Published in final edited form as:

OTJR (Thorofare N J). 2017 October ; 37(4): 218–226. doi:10.1177/1539449217730355.

Analyzing State Autism Private Insurance Mandates for Allied Health Services: A Pilot Study

Megan D. Douglas¹, Teal W. Benevides², and Henry Carretta³

¹Morehouse School of Medicine, Atlanta, GA, USA

²Augusta University, Augusta, GA, USA

³Florida State University, Tallahassee, FL, USA

Abstract

Due to the prevalence, severity, and costs associated with autism spectrum disorders (ASDs), it has become a public health issue. In response, state governments have adopted ASD-specific private insurance mandates requiring coverage of ASD screening, diagnosis, and treatment. Despite rapid uptake of these laws, differences exist in the type and levels of coverage, especially for allied health services including occupational therapy. We piloted a structured legal research methodology to code ASD insurance mandates that impact allied health service provisions. State private insurance mandates were obtained from WestlawNext. A coding methodology was piloted on 14 states and included variables for age and service limits, treatments covered, and medical necessity. Coding methods were feasible and highly reliable among raters. Ten of 12 states had a coverage mandate, many with specific provisions for allied health providers. A full analysis of all 50 states is warranted to identify provisions affecting allied health providers serving individuals with ASD.

Keywords

autism; policy; insurance; access; occupational therapy

The prevalence of autism spectrum disorders (ASDs) is now reported at one in 68 children (Centers for Disease Control and Prevention, 2016) and, due to the prevalence, severity, and costs, has become a public health issue (Newschaffer & Curran, 2003). The rise in diagnoses has resulted in an influx of children with ASD into settings in which allied health professionals, such as occupational therapists, speech–language pathologists, and physical therapists, traditionally provide care. Early identification and intervention has resulted in better functional outcomes for children with ASD, but many families experience significant barriers to treatment (Kalkbrenner et al., 2011; Kogan et al., 2008), which contribute to poor

Reprints and permissions: sagepub.com/journalsPermissions.nav

Corresponding Author: Megan D. Douglas, Satcher Health Leadership Institute, Morehouse, School of Medicine, 720 Westview Dr SW, NCPC Bldg., Suite 300, Atlanta, GA 30310, USA. mdouglas@msm.edu.

This study analyzes autism insurance mandates (laws) and therefore does not constitute human subjects research. This study was not submitted to the Institutional Review Board.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

health and educational outcomes, unemployment, and other health disparities (Healthy People 2020, n.d.).

Healthy People 2020's "Disability and Health" topic puts forth the goal to "[m]aximize health, prevent chronic disease, improve social and environmental living conditions, and promote full community participation, choice, health equity, and quality of life among individuals with disabilities of all ages" (Healthy People 2020, n.d.). Occupational therapists and other allied health professionals play a critical role in advancing this goal to ensure people with ASD not only have the skills to function within their environments but also access to needed services and skills to advocate for themselves throughout their lives. In fact, the occupational therapy (OT) profession is expanding its focus upstream to include population health and advocacy as evidenced by the third edition of the Occupational Therapy Practice Framework (American Occupational Therapy Association [AOTA], 2014). Children with ASD are more likely to have an unmet need for therapy services than children with other disabilities (e.g., Benevides, Carretta, & Lane, 2016). Without access to therapy services, communication and functional needs may go unmet, which poses barriers to optimal functioning and full engagement with education and employment opportunities (Benevides et al., 2016).

Access to and delivery of therapy is often contingent upon insurance coverage, family financial resources, and an adequate supply of health care providers and therapists. These factors can be manipulated through laws and policies at the state and federal levels, through insurance regulations and mandates, health professional licensure, and reimbursement policies. Reported barriers to care have garnered much attention from legislators, public health professionals, families, policy organizations, and researchers and have led to the rapid adoption of upstream laws and policies meant to improve access to care for children with ASD (Autism Speaks, n.d.). Health services research that examines the effects of these policies on access to and delivery of treatment, including OT, is critical to understanding disparities in care experienced by people with ASD and to developing evidence-based individual and policy interventions that advance health equity. Health services research often takes the perspective of population-level analysis of policies and the influence of these factors on downstream objectives such as those proposed by Healthy People 2020. For people with ASD, a growing population of children and adults with disabilities, an opportunity to understand the effects of health policy has emerged with recent passage of multiple state ASD private insurance mandates. ASD private insurance mandates are state laws that require insurance plans to cover the diagnosis and treatment of autism, and are typically intended to address access and cost barriers. Currently, 45 states, as well as the District of Columbia and U.S. Virgin Islands, have adopted ASD private insurance mandates, with the majority of these laws enacted since 2007 (Autism Speaks, n.d.). Because private health insurance is primarily regulated by the states, there is considerable variation across states and over time with regard to specific provisions of autism mandate laws (Hoffman, 2012). This variation provides an opportunity for the use of natural experiment research design to examine the relationship between the particulars of state law and population health outcomes relevant to children with autism and to thereby identify best practices. Typically, health policy studies have examined the effectiveness of ASD private insurance mandates and mental health parity laws using publicly available legal resources

