

California Health Benefits Review Program

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

A Report to the 2013–2014 California Legislature

March 24, 2013





The California Health Benefits Review Program (CHBRP) responds to requests from the State Legislature to provide independent analyses of the medical, financial, and public health impacts of proposed health insurance benefit mandates and proposed repeals of health insurance benefit mandates. CHBRP was established in 2002 to respond to requests from the California Legislature to provide independent analysis of the medical, financial, and public health impacts of proposed health insurance benefit mandates and repeals per its authorizing statute.¹ The program was reauthorized in 2006 and again in 2009. CHBRP's authorizing statute defines legislation proposing to mandate or proposing to repeal an existing health insurance benefit as a proposal that would mandate or repeal a requirement that a health care service plan or health insurer: (1) permit covered individuals to obtain health care treatment or services from a particular type of health care provider; (2) offer or provide coverage for the screening, diagnosis, or treatment of a particular disease or condition; (3) offer or provide coverage of a particular type of health care treatment or service, or of medical equipment, medical supplies, or drugs used in connection with a health care treatment or service; and/or (4) specify terms (limits, timeframes, copayments, deductibles, coinsurance, etc.) for any of the other categories.

An analytic staff in the University of California's Office of the President supports a task force of faculty and staff from several campuses of the University of California to complete each analysis within a 60-day period, usually before the Legislature begins formal consideration of a mandate or repeal bill. A certified, independent actuary helps estimate the financial impacts. A strict conflict-of-interest policy ensures that the analyses are undertaken without financial or other interests that could bias the results. A National Advisory Council, drawn from experts from outside the state of California as well as Loma Linda University, the University of Southern California, and Stanford University, and designed to provide balanced representation among groups with an interest in health insurance benefit mandates or repeals, reviews draft studies to ensure their quality before they are transmitted to the Legislature. Each report summarizes scientific evidence relevant to the proposed mandate, or proposed mandate repeal, but does not make recommendations, deferring policy decision making to the Legislature. The State funds this work through an annual assessment on health plans and insurers in California. All CHBRP reports and information about current requests from the California Legislature are available on the CHBRP website, www.chbrp.org.

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

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PREFACE

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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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.²

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.³ 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)⁴ 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,⁵ 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)⁶ 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 marginal effects of the proposed bills—specifically, how the proposed mandate would affect benefit coverage, utilization, costs, and public health, holding all other factors constant.

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 Simulation of Insurance Markets (CalSIM) model⁷ to help set baseline enrollment for 2014.

² Available at: www.chbrp.org/docs/authorizing_statute.pdf.

³ CHBRP's estimates are available at: www.chbrp.org/other_publications/index.php.

⁴ 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.

⁵ 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.

⁶ 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).

⁷ 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

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).⁸ 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, 2019,⁹ 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).¹⁰ 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 behavioral 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 provided in” current mental health parity law in California, which mandates parity with other benefits in terms of lifetime maximums, copayments, and deductibles.

estimates the impact of provisions in the ACA on employer decisions to offer, and individual decisions to obtain, health insurance.

⁸ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

⁹ 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.

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

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.¹¹ In addition, current California mental health parity law¹² 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.¹³ **Coverage for intensive behavioral intervention therapies for those with PDD/A is required under the current California mental health parity law.**¹⁴

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.¹⁵ **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 plans¹⁶ 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.¹⁷ 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 PDD/A-related behavioral health treatment, regional centers contracting with the California

¹¹ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

¹² H&SC Section 1374.72 and IC Section 10144.5.

¹³ 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.

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

¹⁵ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

¹⁶ California Code of Regulations, (Vol. 38), Title 28, Managed Health Care, Section 1300.74.72(e).

¹⁷ Personal communication, J. Figueroa, CDI, March 2013.

Department of Developmental Services (DDS) may pay,¹⁸ 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.¹⁹

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,²⁰ 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.²¹ 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.

¹⁸ Personal communication, E. Gelber and P. Choate, California Department of Developmental Services (DDS), February 2013.

¹⁹ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

²⁰ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

²¹ 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 large majority 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 majority 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 high-quality studies²² and preponderance of evidence from low-quality 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.

²² 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 ambiguous.

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 ambiguous.

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 law²³ also requires coverage of intensive behavioral intervention therapies for persons with PDD/A²⁴ for most DMHC-regulated plans and CDI-regulated policies.²⁵

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 among these enrollees 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.

²³ H&SC Section 1374.72; IC Section 10144.5.

²⁴ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

²⁵ 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 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).²⁶

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.²⁷ The existing state benefit mandate was enacted before December 31, 2011, and is therefore included in California's EHBs for 2014 and 2015.²⁸ The state would not be required to defray any costs as a result of SB 126 in 2014 and 2015.²⁹

²⁶ Resources on EHBs and other ACA impacts are available on the CHBRP website:

www.chbrp.org/other_publications/index.php.

²⁷ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

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

²⁹ Personal communication, S. Lowenstein, DMHC, February 2013.

INTRODUCTION

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.³⁰

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.³¹ 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)³² 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,³³ 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)³⁴ is expected to dramatically affect health insurance and its regulatory environment in California, with many changes becoming effective in 2014. Beginning in 2014, an expansion of the Medicaid program to cover people up to 133% of the federal poverty level (FPL)³⁵ and the availability of subsidized and unsubsidized health insurance coverage purchased through newly established state health insurance exchanges are expected to significantly increase the number of people with health insurance in the United States.

³⁰ Available at: www.chbrp.org/docs/authorizing_statute.pdf.

³¹ CHBRP's estimates are available at: www.chbrp.org/other_publications/index.php.

³² 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.

³³ 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.

³⁴ 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).

³⁵ The Medicaid expansion, which California is moving forward on, is to 133% of the federal poverty level (FPL)—138% with a 5% income disregard.

State exchanges will sell health insurance in the small-group and individual markets³⁶ through qualified health plans (QHPs), which will be certified by and sold in a state's exchange. QHPs sold through California's state exchange, Covered California,³⁷ will be DMHC-regulated plans or CDI-regulated policies, and as such will be subject to California state benefit mandates.

It is important to note that CHBRP's analysis of proposed benefit mandate bills typically address the marginal effects of the proposed bills—specifically, how the proposed mandate would impact benefit coverage, utilization, costs, and public health, holding all other factors constant. 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 Simulation of Insurance Markets (CalSIM) model³⁸ to help set baseline enrollment for 2014. From this projected baseline, CHBRP estimates the marginal impact of proposed benefit mandates that could be in effect after January 2014. CHBRP's methods for estimating baseline 2014 enrollment from CalSIM projections are provided in further detail in Appendix D.

Bill-Specific Analysis of SB 126

Bill Language

The full text of SB 126 can be found in Appendix A.

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).³⁹ 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, 2019,⁴⁰ but otherwise contains the same language as the existing mandate (enacted in 2011) that requires coverage for behavioral health treatment for PDD/A.

SB 126 would extend the sunset date of an existing state benefit mandate, referred to in this report as the behavioral health treatment mandate, that requires coverage for behavioral health treatment for PDD/A. SB 126 alters the sunset date of the behavioral health treatment mandate, but otherwise contains the same language as the existing mandate.

³⁶ Effective 2017, states may allow large-group purchasing through the exchange, which may make some large-group plans and policies subject to essential health benefits (EHB) requirements [ACA Section 1312(f)(2)(B)].

³⁷ The California Health Benefits Exchange Authorizing Statute is available here: www.healthexchange.ca.gov/Documents/California%20Codes%20Governing%20the%20Health%20Benefit%20Exchange.pdf.

³⁸ 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.

³⁹ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

⁴⁰ 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.

The existing behavioral health treatment mandate defines behavioral health treatment as including, but not limited to, applied behavior analysis (ABA).⁴¹ 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 behavioral health treatment mandate specifically mentions ABA.

The 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), who must be a licensed person or a certified “person, entity, or group;”
- A “qualified autism service professional” (QAS professional), who must be approved as a behavioral service provider by a California regional center, and who has training and experience in providing services for PDD/A; 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 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 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.⁴²

In addition, current California mental health parity law⁴³ 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

⁴¹ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

⁴² H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

⁴³ H&SC Section 1374.72 and IC Section 10144.5.

and CDI-regulated policies; it exempts Medi-Cal Managed Care Plans.⁴⁴ Coverage is required “under the same terms and conditions applied to other medical conditions” including maximum lifetime benefits, copayments, and deductibles.⁴⁵ **Coverage for intensive behavioral intervention therapies for those with PDD/A is required under this mental health parity law.**⁴⁶

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.⁴⁷ **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 does not require new coverage, and CHBRP does not expect SB 126 to have a measurable cost or public health impact.**

Intensive behavioral health treatment

The existing behavioral health treatment mandate, and thus SB 126, defines behavioral health treatment as including, but not limited to, ABA. Specifically, it defines behavioral health treatment as inclusive of the following: “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 because the behavioral health treatment mandate, and thus SB 126, specifically mentions ABA.

