00		
<b>Child characteristics</b>			
ASD	<b>1.69</b>	<b>1.15 2.48</b>	<b>0.01</b>
Special health care needs	<b>2.08</b>	<b>1.85 2.35</b>	<b>&lt;0.01</b>

	<b>OR</b>	<b>95% CI</b>		<b>p-value</b>
Excellent health	<b>0.66</b>	<b>0.62</b>	<b>0.69</b>	<b>&lt;0.01</b>
Female sex	0.98	0.92	1.04	0.47
Child age				
2 to 5	<b>0.80</b>	<b>0.71</b>	<b>0.90</b>	<b>&lt;0.01</b>
6 to 12	0.96	0.88	1.03	0.25
13 to 17	1.00			
Child race/ethnicity				
White Hispanic	<b>0.81</b>	<b>0.68</b>	<b>0.95</b>	<b>0.01</b>
Black non-Hispanic	1.17	0.95	1.43	0.13
Black Hispanic	1.23	0.89	1.70	0.22
Other non-Hispanic	<b>1.21</b>	<b>1.02</b>	<b>1.45</b>	<b>0.03</b>
Other Hispanic	0.79	0.63	1.00	0.05
White non-Hispanic	1.00			
Insurance Status				
Medicaid	1.00			
Private	<b>0.78</b>	<b>0.71</b>	<b>0.86</b>	<b>&lt;0.01</b>
Uninsured	<b>2.60</b>	<b>2.37</b>	<b>2.85</b>	<b>&lt;0.01</b>
year07	<b>1.95</b>	<b>1.68</b>	<b>2.26</b>	<b>&lt;0.01</b>
year11	<b>2.13</b>	<b>1.86</b>	<b>2.44</b>	<b>&lt;0.01</b>
N	154,060			
	-			
Log-likelihood	19757000			

Results in **bold** type are statistically significant at  $p < .05$

\* Quasi-difference-in-difference-in-difference models

**Table 4**

Adjusted predictions of unmet need rates among ASD children

	Unmet Need Level given		Change in Unmet Need Given Average		Additional change in Unmet Need given 1 SD increase in <sup>§</sup>		
	No Waiver <sup>†</sup>	Waiver <sup>‡</sup>	Estimated Cost	Cost Limit	Enrollment Limit		
All Children with ASD							
Unmet need rate	0.185	-0.008	-0.009	-0.032 <sup>***</sup>	-0.032 <sup>***</sup>		
% reduction		-4.2%	-4.5%	-16.6%	-16.5%		
<150% FPL							
Unmet need rate	0.215	0.050	0.096	-0.039	-0.025		
% reduction		23.0%	57.9%	-23.6%	-14.9%		
150% to 400% FPL							
Unmet need rate	0.209	-0.034	-0.048	-0.032	-0.041		
% reduction		-16.1%	-19.5% <sup>***</sup>	-13.3%	-16.9%		
> 400% FPL							
Unmet need rate	0.107	-0.031	-0.064	-0.023	-0.024		
% reduction		-28.7%	-46.6%	-16.6%	-17.2% <sup>***</sup>		

The magnitudes of these 1-standard deviation increases change over time (as the waiver policies change). In 2011, they were: \$18,373 (Estimated Cost); \$57,520 (Cost Limit); and 7.3 per 10,000 children aged 18 and under in the state (Enrollment Limit).

\* p<0.05

<sup>†</sup>Rate of unmet need when there is no HCBS waiver in the state

<sup>‡</sup>Rate of unmet need when the state has a HCBS waiver with average characteristics

<sup>§</sup>Change in unmet need when HCBS waiver characteristic increases by 1 standard deviation over the mean.

<sup>\*\*\*</sup>  
p<0.001