

Assessing early implementation of state autism insurance mandates

Autism
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Abstract

In the United States, health insurance coverage for autism spectrum disorder treatments has been historically limited. In response, as of 2015, 40 states and Washington, DC, have passed state autism insurance mandates requiring many health plans in the private insurance market to cover autism diagnostic and treatment services. This study examined five states' experiences implementing autism insurance mandates. Semi-structured, key-informant interviews were conducted with 17 participants representing consumer advocacy organizations, provider organizations, and health insurance companies. Overall, participants thought that the mandates substantially affected the delivery of autism services. While access to autism treatment services has increased as a result of implementation of state mandates, states have struggled to keep up with the demand for services. Participants provided specific information about barriers and facilitators to meeting this demand. Understanding of key informants' perceptions about states' experiences implementing autism insurance mandates is useful for other states considering adopting or expanding mandates or other policies to expand access to autism treatment services.

Keywords

autism spectrum disorders, health services, policy, qualitative research

Introduction

The purpose of this study is to examine states' experiences of implementing autism insurance mandates, which require certain health insurers to provide coverage for autism services. In response to the Patient Protection and Affordable Care Act (ACA), all US adults are required to have health insurance as of 2014. In order to make this possible, access to health insurance has expanded through two key provisions—expansion of Medicaid to low-income adults and the development of online health insurance exchanges where consumers can shop for private health insurance plans. Even with these provisions, individuals and families most commonly depend on employers for coverage, with more than half of population receiving private health insurance through this means (Janicki, 2013). An employer can opt to self-fund its health plan, which means that the employer takes on all of the risk of paying for employee health benefits. Self-insured employer-sponsored plans, which tend to cover many employees in larger firms, are exempt from state insurance benefit mandates based on the Employee Retirement Income Security Act (ERISA) of 1974. The Kaiser Family Foundation estimated that, in

2000, between 33% and 50% of employees in the United States were in self-insured plans and therefore not covered by state-level regulations like autism mandates. Therefore, even in states where autism mandates have been enacted, a sizable share of the population receives insurance coverage from health plans that are exempt from complying with these policies.

Although the ACA requires that all individuals have health insurance, there is substantial variability across plans in covered benefits. For example, there is a historical lack of coverage for autism assessment and treatment services. In response to the dramatic increase in the number of

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individuals diagnosed with autism spectrum disorder (ASD) over the past decade (CDC, 2014) and the high cost of their care (Buescher et al., 2014), 40 states and Washington, DC, have enacted laws requiring many health plans in the private insurance market to cover autism-specific behavioral therapies, with annual caps ranging from US\$12,000 to 50,000 depending on the state and the age of the child (National Conference of State Legislatures, 2012). Despite some differences in specific provisions, the clear intent of these laws is to make behavioral treatments for autism a mandatory part of any commercial health insurance benefit.

While passage of these mandates has been hailed by autism advocates as a major victory (Lerner, 2013), little information is available on the implementation of these new laws. One recent study suggests that there is no association between state autism mandates, and either access to care or unmet need for services (Chatterji et al., 2015), but that study did not specifically examine individuals with insurance plans subject to the mandates. Insurance companies in most states fought against the mandates, arguing that the number of children diagnosed with autism would increase and that enrollees diagnosed with autism would use services up to the annual dollar caps, resulting in drastic increases in autism-specific health care spending (Bouder et al., 2009). On the other hand, autism advocates have raised the concern that these policies are not living up to their promise, either because insurers continue to deny claims for autism services or because insurer networks do not include appropriate service providers (Bridges, 2008; Francis-Smith, 2008; Rogers, 2009). In addition, providers have expressed concerns that insurance companies attempt to control costs in response to mandates by offering low reimbursement rates for services commonly used by children with autism such as applied behavioral analysis (ABA) and functional therapies (Freudenheim, 2004; Wall, 2014).

In this study, we examined the experiences of five states that have recently implemented autism mandates. The purpose of the study was to describe, from the perspective of advocates, treatment providers, and insurers in each state, the barriers and facilitators to implementation of these mandates with regard to obtaining treatments for children with autism. These stakeholders were selected based on the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009), which offers a typology for implementation research to determine what works, in what context, and why. According to the framework, there are four essential activities in the implementation process: planning, engaging, executing, and reflecting and evaluating. Our goal was to select stakeholders with unique perspectives and concerns that would likely be involved in each stage of the process.

