California Health Benefits Review Program

Executive Summary Analysis of Senate Bill 126: Health Care Coverage: Pervasive Developmental Disorder or Autism

A Report to the 2013-2014 California Legislature

March 24, 2013



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EXECUTIVE SUMMARY

California Health Benefits Review Program Analysis of Senate Bill 126

The California Senate Committee on Health requested on January 23, 2013, that the California Health Benefits Review Program (CHBRP) conduct an evidence-based assessment of the medical, financial, and public health impacts of Senate Bill (SB) 126. In response to this request, CHBRP undertook this analysis pursuant to the provisions of the program's authorizing statute.¹

In 2014, CHBRP estimates that approximately 25.9 million Californians (67%) will have health insurance that may be subject to a health benefit mandate law passed at the state level.² Of the rest of the state's population, a portion will be uninsured (and so has no health insurance subject to any benefit mandate), and another portion will have health insurance subject to other state laws or only to federal laws.

Uniquely, California has a bifurcated system of regulation for health insurance subject to state benefit mandates. The California Department of Managed Health Care (DMHC)³ regulates health care service plans, which offer benefit coverage to their enrollees through health plan contracts. The California Department of Insurance (CDI) regulates health insurers,⁴ which offer benefit coverage to their enrollees through health insurance policies.

DMHC-regulated plans and CDI-regulated policies would be subject to SB 126. However, SB 126 exempts Medi-Cal Managed Care Plans and the California Public Employees' Retirement System (CalPERS). Therefore, the mandate would affect the health insurance of approximately 18.5 million enrollees (48% of all Californians).

Developing Estimates for 2014 and the Effects of the Affordable Care Act

The Affordable Care Act (ACA)⁵ is expected to dramatically affect health insurance and its regulatory environment in California, with many changes becoming effective in 2014. It is important to note that CHBRP's analysis of proposed benefit mandate bills typically address the <u>marginal</u> effects of the proposed bills—specifically, how the proposed mandate would affect benefit coverage, utilization, costs, and public health, <u>holding all other factors constant</u>. CHBRP's estimates of these marginal effects are presented in this report. Because expanded enrollment will not occur until January 2014, CHBRP relies on projections from the California

¹ Available at: <u>www.chbrp.org/docs/authorizing_statute.pdf</u>.

² CHBRP's estimates are available at: <u>www.chbrp.org/other_publications/index.php</u>.

³ The California Department of Managed Health Care (DMHC) was established in 2000 to enforce the Knox-Keene Health Care Service Plan of 1975; see Health and Safety Code (H&SC) Section 1340.

⁴ The California Department of Insurance (CDI) licenses "disability insurers." Disability insurers may offer forms of insurance that are not health insurance. This report considers only the impact of the benefit mandate on health insurance policies, as defined in Insurance Code (IC) Section 106(b) or subdivision (a) of Section 10198.6.

⁵ The federal "Patient Protection and Affordable Care Act" (P.L.111-148) and the "Health Care and Education Reconciliation Act" (P.L 111-152) were enacted in March 2010. Together, these laws are referred to as the Affordable Care Act (ACA).

Simulation of Insurance Markets (CalSIM) model⁶ to help set baseline enrollment for 2014. From this projected baseline, CHBRP estimates the marginal impact of benefit mandates proposed that could be in effect after January 2014.

Bill-Specific Analysis of SB 126

SB 126 would extend the sunset date of an existing state benefit mandate that requires coverage for behavioral health treatment for pervasive developmental disorder or autism (PDD/A).⁷ The existing state benefit mandate, **hereafter referred to as the behavioral health treatment mandate**, sunsets on July 1, 2014. SB 126 would extend the sunset date until July 1, 2019,⁸ but otherwise contains the same language as the existing mandate (enacted in 2011) that requires coverage for behavioral health treatment for PDD/A.

