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State Mandated Coverage of Cleft Lip and Cleft Palate Treatment

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Abstract

We conducted a comprehensive review of state laws and regulations that require private health insurance plans to cover the services needed by children born with cleft lip and/or cleft palate (CL/P). The goal is to better understand how states are reducing the barriers that children with CL/P face when seeking recommended health care services. We identified all state laws and regulations mandating insurance coverage of services for children with CL/P by private insurance carriers from 1999 through 2017 using Westlaw legal database. We categorized laws and regulations into ten services: facial surgery, oral surgery, orthodontics, dental care, habilitation/rehabilitation/speech therapy, prosthetic treatment, audiology, nutrition counseling, genetic testing, and psychological counseling. We also captured broad mandates for all necessary treatment. We find that the number of mandates has increased over the past two decades, although significant variation continues to exist across states. In 1999, 27 states (including Washington, DC) did not have relevant laws or regulations. By 2017, there were 19 states without relevant mandates. The most common mandated service was facial surgery followed by habilitation/rehabilitation/speech therapy, orthodontics, dental care, and oral surgery.

INTRODUCTION

Cleft lip and/or cleft palate (CL/P) are among the most common birth defects in the United States, affecting one in nearly 700 live births (Mai et al., 2014). Children with CL/P typically require extensive multidisciplinary care (ACPA 2018). They use more services for longer periods of their life than unaffected children, including their siblings (Wehby et al., 2012; Pedersen et al, 2015). CL/P may adversely affect the health and wellbeing not only of affected children (Wehby and Cassell, 2010) but also their families (Nidey et al, 2015). Many, however, face major barriers to obtaining needed health services (Wehby and Cassell, 2010; Nidey and Wehby, 2019).

At the Federal level, the 2010 Patient Protection and Affordable Care Act mandates ten essential health benefits. Some of the benefits are particularly relevant to children with CL/P, including ambulatory services, habilitative and rehabilitation services, and pediatric oral and vision care. However, rather than a national standard governing the scope of these benefits,

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each state determines the scope based in part on benefits offered in the state's small-group, state-employee and health maintenance organization insurance plans (Weil 2012).

State laws and regulations that mandate insurance coverage of needed services are key factors in determining the generosity of health insurance plans. However, our knowledge about variations in mandates across states is limited. A recent study of orthodontic treatment for CL/P found significant variation across states in both mandates and in medically necessary requirements (Pfeifauf et al. 2018). In this study we investigate a broader array of services and look into how mandates regulating private insurance have changed over time. By identifying and documenting this information, our work dramatically reduces policy and measurement cost for future research into the interplays between health policy, service use, and health outcomes for children with CL/P.

METHODS

We searched state laws and regulations from 1999 through 2017 for the keywords: "cleft", "birth defect", "congenital", "birth abnormality", and "craniofacial" using Westlaw legal database. We excluded laws and regulations pertaining to the structure and governance of programs and the reporting of birth defects. Our analysis includes both laws, which are passed by legislatures, and regulations, which are rules adopted by agencies to implement the law. The laws and regulations identified and included in the analysis are available as supplemental material (Supplemental Table 1). Medicaid coverage is governed by a different set of regulations and is not included in this study.

After reviewing the laws and regulations, we identified ten service categories relevant to children with CL/P, as well as an eleventh category requiring all necessary treatment. The ten categories are: facial surgery (facial, corrective, reconstructive), oral surgery, orthodontics, dental, habilitation/rehabilitation/speech therapy, prosthetic treatment, ontologic/audiological treatment, nutrition counseling, genetic testing, and psychological counseling. These categories cover the range of services needed by children with CL/P throughout their childhood (ACPA 2018).

Facial, corrective, or reconstructive surgery generally corresponds to the surgical closure of the CL/P including both primary and secondary repair of the lip, palate, or nose needed at various stages from infancy through adulthood (ACPA 2018). We interpret oral surgery to indicate dental and maxillofacial surgeries needed by children with oral clefts for either cleft repair or orthodontic treatments. Many laws and regulations explicitly require oral surgery separately from facial, corrective, or reconstructive surgery. We include dental and orthodontic services because children with CL/P often require these treatments as a direct result of CL/P and because some states have mandated that they be covered as part of medical insurance when needed for the treatment of CL/P.

Habilitation, rehabilitation, and speech therapy are groups under one category because the laws and regulations do not consistently delineate them as separate services. Some states require habilitative services without a definition (Washington D.C.), while others define habilitative services to mean occupational therapy, physical therapy, speech therapy, and other services (Illinois and Maryland). West Virginia defines rehabilitative services as services “to remediate patient’s condition or restore patients to their optimal physical, medical, psychological, social, emotional, vocational and economic status”, such as the use of diagnostic testing, assessment, monitoring and treatment. Some states require speech therapy (New Jersey), while others list it as one of several therapies that must be provided (Colorado). Since the provisions cannot be separated out in every state, we group them together.