Methods

Between July 2014 and November 2014, semi-structured, key-informant interviews were conducted with stakeholders

in five states that have implemented state autism insurance mandates in each of the past 6 years. We included participants in states in different parts of the country, with a high treated prevalence of autism, and with some variation in the scope of their mandate policies and in their implementation dates. Interviews were conducted with informants from California, Maryland, Massachusetts, Minnesota, and Pennsylvania. We did not have a specific sample size in mind, but wanted adequate representation from each respondent group across states, with a goal of reaching saturation. Active autism consumer advocacy groups within the selected states were initially identified by the principal investigators for interviews. The advocacy groups all focus on connecting individuals and families with autism to treatment and providing educational information about health insurance and services for patients and providers. Some groups contribute legal resources to families, and one organization funds research, provides resources, and advocates to Congress. From these interviews, a snowball sampling technique was used to identify dominant health insurance companies and provider organizations. Particular attention was paid to identifying participants from a diverse set of provider organizations. We aimed to include provider organizations from both medium to large group practices and small group (less than five providers) or individual practices, as well as organizations providing services to the general population or specifically to children with developmental disabilities. It is important to note that while we attempted to contact providers from different types of organizations and representatives from health insurance companies in each state, we were not always successful and therefore do not have full representation of providers and insurance companies in each state.

In all, 17 interviews were conducted across the five states with six participants representing consumer advocacy groups, eight representing autism service provider organizations and general service provider agencies, and three behavioral health directors from health care insurance companies (see Table 1). At this point, the study team felt that no new themes were emerging and saturation was achieved. Of the eight participants representing autism service provider organizations, five represented large group practices and three presented small group or individual practices. The role of the respondents ranged from direct service provider to clinical directors to a public policy representative. Of the large group practices, two exclusively provide services to children with developmental disabilities and three provide general services. Of the small group or individual practices, all exclusively provide services to children with developmental disabilities. Two interviews were completed with participants in California, two in Maryland, six in Massachusetts, three in Minnesota, and four in Pennsylvania.

We developed a semi-structured interview protocol (see Technical Appendix 1) based on techniques described by Bernard (1988), which typically include open-ended questions that allow for the interviewer to follow relevant

Table 1. Summary of study participants by category of organization and by state.

States	Consumer advocacy organization	Provider organization	Health insurance company	Total
California	1	1	0	2
Maryland	1	1	0	2
Massachusetts	2	2	2	6
Minnesota	1	2	0	3
Pennsylvania	1	2	1	4

Table 2. Characteristics of autism insurance mandates in five study states.

Characteristics	States				
	California	Maryland	Massachusetts	Minnesota	Pennsylvania
Year of enactment	2011	2012	2010	2013	2008
Effective date	7/1/2012	3/1/2014	1/1/2011	1/1/2014	7/1/2009
Affected groups	Individual Fully insured large group Fully insured small group	State employee Individual Fully insured large group Fully insured small group	State employee Individual Fully insured large group Fully insured small group	State employee (as of 2016) Fully insured large group	State employee Fully insured large group
Services covered	Behavioral health treatment	Habilitative care Therapeutic care Psychological care	Diagnosis Habilitative or rehabilitative care Pharmacy care Psychiatric care Therapeutic care	Diagnosis Early intensive behavioral and developmental therapy Neurodevelopmental and behavioral health treatment Therapeutic care Pharmacy care	Diagnosis Pharmacy care Psychiatric care Psychological care Rehabilitative care Therapeutic care
Age limits	None	Under 19 years of age	None	Under 19 years of age	Under 21 years of age
Dollar caps	None	None	None	None	US\$36,000/year

topics that may stray from the protocol. The interview protocol was based on the CFIR, and included questions related to the role of the participant’s organization in the planning, engaging, and executing of the mandates, reflection and evaluation of the effects of the mandate on the participant’s organization, reflection and evaluation of the effects of the mandate on families with a child with autism living in the state, and perceptions about the role of the mandate in the broader health policy context within the participant’s state.

All study participants were initially contacted via email and all interviews were conducted over the phone with the first author and at least one other study team member. The lead author was responsible for conducting the interview to ensure consistency, while the other team member took notes. Interviews were audio-recorded and transcribed by a transcription company. All transcriptions were checked for accuracy. In addition, field notes were also compiled for each interview to document key observations and emerging themes.