The existing behavioral health treatment mandate defines behavioral health treatment as including but not limited to applied behavior analysis (ABA).⁹ Specifically, it defines behavioral health treatment as "professional services and treatment programs, including applied behavior analysis and evidence-based behavior intervention programs, that develop or restore, to the maximum extent practicable, the functioning of an individual with pervasive developmental disorder or autism." In this report, interventions based on ABA and other theories of behavior are referred to as intensive behavioral intervention therapies. This report focuses on intensive behavioral intervention therapies based on ABA because the behavorial health treatment mandate specifically mentions ABA.

The existing behavioral health treatment mandate requires that treatment be prescribed by a licensed physician and surgeon or developed by a licensed psychologist. The mandate requires that the treatment be "provided under a treatment plan prescribed by a qualified autism service provider," and administered by a "qualified autism service provider" (QAS provider), a "qualified autism service professional" (QAS professional), or a "qualified autism service paraprofessional" (QAS paraprofessional) who can be an "unlicensed and uncertified" person.

Of those persons who can administer intensive behavioral intervention therapies to enrollees with PDD/A under the behavioral health treatment mandate, QAS professionals and paraprofessionals must be employed and supervised by a QAS provider. The mandate requires that DMHC-regulated plans and CDI-regulated policies maintain an adequate network of QAS providers to supervise and employ QAS professionals and paraprofessionals.

The existing behavioral health treatment mandate additionally requires that the mandated benefits be provided in the "same manner and shall be subject to the same requirements as

⁶ CalSIM was developed jointly and is operated by the University of California, Los Angeles Center for Health Policy Research and the University of California, Berkeley Center for Labor Research and Education. The model estimates the impact of provisions in the ACA on employer decisions to offer, and individual decisions to obtain, health insurance.

⁷ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

⁸ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52 (as enacted by SB 946, 2011) become inoperative on July 1, 2014, and repealed on January 1, 2015. SB 126 would be inoperative on July 1, 2019, and repealed on January 1, 2020. Once the mandate is inoperative, coverage is no longer required, and therefore this analysis focuses on the date the mandate would become inoperative.

⁹ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

provided in" current mental health parity law in California, which mandates parity with other benefits in terms of lifetime maximums, copayments, and deductibles.

Interaction With Other California Requirements

As stated, SB 126 extends the sunset date of the existing behavioral health treatment mandate that requires coverage for behavioral health treatment for PDD/A.¹⁰ In addition, current California mental health parity law¹¹ requires coverage for the diagnosis and medically necessary treatment of severe mental illnesses, including for PDD/A, for persons of any age. The current California mental health parity law applies to most DMHC-regulated plans and CDI-regulated policies; it exempts Medi-Cal Managed Care Plans.¹² Coverage for intensive behavioral intervention therapies for those with PDD/A is required under the current California mental health parity law.¹³

Analytic Approach and Key Assumptions

The existing behavioral health treatment mandate requires coverage for intensive behavioral intervention therapies for persons with PDD/A, as does the current California mental health parity law.¹⁴ Therefore, as coverage for intensive behavioral intervention therapies for PDD/A is currently required under both the existing behavioral health treatment mandate and the current California mental health parity law, SB 126 would not require new coverage, and CHBRP does not expect SB 126 to have a measurable cost or public health impact.

Pervasive developmental disorder or autism

Current law does not define PDD/A, but regulations governing DMHC-regulated plans¹⁵ define PDD/A as inclusive of Asperger's Disorder, Autistic Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified (including atypical autism) (PDD-NOS), and Rett's Disorder, in accordance with the *Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition* (DSM-IV)–Text Revision (June 2000). CDI also includes these five disorders within PDD/A.¹⁶ This report uses the term "PDD/A" in an effort to make clear that treatment is required for all five disorders.

Payers Other Than Health Plans and Insurers

Payment for intensive behavioral intervention therapies for PDD/A for persons enrolled in DMHC-regulated plans or CDI-regulated policies may come from other sources—a situation that may be more common than is the case for persons with other disorders. Patients (or their families) may pay directly for care, and charities may also become involved. Moreover, for

¹⁰ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

¹¹ H&SC Section 1374.72 and IC Section 10144.5.