Pervasive developmental disorder or autism

Current law does not define PDD/A, but regulations governing DMHC-regulated plans⁴⁸ 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)* (APA, 2000). It is expected that the DSM will be updated this year to the Fifth Edition (DSM-V). As the DSM-V is still forthcoming and the DSM-IV is cited in the aforementioned California regulations, DSM-IV is used for this analysis. CDI also includes these five disorders within PDD/A.⁴⁹

⁴⁴ 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.

⁴⁵ H&SC Section 1374.72; IC Section 10144.5.

⁴⁶ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

⁴⁷ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

⁴⁸ California Code of Regulations, (Vol. 38), Title 28, Managed Health Care, Section 1300.74.72(e).

⁴⁹ Personal communication, J. Figueroa, CDI, March 2013.

This report uses the term “PDD/A” in an effort to make clear that treatment is required for all five disorders. The terms “autism,” “Autistic Disorder,” or “autism spectrum disorders (ASD)” are commonly used, but may be used as a synonym for “Autistic Disorder,” not necessarily intending inclusion or exclusion of the two generally less severe disorders (Asperger’s Disorder and PDD-NOS) and/or the two less common disorders (Rett’s Disorder and Childhood Disintegrative Disorder) that are technically part of PDD/A. In this report, use of the term “PDD/A” intends inclusion of all five disorders.

Persons who can administer intensive behavioral health treatment

Under the existing behavioral health treatment mandate,⁵⁰ QAS providers, QAS professionals, and QAS paraprofessionals can provide intensive behavioral intervention therapies. The current California mental health parity law⁵¹ does not include the specificity of language around those who can administer intensive behavioral intervention therapies, and it is unclear whether QAS professionals and QAS paraprofessionals would be allowed to administer intensive behavioral intervention therapies under the mental health parity law. This report analyzes SB 126 and so assumes, were the proposed benefit mandate to be enacted, that QAS providers, QAS professionals, and QAS paraprofessionals would continue to administer intensive behavioral intervention therapies as they currently can under the existing behavioral health treatment mandate.

Mental health parity

The existing behavioral health treatment mandate specifies that benefit coverage be provided in the same manner and be subject to the same requirements as are the mental health benefits mandated by current law.⁵² Current mental health parity law requires that terms and conditions applicable to the mandated benefits be equal to those applied to all benefits covered under the plan contract or policy. Therefore, CHBRP assumes that the existing behavioral health treatment mandate requires that terms and conditions for coverage of intensive behavioral intervention therapies for PDD/A be in parity with benefit coverage provided for physical or mental health, and that SB 126 would require the same if enacted.

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 PDD/A-related behavioral health treatment, regional centers contracting with the California Department of Developmental Services (DDS) may pay.⁵³ Further, public schools in California

⁵⁰ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, enacted by SB 946 (2011).

⁵¹ H&SC Section 1374.72; IC Section 10144.5.

⁵² H&SC Section 1374.72; IC Section 10144.5.

⁵³ Personal communication, E. Gelber and P. Choate, California Department of Developmental Services (DDS), February 2013.

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.⁵⁴

Regional centers with contracts from DDS are nonprofit, private corporations that contract with DDS to provide or coordinate services and support for individuals with developmental disabilities.⁵⁵ In particular, DDS facilitates the federal Early Start intervention program for infants and toddlers with suspected developmental delays. In California, 21 regional centers have more than 40 offices (DDS, 2013). Regional centers provide or pay for some services to persons with full spectrum, suspected, or residual autism, but do not serve all persons diagnosed with PDD/A (California Legislature, 2007). The population served by DDS would be expected to overlap with enrollees with health insurance subject to the behavioral health treatment mandate, and thus SB 126, but the populations would not be identical. DDS does not collect information about the sources of health insurance that would allow clients to be identified as having health insurance subject or not subject to the existing behavioral health treatment mandate,⁵⁶ and regional centers may serve persons without health insurance. In addition, some enrollees with health insurance subject to the behavioral health treatment mandate may not seek assistance from a regional center or may not meet severity threshold criteria to qualify for services per program eligibility rules. Therefore, the overlap between those with PDD/A served by DDS and those who are enrollees with health insurance subject to the behavioral health treatment mandate is not clear.

Public schools provide some services to some persons with PDD/A who have been found eligible to receive special education and related services, including psychological services.⁵⁷ Although the California Department of Education (CDE) is not mandated to collect information that allows such specificity, such services may include intensive behavioral intervention therapies. Again, such a population would be expected to overlap with enrollees whose health insurance would be subject to the existing behavioral health treatment mandate, and thus SB 126, but the populations would not be identical. CDE does not collect information on the health insurance status of public school students,⁵⁸ and CDE-affiliated schools may serve persons without health insurance. In addition, some enrollees with health insurance subject to the behavioral health treatment mandate may attend private schools, may be too young to attend school, or may not have impairments sufficient to justify CDE-supported services (California Legislature, 2007). Therefore, the overlap between those with PPD/A serviced by CDE and those who are enrollees with health insurance subject to the behavioral health treatment mandate 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 (BCBSA, 2012). States place various requirements around their benefit

⁵⁴ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

⁵⁵ Services provided by regional centers are related to the federal Lanterman Developmental Disabilities Services Act (1969) and Part C of the federal Individuals with Disabilities Education Act (2004).

⁵⁶ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

⁵⁷ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

⁵⁸ Personal communication, A. Smith, California Department of Education, March 2013.

mandates related to autism, such as limiting coverage by age (e.g., only requiring coverage for those under age 21), and/or placing lifetime or annual limits on coverage for treatments for autism (NCSL, 2012). Some states also 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 (NCSL, 2012).

Interaction With the Federal Mental Health Parity and Addiction Equity Act

The federal Mental Health Parity and Addiction Equity Act (MHPAEA) addresses parity for mental health benefits.⁵⁹ The MHPAEA requires that if mental health or substance use disorder services are covered, cost-sharing terms and treatment limits be no more restrictive than the predominant terms or limits applied to medical/surgical benefits. The MHPAEA applies to the large-group market, but starting in 2014, the ACA requires small-group and individual market plans and policies purchased through a state health benefits exchange to comply with the MHPAEA. The MHPAEA is similar to the current California mental health parity law,⁶⁰ but the state law applies to some DMHC-regulated plans and CDI-regulated policies not subject to the MHPAEA.

Interaction With the Affordable Care Act

A number of ACA provisions have the potential to or do interact with state benefit mandates. Below is an analysis of how this proposed benefit mandate may interact with requirements in the ACA, specifically, the requirement for certain health insurance to cover “essential health benefits” (EHBs).⁶¹

Essential Health Benefits

Effective 2014, the ACA requires nongrandfathered small-group and individual market health insurance—including but not limited to QHPs that will be sold in Covered California—to cover 10 specified categories of EHBs.⁶² The U.S. Department of Health and Human Services (HHS) has allowed each state to define its own EHBs for 2014 and 2015 by selecting one of a set of specified benchmark plan options.⁶³ California has selected the Kaiser Foundation Health Plan Small Group Health Maintenance Organization (HMO) 30 plan as its benchmark plan.⁶⁴

⁵⁹ Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), as amended by the ACA.

⁶⁰ H&SC Section 1374.72 and IC Section 10144.5.

⁶¹ Resources on EHBs and other ACA impacts are available on the CHBRP website:

www.chbrp.org/other_publications/index.php.

⁶² The 10 specified categories of essential health benefits (EHBs) are: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care. [ACA Section 1302(b)].

⁶³ CCIIO, Essential Health Benefits Bulletin. Available at:

http://cciio.cms.gov/resources/files/Files2/12162011/essential_health_benefits_bulletin.pdf.

⁶⁴ H&SC Section 1367.005; IC Section 10112.27.

The ACA allows a state to “require that a qualified health plan offered in [an exchange] offer benefits in addition to the essential health benefits.”⁶⁵ If the state does so, the state must make payments to defray the cost of those additionally mandated benefits, either by paying the purchaser directly or by paying the QHP. However, state benefit mandates enacted on or before December 31, 2011, would be included in a state’s EHBs for 2014 and 2015, and there would be no requirement that the state defray the costs of those state mandated benefits.⁶⁶

For state benefit mandates enacted after December 31, 2011 that are identified as exceeding EHBs, the state would be required to defray the cost. State benefit mandates that could exceed EHBs would “be specific to the care, treatment, and services that a state requires issuers to offer to its enrollees,” whereas “state rules related to provider types, cost-sharing, or reimbursement methods” would not meet the definition of state benefit mandates that could exceed EHBs. A state’s exchange would be responsible for determining when a state benefit mandate exceeds EHBs, and QHP issuers would be responsible for calculating the cost that must be defrayed.⁶⁷

SB 126 and essential health benefits

SB 126 states that the proposed 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.⁶⁸ The existing state benefit mandate was enacted before December 31, 2011, and is therefore included in California’s EHBs for 2014 and 2015.⁶⁹ The state would not be required to defray any costs as a result of SB 126 in 2014 and 2015.⁷⁰

⁶⁵ ACA Section 1311(d)(3).