The transcripts were read to identify an initial organizing framework for code types. Using this framework, a

combination of deductive and inductive approaches was used to develop codes and themes (Bradley et al., 2007). Emerging codes and themes were discussed throughout the interview process and over the course of several weekly meetings with study team. Any disagreement was reconciled by the two study principal investigators (D.S.M. and C.L.B.). All transcripts were first reviewed line-by-line to identify and classify recurring topics and concepts. These recurring topics were used to refine codes and to classify codes into categories and themes. Transcripts were then coded and analyzed by the lead author and reviewed with the two principal investigators. Because the coding process was reviewed on a weekly basis, the study team opted to use a single coder, and therefore did not calculate inter-rater reliability. Key informant quotations were collected to illustrate categories and themes.

The study team also collected the state laws from LexisNexis in order to understand the variation in the characteristics of the law across states. Table 2 includes detailed information on the characteristics of each of the study states’ autism mandate laws (An Act Relative to Insurance Coverage for Autism, 2010; California Health and Safety

Table 3. Quotes related to delivery system changes in response to implementation of state mandates.

States	Deliver system changes	Illustrative quotation
Service use		
California Massachusetts Maryland Minnesota Pennsylvania	Increase in service utilization	“The mandate has resulted in greater demand for services, definitely. I don’t know that a lot of people got services before. I think that it has resulted in more people getting services and more people getting better quality services ... because there is more one-on-one.”
California Massachusetts Minnesota Pennsylvania	Types of services available	“We were ... one of the first five states in the nation to provide access to intensive treatment for children under three to all families ... With the introduction of the mandate, most of those families wanted to continue on and continue to receive intensive treatment now through a more combined approach where they would go to preschool half-day and then they would receive additional services through their health insurance.”
Providers		
California Massachusetts Maryland Minnesota Pennsylvania	Number of service providers	“We keep adding providers almost monthly or every couple of months. We have a new provider who comes in because they hear about the mandates and insurance coverage. We also have national companies coming in and setting up offices.”
California Massachusetts Pennsylvania	Types of service providers	“So, what we had was kind of a dual system of community mental health agencies who had been providing services being able now to access commercial insurance and then prior to the licensure reg[ulations], we had this other set of providers who were generally individual practitioners who ... were strictly private pay ... So, with the promulgation of the licensure reg[ulations] ... now we have these private practitioners getting their license, and as a result of getting a license recognized under state statute, they can now enroll in commercial health plans. So this opens the door to more families a wider pool of providers.”
Payment		
California Maryland Minnesota Pennsylvania	Source of payment	“So the initial effect ... was that agencies ... who had been providing autism treatment services under our state’s Medicaid program ... were now getting enrolled in commercial insurance plans that were subject to [the mandate] ... and were now able to bill for their services ... [W]hat we saw was that the same services were pretty much being delivered by the same providers, but that the providers were now initially billing the commercial insurance plan. Then, Medicaid was picking up the co-pays and deductibles.”

Code, 2011; Health Insurance Coverage for Autism Spectrum Disorders, 2014; Law of Minnesota, 2013; The Insurance Company Law of 1921, 2008).

Results

Responses from the key-informant interviews were categorized into three main themes: (1) delivery system-level changes affecting autism services following mandate implementation; (2) features of successful state mandate implementation efforts; and (3) barriers encountered to implementing state mandates. We describe responses related to each theme below.

Delivery system changes in response to implementation of state mandates

Participants noted that the mandates affected the delivery of autism services in their states in a number of ways, including

service use, providers, and payment (see Table 3). Participants from all five states indicated that the state mandates affected the amount of services used, typically increasing both families’ expectations about what services would be available and subsequent service use. Participants from four states mentioned that the mandates affected the types of services available to children with autism. Participants from three states discussed the positive change of having increased availability of new types of services; however, participants from Massachusetts mentioned that because the mandate exclusively covers ABA, access to behavioral treatments that are not specifically identified as ABA such as Floortime (Liao et al., 2014), and the Denver Early Start Model (Rogers and Dawson, 2010) was restricted.

In response to the increased demand for autism services, participants from all five states discussed changes to the number of providers delivering autism services. While most participants described an increase in the real or anticipated number of providers, participants from California,

Table 4. Quotes related to features of states’ successful autism insurance mandate implementation.