¹² The current California mental health parity law discussed here exempts Medi-Cal Managed Care (H&SC Section 1374.72 and IC Section 10144.5), as does the existing behavioral health treatment mandate, and thus SB 126.

¹³ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

¹⁴ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

¹⁵ California Code of Regulations, (Vol. 38), Title 28, Managed Health Care, Section 1300.74.72(e).

¹⁶ Personal communication, J. Figueroa, CDI, March 2013.

PDD/A-related behavioral health treatment, regional centers contracting with the California Department of Developmental Services (DDS) may pay,¹⁷ and public schools in California are mandated by state and federal law to provide related services to students that are found eligible by an individualized education program team to receive special education.¹⁸

DDS does not collect information about the sources of health insurance that would allow clients to be identified as having health insurance subject to the existing behavioral health treatment mandate,¹⁹ and regional centers may serve persons without health insurance. Similarly, California Department of Education (CDE)-affiliated schools may serve persons without health insurance, but does not collect information on the health insurance status of public school students.²⁰ In addition, some enrollees with health insurance subject to the behavioral health treatment mandate may not seek assistance from a regional center or school, may pay directly for care, or may not meet severity threshold criteria to qualify for services per program eligibility rules. Therefore, the overlap between those with PDD/A who are served by DDS and/or CDE and those who are enrollees with health insurance subject to the behavioral health treatment mandate, and thus SB 126, is not clear.

Requirements in Other States

At least 32 states and the District of Columbia have passed health insurance benefit mandates related to autism. Some states identify treatments for which coverage is specifically required. Over half of the states with health insurance benefit mandates related to autism specifically require coverage for ABA.

Background on Pervasive Developmental Disorder or Autism

PDD/A includes neurodevelopmental disorders that typically become symptomatic in children aged 2 to 3 years, but may not be diagnosed until age 5 or older. PDD/A is a chronic condition characterized by impairments in social interactions, communication, sensory processing, stereotypic (repetitive) behaviors or interest, and sometimes cognitive function. Symptoms of PDD/A range from mild to severe. The cause of PDD/A is unknown, and there is no cure. PDD/A is associated with other comorbidities such as epilepsy and cognitive impairment.

Medical Effectiveness

Many children with PDD/A are treated with intensive (e.g., 25 or more hours per week) interventions based on ABA, hereafter referred to as intensive behavioral intervention therapies, that are aimed at improving behavior and reducing deficits in cognitive function, language, and social skills. The medical effectiveness review focuses on intensive behavioral intervention therapies based on ABA because SB 126 specifically mentions ABA.

¹⁷ Personal communication, E. Gelber and P. Choate, California Department of Developmental Services (DDS), February 2013.

¹⁸ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

¹⁹ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

²⁰ Personal communication, A. Smith, California Department of Education, March 2013.

CHBRP Terminology for Grading Evidence of Medical Effectiveness

CHBRP uses the following terms to characterize the strength of the evidence it identifies regarding the medical effectiveness of a treatment for which a bill would mandate coverage:

- Clear and convincing evidence;
- Preponderance of evidence;
- Ambiguous/conflicting evidence; and
- Insufficient evidence.

A grade of *clear and convincing evidence* indicates that there are multiple studies of a treatment and that the <u>large majority</u> of studies are of high quality and consistently find that the treatment is either effective or not effective.

A grade of *preponderance of evidence* indicates that the <u>majority</u> of the studies included in the medical effectiveness review are consistent in their findings that treatment is either effective or not effective. This can be further subdivided into preponderance of evidence from <u>high-quality</u> studies²¹ and preponderance of evidence from <u>low-quality</u> studies.

A grade of *ambiguous/conflicting evidence* indicates that although some studies included in the medical effectiveness review find that a treatment is effective, a similar number of studies of equal quality suggest the treatment is not effective.

A grade of *insufficient* evidence indicates that there is not enough evidence available to know whether or not a treatment is effective, either because there are too few studies of the treatment or because the available studies are not of high quality. It does not indicate that a treatment is not effective.