developed by advocacy and policy organizations such as the National Conference of State Legislatures (NCSL) and the National Alliance on Mental Illness (Bilaver & Jordan, 2013; Johnson, Danis, & Hafner-Eaton, 2014). These studies provide a global perspective on the impact of ASD private insurance mandates, often by examining whether the presence or absence of an insurance mandate is associated with a particular health or financial outcome. Many of the granular policy variations across states are lost from such analyses due to the independent variable being rolled up into a single categorical variable; for example, a state law is present or not present (e.g., Parish, Thomas, Rose, Kilany, & McConville, 2012). Even where more granular policy provisions are studied, the methods used to collect and assess the laws of interest remain unclear (Baller et al., 2016; Chatterji, Decker, Markowitz, 2015). Studying the variation in specific provisions may provide greater context for measuring the impact of the laws on specific outcomes (Johnson et al., 2014).

Structured legal research methods have been delineated and are being used to evaluate the impact of laws and policies on a variety of public health outcomes (Ibrahim, Anderson, Burris, & Wagenaar, 2011; Lynne-Landsman, Livingston, & Wagenaar, 2013; Presley, Reinstein, Webb-Barr, & Burris, 2015; Wagenaar & Burris, 2013). At present, no such methodology has been formally implemented to evaluate the nuances of autism insurance laws. Occupational therapists are typically described within autism private insurance mandates, and as such, the details of each mandate may have significant impacts on the professional practice in each state. The AOTA is committed to policy advocacy in the United States, and conducting legal research analysis on the impact of state-level nuances on specific outcomes will provide practitioners, families, and legislators opportunities to understand how such nuances impact access, costs, and health outcomes. The purpose of this study was to pilot a structured legal research methodology to code ASD insurance mandates that impact access to services such as allied health services, and to report on the methods, feasibility, and preliminary policy data from a comprehensive set of states associated with the Autism and Developmental Disability Monitoring (ADDM) Network. A multidisciplinary team of subject-matter experts is a critical component of policy surveillance and development of legal datasets to advise on the practical impact of legal provisions and to guide decisions on inclusion of specific policy variables into the coding schema (Burris, Hitchcock, Ibrahim, Penn, & Ramanathan, 2016). The subject-matter experts involved in this study included attorneys, an epidemiologist, a behavioral scientist, ASD research program officers, public health professionals, a health economist, occupational therapist, audiologist, psychiatrist, and a developmental psychologist. The findings from this pilot study will serve as a basis for development of a 50-state legal dataset and future evaluation research using granular data related to the effect of autism insurance mandates on service provision and outcomes in OT.

Method

We developed a scientifically rigorous data collection and coding methodology of ASD private insurance laws and piloted the methodology in 14 states. We adapted the protocol of Ibrahim et al. for this study, and methods are fully described below (Ibrahim et al., 2011). Autism insurance laws are lengthy legal documents with multiple provisions. Due to the extensive coding required for each law, this pilot legal coding study was implemented to

determine the feasibility of this method and to identify specific variables that would be relevant for future analysis in examining the effect of nuanced mandate codes on service access and utilization.

Sample

For this methodological pilot, we used a sample of 14 states that were part of the ADDM Network as of 2012. These states were selected because variation in prevalence rates (range: 8.2 per 1,000 [Maryland] to 24.6 per 1,000 [New Jersey]) had been identified across these particular states based on ADDM monitoring data (Centers for Disease Control and Prevention, 2016), which led to the question of what role state-level policies such as ASD private insurance laws might play with regard to higher or lower prevalence rates and services/supports available for individuals with ASD in particular states. A comprehensive survey of the state laws in Alabama, Arizona, Arkansas, Colorado, Florida, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Wisconsin, and Utah was conducted.

Legal Data Sources

The legal database WestlawNext was used to search for existing laws within the sample states, with the last search conducted on December 31, 2014. The final search protocol included the following terms: *autism*, *ASD*, *developmental*, *insur**, *pay**, *mandate*, *Medicaid*, *health benefit plan*, and *access*. The search terms were verified by comparing the results with the publicly available information from Autism Speaks, Easterseals, and the NCSL to ensure that all relevant statutes in the sample states were identified (Easterseals, 2014; NCSL, 2015; Warren et al., 2011).

Laws that did not mention autism and were not explicitly related to private insurance coverage were excluded (e.g., Medicaid and the Children's Health Insurance Program). General mental health parity laws were excluded because the impacted population was not specific to autism. Autism-specific parity laws requiring similar coverage of ASD as compared with other physical and/or mental health conditions, including deductibles, coinsurance, and copayments, were included.