⁶⁶ Department of Health and Human Services. Patient Protection and Affordable Care Act: Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation. Final Rule. Federal Register, Vol. 78 , No. 37. February 25, 2013. 12843. Available at: www.gpo.gov/fdsys/pkg/FR-2013-02-25/pdf/2013-04084.pdf.

⁶⁷ Essential Health Benefits. Final Rule.

⁶⁸ H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

⁶⁹ Personal communication, S. Lowenstein, DMHC, February 2013.

⁷⁰ Personal communication, S. Lowenstein, DMHC, February 2013.

BACKGROUND ON PERVASIVE DEVELOPMENTAL DISORDERS AND AUTISM

Pervasive developmental disorders or autism (PDD/A) are neurodevelopmental disorders that typically become symptomatic in children aged 2 to 3 years, but may not be diagnosed until age 5 or older, especially in cases of Asperger's Disorder (Pasco, 2010). They are chronic conditions characterized by impairments in social interactions, communication, sensory processing, stereotypic (repetitive) behaviors or interests, and sometimes cognitive function (CDC, 2009; Walker et al., 2004). The symptoms of PDD/A range from mild to severe, as reflected by the phrase "autism spectrum disorders" (ASD). This report uses PDD/A to describe (unless otherwise specified) all five disorders covered, as discussed in the *Introduction*.

The cause (or causes) of PDD/A is unknown, and research into genetic etiology as well as environmental factors continues to be explored. There is no cure for PDD/A; however, there is some evidence that treatment, such as speech therapy, pharmacotherapy, and behavioral treatments, may improve symptoms (see the *Medical Effectiveness* section).

PDD/A is associated with other comorbidities, such as epilepsy and intellectual disability. The Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring Network reports that 38% of their network's PDD/A population (children aged 8 years) are classified as intellectually disabled (intelligence quotient [IQ] ≤ 70) and 24% are classified as borderline status (IQ 71–85) with the remaining 38% scoring in the average to above-average IQ range (CDC, 2012). In California, the Department of Developmental Services (DDS) reported that 23% of its clients with PDD/A had some form of intellectual disability (mild, moderate, severe, or profound), of which 4.3% were severely or profoundly impaired.⁷¹

PDD/A Prevalence in California

Estimates of prevalence of PDD/A in the United States and worldwide have been increasing over the last 20 years (Fombonne, 2009a). For example, the number of Californians with autism served by DDS increased 15-fold between 1987 and 2012.⁷² The overall PDD/A prevalence estimates found in the more recent literature range from 78/10,000 (UCLA, 2006) to 114/10,000 (CDC, 2012; Kogan et al., 2009). For children aged 6-17 years, the CDC just released a report showing the national prevalence to be 200/10,000 (1 in 50 children) in 2011-2012 (Blumberg et al., 2013). Researchers frequently note that increasing prevalence rates and variation in published rates over time may be attributable to multiple reasons (Charman et al., 2009; Croen et al., 2002; Leonard et al., 2010; Williams et al., 2006) such as:

- Increased absolute risk for PDD/A;
- Health care provider variation in diagnosis;
- Heterogeneous study methodologies (e.g., sample size, administrative vs. survey data, and population demographic characteristics);

⁷¹ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

⁷² Personal communication, E. Gelber and P. Choate, DDS, February 2013.

- Reliability and sensitivity of screening tests;
- Changing PDD/A definitions; and
- Increasing availability or awareness of PDD/A (as a condition) or of services used to treat PDD/A.

Fombonne (2009b) estimates that the prevalence of PDD/A subcategories to be:

- Autistic Disorder: 20.6/10,000
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS): 37.1/10,000
- Asperger’s Disorder: 6.0/10,000
- Rett’s Disorder: 1.0/10,000–13,000⁷³
- Childhood Disintegrative Disorder: 2.0/100,000

Estimated Prevalence of PDD/A in California

PDD/A is not a reportable condition nor are there registries established in the United States; therefore, the true prevalence of PDD/A is unknown. CHBRP reviewed multiple sources to determine the best estimated PDD/A prevalence rate for the analysis of SB 126. Data sources include epidemiological studies (population- and survey-based), survey data, and California program data generated by analysts from DDS.

After an analysis of the strengths and limitations of the aforementioned data sources, CHBRP chose to adjust 2012 DDS data to estimate California-specific prevalence rates by age group and PDD/A subtype. This level of specificity recognizes the variation in PDD/A prevalence by age group. **Understanding the differences in prevalence rates by age group are useful to this analysis since SB 126 focuses on intensive behavioral treatment therapies which are generally administered to younger children.**

These estimated rates use baseline data about Californians with PDD-A who are eligible for services from DDS, and use assumptions from the literature to capture the extant population that is ineligible for DDS services (generally, those persons with less severe PDD/A). See Appendix F for further description of calculations and rationale. Table 1 offers a “snapshot” in time (2012), and does not represent a declining prevalence rate in PDD/A as a cohort ages. Rather, the lower prevalence rates in the older population are artifacts of differences in true risk of PDD/A, changes to diagnostic criteria over time, and/or other factors discussed previously in this section.

The estimated rates in Table 1 for California are higher than national estimates, but the estimates are based on adjustments to the actual number of Californians known to be served by DDS rather than a national, population-based surveillance prevalence rate (see Appendix F for rate calculation methodology).⁷⁴ For many years, California has been among the leaders in offering

⁷³ Prevalence of Rett’s Disorder estimated by Kerr, 2002.

⁷⁴ The CDC’s March 20, 2013 report on the prevalence of autism now estimates 200/10,000 (1 in 50 children ages 6-17 yrs), which closely aligns with CHBRP’s estimates for that age group (Table 1).

publicly supported programs for the developmentally disabled,⁷⁵ and it is assumed that DDS offers the most accurate accounting of the number of Californians with PDD/A (King and Bearman, 2009) as its services are used widely by Californians.⁷⁶ For the purposes of this analysis, it is assumed that representation of the PDD/A population is similar between the insured and uninsured populations.

Table 1. Estimated Prevalence Rates of Persons Diagnosed with PDD/A in California, 2012

Age Groups (years)	Estimated Prevalence of Autistic-Only Disorder in California (per 10,000)	Estimated Prevalence of “Other” PDD in California (per 10,000)	Estimated Prevalence of All PDD/A in California (per 10,000)
0–4	31.4	39.6	71.1
5–9	92.4	147.6	240.0
10–14	63.9	116.7	180.7
15–19	39.4	94.0	133.4
20–24	23.0	78.5	101.4
25–29	9.6	35.5	45.1
30–34	5.5	21.8	27.3
35–39	3.9	13.9	17.8
40–44	3.2	12.4	15.6
45–49	3.4	9.9	13.3
50+	1.3	4.1	5.4

Source: California Health Benefits Review Program, 2013 (based on 2012 data from DDS,⁷⁷ and Appendix F).

Note: These estimated prevalence rates are based on persons with PDD/A who are eligible for DDS services rather than a surveillance of the population for those medically diagnosed with PDD/A. This table offers a “snapshot” in time (2012), and does not represent a declining prevalence rate in PDD/A as a cohort ages. Appendix F provides more details on calculation methodology.

Key: DDS=California Department of Developmental Services; PDD/A=pervasive developmental disorders or autism.

Baseline Differences in Prevalence by Gender and Race/Ethnicity

Multiple studies reported a higher PDD/A prevalence rate among males, in whom rates are three to seven times higher than in females (CDC, 2009; Newschaffer and Curran, 2003; Yeargin-Allsopp et al., 2003). DDS reported a ratio of males to females with autism as 4.6:1, which corresponds with findings from other studies cited above. DDS also reported that the male-dominated prevalence crossed all races and geographic regions in California (DDS, 2009).

Beyond prevalence of PDD/A in the population, there is some conflicting evidence of gender differences in PDD/A symptoms, but no evidence of gender differences in treatment patterns or health outcomes related to PDD/A. Several studies found that females diagnosed with autism were more likely to have cognitive impairment as compared with males (CDC, 2009, 2012; Werling and Geschwind, 2013; Yeargin-Allsopp et al., 2003). However, DDS reported that males with PDD/A had a higher prevalence at every severity level of intellectual disability diagnosis, although the rates varied (5.2:1 for no impairment to 2.4:1 for profound intellectual impairment) (DDS, 2009). Hartley and Sikora summarized results from previous studies that conflicted; two studies that controlled for differences in cognitive function found no difference in

⁷⁵ Personal communication, report content expert N. Akshmooff, February 2011.