Methodological Considerations

The literature on intensive behavioral intervention therapies based on ABA has several important limitations.

• Most studies do not randomize participants to intervention and comparison groups. In nonrandomized studies, it is possible that differences between groups are due to differences in the characteristics of persons in the two groups rather than differences in the interventions studied. In addition, some studies assign children to intervention and comparison groups based on parent preferences, which may introduce bias.

²¹ High-quality studies are studies that: (1) have sample sizes that are sufficiently large to detect statistically significant differences between the intervention and comparison groups (100 or more subjects); (2) have low attrition rates (less than 20%); (3) have intervention and comparison groups that are statistically equivalent prior to the intervention, with respect to baseline measures of the outcome and important factors associated with the outcome; (4) use controlled before and after designs (i.e., collect data on both the intervention and comparison groups prior to the intervention and after the intervention); and (5) either randomly assign participants to intervention and comparison groups or use instrumental variables, propensity scores, or other sophisticated statistical methods to address selection bias and control for confounders.

- Many studies have small sample sizes, which limit their ability to detect statistically significant differences between intervention and comparison groups.
- Most studies of intensive behavioral intervention therapies only assess outcomes immediately after treatment is complete. Because only a limited number of studies collect data on outcomes posttreatment, there is insufficient evidence to determine whether use of intensive behavioral intervention therapies has benefits that persist throughout childhood and into adulthood.

Findings from studies of intensive behavioral intervention therapies based on ABA are difficult to synthesize because:

- The duration and intensity of treatments studied vary widely as do the settings in which treatment is provided.
- The characteristics of comparison groups also vary. Some studies compare more intensive to less intensive ABA-based interventions. Others compare intensive ABA-based interventions to treatment as usual, which typically consists of an eclectic mix of interventions.
- The outcomes assessed also vary. Only four outcomes are measured by a plurality of studies: adaptive behavior, intelligence quotient (IQ), language, and academic placement.

Study Findings

Characteristics of populations studied

- Nine recent meta-analyses and systematic reviews and eight individual studies published after the literature searches that informed the meta-analyses and systematic reviews were completed assessed the effectiveness of intensive behavioral intervention therapies based on ABA.
- Only two randomized controlled trials (RCTs) on intensive behavioral intervention therapies based on ABA have been published. Each of these RCTs enrolled fewer than 30 participants. In addition, their findings are inconsistent in part due to differences between the comparison groups in the two studies. In light of the small size of these RCTs and their inconsistent findings, CHBRP assessed a broader body of literature consisting of all studies of intensive behavioral intervention therapies based on ABA that had a comparison group.
- The intensive behavioral intervention therapies studied were provided by a wide range of personnel including certified applied behavioral therapists, child care workers, nurses, occupational therapists, psychologists, speech and language therapists, students, teachers, teachers' aides, and parents. Persons who did not have graduate degrees in behavior analysis or a related field were typically supervised by personnel with graduate degrees.
- Most children enrolled in these studies were treated for 1 to 2 years.

- Studies of intensive behavioral intervention therapies enrolled children who ranged in age from 18 months to 9 years. Most of the children enrolled had Autistic Disorder or PDD-NOS and had IQs within the ranges for Mild or Moderate Mental Retardation.
- CHBRP identified no studies regarding effectiveness of intensive behavioral intervention therapies in children younger than 18 months and persons older than 9 years, nor is there direct evidence about the effectiveness of these treatments for persons diagnosed with Asperger's Disorder, Rett's Disorder, or Childhood Disintegrative Disorder. *The absence of evidence is not evidence of no effect.* Intensive behavioral intervention therapies may be appropriate for some persons with PDD/A who fall outside the populations that have been studied.
- Outcomes for individual children enrolled in studies of intensive behavioral intervention therapies vary widely. Findings from studies that have attempted to identify the characteristics of children who are most likely to benefit from these interventions suggest that children who are younger and who have higher IQs and greater adaptive behavior skills (e.g., communication, daily living, motor, and social skills) at initiation of treatment derive greater benefit from treatment.