Policy Themes and Variables

Each state law was reviewed initially by one attorney, and a list of common themes was developed. The advisory team reviewed and recommended inclusion or exclusion of policy themes based on significance of each theme. Themes included scope of law, effective date, compliance date, insurance plans, age limits, service limits, treatments covered, medical necessity, and coverage for medical treatment only. Within each theme, specific policy variables were identified for which each law would be coded. For example, within "scope of law," laws were coded on three dichotomous (Y/N) variables: whether the law provided "parity," "mandate," or "offer" coverage. Through this iterative process, a list of coding questions and definitions were developed and reviewed by the team to ensure consistent interpretations and comprehensive data extraction. The final list of coding questions consisted of nine themes and 63 variables. One attorney investigator (first author) coded the laws in the 14-state sample. A second attorney, blinded to the initial results, also coded the

14 state laws to determine consistency in coding methods across the 882 variables (63 variables/state $\times$ 14 states). Interrater reliability was determined using the Kappa statistic. The variables, categories, and definitions are listed in Table 1. Descriptive analysis of each mandate variable using frequency counts and percentages was conducted.

Results

Feasibility and Reliability of Coding Mandates

Due to the unique nature of state legislative processes and legal code structures, the number of separate laws (i.e., code sections) comprising each state's ASD private insurance mandate ranged from one to 19. For most states, the ASD private insurance mandate was contained in a single code section but referred to additional code sections to define specific terms. For example, Arizona's primary autism insurance mandate is codified in Title 20, Chapter 4, Article 9 (i.e., Arizona Revised Statutes Annotated § 20–1057.11). Conversely, New Jersey's ASD private insurance mandate and parity laws are codified in 19 separate code sections (14 within Title 17, two in Title 26, and three in Title 52) with identical provisions except for the type of insurers and health plans obligated to comply with the laws. Due to the nuances in legal terminology and the complexity of state legal codes, it was beneficial to have attorney raters. The interrater reliability for the two attorney raters was found to be Kappa = 0.94, $p < .001$. Discrepancies were discussed by the research team and resolved based on consensus.

Scope of Law

Three types of laws were distinguished in this study, those that (a) required private insurance plans to “cover” ASD treatment, (b) required insurance plans to “offer” ASD coverage, and (c) required parity of ASD services when compared with other physical or mental health conditions.

Twelve of the 14 analyzed states had enacted an ASD private insurance mandate as of the time of this analysis (AL, AR, AZ, CO, FL, MD, MO, NJ, PA, SC, UT, and WI). Since the time of this coding in 2014, the other two states (GA, NC) have passed autism insurance mandates; however, their data were not included in this pilot.

Twelve of the 14 states either included a parity provision within the ASD private insurance mandate or as a stand-alone parity law. Parity does not require coverage of ASD, but, when coverage is provided, prevents discrimination on the basis of an ASD diagnosis via dollar limits, deductibles, and coinsurance provisions. Two of the 12 states with an insurance mandate did not have corresponding parity provisions (AZ, MD). Conversely, although GA and NC did not have private autism insurance mandates, they did have stand-alone parity laws applicable to ASD.

Laws requiring insurers to “offer” coverage allow the employers and insurance companies providing coverage and individuals to decide whether ASD coverage will be included in the resulting plan, as opposed to laws requiring payers to “cover” ASD treatment in all plans. Eleven of the state laws required payers to “cover” ASD in all plans. One state (AL) required large group insurance plans to “offer” ASD coverage but did not mandate coverage. Results for the 14 states at the time of coding are described below and presented in Table 2.

Effective and Compliance Dates

Half of our state sample had the same effective and compliance date for insurers ($n = 6$). However, for some states ($n = 3$; FL, MO, PA), effective and compliance dates differed, with compliance dates occurring later than effective dates (range= 4–11 months). Three states did not include a compliance date requirement.

Insurance Plans

Four types of insurance plans were found in the majority of the state laws: large group, small group, individual, and state employee health plans. A fifth category of “other” was included to capture additional state-specific insurance plan categories. All 12 states (100%) had mandates which applied to large group policies, 10 (83%) applied to state employee health plans, six (50%) to small group policies, and five states (41.7%) mandated coverage in plans sold on the individual market. Nine states (75%) applied their law to “other” health benefit plans, including health maintenance organization policies, supplemental policies, and hospital/medical service plans.