⁷⁶ Personal communication, report content expert R. Wachtel, February 2011.

⁷⁷ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

autistic symptoms, whereas three studies, which also controlled for cognition, reported higher rates of repetitive behaviors in boys than girls (Hartley and Sikora, 2009). The authors reported results from their own study that found small, but significant, differences in communication skills and sleep issues (greater deficits for girls), and repetitive behaviors (dominated by boys).

The literature also provides mixed conclusions regarding distribution of PDD/A by race and ethnicity. Some studies indicated no significant differences in PDD/A prevalence by race (Bertrand, et al., 2001; Dyches et al., 2002; Fombonne, 2003; Yeargin-Allsopp et al., 2003), whereas other studies found some differences including a study on the California population, which found higher rates among Blacks (Croen et al., 2002, Newschaffer et al., 2007). By contrast, the CDC's more recent study of 14 sites across the United States reported significantly greater pooled prevalence among White children (12.0/1,000) than among Black children (10.2/1,000) and Hispanic children (7.9/1,000) (CDC, 2012), although prevalence by race varied by individual sites. Among those provided PDD/A services by California's DDS, the four largest race/ethnic groups were distributed as follows: Whites accounted for 36% of the clients, Hispanics 31%, Asians 9%, and Blacks 8%. The remaining 17% were "other," Filipino, Native American, and Polynesian (DDS, 2012).

MEDICAL EFFECTIVENESS

As discussed in the *Introduction*, Senate Bill (SB) 126 would extend the sunset date for an existing state benefit mandate that requires coverage of behavioral health treatment for pervasive developmental disorder or autism (PDD/A). Many children with PDD/A are treated with intensive (e.g., 25 or more hours per week) behavioral intervention therapies based on applied behavioral analysis (ABA), an approach to behavior change that draws upon the theories of B.F. Skinner regarding general principles of human behavior (Howlin et al., 2009), hereafter referred to as intensive behavioral intervention therapies.⁷⁸ The medical effectiveness review focuses on intensive behavioral intervention therapies based on ABA because SB 126 specifically mentions ABA. The review relied on meta-analyses and systematic reviews of literature published through 2010 and on individual studies published from 2011 to present.

Research Approach and Methods

Studies of intensive behavioral intervention therapies for PDD/A were identified through searches of MEDLINE (PubMed), the Cochrane Database of Systematic Reviews, the Cochrane Register of Controlled Clinical Trials, PsycINFO, Web of Science, Business Source Complete, and EconLit. In addition, websites maintained by the following organizations that index or publish systematic reviews and evidence-based guidelines were searched: the Agency for Healthcare Research and Quality, International Network of Agencies for Health Technology Assessment, National Health Service Centre for Reviews and Dissemination, National Institute for Health and Clinical Excellence, and the Scottish Intercollegiate Guideline Network.

The search was limited to abstracts of studies published in English. Because the California Health Benefits Review Program (CHBRP) had previously conducted thorough literature searches on this topic in 2011 for SB TBD-1, the search was limited to studies published from 2011 to present.

A total of 495 abstracts were retrieved and reviewed. Seventeen studies were included in the medical effectiveness review. The medical effectiveness review relied heavily on nine meta-analyses and systematic reviews of studies of behavioral intervention therapies that were published from 2008 through 2012 (Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow and Wolery, 2009; Reichow et al., 2012; Spreckley and Boyd, 2009; Virués-Ortega, 2010; Warren et al., 2011). Eight articles published after the studies included in the meta-analyses and systematic reviews were published were also included (Eikeseth et al., 2012; Fava et al., 2011; Fernell et al., 2011; Flanagan et al., 2012; Grindle et al., 2012; Kovshoff et al., 2011; Reed et al., 2012; Strauss et al., 2012). In addition, a study on the Early Start Denver Model, an intensive behavioral intervention therapy that combined approaches based on ABA and developmental theory, was included (Dawson et al., 2010). The other articles were eliminated because they did not focus on intensive behavioral

⁷⁸ Other treatments for PDD/A include pharmacotherapy, occupational therapy, physical therapy, speech therapy, psychiatric care, and psychological care. Persons with Rett's Disorder may also need durable medical equipment to cope with the physical manifestations of the disorder. These treatments are discussed in CHBRP's report on AB 171 (2011).

intervention therapies provided to persons with PDD/A, were of poor quality, or did not report findings from research studies.

A more thorough description of the methods used to conduct the medical effectiveness review and the process used to grade the evidence for each outcome measure is presented in Appendix B: Literature Review Methods. Appendix C includes a table describing the studies that CHBRP reviewed (Table C-1) and a table summarizing evidence of effectiveness (Table C-2).

Methodological Considerations

Only two randomized controlled trials (RCTs) on intensive behavioral intervention therapies based on ABA have been published (Sallows and Graupner, 2005; Smith et al., 2000). Neither of these RCTs met CHBRP's criteria for classification as high-quality studies⁷⁹ because they had 24 and 28 participants, respectively. When sample sizes are that small, effects of an intervention are difficult to detect unless they are very large. In addition, the findings of these RCTs 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.

Studies of intensive behavioral intervention therapies for PDD/A have several important methodological limitations. Most studies have limited ability to ascertain whether observed differences in outcomes between groups are due to differences in the treatments provided to them because subjects were not randomly assigned to intervention and comparison groups (Howlin et al., 2009; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow et al., 2012; Warren et al., 2011). 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.

Most studies of intensive behavioral intervention therapies also have small sample sizes and, thus, may not have sufficient statistical power to detect differences between intervention and comparison groups (Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow et al., 2012). In addition, 34 of the 50 studies only assess outcomes immediately following treatment. Seven studies assess outcomes after treatment ends, but their findings are difficult to compare because the time periods range from 1 month to more than 6 years after treatment is completed. (Nine studies do not report when data on outcomes were collected.) Because only a limited number of studies collect data on outcomes posttreatment, there is insufficient evidence

⁷⁹ 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.

to determine whether use of intensive behavioral intervention therapies has benefits that persist throughout childhood and into adulthood.

Moreover, the literature on the effectiveness of intensive behavioral intervention therapies for PDD/A is difficult to synthesize because the children enrolled in these studies differ with regard to age, severity of autism, and the extent of co-occurring mental retardation (Warren et al., 2011). The duration and intensity of treatments vary widely, as do the settings in which treatment is provided and the characteristics of treatments provided to the intervention and comparison groups (Reichow et al., 2012; Warren et al., 2011). Some studies compare more intensive to less intensive ABA-based interventions. Others compare intensive ABA-based interventions to usual treatment, which typically consists of an eclectic mix of interventions.

The outcomes examined by studies of intensive behavioral intervention therapies also differ considerably across studies. Only four outcomes are measured by a plurality of studies: adaptive behavior (i.e., communication, daily living, motor, and social skills); intelligence quotient (IQ); language; and academic placement. Even findings regarding these outcomes cannot always be easily pooled across studies because authors use different measures or scales to collect information on these outcomes (Howlin et al., 2009; Virués-Ortega, 2010). For example, full-scale measures of IQ should not be combined with nonverbal measures of intelligence because children with PDD/A tend to perform better on nonverbal tests of intelligence (e.g., visual-spatial tasks) than tests of other types of intelligence (Eldevik et al., 2009).

Outcomes Assessed

The medical effectiveness review focused on the four outcomes of intensive behavioral intervention therapies for PDD/A that were assessed by a plurality of studies of these interventions: adaptive behavior; IQ; language; and academic placement. Adaptive behavior measures engagement in behaviors that facilitate self-care and interaction with others, such as communication, daily living, motor, and social skills. With regard to language, studies assessed effects of intensive behavioral intervention therapies 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).

Study Findings

Nine meta-analyses and systematic reviews of RCTs and nonrandomized studies regarding the impact of intensive behavioral intervention therapies based on ABA for preschool children were published between 2009 and 2012 (Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow and Wolery, 2009; Reichow et al., 2012; Spreckley and Boyd, 2009; Virués-Ortega, 2010; Warren et al., 2011). Each of these meta-analyses and systematic reviews used different inclusion criteria, resulting in the inclusion of overlapping groups of studies (Table 2). For example, some meta-analyses and systematic reviews only included RCTs and nonrandomized studies with comparison groups, whereas others included pre/post studies that do not include a comparison group. The meta-analyses and systematic reviews also differed with respect to the databases searched and the methods used to pool findings across studies (Eldevik et al., 2009; Makrygianni and Reed, 2010). A total of 42

articles are included in these meta-analyses. CHBRP also reviewed eight individual articles that presented findings from nonrandomized studies with comparison groups and that were published after the studies that informed the meta-analyses and systematic reviews (Eikeseth et al., 2012; Fava et al., 2011; Fernell et al., 2011; Flanagan et al., 2012; Grindle et al., 2012; Kovshoff et al., 2011; Reed et al., 2012; Strauss et al., 2012).