States	Features of successful implementation	Illustrative quotation
Key stakeholder involvement		
California Massachusetts Maryland Minnesota Pennsylvania	Outreach by consumer advocacy groups	“There is a consumer advocacy group that does a lot of advertisement and promotion of its services at various autism events. So what we’ll do is refer our families to them and then that group will help the family understand what their insurance company covers and what it doesn’t cover.”
Massachusetts Maryland Minnesota Pennsylvania	Outreach by providers	“So we have three master’s level clinicians who are a ... family resource team and with each patient that’s seen in our group, they connect with one of these resource specialists to help the families figure out the best and most services that would be appropriate for that person, and their job is now easier because people have better [insurance] coverage.”
California Minnesota Pennsylvania	Cooperative commercial insurance companies	“The private insurance has been phenomenal to work with. They work with you, they answer questions, they allow you to implement.”
California Massachusetts Minnesota	State agency involvement in regulatory process	“The state government utilized the regulatory process to establish what insurers were required to do and when there have been specific issues with implementation ... we’ve contacted them to work through some of those issues, more or less successfully.”
California Massachusetts Maryland	Availability of child-only health plans	“A year ago, we couldn’t help them and now ... on our exchange you can buy a policy just for your child ... So it’s really expanded the availability of and access to policies that will cover certain insurance plans and then even more than that.”
Accessibility of autism treatment services		
California Massachusetts Minnesota Pennsylvania	Robust autism delivery system available prior to mandate	“People are using the services ... but people were getting services prior to the mandate through the Regional Center system. They were getting ABA. So the services were already in place.”
Massachusetts Maryland	Reduced family cost-sharing associated with accessing autism services	“Parents are starting ABA services where they previously paid out of pocket and had to stop therapy because they could no longer afford it.”

specifically, mentioned that many small behavioral practices have had to close due to the stringency of licensing requirements following the mandate. For example, one provider in California mentioned:

So they’re saying to these vendors, well, you don’t have the credentials, you don’t have the right staff ... everybody has to have a BA, you can’t have students work with you anymore ... People that had private practices said ... I think I’m gonna have to close my doors.

Participants from three states had the opposite experience. For example, several participants in Pennsylvania noted that small private practices that were previously unable to bill insurers were, for the first time, able to access reimbursement from private health insurers and were entering the market.

In four of five states, participants mentioned that the state mandates resulted in a shift in the source of payment for autism services. In those four states, the services covered under the mandates such as ABA or habilitative services were already financed for some consumers prior to

the mandate’s implementation through Medicaid, state-specific payment sources or by families out-of-pocket. The mandate created an opportunity for agencies to seek reimbursement from commercial insurers for these services. In contrast, participants in one state (Minnesota), which implemented its autism insurance mandate in 2014, commented that many commercial health insurers were already paying for these types of autism services, so there has been less of a shift in the source of payment.

Features of successful state mandate implementation efforts

Table 4 summarizes participant perceptions of what resulted in successful mandate implementation along with illustrative quotes. Participants from all states, particularly providers, underscored the critical importance of having consumer advocacy groups and providers educate parents about the mandates. Providers in all five states mentioned that consumer advocacy outreach was essential to providing information to parents or providers, and consumer

advocates from all states mentioned education as one of their key job functions. Consumer advocates from four states also discussed the importance of provider outreach to families during appointments or through targeted outreach events, but providers in only two states mentioned the essential role of providers in educating patients.

Providers and a consumer advocate from three states—California, Minnesota, and Pennsylvania—mentioned that some private insurance companies were surprisingly easy to work with and aided in a seamless billing transition. One provider from Minnesota stated,

I think it's safe to say that the commercial plans are very collaborative or are reaching out to groups in Minnesota in talking about rate setting and addressing licensure ... We're talking to the payer in terms of what type of information should we be collecting to document medical necessity? What are the specific domains? How should treatment plans be written in a way that meets your requirements? So it's been communication on both sides.

Providers and consumer advocates in three states mentioned the critical role of regulators that supported mandate implementation. For example, one provider in California mentioned that the state regulators who developed the state ABA licensure regulations had deep knowledge of autism treatments and behavior analyst credentialing, which helped to streamline promulgation of the licensure regulations and expedited provider entry into the marketplace. In contrast, a provider in Minnesota mentioned that the board tasked with developing licensure regulations was viewed as having little knowledge of behavioral treatments and providers, resulting in substantial delays in increasing the supply of providers.

In addition, participants from three states mentioned that the increased availability of child-only plans through state health insurance exchanges has been a driver of success. Child-only plans are typically purchased by parents receiving health insurance through self-insured plans, which, as described above, are not subject to state insurance mandates. As a result of the Patient Protection and ACA, these parents are now able to buy child-only plans through the exchange, which may be subject to state mandates.