Age Limits

Coverage varied depending on the age of the insured. Two types of age limits were identified: (a) those capping the age at which a child must have been diagnosed with ASD to receive treatment and (b) those capping the age a child is eligible to receive ASD treatment under the mandate. Only one state (SC) required the ASD diagnosis to occur before the age of 8 to be eligible for benefits. Ten states (83%) imposed age limits that capped ASD-related treatment. The age cap ranged from 9 years of age (AL) through 21 years (NJ, PA), with some treatment caps applying to all treatment covered by the mandate and some applying only to behavioral therapy (including applied behavioral analysis [ABA]). One state did not have an age cap for treatment (WI). Colorado capped treatment coverage at age 18 only if the child had not been diagnosed by the age of 8, but if diagnosed by age 8, coverage extended beyond the age of 18 as long as the individual was in high school. The mean age at which ASD-related services were capped was 13.8 years.

Service Limits

Service limits were described as limits in both dollars and hours. Three primary types of service limits were observed: (a) limits on services for all ASD treatments, (b) limits on behavioral therapy only, and (c) limits based on a combination of an insured’s age and service costs. Three state mandates (25%) limited coverage for all ASD treatments, ranging from US\$12,000 per year to US\$200,000 per lifetime, adjusted annually for inflation. Three states (25%) imposed minimum dollar limits on the benefits generally, meaning that covered insurance plans must provide services for at least the dollar amount included in the law. Eight state mandates (66.7%) specifically limited coverage for behavioral therapy, ranging from US\$25,000 to US\$50,000 per year, with one (UT) capping behavioral therapy at 600 hr per year. Two states (16.67%; AZ and CO) imposed different service limits based on the insured’s age. Arizona capped coverage for children up to 9 years of age at US\$50,000 per year and children between the ages of 9 and 19 years at US\$25,000 per year. Colorado’s law

included service limits that were “actuarially equivalent” to US\$34,000 per year for children between the ages of 1 and 8 and US\$12,000 per year for children aged 9 to 19 years.

Treatments Covered

All of the state mandates distinguished between behavioral therapy and allied health services as types of treatments covered. Therefore, in the coding schema, types of treatment covered were categorized according to behavioral therapy and allied health services, which typically included speech–language pathology, OT, and physical therapy.

Ten state mandates (83.3%) required coverage of allied health services, with AZ and SC not requiring coverage of allied health services. Of the 10 states requiring allied health services, three (30%; CO, FL, and PA) imposed general dollar limits (as opposed to specific limits on these services), which would apply to provision of allied health services. Nine of the 10 states (90%) specifically required coverage of therapeutic services provided by occupational, physical, and speech therapists. Wisconsin’s mandate required coverage of services provided by occupational and speech therapists but did not mention physical therapists. Six of the 10 mandates requiring coverage of therapy services included licensure requirements for therapists. These requirements ranged from broad (e.g., Alabama and Maryland required allied health service providers to be licensed and certified, but had no other criteria), to specific (e.g., Colorado included allied health service providers within the “autism services provider” definition, which required state licensure in addition to having a master’s degree or higher, proper credentials, and at least 1 year of direct supervised experience in behavioral therapies, and could include a licensed OT assistant). In addition, a 2013 amendment to Colorado’s ASD private insurance mandate changed the requirement that occupational therapists be “registered” in the state to “licensed” in the state, which coincided with the state of CO requiring licensure for OTs, which is now a requirement in all states.

Coding questions distinguished between coverage of behavioral therapy generally and ABA specifically. Six mandates explicitly required coverage of behavioral therapy (50%). Ten mandates (83.3%) explicitly required coverage of ABA. Most states required either state or national licensure by the Behavior Analyst Certification Board (BACB); however, three (25%) recognized only state-level licensure and one state (8.3%) recognized only national-level certification by the BACB.

Medical Necessity

Three variables emerged regarding medical necessity: (a) whether a treatment plan was required prior to payment of services, (b) what type of provider was authorized to prescribe the treatment plan, and (c) how often an insurance policy could review the treatment plan for medical necessity. Seven states (58.3%) explicitly required a treatment plan to receive services, with most requiring that a licensed physician or psychologist prescribe the treatment. Six (50%) limited utilization review to once per 6 months, and one (8.3%, AR) limited it to the same frequency as other illnesses.

Coverage for Medical Treatment Only

Six states (50%) distinguished between medical and educational services, stating that services provided under the mandate do not affect any obligation to provide services under the Individuals With Disabilities Education Act (IDEA).

Discussion

This study establishes that granular legal data collection and coding methodologies can be applied to promote scientifically rigorous evaluation of ASD private insurance mandates. We found extensive variability in how the laws are written and thus how states make provisions for the types of providers, cost caps, and age limitations that private insurers may impose on autism-related services such as occupational therapists and other allied health service providers. These differences, even within our small state sample, are sufficiently variable to warrant further study. This study revealed that use of an explicit legal method with a codebook and definitions resulted in highly reliable ratings between two attorney raters for the autism insurance mandates.