We include mandates that specifically target CL/P, as well as mandates targeting birth anomalies generally. States vary from specifically targeting CL/P, to including CL/P as one of a specific group of conditions covered, to generally covering birth anomalies. For example, Louisiana targets CL/P, requiring insurance to “include coverage for the treatment and correction of cleft lip and cleft palate”. Oregon includes CL/P as one of a set of conditions, defining craniofacial anomaly as a “physical disorder identifiable at birth that affects the bony structures of the face or head, including but not limited to cleft palate, cleft lip, craniosynostosis, craniofacial microsomia and Treacher Collins syndrome”. In contrast, Oklahoma targets birth defects generally, prohibiting insurance companies from excluding reconstructive surgery due to a congenital defect.

The generosity of coverage requirements ranges from broad, generous coverage to limited coverage with qualifiers. For example, the lack of qualifiers on the Louisiana mandate requiring coverage of orthodontic treatment and management for children with CL/P suggests generous coverage. Alternatively, Connecticut does not require coverage for cosmetic surgery and limits orthodontic processes and appliances to what is medically necessary as prescribed by an American Cleft Palate-Craniofacial Association recognized craniofacial team. Age limitations were an additional limitation to required coverage. Some laws and regulations only applied to newborns, covered dependents or children under 18, 19, 21, or 26 years old.

Despite the variation in scope, applicability and generosity, we group mandates that cover similar health services together. These groupings allow us to identify larger trends and generate common policy measures that can be incorporated in research, instead of relying on less frequent, narrowly defined measures with limited value for research.

RESULTS

Over time the number of mandates addressing healthcare needs of children with CL/P has increased. In 1999, 27 states had no laws or regulations mandating coverage for children born with CL/P or birth defects in general (Figure 1). By 2017, that number had decreased to 19 states. Of the 32 states with mandates in 2017, 17 states had at least one law or regulation specifically targeting CL/P. The remaining focused more generally on congenital defects and birth abnormalities.

Most of the increase in mandates occurred between 2001 and 2013. However, even during that period, most states only adopted one or two mandates. Very few states mandate comprehensive coverage. In 1999, only three states had more than four services mandated, including Colorado with six, Louisiana with eight, and South Carolina with seven mandates. As of 2017, states with comprehensive coverage increased by two, including Massachusetts with eight and Oklahoma with six mandates.

The largest share of mandates focuses on facial, corrective, or reconstructive surgery (Figure 2). Between 1999 and 2017 the number of states requiring coverage of such surgery increased from 16 to 23 states. However the specificity of the requirements varies. For example, Arkansas requires coverage of corrective surgery if an accredited cleft-craniofacial team has determined it to be medically necessary. Other states have fewer restrictions. California requires coverage of surgery to correct or repair abnormal structures caused by a congenital defect, although a specific reference to clefts was added several years after initial adoption.

One common provision is to prevent insurance plans from categorizing reconstructive surgery for a congenital disease as a prohibited cosmetic surgery. However, some states do allow limits on reconstructive surgery so that the only coverage required is to correct a functional impairment and not to improve appearance. These provisions do not target CL/P specifically, but are written broadly for congenital diseases or anomalies. For example, Wisconsin requires coverage of functional repair or restoration and does not require surgery to improve appearance. In contrast, some states are more generous in their requirements. California requires coverage of reconstructive surgery if it improves function or creates a normal appearance to the extent possible.

The number of state mandates requiring coverage of oral surgery increased from seven in 1999 to ten by 2017. These provisions all target children with CL/P, however the coverage of oral surgery varies. Maryland and Indiana require coverage of inpatient and outpatient treatment for various services, including oral surgery. Oklahoma mandates coverage of medically necessary oral surgery. Other states simply list oral surgery as one of a number of services that must covered.

Orthodontic treatment is another common mandate. Between 1999 and 2017, the number of states requiring orthodontic coverage as part of medical treatment increased from 9 to 13. These provisions typically target children with CL/P. Some states have generous requirements. For example, Colorado requires coverage of orthodontics for CL/P and prohibits an age limit. Other states have more prescribed limits. Connecticut mandates coverage of medically necessary orthodontic processes and procedures for individuals under 19 years old with a craniofacial disorder if the procedure is prescribed by a craniofacial team recognized by the American Cleft Palate-Craniofacial Association. Hawaii imposes a maximum limit of $5,500 per phase of orthodontic treatment, but does not allow a limit on the number of orthodontic visits.