Participants in all five states described factors that increased access to autism treatment after the mandates were implemented. Participants in four states attributed successful implementation in part to the robust autism delivery system in place in their states prior to passage of the mandate. In California, Massachusetts, Minnesota, and Pennsylvania, behavioral treatments were available through Medicaid and private insurance prior to the mandate, easing the transition to mandate implementation. In addition, insurers and consumer advocates in two states mentioned that the mandates reduced the amount of family cost-sharing associated with autism services. However, a

provider and consumer advocate from the same state mentioned that while the mandates helped families bear some of the costs of treatment, the co-pays were still unaffordable and left many lacking access to services.

Barriers to implementing state mandates

Table 5 summarizes the primary barriers to implementation participants noted, many of which focus on difficulties families have in accessing appropriate autism-related services under commercial insurance. Participants from all five states discussed the lack of supply of autism services and service providers. All participant types from five states discussed the overall lack of service capacity to handle the demand for autism services. Consumer advocates said that families were having difficulty accessing the full range of autism-related services through their commercial insurance policies, including diagnostic or evaluation services, ABA, community-based services, and crisis services. Insurers, on the other hand, mentioned the challenges of finding a network of contracted providers. Participants from four states ascribed the lack of supply to challenges with provider credentialing. Providers must be credentialed with each private insurance company in order to bill for services, a process that is completed separately for each insurance company. This process can be particularly challenging for small practices. In addition, providers from four states mentioned that private insurers offered low reimbursement rates, reducing the incentive for providers to go through the credentialing process.

The issue of supply is also likely the result of licensure and coverage regulations. Participants from four states said that it took between 1 and 4 years for states to have the licensure and coverage regulations after passage of the mandate. For example, a consumer advocate in Minnesota said that the mandate was passed as the state's Medicaid program decided to include new coverage for autism treatments. As a result, private insurers decided to wait for guidance from the Minnesota Department of Human Services for Medicaid to develop specific coverage regulations, resulting in a delay in implementing the mandate. As consumer advocacy groups and providers publicized the mandates, parents' expectations increased dramatically. However, providers often could not bill private insurance companies without coverage and licensure regulations in place. Participants from three states also discussed difficulty complying with the licensure requirements once regulations were in place. For example, the Massachusetts mandate requires ABA be performed by a state-licensed board certified behavioral analyst (BCBA) with a national BCBA certification. Qualifications for a state designation of applied behavior analyst include (1) passed a board-approved exam, (2) doctoral degree with a minimum of 60 graduate credit

Table 5. Quotes related to barriers encountered in state autism insurance mandate implementation.

States	Challenges to successful implementation	Illustrative Quotation
Barriers relating to supply of autism services		
California	Lack of service capacity	“The strain was on us to try to meet new demand of kids coming in ... To this day, we’re still struggling with explosive growth in our system of the home-based treatment.”
Massachusetts		
Maryland		
Minnesota		
Pennsylvania	Credentialing with individual private insurance companies	“We had to credential them again on the private end of things and for each insurance company. Some of them run through a national bank of credentialing, and that’s the easy one. For some of the other ones ... we have to credential individually. So every new insurance company that comes through is a new set of how we credential out people.”
California		
Maryland		
Minnesota		
Pennsylvania	Low reimbursement rates	“There’s been limited participation by professionals because they just can’t afford to hire professionals to work at the rates being offered.”
California		
Massachusetts		
Maryland		
Pennsylvania	Delay in promulgation of regulations	“It took quite a while to finally get the licensure regulations promulgated ... So there’s been a staggered effect of the statute.”
Massachusetts		
Maryland		
Minnesota		
Pennsylvania	Compliance with provider licensure requirements	“Let me just highlight the need to get a licensed psychologist to be able to get the stamp of approval on the secondary services. That’s a huge bear.”
California		
Massachusetts		
Pennsylvania		
California	Lack of network of contracted providers	“The biggest piece of feedback is we need a network of contracted providers. So they’re trying to figure out how to have a licensing board to approve who we will pay for. As it stands now, we don’t have a contracted network of providers, which we want.”
Massachusetts		
Minnesota		
Pennsylvania		
Barriers relating to demand for autism treatment services		
California	Lack of available information for parents	“The first challenge is information for parents based on what it is, how it works, are they subject to it, and how you get access to it.”
Massachusetts		
Maryland		
Pennsylvania		
California	High cost-sharing levels for autism services	“I looked at what the co-pays would be and I make a lot of money and I couldn’t even cover them.”
Massachusetts		
Maryland		
Pennsylvania		
California	Disparities in insurance coverage between publicly and privately insured individuals	“It’s gross inequities that have played themselves out for low-income families. They certainly aren’t getting any classic home-based treatment over three unless they have private health insurance; if they have Medicaid, they would not be getting anything.”
Massachusetts		
Maryland		
Barriers relating to private insurance companies		
California	Lack of compliance by commercial insurance companies	“There are some insurers who are not covering them. They’re finding excuses for not doing them when they should be covered under the mandate.”
Massachusetts		
Maryland		
Pennsylvania		
Massachusetts	Lack of specificity of the mandate	“One of the things we found at least in reading the mandate is specifically non-specific ... and lays a lot of room for a variety of interpretations ... It says we are required to provide coverage period. It doesn’t say what kind of coverage ... The only requirement we had was that we would cover ABA.”
Minnesota		