Study outcomes

Adaptive behavior:

- The preponderance of evidence, which comes from low-quality studies, suggests that intensive behavioral intervention therapies based on ABA are more effective than usual treatment and that more-intensive ABA-based therapies are more effective than less intensive ABA-based therapies in improving adaptive behavior (e.g., communication, daily living, motor, and social skills).
- One meta-analysis of studies, which are primarily of low quality, found that the intensive behavioral intervention therapies of longer duration have greater impact on adaptive behavior.

Intelligence quotient:

- The preponderance of evidence, which comes from low-quality studies, suggests that intensive behavioral intervention therapies based on ABA are more effective in increasing IQ than usual treatment and that more intensive ABA-based therapies are more effective than less intensive ABA-based therapies.
- Most studies found that the changes in intelligence is not sufficiently large to enable the majority of children with PDD/A to achieve levels of intellectual and educational functioning similar to peers without PDD/A.

Language:

• Findings are ambiguous as to the effects that intensive behavioral intervention therapies based on ABA have on both expressive language (i.e., ability to verbally express one's needs and wishes) and receptive language (i.e., ability to respond to requests from others)

relative to usual treatment. Evidence regarding the relative effectiveness of more intensive versus less intensive ABA-based therapies is also ambigious.

Academic placement:

• Findings are ambiguous as to the effect that intensive behavioral intervention therapies based on ABA have on academic placement relative to usual treatment. Evidence regarding the relative effectiveness of more intensive versus less intensive ABA-based therapies is also ambigious.

Benefit Coverage, Utilization, and Cost Impacts

SB 126 extends the sunset date of California's existing behavioral health treatment mandate that requires coverage for intensive behavioral intervention therapies for PDD/A. Current California mental health parity law²² also requires coverage of intensive behavioral intervention therapies for persons with PDD/A²³ for most DMHC-regulated plans and CDI-regulated policies.²⁴ Therefore, as coverage for intensive behavioral intervention therapies for PDD/A is currently required under both the existing behavioral health treatment mandate and the current California mental health parity law, SB 126 would not require new coverage, and CHBRP does not expect SB 126 to have a measurable cost impact.

CHBRP estimates that 100% of DHMC-regulated plans and CDI-regulated policies subject to these two state benefit mandates that require coverage for intensive behavioral intervention therapies as a treatment for PDD/A provide this coverage. CHBRP estimates that 100% of DHMC-regulated plans and CDI-regulated policies subject to the existing behavioral health treatment mandate maintain an adequate network that includes QAS providers who supervise and employ QAS professionals or paraprofessionals who provide and administer behavioral health treatment.

CHBRP estimates that 127,000 enrollees are diagnosed with PDD/A in DMHC-regulated plans or CDI-regulated policies subject to SB 126, of which 12,700 are estimated to currently use intensive behavioral intervention therapies. Current annual expenditures for intensive behavioral intervention therapies is estimated to be \$686 million.

Coverage Impacts

• No measurable change in coverage for these services is expected as CHBRP estimates that 100% of DHMC-regulated plans and CDI-regulated policies subject to SB 126 currently provide coverage for intensive behavioral intervention therapies as required by two existing California state benefit mandates.

²² H&SC Section 1374.72; IC Section 10144.5.

²³ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

²⁴ The current California mental health parity law (H&SC Section 1374.72 and IC Section 10144.5) exempts Medi-Cal Managed Care, as does the existing behavioral health treatment mandate (H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 [2011]).

Utilization Impacts

• As no measurable change in benefit coverage is expected, no measurable change in utilization is projected.

Cost Impacts

• As no measurable change in benefit coverage is expected, no measurable changes in total premiums and total health care expenditures are expected.

Public Health Impacts

CHBRP expects the coverage and utilization of intensive behavioral intervention therapies to remain unchanged as coverage for this therapy for PDD/A is currently required under both the existing behavioral health treatment mandate and the current California mental health parity law. Therefore, CHBRP does not expect SB 126 to produce a public health impact on persons with PDD/A. Additionally, CHBRP estimates SB 126 would have no impact on possible gender and racial/ethnic disparities in health outcomes or economic loss, and no measurable impact on long-term health outcomes.