The analysis also revealed observational challenges with coding laws at such a granular level. Most of the coding questions were relatively straightforward and could be answered by the language in each of the 14 pilot states' laws using categorical (Y/N) responses. However, some of the coding questions underwent multiple iterations as the language in a single state law made the question irrelevant to that state. For example, the training and licensure requirements for allied health services in most of the states were simply licensure or certification in the state. However, the language in Colorado's law presented nuances that were not covered in the previous iteration of the coding questions, which resulted in changes to the coding question to adapt to the state's unique language. This issue will remain a consideration as this method is applied to all 50 states. In addition, other variables underwent revision as field experts from other professions including OT were involved in the review of coded data. Based on this pilot, future legal methods that analyze insurance mandates should include a minimum of two attorneys or individuals with experience reviewing legal codes and inclusion of other autism service providers who can address the coding nuances required to understand each service discussed in the law.

Although our results are not generalizable to all states, and further analysis is needed to understand the effect of autism insurance mandates on OT practice, our findings have specific implications for practitioners, researchers, and policy makers interested in advancing public health outcomes for individuals with autism. Policy research resulting from this type of legal dataset takes the OT lens upstream to study how policy, in this case private insurance laws, may impact OT practice and the individuals with ASD served by OT practitioners. Practitioners working with individuals with autism should be aware of the general differences across states related to their ability to provide autism-related services, the age limits, and treatment caps for medically related services billed to private insurance. For example, practitioners in Arizona working with individuals with ASD should be aware that cost caps were based on the child's age and that ASD treatment was not required to be covered after the age of 16. At the time of this study, Utah did not require insurers to pay for autism-related services beyond 600 hr a year, which translates to approximately 11.5 hr a

week, far less than recommended service limits for intensive autism treatments (National Autism Center, 2009). These nuances are important distinctions that affect service provision, and should be recognized by researchers, as well. Due to racial and ethnic disparities in age of diagnosis, mandated age limits found within our preliminary analysis have the potential to disadvantage minority populations and are also therefore ripe for research on their health equity impact (Mandell et al., 2009).

ASD is considered a developmental condition and therefore will impact an individual throughout their life span. However, the majority of the 14 states capped ASD-related treatments, with the mean age of treatment caps occurring in adolescence. Cidav and colleagues identified that adolescents with ASD experience significant increases in mental health care, pharmacological management, and decreases in habilitative therapies (Cidav, Lawer, Marcus, & Mandell, 2013), all outcomes identified in the Healthy People 2020 “Disability and Health” objectives (e.g., DH-7, DH-17, DH-18). OT is a qualified service provider for addressing mental health concerns resulting from disruptions in occupational performance at key transitions such as adolescence. And, although a recent push for provision of OT services for adolescents and adults with autism has received attention, these services may be limited by the ability of the family to pay for them due to such age caps. Future research should study how age caps alter the types and amount of care that families are able to attain for their adolescent and adult children.

Our analysis of this small sample of state mandates indicates that interactions with other laws may be a future area of analysis. Self-insured large group health plans are subject to the federal Employee Retirement Income Security Act (ERISA) rather than the state laws under review here, which potentially exempts a significant segment of large group plans from complying with these laws (Buchmueller, Cooper, Jacobson, & Zuvekas, 2007). Adoption and implementation of the Affordable Care Act (ACA) and the Mental Health Parity and Addiction Equity Act (MHPAEA) also affect these state-level insurance laws. For example, fewer than 50% of our sample of states required individual plans purchased on the insurance market (now required by the ACA of 2014) to cover autism-related services. Given that many caregivers of children with autism must give up work or change their employment to accommodate the needs of their child (Ooi, Ong, Jacob, & Khan, 2016), such differences in the type of insurer covered by the state mandate can have detrimental effects on families and individuals seeking service coverage. In addition, the existence of a law should be distinguished from the implementation of that law. A recent study of the individual insurance plans available through the ACA’s health insurance marketplaces demonstrated noncompliance with essential health benefit benchmark standards for habilitative services (AOTA, 2016). Detailed examination of the regulations (resulting from these private insurance mandates) and whether and how insurance plans are complying with these private insurance mandates and regulations is needed.

Researchers should be aware of specific policy provisions when evaluating policy interventions for effectiveness. For example, different effective and compliance dates determine length of exposure to the laws (typically in years), which is critical to interpreting health outcome data when merged with state-level policy data. The types of plans subject to the ASD private insurance mandates determine how many individuals with ASD receive

treatment under the laws. OT researchers, specifically, should attend to these policy interventions as another area for future investigation.

Limitations

This analysis was based on the explicit language of the laws reviewed. Only laws requiring private insurers to cover autism were analyzed; therefore, ASD coverage by public insurance and federal programs was outside the scope of this study. Our analysis occurred at a time in which states were actively passing autism insurance mandates, and our analysis reflects only those state laws available at the time of extraction of the state law; therefore, further work to quantify these variables across all 50 states is necessary.