hours in courses related to ABA or master’s degree with a minimum of 30 graduate credit hours in courses related to ABA and approved course sequence, and (3) completion

of a practicum or supervised experience in the practice of behavior analysis (An Act providing for the licensing of applied behavior analysts, 2012). A consumer advocate in

Massachusetts mentioned that many providers were unable to find this type of qualified workforce.

Participants from all states also discussed lack of accurate information about the mandates and lack of specificity in the mandates' language as a barrier to implementation. Participants from four states emphasized that parents lacked the necessary information to take advantage of the new benefits. Parents sometimes misunderstood which plans are affected by the mandate, what types of services are covered by plans affected by the mandate, and the cost-sharing associated with using the benefit. Participants from four states said that the mandates required a substantial co-payment from parents, which can reduce access to appropriate services. Participants from three states discussed the unintended consequence of creating disparities in accessing care between children covered under health insurance plans affected by state mandates and those covered under plans that are not affected, particularly for children living in states where Medicaid does not cover behavioral treatments.

Participants from all five states described challenges with private insurance companies that may indirectly affect the supply of and demand for autism services. Participants from four states said that commercial insurance companies were not complying with the mandate regulations, for example, not covering services covered under the mandate or denying reimbursement. One provider mentioned that an insurance company expressed no interest in credentialing the provider group with which he worked and had no plans to do so in the future. After several communications with the insurance company, the provider brought in county representatives to mediate the conversation, but the insurance company still has not worked with the group. Consumer advocates in two states hypothesized that these issues with private insurance companies were likely the result of a lack of specificity in the statutory language and subsequent regulations of the mandate. This lack of specificity was noted as having negative implications for successful reimbursement for services, which directly affected access to services for individuals with autism. These participants viewed private health insurers as defaulting to either reimbursement of the least expensive option or complete denial of services. Lack of guidance surrounding which services are covered, the amount of services covered, and the billing codes to be used for reimbursement were all noted.

Discussion

The results of our study suggest that state autism mandates are perceived to have increased use of autism services and the number and type of providers serving children with autism, while shifting the source of payment for services from families and Medicaid to private insurers. Recent quantitative research using survey data suggests that while

families living in states with autism mandates do not have significantly better access to care than families living in states without mandates, they do have reduced out-of-pocket spending (Chatterji et al., 2015; Parish et al., 2012). It is important to note that current quantitative studies rely on survey data that cannot disentangle which respondents are affected by the mandate. In other words, the data sources do not specify whether a child is covered under a self-insured private plan that is not subject to the mandate. Future research is necessary to isolate those individuals who are affected by the mandate to accurately assess the impact of the laws. If the mandates do not affect access to services, improving provider awareness may be necessary to ensure that patients with autism are receiving the services that they need.

Despite some differences in implementation across the states, a number of common themes emerged regarding barriers and facilitators to implementation of these new laws. Participants thought successful implementation depended on the involvement of a variety of key stakeholders, especially consumer advocacy groups and providers, and was most successful when built on existing robust service systems.

The most commonly cited challenge to implementation was lack of service capacity for children with autism, suggesting that implementing an insurance mandate will not achieve the desired results unless the infrastructure is in place for the newly covered services. This requires both increasing the supply of providers in order to meet the anticipated increased demand, and also ensuring accessibility to high-quality, evidence-based services. Incentives therefore must be in place to get qualified providers to enter the market (Armour et al., 2001). These incentives could include training, a clear path to licensure and credentialing, and enhanced rates for evidence-based services. While these incentives may help increase the supply of qualified providers, mandates, on their own, may not be sufficient to improve the quality of care provided to individuals with autism (Bao and Sturm, 2004). One insurer mentioned the difficulty in figuring out how well these services are working because the mandates do not encourage people to evaluate the quality and outcomes of care. Other policy mechanisms, such as payment models tied to specific performance measures, can be used in combination with mandates to drive the quality of care (Campbell et al., 2007). However, as another insurer stated, there are currently no agreed-upon outcome measures for this population. Additional research is needed to establish appropriate metrics for adults and children with autism.