Interaction With the Federal Affordable Care Act

Below is an analysis of how this proposed benefit mandate may interact with the ACA's requirement for certain health insurance to cover "essential health benefits" (EHBs).²⁵

SB 126 and Essential Health Benefits

SB 126 states that the benefit mandate would "not require any benefits to be provided that exceed the essential health benefits." SB 126 extends the sunset date of the existing behavioral health treatment mandate requiring coverage of intensive behavioral intervention therapies for enrollees with PDD/A.²⁶ The existing state benefit mandate was enacted before December 31, 2011, and is therefore included in California's EHBs for 2014 and 2015.²⁷ The state would not be required to defray any costs as a result of SB 126 in 2014 and 2015.²⁸

²⁵ Resources on EHBs and other ACA impacts are available on the CHBRP website: www.chbrp.org/other_publications/index.php.

²⁶ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

²⁷ Personal communication, S. Lowenstein, DMHC, February 2013.

²⁸ Personal communication, S. Lowenstein, DMHC, February 2013.

ACKNOWLEGMENTS

This report provides an analysis of the medical, financial, and public health impacts of Senate Bill 126. In response to a request from the California Senate Committee on Health on January 23, 2013, the California Health Benefits Review Program (CHBRP) undertook this analysis pursuant to the program's authorizing statute.

Janet Coffman, MPP, PhD, Gina Evans-Young, and Margaret Fix, MPH, all of the University of California, San Francisco, prepared the medical effectiveness analysis. Penny Coppernoll-Blach, MLIS, of the University of California, San Diego, conducted the literature search. Diana Cassady, DrPH, and Dominique Ritley, MPH, of the University of California, Davis, prepared the public health impact analysis. Todd Gilmer, PhD, of the University of California, San Diego, prepared the cost impact analysis. Robert Cosway, FSA, MAAA, and Scott McEachern of Milliman, provided actuarial analysis. Content expert Natacha Akshoomoff, PhD, of the University of California, San Diego, provided technical assistance with the literature review and expert input on the analytic approach. Laura Grossmann, MPH, of CHBRP staff prepared the *Introduction* and synthesized the individual sections into a single report. A subcommittee of CHBRP's National Advisory Council (see final pages of this report) reviewed the analysis for its accuracy, completeness, clarity, and responsiveness to the Legislature's request.

CHBRP gratefully acknowledges all of these contributions but assumes full responsibility for all of the report and its contents. Please direct any questions concerning this report to:

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California Health Benefits Review Program Committees and Staff

A group of faculty and staff undertakes most of the analysis that informs reports by the California Health Benefits Review Program (CHBRP). The CHBRP **Faculty Task Force** comprises rotating representatives from six University of California (UC) campuses. In addition to these representatives, there are other ongoing contributors to CHBRP from UC. This larger group provides advice to the CHBRP staff on the overall administration of the program and conducts much of the analysis. The **CHBRP staff** coordinates the efforts of the Faculty Task Force, works with Task Force members in preparing parts of the analysis, and coordinates all external communications, including those with the California Legislature. The level of involvement of members of the CHBRP Faculty Task Force and staff varies on each report, with individual participants more closely involved in the preparation of some reports and less involved in others. As required by CHBRP's authorizing legislation, UC contracts with a certified actuary, Milliman Inc., to assist in assessing the financial impact of each legislative proposal mandating or repealing a health insurance benefit. Milliman also helped with the initial development of CHBRP methods for assessing that impact.

The **National Advisory Council** provides expert reviews of draft analyses and offers general guidance on the program to CHBRP staff and the Faculty Task Force. CHBRP is grateful for the valuable assistance and thoughtful critiques provided by the members of the National Advisory Council. However, the Council does not necessarily approve or disapprove of or endorse this report. CHBRP assumes full responsibility for the report and the accuracy of its contents.

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