Conclusion

This pilot study detailed coding methods for ASD private insurance mandates in 14 states. This research demonstrates the feasibility of extracting granular variables using a structured legal research method, and preliminary results suggest heterogeneity across states on extracted variables. Although many studies examining the effect of autism insurance mandates dichotomize states into “mandate” or “no mandate,” our analysis of a small subsample of states suggests that this type of analysis may not truly reflect the impact that state mandates may have on children and families trying to coordinate and pay for services across a broad variety of service providers. Future work is needed to further quantify the differences across states and evaluate the impact of these state laws on providers, families, and individuals with ASD. Occupational therapists and other health professionals who work with and on behalf of families and individuals with ASD have a stake in this debate and can advocate for policies that best serve their fellow professionals and their patients.

Acknowledgments

The authors acknowledge investigators associated with the Autism and Developmental Disability Monitoring Network for their advice on this project.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Funding was received from the National Center on HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention; the Office of Minority Health, Department of Health and Human Service; Kaiser Permanente; Health Resources and Service Administration; and Northrop Grumman in support of the Health Policy Leadership Fellowship in the Satcher Health Leadership Institute at Morehouse School of Medicine. Research reported in this publication was supported by the National Institute On Minority Health And Health Disparities of the National Institutes of Health under Award Number U54MD008173. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

- American Occupational Therapy Association. Occupational therapy practice framework: Domain and process (3rd ed). American Journal of Occupational Therapy. 2014; 68(Suppl 1):S1–S48. DOI: 10.5014/ajot.2014.682006
- American Occupational Therapy Association. Analysis of rehabilitation and habilitation benefits in qualified health plans. 2016. Available from <http://aota.org>
- Autism Speaks. Geographic illustration of state autism insurance mandates—State initiatives. n.d. Retrieved from <http://www.autismspeaks.org/state-initiatives>

- Baller JB, Barry CL, Shea K, Walker MM, Ouellette R, Mandell DS. Assessing early implementation of state autism insurance mandates. *Autism*. 2016; 20:796–807. DOI: 10.1177/1362361315605972 [PubMed: 26614401]
- Benevides TW, Carretta HJ, Lane SJ. Unmet need for therapy among children with autism spectrum disorder: Results from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs. *Maternal and Child Health Journal*. 2016; 20:878–888. DOI: 10.1007/s10995-015-1876-x [PubMed: 26662279]
- Bilaver LA, Jordan N. Impact of state mental health parity laws on access to autism services. *Psychiatric Services*. 2013; 64:967–973. DOI: 10.1176/appi.ps.201200411 [PubMed: 23771517]
- Buchmueller TC, Cooper PF, Jacobson M, Zuvekas SH. Parity for whom? Exemptions and the extent of state mental health parity legislation. *Health Affairs*. 2007; 26:W483–W487. DOI: 10.1377/hlthaff.26.4.2483 [PubMed: 17556379]
- Burris S, Hitchcock L, Ibrahim J, Penn MS, Ramanathan T. Policy surveillance: A vital public health practice comes of age. *Journal of Health Politics, Policy and Law*. 2016; 41(6):1061–1083. DOI: 10.1215/03616878-3665931
- Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summary*. 2016; 65(3):1–23.
- Chatterji P, Decker SL, Markowitz S. The Effects of Mandated Health Insurance Benefits for Autism on Out-of-Pocket Costs and Access to Treatment. *Journal of Policy Analysis and Management*. 2015; 34(2):328–353. [PubMed: 25893237]
- Cidav Z, Lawer L, Marcus SC, Mandell DS. Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders*. 2013; 43:924–931. DOI: 10.1007/s10803-012-1637-2 [PubMed: 22941343]
- Easterseals. State autism profiles. 2014. Retrieved from <http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html>
- Healthy People 2020. Disability and health objectives. Office of Disease Prevention and Health Promotion, Healthy People 2020; n.d. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health/objectives>
- Hoffman LC. Ensuring access to health care for the autistic child: More is needed than federal health care reform. *Southwestern Law Review*. 2012; 41:435–486.
- Ibrahim JK, Anderson ED, Burris SC, Wagenaar AC. State laws restricting driver use of mobile communications devices—Distracted-driving provisions, 1992–2010. *American Journal of Preventive Medicine*. 2011; 40:659–665. [PubMed: 21565659]
- Johnson RA, Danis M, Hafner-Eaton C. US state variation in autism insurance mandates: Balancing access and fairness. *Autism*. 2014; 18:803–814. DOI: 10.1177/1362361314529191 [PubMed: 24789870]
- Kalkbrenner AE, Daniels JL, Emch M, Morrissey J, Poole C, Chen JC. Geographic access to health services and diagnosis with an autism spectrum disorder. *Annals of Epidemiology*. 2011; 21:304–310. DOI: 10.1016/j.annepi-dem.2010.11.010 [PubMed: 21376278]
- 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:e1149–e1158. DOI: 10.1542/peds.2008-1057 [PubMed: 19047216]
- Lynne-Landsman SD, Livingston MD, Wagenaar AC. Effects of state medical marijuana laws on adolescent marijuana use. *American Journal of Public Health*. 2013; 103:1500–1506. DOI: 10.2105/AJPH.2012.301117 [PubMed: 23763418]
- Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGuseppi C, Durkin MS, ... Kirby RS. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*. 2009; 99:493–498. DOI: 10.2105/AJPH.2007.131243 [PubMed: 19106426]
- National Autism Center. National Standards Project: Findings and conclusions. 2009. Available from www.nationalautismcenter.org