While ensuring access to high-quality services and providers is essential for the success of these types of policies, respondents underscore that mandates may have unintended negative consequences if they construe covered services too narrowly. In this case, especially if a robust

service system is already in place, families may find that services used prior to implementation of a mandate are no longer available. For example, the mandate in Massachusetts exclusively applies to treatments in the family of ABA. However, given the spectrum of disability associated with the disorder, other types of treatments and supports may be equally important (Peters-Scheffer et al., 2011). Covering solely ABA severely limited the types of evidence-based behavioral treatments that were accessible to individuals with autism in the state. In contrast, participants in Minnesota discussed flexibility in terms of the types of behavioral services covered under the mandate, such as a ABA, Floortime (Liao et al., 2014), and the Early Start Denver Model (Rogers and Dawson, 2010), as a key reason for successful implementation of the state autism mandate. Providing coverage for a variety of evidence-based behavioral treatments likely reduces the increase in demand for a specific type of service and allows for a more inclusive set of provider types in the market.

Participants noted that some changes instituted through the Patient Protection and ACA could bolster state mandate laws and improve access to services. For example, autism insurance mandates affect individual plans in three of the five included states (California, Massachusetts, and Maryland), such as those that can be purchased through health insurance exchanges set up as a result of the Patient Protection and ACA (2010). Participants from these three states cited the availability of child-only plans through the exchange as an important reason for successful implementation of their state's autism mandate. This is particularly important for families where parents receive insurance through plans offered by employers that are self-insured and, as a result, unaffected by state autism insurance mandates. For many of these families, purchasing child-only plans through the health insurance exchanges can substantially increase access to coverage for autism services and reduce out-of-pocket spending (Parish et al., 2012). As states consider which plans will be under the purview of the mandates, consideration should be given to individual plans.

As insurance mandates and provisions in the ACA are helping to ensure access to appropriate services, the accompanying increased cost of service utilization is a growing concern (Lavelle et al., 2014). In response, mandates might unintentionally exacerbate incentives to control utilization and subsequent spending on the supply side by requiring prior authorization, increasing utilization review mechanisms, constraining networks, or controlling provider reimbursement (Barry et al., 2003). Prior research has demonstrated that use of such mechanisms can have effects similar to treatment limits and high co-payments on access to care (Frank and McGuire, 2000). Regulating the use of these mechanisms may be necessary to limit this sort of rationing.

Several study limitations should be noted. First, our findings are limited to the perspectives of participants in

five states that have passed state autism insurance mandates and may not reflect the experiences of other states that have passed mandate policies. Additionally, the consumer advocacy organizations may represent the opinions of all consumer advocacy groups in a state. The similarities in characteristics of respondents, for example, support for neurodiversity or a cure, in this group could affect the nature of our findings. Second, our study states implemented mandates from 2009 to 2014; recall bias could be an issue to the extent that participants are describing implementation issues that occurred a number of years ago. Participants in states that implemented autism mandates more recently may have a better recollection of dynamics associated with early implementation than states that adopted autism insurance mandates in earlier years. Furthermore, it is possible that states that have more recent state autism mandates may have not had sufficient time to identify solutions to the barriers presented during implementation. Finally, participants focused heavily on changes to the delivery system due to implementation of insurance mandates; however, qualitative methods are less well suited to assess other outcomes of interest such as changes in service use or spending attributable to these new policies. It will be important to put these findings in context with research relying on other approaches such as analysis of administrative claims data to develop a fuller understanding of how these policies are affecting access to care and spending on treatment for children with autism.

Conclusion

This study sought to describe the effects of implementation of state autism insurance mandates from a variety of key stakeholders. While the study focuses on a single policy lever currently being employed in the United States, the tensions that arise in trying to provide the highest quality of care for children with autism within spending constraints is not unique to the US context. Results suggest that although state autism mandates are perceived as having improved access to autism services for children, substantial increases in service utilization have left states struggling to meet the demand. As additional changes to insurance coverage emerge with the implementation of the ACA, states must focus on developing the service capacity necessary to ensure that individuals with autism have access to appropriate diagnostic and treatment services.