Characteristics of Intensive Behavioral Intervention Therapies Studied

Treatment methods

Most of the intensive behavioral intervention therapies studied incorporated discrete trials training, an ABA-based intervention that was developed by O. Ivar Lovaas and colleagues at the University of California, Los Angeles (Lovaas, 1987).⁸⁰ In discrete trials training, children are taught appropriate behaviors on a one-on-one basis and gradually transitioned to group settings. Treatment is individualized and emphasizes systematic teaching of measurable behaviors, repetition, and structured presentation of tasks. The UCLA/Lovaas intervention was originally provided to children with Autistic Disorder with a mean age of 3 years at the time the study began, for an average of 40 hours per week for 2 or more years. Treatment was provided primarily by student therapists. Parents were trained to assist with treatment.

Some of the interventions that have been studied adhered closely to the original UCLA/Lovaas model. Others treated children for less than 2 years or provided fewer hours of treatment per week. Some interventions also utilized parents to provide treatment under the guidance of trained therapists rather than relying on therapists to deliver the intervention.

One RCT assesses the impact of the Early Start Denver Model, an intensive behavioral intervention therapy for infants and toddlers that integrates techniques based on ABA with techniques based on developmental and relationship-based theories of behavior (Dawson et al., 2010). The RCT compares the Early Start Denver Model to other behavioral interventions commonly available in the community in which the study took place. The intervention was provided for 2 years, a length of time consistent with the duration of the original UCLA/Lovaas intervention.

Personnel delivering interventions

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. Paid personnel who did not have graduate degrees in behavior analysis or a related field were typically supervised by paid personnel with graduate degrees. Some studies compared intensive behavioral intervention therapies provided by paid personnel to similar interventions provided by parents (e.g., Sallows and Graupner, 2005). ***No studies compared intensive behavioral intervention therapies delivered by different configurations of personnel. Thus, the optimal staffing for delivering these interventions is unknown.***

⁸⁰ The principles of ABA have also been used to develop interventions focused on specific challenges faced by persons with PDD/A, such as communication and social skills.

Duration of interventions

Forty-nine articles reported the length of time during which intensive behavioral intervention therapies were provided to children enrolled in the study. The duration of treatment varied widely across studies, ranging from 5 weeks to 4 years. The median duration was 16 months. Most children were treated for 1 to 2 years.

Length of follow-up

Thirty-four of the 50 studies only assessed outcomes immediately following treatment. Seven studies assessed outcomes after treatment ended, but their findings are difficult to compare because the time periods ranged from 1 month to more than 6 years after treatment was completed. Nine studies did not report when data on outcomes were collected.

Control and comparison groups

Among RCTs and nonrandomized studies with comparison groups that assessed intensive behavioral intervention therapies, the treatments received by control or comparison groups varied widely. Some control and comparison groups received less intensive versions of an intensive behavioral intervention therapy provided to the intervention group, whereas others received different therapies. In some cases, a clinic-directed version of an intensive behavioral intervention therapy was compared to a parent-directed version. In others, subjects in the comparison group received an “eclectic intervention” that combined multiple types of treatments.

Populations studied

Table 3 describes the characteristics of the populations enrolled in the 50 articles regarding intensive behavioral intervention therapies (i.e., the 42 articles included in the 9 meta-analyses plus the 8 individual articles). The studies enrolled children ranging in age from 18 months to 9 years. In most studies, the mean age of the children enrolled was between 2 and 5 years.

CHBRP identified no studies regarding effectiveness of intensive behavioral intervention therapies in children younger than 18 months and persons older than 9 years, nor was there direct evidence about these therapies’ effectiveness for persons diagnosed with Asperger’s Disorder, Rett’s Disorder, or Childhood Disintegrative Disorder. *The absence of evidence is not evidence of no effect.* These therapies or less intensive behavioral therapies may be appropriate for some persons with PDD/A who fall outside the populations that have been studied.

The diagnoses of children enrolled varied across the 48 articles that report diagnosis at time of enrollment. Twenty-three studies enrolled only children with Autistic Disorder. Eighteen studies enrolled children with either Autistic Disorder or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Six studies also enrolled children with unspecified PDD/A diagnoses.

Forty of the 50 articles identified by CHBRP report the degree to which children enrolled in the studies have comorbid mental retardation as defined in the *Diagnostic and Statistical Manual for*

*Mental Disorders, Fourth Edition (DSM-IV)–Text Revision (APA, 2000).*⁸¹ Most studies enrolled children whose mean IQ at baseline was within the ranges for Mild and/or Moderate Mental Retardation. One study enrolled children with a mean IQ within the range for Severe Mental Retardation (Smith et al., 1997), and one enrolled children with a mean IQ within the range for Profound Mental Retardation (Matos and Mustaca, 2005). Five studies enrolled children whose mean IQ at enrollment was above the threshold for mental retardation (Anan et al., 2008; Ben-Itzhak et al., 2008; Magiati et al., 2007; Zachor et al., 2007, 2009).

Overall Effects on Outcomes

Findings regarding the effects of intensive behavioral intervention therapies on the four outcomes assessed by a plurality of studies (adaptive behavior, IQ, language, and academic placement) are summarized below.

Adaptive behavior

All nine meta-analyses and systematic reviews and all eight of the individual articles assessed the impact of ABA-based intensive behavioral intervention therapies on adaptive behavior (Eikeseth et al., 2012; Eldevik et al., 2009; Fava et al., 2011; Fernell et al., 2011; Flanagan et al., 2012; Grindle et al., 2012; Howlin et al., 2009; Kovshoff et al., 2011; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reed et al., 2012; Reichow and Wolery, 2009; Reichow et al., 2012; Spreckley and Boyd, 2009; Strauss et al., 2012; Virués-Ortega, 2010; Warren et al., 2011).⁸² The preponderance of evidence from these studies, most of which are of low quality, suggests that these interventions are more effective than the other interventions to which they are compared in improving adaptive behavior.

The only meta-analysis that found no difference in adaptive behavior between intervention and comparison groups (Spreckley and Boyd, 2009) included only three studies. These studies included RCTs conducted by Sallows and Graupner (2005) and Smith and colleagues (2000), plus a quasi-randomized study conducted by Eikeseth and colleagues (2002, 2007). Smith et al. (2000) compared a clinic-directed behavioral intervention therapy that was delivered 25 hours per week for 2 to 3 years to parent training provided 5 hours per week for 3 to 9 months plus 10 to 15 hours of special education per week. Sallows and Graupner (2005) compared clinic-directed and parent-directed behavioral intervention therapies based on ABA that were of similar intensity (37 to 39 hours per week for the clinic-directed intervention vs. 31 to 32 hours for the parent-directed intervention). Eikeseth and colleagues (2002, 2007) compared an intensive behavioral intervention therapy based on ABA with an eclectic intervention of similar intensity (18 to 28 hours per week versus 16 to 29 hours per week).

Although limiting a meta-analysis to RCTs and quasi-randomized studies is generally appropriate, in this case, the pooled effect across the studies may be misleading because the

⁸¹ The DSM-IV classifies persons diagnosed with mental retardation into four categories based on the level of intellectual impairment: Mild Mental Retardation (IQ level 50–55 to 70), Moderate Mental Retardation (IQ level 35–40 to 50–55), Severe Mental Retardation (IQ level 20–25 to 35–40), Profound Mental Retardation (IQ level below 20–25).

⁸² Many of the studies included in the meta-analyses used the Vineland Adaptive Behavior Scales to assess adaptive behavior. These scales assess communication, daily living, motor, and social skills. Scores can be reported as a composite or by scale.

intensity and duration of interventions provided to the intervention and comparison groups in the three studies varied widely. On the other hand, meta-analyses that included studies with weaker designs may have obtained statistically significant findings because they included more studies and/or studies with larger sample sizes and, hence, had greater power to detect statistically significant differences. The meta-analyses that included studies with weaker designs may have also obtained statistically significant findings due to selection bias in the nonrandomized studies. For example, in studies in which parents selected the intervention, selection bias may have occurred because parents' beliefs about what treatments are effective may have influenced their choice and their motivation to reinforce training provided by therapists.

The preponderance of evidence, which comes from low-quality studies, suggests that these intensive behavioral intervention therapies are more effective than the other interventions to which they are compared in improving adaptive behavior.