- National Conference of State Legislatures. Autism and Insurance Coverage: State Laws. 2015. Retrieved from <http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx>
- Newschaffer CJ, Curran LK. Autism: An emerging public health problem. Public Health Reports. 2003; 118:393–399. DOI: 10.1093/phr/118.5.393 [PubMed: 12941851]
- Ooi KL, Ong YS, Jacob SA, Khan TM. A meta-synthesis on parenting a child with autism. Neuropsychiatric Disease and Treatment. 2016; 12:745–762. DOI: 10.2147/NDT.S100634 [PubMed: 27103804]
- Parish S, Thomas K, Rose R, Kilany M, McConville R. State insurance parity legislation for autism services and family financial burden. Intellectual and Developmental Disabilities. 2012; 50:190–198. DOI: 10.1352/1934-9556-50.3.190 [PubMed: 22731968]
- Presley D, Reinstein T, Webb-Barr D, Burris S. Creating legal data for public health monitoring and evaluation: Delphi standards for policy surveillance. Journal of Law, Medicine & Ethics. 2015; 43(Suppl s1):27–31. DOI: 10.1111/jlme.12210
- Wagenaar, AC., Burris, SC. Public health law research: Theory and methods. San Francisco, CA: Jossey-Bass; 2013.
- Warren Z, McPheeters ML, Sathe N, Foss-Feig JH, Glasser A, Veenstra-Vanderweele J. A systematic review of early intensive intervention for autism spectrum disorders. Pediatrics. 2011; 127:e1303–e1311. DOI: 10.1542/peds.2011-0426 [PubMed: 21464190]

Table 1

Variables, Variable Categories, and Variable Definitions for Autism Private Insurance Mandates.

Policy variables	Variable categories	Definitions
Effective date	NA	Date on which the law became effective
Compliance date	NA	Date on or after which payers must comply with the law
Scope of law	Parity	If covered, coverage must be comparable with some other health condition
	Mandate	Applicable payers must cover autism diagnosis and treatment for enrollees
	Offer	Applicable payers must offer to cover autism diagnosis and treatment for enrollees, but the choice is made by the group administrator
Types of insurers	Large group	Law applies to plans for employers with 51 or more employees and their families
	Small group	Law applies to plans for employers with less than 50 employees and their families
	Individual	Law applies to plans covering individuals and/or families
	State employees	Law applies to plans covering state employees and their families
	Other	Law applies to other plans defined by statute, including health maintenance organizations, supplemental plans, health service organizations, and so on
Age limits	Treatment caps	Payer is required to cover ASD treatment for children up to a defined age
	Diagnosis	Payer is required to cover ASD treatment for children diagnosed with ASD before a defined age
Service limits	Maximum benefits	Payers must cover all ASD treatment up to a defined dollar limit
	Behavioral therapy caps	Payers must cover behavioral therapy up to a defined dollar limit
	Caps based on age	Coverage limits differ based on the child's age as defined by the law
Treatment	ABA	Payer is required to cover ABA therapy as defined by the statute
	ABA licensure	Law defines the licensure necessary for ABA providers
	Allied health services	Payer is required to cover services such as occupational and physical therapy, speech–language pathology, audiology, and so on
	Allied health services licensure	Law defines the licensure necessary for allied health services providers
Medical necessity	Treatment plan	Coverage is dependent on a treatment plan
	Provider diagnosis	Coverage is dependent on a diagnosis made by specified health care providers
	Limitations on utilization review	Review of the treatment plan for medical necessity is limited by the statute
Coverage for medical treatment only	NA	The law specifies that coverage applies to medical treatment only and does not apply to treatment paid for or provided by other means, including under individualized education plans or individualized service plans

Note. ASD = autism spectrum disorder; ABA = applied behavioral analysis.

Coding Results of Autism Private Insurance Mandates in 14 States.