The number of states that require medical insurance plans to cover dental care for children with CL/P increased from nine in 1999 to twelve by 2017. Some states target birth defects in general. For example, New York allows dental care to be excluded, unless it is necessary due to a congenital disease or anomaly. Other states specify that dental services must be covered for children with CL/P. For example, in Oregon medically necessary dental care is specified as a procedure necessary to restore function for an individual with CL/P. Vermont requires coverage of inpatient and outpatient dental services if necessary for the treatment of CL/P.

States with habilitative, rehabilitation or speech therapy mandates increased from six to thirteen between 1999 and 2017. Typically these provisions refer to children with birth anomalies in general. For example, West Virginia's law applies to congenital deformity as well as other illnesses. A few states, such as Louisiana, have mandates specifically referencing children with CL/P.

The number of states with mandates requiring audiology and/or otolaryngology services increased from five to nine between 1999 and 2017. All the states' mandates were specifically aimed at individuals with CL/P. Some states specified that audiology is covered, others specified otologic treatment, and a few states specified both services separately.

Mandates on nutrition, genetic testing and psychological services are rare. States with mandates for nutrition services increased from one to three. Florida and Massachusetts, require nutrition services if it is medically necessary due to CL/P. Alternatively, Oklahoma offered lactation consultant services for breastfeeding help when there is a congenital defect. Only one state, Louisiana, required psychological assessment and counseling and genetic assessment and counseling for patients with CL/P and their parents.

An alternative approach to prescribing specific services is to mandate all necessary care. With the exception of North Carolina, these mandates initially were not specific to CL/P and were passed decades ago. For example, Alabama, Pennsylvania and Oklahoma all passed laws in 1975 that provided for all necessary care and treatment of newly born children with congenital defects and birth abnormalities. Since that provision, Oklahoma passed an additional law in 2004 that applied to CL/P and listed specific services that must be provided. Massachusetts enacted a provision in 2011 that mandated the necessary care and treatment of congenital defects and birth abnormalities. The following year, Massachusetts passed a law that required the provision of a large number of services to children with CL/P. Alternatively, North Carolina requires that coverage include but not be limited to all necessary treatment and care of CL/P.

Approximately half of the laws and regulations reviewed had an age restriction. Twenty-six laws and regulations limited coverage to individuals under a certain age or to covered dependents. An additional nine were aimed at newborns. The remainder of laws and regulations did not specify an age limit.

DISCUSSION

To our knowledge, this study is the first to systematically and comprehensively review and categorize the full range of private health insurance services that state laws and regulations mandate for CL/P. By looking over time, we are able to assess how the use of mandates has changed. Most states in 1999 did not have mandates. Over the following 18 years the largest share of states passed laws or enacted regulations mandating one or two services. A few states passed laws with a more comprehensive list of services specifically targeting children with CL/P. Many states, however, continue to have age limits on their requirements. The age limits present a serious restriction on individuals who continue to need services, including surgery, as adults.

An advantage of mandating specific services is that it increases the likelihood of coverage of the specified services. Mandating specific services brings clarity and certainty to patients about what will be covered. However, the risk to mandating specific services is that the services not specified in the law could be interpreted as not being required. In other words, it could give insurance plans leeway to restrict non-mandated services. On the other hand, not imposing any mandates or the general coverage of all medically necessary care enables insurance companies to implement their own definitions of what services are needed. The observation that some states with general coverage mandates later added specific services targeting CL/P suggests that the earlier general laws were not sufficient to ensure coverage of all services needed by individuals with CL/P.

Another issue is whether states should have mandates. Mandates add costs, which reduce affordability of insurance. The consequence could be to drive more people away from comprehensive health insurance. Nonetheless, in the case of children, especially those with congenital anomalies, mandates may be a useful policy tool to facilitate timely access to needed services.

One limitation of this study is that it does not address how mandates have been implemented practice. Insurance policy providers may at their discretion still offer coverage of services for treatment of CL/P. Analyzing legal texts, however, gives us an idea of the wide variation in approaches that states are using to modify insurance coverage for CL/P and lays the groundwork for future research quantitative into how these policy variations impact health service use and health outcomes.

A second limitation not addressed in this study is the extent of parental knowledge about these mandates and how parents are able to use that knowledge to make informed choices about insurance coverage for their children and to obtain needed care. The ability of parents to understand the rules, to navigate the system and advocate for their child varies significantly. Providing tools and resources for parents that would increase their knowledge about covered services would help increase access to care regardless of the laws in place. This is particularly relevant because of the importance of household socioeconomic differences in explaining disparities in outcomes and use of services (e.g. Guarnizo-Herreño and Wehby, 2012a and 2012b). Increasing the awareness of providers and patient support organizations about these mandates may also help in facilitating access of patients.