Intelligence quotient

All nine meta-analyses and systematic reviews also examined the impact of intensive behavioral intervention therapies on IQ as did four of the individual studies (Eldevik et al., 2009; Flanagan et al., 2012; Grindle et al., 2012; Howlin et al., 2009; Kovshoff et al., 2011; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reed et al., 2012; Reichow and Wolery, 2009; Reichow et al., 2012; Spreckley and Boyd, 2009; Virués-Ortega, 2010; Warren et al., 2011). The studies included in these meta-analyses used a variety of instruments to measure IQ.⁸³ The preponderance of evidence from these studies, most of which are of low quality, suggests that intensive behavioral intervention therapies based on ABA are associated with greater increases in IQ than the interventions to which they are compared. Three meta-analyses reported mean differences in IQ scores, which ranged from 11 to 13 points (Howlin et al., 2009; Peters-Scheffer, 2011; Reichow et al., 2012). Five meta-analyses reported standardized effect sizes, statistics that are frequently used to estimate the pooled effect of an intervention across multiple studies. The standardized effect sizes ranged from 0 to 1.3 (Eldevik et al., 2009; Makrygianni and Reed, 2010; Reichow et al., 2012; Spreckley and Boyd, 2009; Virués-Ortega, 2010). One meta-analysis did not present quantitative findings (Reichow and Wolery, 2009). Effect sizes greater than 0.8 are considered large.

The only meta-analysis that found no difference in IQ (Spreckley and Boyd, 2009) included only three studies, the RCTs by Sallows and Graupner (2005) and Smith and colleagues (2000), plus a quasi-randomized study conducted by Eikeseth and colleagues (2002, 2007). As indicated above, the pooled effect across these three studies may be misleading because the intensity and duration of interventions provided to the intervention and comparison groups in the three studies varied widely. On the other hand, meta-analyses that included studies with weaker designs may have obtained statistically significant findings because they included more studies or because selection bias was present in the nonrandomized studies.

It is important to recognize that the reported gains in IQ do not indicate that children who receive intensive behavioral intervention therapies are “cured.” ***Most studies find that the increases in***

⁸³ IQ tests have important limitations for assessing the intelligence of children with Autistic Disorder (Wolery and Garfinkle, 2002). For example, some IQ tests are administered verbally and may require verbal responses, which may be difficult for autistic children who have poor verbal communication.

intelligence were not sufficiently large to enable the children with PDD/A to achieve levels of intellectual and educational functioning similar to peers who do not have PDD/A. Although Lovaas' (1987) initial study of discrete trials training found that 47% of subjects receiving the intervention achieved normal intellectual functioning, no subsequent studies have replicated this finding (Howlin et al., 2009). One explanation for the difference between Lovaas's findings and those of subsequent studies is that Lovaas enrolled children who had a higher average IQ at baseline than children enrolled in some subsequent studies. Some subsequent studies also used more rigorous methods to control for the possible impact of selection bias on their findings.

Nevertheless, any increase in an IQ score is an improvement because IQ scores are adjusted for age. An increase of 5 to 10 points is clinically important, especially for children who have lower IQ scores prior to receiving an intervention.⁸⁴

The preponderance of evidence, most of which comes from low-quality studies, suggests that these intensive behavioral intervention therapies are more effective than the other interventions to which they are compared in increasing IQ, but that increases are not sufficiently large to enable children with PDD/A to function at the same level as peers without PDD/A.

Language skills

Seven meta-analyses and systematic reviews as well as two individual studies assessed the impact of intensive behavioral intervention therapies based on ABA on language skills (Fava et al., 2011; Howlin et al., 2009; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow and Wolery, 2009; Reichow et al., 2012; Spreckley and Boyd, 2009; Strauss et al., 2012; Virués-Ortega, 2010). Some studies assessed effects on general language skills, whereas others examined expressive language (i.e., ability to verbalize needs and wishes) and receptive language (i.e., ability to respond to verbal requests from others) separately.

Findings from studies that have examined the impact of intensive behavioral intervention therapies on language are ambiguous. The two meta-analyses that examined effects on general language skills found that intensive behavioral intervention therapies were more effective than the interventions to which they were compared (Makrygianni and Reed, 2010; Virués-Ortega, 2010). Four of the six meta-analyses and one of the two individual articles that compared the effect of intensive behavioral intervention therapies on receptive language found statistically significant differences favoring ABA-based interventions (Fava et al., 2011; Howlin et al., 2009; Peters-Scheffer et al., 2011; Reichow et al., 2012; Virués-Ortega, 2010), whereas the others did not (Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Strauss et al., 2012). Differences in findings may be related to differences in the number and characteristics of studies included in the analyses.

Two of the five meta-analyses and both of the individual articles that evaluated the impact of intensive behavioral intervention therapies on expressive language found statistically significant differences favoring ABA-based interventions (Fava et al., 2011; Peters-Scheffer et al., 2011; Reichow et al., 2012; Strauss et al., 2012), whereas three meta-analyses found no statistically significant difference in this outcome between children who received these interventions and the

⁸⁴ Personal communication, N. Akshoomoff, PhD, and A. Stahmer, PhD, University of California, San Diego Autism Intervention Research Program, March 2013.

other interventions to which they were compared (Howlin et al., 2009; Reichow and Wolery, 2009; Spreckley and Boyd, 2009).

Findings from studies that have examined the impact of intensive behavioral intervention therapies on language are ambiguous.

Academic placement

Findings from a systematic review of studies that compared the effects on academic placement of intensive behavioral intervention therapies based on ABA to other interventions or less intensive ABA-based interventions are ambiguous (Howlin et al., 2009). Some studies found that children receiving intensive behavioral intervention therapies were more likely to be placed in a mainstream classroom (with or without assistance) than children in comparison groups. For example, the RCT conducted by Smith et al. (2000) found that 4 of the 15 children who received an intensive behavioral intervention therapy were in *unsupported* placements in mainstream classrooms (i.e., did not have an aide), whereas none of the 13 children in the control group had been placed in mainstream classrooms without support. Magliati et al., 2007, reported that 23 of the 28 children who received an intensive behavioral intervention therapy were in *supported* placements in mainstream classrooms, whereas all of the 16 children in the comparison group were placed in special education classes.⁸⁵ However, no study found that the majority of children receiving intensive behavioral intervention therapies were in unsupported placements in mainstream classrooms.⁸⁶ Two studies reported that children receiving either the intensive behavioral intervention therapy or the comparison intervention continued to experience substantial developmental delay following treatment (Eldevik et al., 2006; Smith et al., 1997).

Findings regarding effects of intensive behavioral intervention therapies on academic placement should be interpreted with caution because placement is often affected by factors other than a child's level of disability (Wolery and Garfinkle, 2002). These factors include the extent to which local school officials endorse placement of children with disabilities in "mainstream" classrooms, the policies used to determine placement, and the level of parental influence on placement. In addition, a child's placement may not reflect the level of support he or she needs.

Findings regarding effects of intensive behavioral intervention therapies on academic placement are ambiguous and should be interpreted with caution.

Effects of duration and intensity of intensive behavioral intervention therapies

One meta-analysis used meta-regression analysis to assess the impact of duration and intensity of intensive behavioral intervention therapies on the likelihood of achieving greater improvement in outcomes relative to the treatments to which they were compared (Virués-Ortega, 2010). Duration was defined as the number of weeks of treatment. Intensity was defined as the number of hours of treatment per week. The author found that intensive behavioral intervention therapies that were provided for more hours per week had more impact on adaptive behavior but that gains

⁸⁵ Magliati and colleagues (2007) may have found greater effects on academic placement than most other studies because none of the children enrolled in the study had mental retardation.

⁸⁶ Lovaas (1987) reported that 47% of children who received intensive ABA-based therapy were enrolled in "mainstream" classrooms during first grade. No subsequent study has replicated this rate of success.

in IQ and language skills did not differ by the number of hours of treatment per week. Even for adaptive behavior, the size of the effect of hours of treatment per week was small (standardized effect size = 0.05). Intensive behavioral intervention therapies that provided more weeks of treatment had larger effects on language skills, but not on adaptive behavior and IQ. Once again, the effect size was small (standardized effect size = 0.01)

The preponderance of evidence, most of which comes from low-quality studies, suggests that providing intensive behavioral intervention therapies more weeks or for more hours per week may lead to larger improvements in some outcomes.

Children Most Likely to Benefit From Intensive Behavioral Intervention Therapies

Outcomes for individual children enrolled in studies of intensive behavioral intervention therapies vary widely (Howlin et al., 2009). One explanation may be that the characteristics of children enrolled in the studies differed (see Table 3). As indicated previously, some studies enrolled only children with Autistic Disorder, whereas others also enrolled children with PDD-NOS, a condition associated with less severe disabilities. Similarly, some studies enrolled only children with mild comorbid mental retardation, whereas others enrolled children with Moderate, Severe, or Profound Mental Retardation.

Several meta-analyses attempted to identify the characteristics of children enrolled in the studies who received the greatest benefit from intensive behavioral intervention therapies. Findings from one meta-analysis suggested that children who are younger at initiation of treatment and who have higher IQs and greater adaptive behavior abilities derive greater benefit from these therapies (Howlin et al., 2009). The RCT by Sallows and Graupner (2005) found that children with higher pretreatment scores on instruments measuring IQ, receptive language, verbal and nonverbal imitation, and daily living experienced greater improvement in IQ, language skills, and social skills. By contrast, the RCT by Smith and colleagues (2000) found that IQ at initiation of treatment did not predict treatment outcomes. The authors of one meta-analysis used multivariate meta-regression to examine the impact of pretreatment IQ while holding the child's age at initiation of treatment and the treatment characteristics constant. They concluded that IQ at initiation of treatment was not associated with response to treatment (Reichow and Wolery, 2009). None of the studies examined differences in response to treatment by gender or race/ethnicity.