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Technical Appendix I

Semi-structured key-informant interview protocols

Protocol 1: Insurance administrators

Introduction

You are being asked to participate in an interview because your state passed a law in (Year) that mandated private insurance companies to pay for autism spectrum disorder (ASD) services. The mandate was implemented in (Year). We are interested to learn about the process, such as the successes, challenges, and lessons learned.

- From the time the state autism mandate passed to implementation, what steps did your organization take to address the upcoming changes?
- What benefit changes or other plan design changes, if any, did you make in response to the state autism mandate?
 - Were intensive one-to-one therapies such as applied behavior analysis (ABA) or other evidence-based practices covered before the mandate? After the mandate?
 - What changes were made to the coverage of services such as occupational therapy, physical therapy, or speech therapy as a result of the state autism mandate?
 - What changes were made to the coverage of diagnostic and assessment procedures for ASD?
 - What specific changes were made to coverage of recommended or required diagnostic tools as a result of the state autism mandate? (e.g. Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview-Revised (ADI-R))?
 - How much time is allotted for assessment?
 - When considering alternatives for benefit design changes, was consideration given to parity?
 - With regard to parity laws, is autism considered a mental health disorder?
- When considering alternatives for benefit design changes, was consideration given to the provisions of the Affordable Care Act (ACA)?
- What effects, if any, do you anticipate the ACA will have on coverage of autism-related services?
- What consideration was given to autism-related services as an essential health benefit offered in the individual and small group Health Insurance Marketplaces?
- What actions were taken by the state government to enforce benefit design changes in response to the state autism mandate?
- What provider network design changes did you make in response to the state autism mandate?
- What plan management design (e.g. treatment plan, prior authorization, utilization review) changes did you make in response to the state autism mandate?
- What actions were taken to address licensing requirements for behavioral therapists?
- What changes did you make with regard to contracting with a managed behavioral health firm in response to the state autism insurance mandate?
- What interactions have you had with service providers in response to the state autism mandates regarding setting rates, addressing licensure or credentialing requirements, or providing reimbursement?
- What challenges did you have complying with the mandate?
- How has the state autism mandate affected parents' decisions to seek payment for services for their child with autism through private insurance?
- What interactions have you had with consumers about the autism mandate? Have there been difficulties in getting services paid?
- What interactions have you had with consumer advocate organizations about the autism mandate?
- Is there anything else you think is important to understand about the implementation of the autism mandate in your state?

Protocol 2: Provider organizations

Introduction

You are being asked to participate in an interview because your state passed legislation in (Year) that mandated private insurance companies to pay for ASD services. The mandate was implemented in (Year). We are interested to learn about the process, such as the successes, challenges, and lessons learned.

- What new service types did you offer in response to the state autism mandate?
 - If no response or the following services are not mentioned, prompt with ABA, occupational therapy, physical therapy, speech therapy.

- What new training is provided to clinical staff in response to the state autism mandate?
- What actions were taken to address licensing requirements for behavioral therapists?
- What effects do you anticipate the ACA will have on autism-related services?
- What actions were taken by the state government to enforce benefit design changes in response to the autism mandate?
- What interactions have you had with insurance companies in response to the autism mandates about setting rates, addressing licensure, and credentialing or obtaining reimbursement?
- What challenges did you have complying with the mandate law?
- How has the autism mandate affected parents' decisions to seek payment for autism-related services through private insurance?
- Has there been an increase or decrease in autism service utilization by patients?
- Is there anything else you think is important to understand about the implementation of the autism mandate in your state?

Protocol 3: Consumer advocate organizations

Introduction

You are being asked to participate in an interview because your state (ST) passed legislation in (Year)/many states have passed legislation that mandated private insurance companies to pay for ASD services. The mandate was implemented in (Year). We are interested to learn about the process, such as the successes, challenges, and lessons learned.

- How do you believe the state autism mandate has affected provision of autism services through the healthcare system?
- How do you believe the state autism mandate has affected provision of autism services through public schools?
- Are any behavioral services provided in the schools? Who provides these services?
- What effects, if any, do you anticipate the ACA will have on the availability of and payment for autism-related services?
- What actions were taken by the state government to enforce benefit design changes in response to the state autism mandate?
- How has the state autism mandate affected parents' decisions to seek payment for autism-related services through private insurance?
- What challenges do families face in successfully using the new benefit?
- What has helped to facilitate families' successful use of the new benefit?
- Is there anything else you think is important to understand about the implementation of the autism mandate in your state?