A key outcome of this study is that it demonstrates the wide range of approaches that states have taken. Comparing the different approaches allows us to begin to formulate hypotheses about the consequences of laws and regulations. Future research that examines impacts of different mandates on health care use and outcomes can provide an empirical basis for public policies that improve care for children with CL/P.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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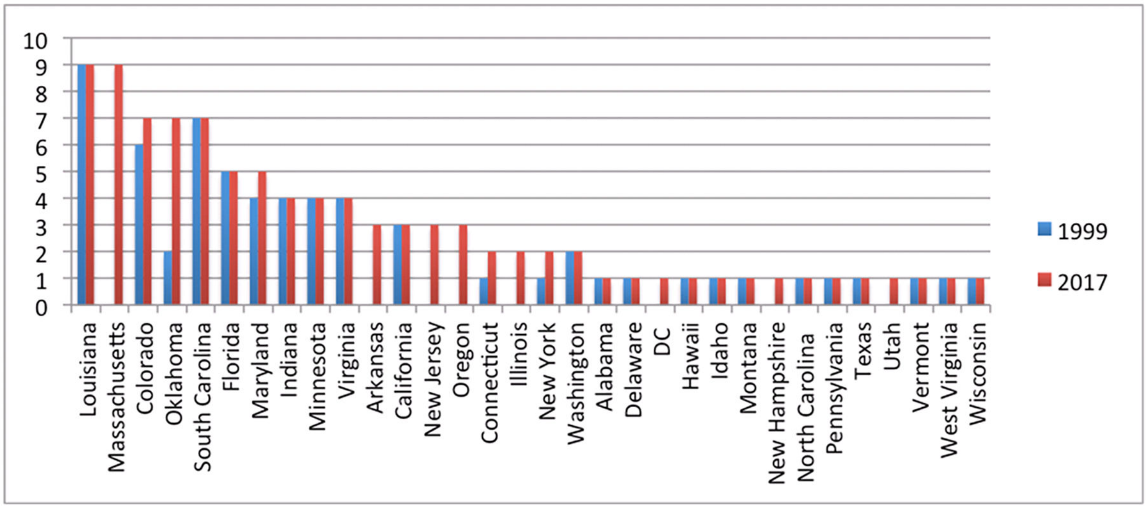

Figure 1.

Change in number of mandates from 1999 to 2017 for states with any mandates in this period

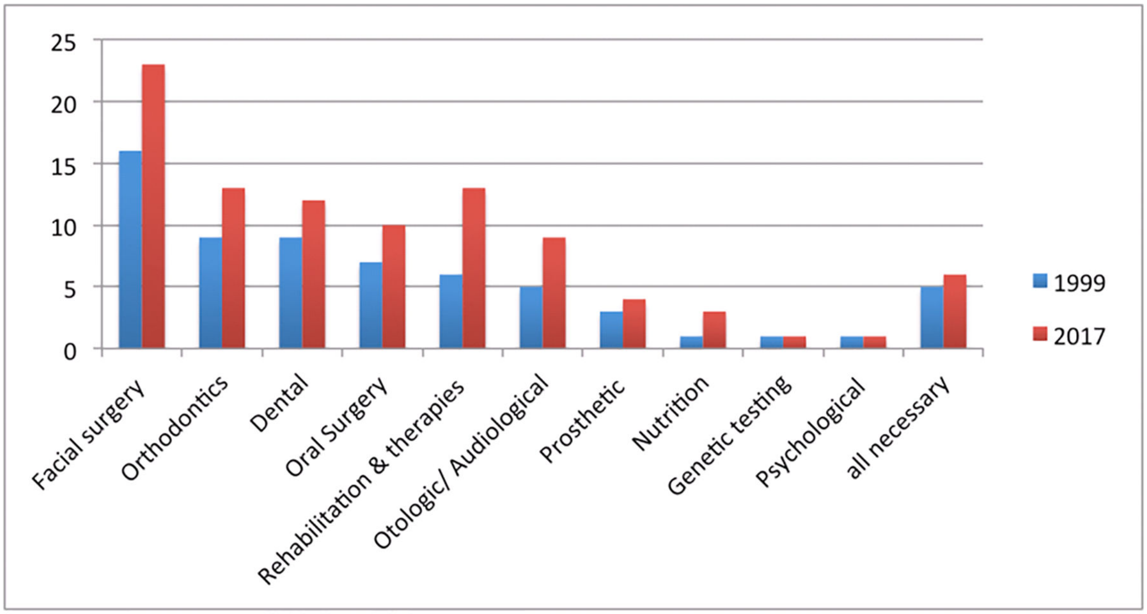

Figure 2.

Number of states with mandates for specific health care services in 1999 and 2017