Evidence as to the characteristics of children most likely to benefit from intensive behavioral intervention therapies is ambiguous.

Harms Associated With Treatment

CHBRP did not identify any studies that assessed whether there are harms associated with intensive behavioral intervention therapies for PDD/A.

Summary of Findings

The literature on intensive behavioral interventions based on ABA has several important limitations. Most studies:

- Do not randomize participants to intervention and comparison groups;
- Have small sample sizes; and
- Only measured outcomes immediately after treatment is complete and, thus, do not provide information about whether improvements evident immediately following treatment persist throughout childhood and into adulthood.

Findings from studies of intensive behavioral intervention therapies based on ABA are difficult to synthesize because the characteristics of intervention and comparison groups vary as do the outcomes assessed.

Study Findings

Characteristics of populations studied

- Nine recent meta-analyses and systematic reviews and eight individual studies published after the searches that informed the meta-analyses and systematic reviews were completed assessed the effectiveness of intensive behavioral intervention therapies based on ABA.
- 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 a graduate degree 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 these therapies' effectiveness 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 study populations.
- Outcomes for individual children enrolled in studies of intensive behavioral intervention therapies vary widely. Findings from studies that attempt to identify the characteristics of children with 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 primarily 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 interventions in improving adaptive behavior (e.g., communication, daily living, motor, and social skills).
- A single RCT of the Early Start Denver Model, an intensive behavioral intervention therapy that integrates ABA-based and developmental and relationship-based approaches to treating PDD/A, found that this model is associated with greater improvement in adaptive behavior relative to other interventions available in the community.
- 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 primarily from low-quality studies, suggested 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 increasing IQ.
- A single RCT of the Early Start Denver Model found that receipt of this intensive behavioral intervention therapy is associated with greater improvement in IQ relative to other interventions available in the community.
- Most studies found that the changes in intelligence are not sufficiently large to enable children to achieve levels of intellectual and educational functioning similar to peers without PDD/A.

Language:

- Findings are ambiguous as to the effect of intensive behavioral intervention therapies based on ABA 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 effects of more intensive versus less intensive ABA-based interventions on language is also ambiguous.

Academic placement:

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

Table 2. Studies of Intensive Behavioral Intervention Therapy for Preschool and Elementary School Children With PDD/A That Are Included in Meta-Analyses and Systematic Reviews Published From 2009 to 2012

Individual Study	Eldevik et al., 2009	Howlin et al., 2009	Reichow and Wolery, 2009	Spreckley and Boyd, 2009	Makrygianni and Reed, 2010	Virués-Ortega, 2010	Peters-Scheffer et al., 2011	Warren et al., 2011	Reichow et al., 2012
Anderson et al., 1987			X		X	X			
Lovaas et al., 1987	X	X	X		X	X			
Harris et al., 1991						X			
Birnbrauer and Leach, 1993	X		X			X			
McEachin et al., 1993				X					
Koegel et al., 1996				X					
Smith et al., 1997	X	X	X		X	X	X		
Jocelyn et al., 1998				X					
Sheinkopf and Siegel, 1998			X	X		X	X		
Weiss, 1999					X	X			
Harris and Handleman, 2000						X			
Luiselli et al., 2000								X	
Smith et al., 2000	X	X	X	X	X	X	X	X	X
Bibby et al., 2001			X			X			
Boyd and Corley, 2001			X						
Mudford et al., 2001								X	
Eikeseth et al., 2002	X	X		X		X	X	X	
Bernard-Opitz et al., 2004				X					
Dillenburger et al., 2004								X	
Beglinger and Smith, 2005								X	
Farrell et al., 2005								X	
Howard et al., 2005	X	X		X	X	X	X	X	X
Matos and Mustaca, 2005						X			
Sallows and Graupner, 2005		X	X	X	X	X	X		
Cohen et al., 2006	X	X	X	X	X	X		X	X
Eldevik et al., 2006	X	X	X	X	X	X	X		
Baker-Ericzen et al., 2007						X			
Ben Itzhak and Zachor, 2007					X	X			

Table 2. Studies of Intensive Behavioral Intervention Therapy for Preschool and Elementary School Children with PDD/A That Are Included in Meta-Analyses and Systematic Reviews Published From 2009 to 2012 (Cont'd)

Individual Study	Eldevik et al., 2009	Howlin et al., 2009	Reichow and Wolery, 2009	Spreckley and Boyd, 2009	Makrygianni and Reed, 2010	Virués-Ortega, 2010	Peters-Scheffer et al., 2011	Warren et al., 2011	Reichow et al., 2012
Eikeseth et al., 2007			X	X		X	X		
Magiati et al., 2007		X	X	X	X	X	X		X
Reed et al., 2007a					X	X	X	X	
Reed et al., 2007b					X	X	X		
Remington et al., 2007	X	X			X	X	X		X
Zachor et al., 2007								X	
Anan et al., 2008						X			
Ben Itzchak et al., 2008						X			
Perry et al., 2008								X	
Eikeseth et al., 2009								X	
Granpeesheh et al., 2009								X	
Hayward et al., 2009								X	
Ben Itzchak and Zachor et al., 2009								X	
Dawson et al., 2010								X	

Sources: Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow et al., 2012; Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Virués-Ortega, 2011; Warren et al., 2011.

Key: PDD/A=pervasive developmental disorder or autism.

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review

Study	No. of Subjects	Age at Entry ⁸⁷	PDD/A Diagnoses	Degree of Mental Retardation at Entry ⁸⁸	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Anderson et al., 1987	14	Mean age=3.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	1 year	Not reported	Undergraduate college students, parents
Lovaas, 1987	59	Mean age=3 years	Autistic Disorder	Mean IQ within ranges for Mild to Moderate Mental Retardation	2 years	Immediately following intervention	Trained student therapists
Harris et al., 1991	28	Mean age=3.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	11 months	Immediately following intervention	Teacher, teaching assistants
Birnbrauer and Leach, 1993	14	Mean age=3 years	Autistic Disorder	Mean IQ at entry was within range for Moderate Mental Retardation	2 years	Immediately following intervention	Undergraduate college students, parents
McEachin et al., 1993	38	Mean age=3 years	Autistic Disorder	Mean IQ within ranges for Mild to Moderate Mental Retardation	2 years	6+ years	Trained student therapists
Koegel et al., 1996	17	Age range=3 to 9 years	Autistic Disorder	Not reported	Not stated	Immediately following intervention	Trained parents
Smith et al., 1997	21	Mean age=3 years	Autistic Disorder, PDD-NOS	Mean IQ at entry was within range for Severe Mental Retardation	≥2 years	1 month to 4 years	Student therapists, project directors, clinic supervisors, and senior therapists
Jocelyn et al., 1998	35	Age range=2 to 5 years	Autistic Disorder, PDD	Mean IQ within range for Mild Mental Retardation	3 months	Immediately following intervention	Parents, child care workers

⁸⁷ Age at entry=age at which a child was enrolled in a study.

⁸⁸ The DSM-IV classifies persons diagnosed with mental retardation into four categories based on the level of intellectual impairment: Mild Mental Retardation (IQ level 50–55 to 70), Moderate Mental Retardation (IQ level 35–40 to 50–55), Severe Mental Retardation (IQ level 20–25 to 35–40), Profound Mental Retardation (IQ level below 20–25).

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review (Cont’d)

Study	No. of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Sheinkopf and Siegel, 1998	22	Mean age=2.5 years	Autistic Disorder, PDD, PDD-NOS	Mean IQ within range for Mild Mental Retardation	16 months	Immediately following intervention	Parents, community-based clinicians, conventional school-based paraprofessional therapists (occupational, speech, etc.)
Weiss, 1999	20	Mean age=3.5 years	Autistic Disorder, PDD-NOS	Not reported	2 years	Immediately following intervention	Trained instructors (college graduates)
Harris and Handleman, 2000	27	Mean age=6 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	Varied across children	4 to 6 years	Teacher in autism only class, teacher in mainstream class
Luiselli et al., 2000	16	Two groups: 1 with mean age=2.63 years and 1 with mean age=3.98 years	Autistic Disorder, PDD-NOS	Not reported	Varied across children	Immediately following intervention	Trained therapists (BA or MA in psychology, early childhood education, or special education)
Smith et al., 2000	28	Mean age=3 years	Autistic Disorder, PDD, PDD-NOS	Mean IQ within ranges for Mild to Moderate Mental Retardation	2 to 3 years	2 to 3 years	Student therapists and parents, parent only
Bibby et al., 2001	22	Mean age=3.5 years	Autistic Disorder, PDD	Mean IQ at entry within range for Moderate Mental Retardation ⁸⁹	7 months	Immediately following intervention	Clinicians, parents
Boyd and Corley, 2001	22	Age range=2 to 4 years	Autistic Disorder, PDD-NOS	68% of subjects had mental retardation of an unspecified level	9 to 36 months (mean=23 months)	Not reported	Trained tutors

⁸⁹ Pre-treatment IQ scores available for only 22 of 66 subjects.