Table 2

State	Mandate	Party	Effective date	Comply date	Types of insurers				Age limits				Service limits				ABA behavioral therapy			Allied health services					
					Large group	Small group	Individual	State employer	Other	Treatment cap	Age for treatment cap (years)	Diagnosis cap	Diagnosis age cap (years)	Max benefits (general)	Max benefit amount	Behavioral therapy cap	Behavioral therapy cap amount	Cap/age group	Age (years)	ABA covered	ABA required	Covered	Types of providers	License required	
AL	Other	Y	10/1/2012	None	Y	N	N	N	Y	Y	9	N	NA	N	NA	Y	US\$36,000	N	NA	Y	Y	State	Y	OT, PT, SLP	Y
AK	Y	Y	10/1/2011	None	Y	Y	N	Y	Y	ABA	18	N	NA	N	NA	Y	US\$50,000	N	NA	N	Y	National	Y	OT, PT, SLP	Y
AZ	Y	N	9/26/2008	None	Y	N	N	Y	Y	BT	16	N	NA	N	NA	Y	US\$50,000 US\$25,000	Y	Age based	Y	Y	State	N	NA	NA
CO	Y	Y	7/1/2010	On or after 7/1/2010	Y	Y	Y ^d	Y	Y	N	NA	N	NA	Y	Age based	N	NA	Y	Age based	Y	Y	State or national	Y	OT, PT, SLP, ASD, SLP	Y
FL	Y	Y	7/1/2008	On or after 4/1/2009	Y	N	N	Y	N	Y ^b	18 ^b	Y ^b	8 ^b	Y	US\$36,000/year US\$200,000 lifetime	N	NA	N	NA	N	Y	State or national	Y	OT, PT, SLP	N
GA ^c	N	Y																							
MD	Y	N	10/1/2002	On or after 10/1/2002	Y	Y	Y	Y	Y	Age-based	18	N	NA	N	NA	N	NA	N	NA	N	N	NA	Y	OT, PT, SLP	N
MO	Y	Y	8/28/2010	On or after 1/1/2011	Y	Y	Other	Y	Y	ABA	18	N	NA	N	NA	Y	US\$40,000 (ABA)	N	NA	N	Y	State or national	Y	OT, PT, SLP	Y
NC ^d	N	Y																							
NJ	Y	Y	2/9/2010	On or after 2/9/2010	Y	Y	Y	Y	Y	behavioral interventions	21	N	NA	N	NA	Y	US\$36,000	N	NA	Y	Y	N	Y	OT, PT, SLP	N
PA	Y	Y	7/9/2008	On or after 7/1/2009	Y	N	N	Y	Y	all	21	N	NA	Y	US\$36,000	N	NA	N	NA	N	Y	State	Y	OT, PT, SLP	N
SC	Y	Y	7/1/2008	On or after 7/1/2008	Y	N	N	Y	N	all	16	Y	8	N	NA	Y	US\$50,000	N	NA	N	N	NA	N	NA	NA
UT	Y	Y	1/1/2016	On or after 1/1/2016	Y	N	Y	N	N	all	2–10	N	NA	N	NA	Y	600 hr	N	NA	Y	Y	State or national	Y	OT, PT, SLP	Y
WI	Y	Y	11/1/2009	On or after 1/1/2009	Y	Y	Y	Y	Y	N	NA	N	NA	N	NA	Y	US\$50,000/year for 4 years US\$25,000/year after 4 years	N	NA	Y	N	State and/or national	Y	OT, SLP	Y (OT) N (SLP)

Note. ABA = applied behavioral analysis; Y = Yes; N = No; NA = not applicable; BT = behavioral therapy; OT = occupational therapy; PT = physical therapy; SLP = speech–language pathology; ASD-SP = autism spectrum disorder service provider.

^aColorado individual plan insurers: Except grand-fathered cases.

^bFlorida treatment cap/cap by age: An “eligible individual” means an individual below 18 years of age or an individual 18 years of age or older who is in high school who has been diagnosed as having a developmental disability at 8 years of age or younger.

^cGeorgia: At the time of extraction of legal mandates and coding, GA did not have a mandate. GA presently has a mandate which passed on 4/29/2015. That data are not included in this analysis.

^dNorth Carolina: At the time of extraction of legal mandates and coding, NC did not have a mandate. NC presently has a mandate which passed on 10/15/2015. That data are not included in this analysis.

^{*}Arizona: Age-based service limit caps for behavioral therapy: Up to age 9 years, US\$50,000; ages 9 to 16 years, US\$25,000.

^{**}Colorado service limits: 1 to 8 years old: Caps actuarially equal to US\$34,000; 9 to 19 years old: US\$12,000.

^{***}Maryland: Treatment cap on “habilitative services,” defined as services, including OT, physical therapy, and speech therapy, for the treatment of a child with congenital and genetic birth defects to enhance the child’s ability to function.