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review (Cont’d)

Study	No. of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Mudford et al., 2001	75	71% started treatment by age 4 years	Autistic Disorder, PDD-NOS, Asperger’s Disorder	Mean IQ within the range for Mild Mental Retardation among children with an IQ <37 (84% of children for whom IQ scores were available) ⁹⁰	Varied across the children studied	Not applicable—did not measure outcomes of treatment	Varied (21%, received consultancy from individuals with UCLA level II qualifications for supervising treatment)
Eikeseth et al., 2002	25	Mean age=5.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	1 year	Immediately following intervention	Teacher, parents, and trained aides
Bernard-Opitz et al., 2004	16	Age range=2 to 3.5 years	Autistic Disorder	Not reported	5 weeks	Immediately following intervention	Graduate student trainers and play coordinators
Dillenburger et al., 2004	22	Long-term group (n=12): 91 months; Short-term group (n=10): 46 months	Autistic Spectrum Disorder	Not reported	Long-term group: (LTG) average of 35.5 months (range 18–72 months); Short-term group: average of 6.1 months (range 2–12 months).	Immediately following intervention	Parents
Beglinger and Smith, 2005	37	Mean age=5.42 years	Autism	Mean IQ within ranges for Mild to Moderate Mental Retardation	26.2 months	Not reported	Project director, supervisor, lead therapist, student therapists, and parents

⁹⁰ Pre-treatment IQ scores were available for only 37 of 75 subjects.

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review (Cont’d)

Study	No. of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Farrell et al., 2005	8	Mean age=6.3 years	Autistic Disorder	Not reported	2 years	Not reported	Parents, lead therapist, team of therapists
Howard et al., 2005	51	Mean age=2.5 years	Autistic Disorder, PDD	Mean IQ within range for Mild Mental Retardation	13 to 14 months	Immediately following intervention	Trained instructional assistants; special education teacher, para-educational aides, speech and language therapists
Matos and Mustaca, 2005	9	Mean age=3.5 years	Autistic Disorder PDD-NOS	Mean IQ within range for Profound Mental Retardation	11 months	Not reported	Therapist
Sallows and Graupner, 2005	23	Mean age=2.5 years	Autistic Disorder	Mean IQ within ranges for Mild to Moderate Mental Retardation	4 years	Immediately following intervention	Clinic therapist, parents
Cohen et al., 2006	42	Mean age=2.5 years	Autistic Disorder, PDD, PDD-NOS	Mean IQ within range for Mild Mental Retardation	3 years	Immediately following intervention	Trained tutors, special education teachers, certified applied behavioral therapists, parents
Eldevik et al., 2006	28	Mean age=4 years	Autistic Disorder	Mean IQ within range for Moderate Mental Retardation	20 months	Immediately following intervention	Trained therapists, teacher aides
Baker-Ericzen et al., 2007	158	Age range=2 to 9 years	Autistic Disorder, PDD-NOS	Not reported	3 months	Immediately following intervention	Therapists (master’s-level developmental specialists or doctoral-level clinical psychologists), parents
Ben Itzhak and Zachor, 2007	25	Mean age=2.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	1 year	Immediately following intervention	Skilled behavioral therapists
Eikeseth et al., 2007	25	Mean age=5.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	2.5 years	Immediately following intervention	Special education teachers, aides

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review (Cont’d)

Study	No. of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Magiati et al., 2007	44	Mean age=3 years	Autistic Disorder, PDD, PDD-NOS	Mean IQ at entry was above the threshold for a diagnosis of mental retardation	2 years	Immediately following intervention	ABA supervisor/consultant, special education teachers
Reed et al., 2007a	27	Mean age=3 years	Not specified but mean IQ below the threshold for Mental Retardation suggests none had Asperger’s Disorder	Mean IQ within range for Mild to Moderate Mental Retardation	9 to 10 months	Immediately following intervention	Trained tutors, trained assistants
Reed et al., 2007b	48	Mean age=3 years	Not specified but mean IQ below the threshold for Mental Retardation suggests none had Asperger’s Disorder	Mean IQ within range for Mild Mental Retardation	9 to 10 months	Not reported	Board-certified behavior analysts, special education specialists
Remington et al., 2007	44	Mean age=3 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	2 years	2 years	Trained tutors, teachers, therapists
Zachor et al., 2007	39	Mean age=2 years	Autistic Disorder, PDD-NOS	Mean IQ at entry was above the threshold for a diagnosis of mental retardation; some children had IQs in the range for Mild to Moderate Mental Retardation	1 year	Immediately following intervention	Behavior analyst, behavior therapists, occupational therapists, speech therapists, special education teacher
Anan et al., 2008	72	Mean age=3.5 years	Autistic Disorder, PDD-NOS	Mean IQ at entry was above the threshold for a diagnosis of mental retardation	3 months	Immediately following intervention	Parents

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review (Cont’d)

Study	No. of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Ben Itzchak, et al., 2008	81	Mean age=2 years	Autistic Disorder	Mean IQ at entry was above the threshold for a diagnosis of mental retardation	1 year	Immediately following intervention	Multidisciplinary team
Perry et al., 2008	332	Mean age=4.5 years	Autistic Disorder, PDD-NOS	Mean IQ at entry within range for Moderate Mental Retardation	Mean 18 months (range from 4 to 47 months)	Usually immediately following intervention	Instructor-therapists (had bachelor’s degrees), senior therapists
Eikeseth et al., 2009	20	Mean age=34.9 months	Autistic Disorder	Mean IQ within ranges for Mild to Moderate Mental Retardation	14 months	Not reported	Therapists/tutors, consultants/supervisors, parents
Granpeesheh et al., 2009	38	Mean age=40 months	Autistic Disorder	Mean IQ at entry was above the threshold for a diagnosis of mental retardation			
Hayward et al., 2009	44	Mean age=3 years	Autistic Disorder	Mean IQ within range for Mild to Moderate Mental Retardation	1 year	Immediately following intervention	Parents, programme consultant, senior tutor, two to five tutors
Ben Itzchak and Zachor et al., 2009	39	Comparison group: 28.8 months, Intervention group: 27.7 months	Autistic Disorder, PDD-NOS	Mean IQ at entry was above the threshold for a diagnosis of mental retardation	1 year	Immediately following intervention	Trained therapists, behavior analyst, special education teacher, occupational therapists, speech therapists
Dawson et al., 2010	48	Age range=1.5 to 2.5 years	Autistic Disorder, PDD-NOS	Mean IQ within range for Mild Mental Retardation	2 years	2 years	Trained therapists and parents, community providers
Fava et al., 2011	22	Age range=26 to 81 months	Autistic Disorder, PDD-NOS	Not reported clearly	6 months	Immediately following treatment	Trained staff, parents, trained therapists, supervisor
Fernell et al., 2011	198	Age range=1.5 to 4.5 years	Autism Spectrum Disorder	37% had an IQ at or below the threshold for Mild Mental Retardation	2 years	Immediately following intervention	Preschool resource assistants, parents, trained preschool teachers, nurses, and personnel, highly skilled ABA specialists

Table 3. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in CHBRP’s Review (Cont’d)

Study	No. of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up After Treatment	Personnel Providing Intervention
Kovshoff et al., 2011	41	Age range=2.5 to 3.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	2 years	2 years	Team employed by university, professional ABA consultants, parents, trained therapists
Eikeseth et al., 2012	59	Age range=3 to 7.3 years	Autistic Disorder	Not reported	1 year	Immediately following intervention	Trained therapists, school staff members, supervising psychologists, parents, other significant adults
Flanagan et al., 2012	122	Mean age=43 months intervention, 43 months comparison	Autistic Disorder, PDD-NOS	Mean IQ within ranges for Mild to Moderate Mental Retardation	Varied across children: mean=28 months in intervention, mean=17 months in control	Immediately following intervention	Service professionals, treatment staff, parents
Grindle et al., 2012	26	Age range=43 to 72 months	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	2 years	Immediately following intervention	Trained therapists, consultant behavior analyst, parents, senior staff
Reed et al., 2012	66	Age range=2.5 to 4 years	Autistic Disorder, PDD-NOS	Mean IQ within range for Mild or Moderate Mental Retardation	9 months	Immediately following intervention	Behavioral analysts, teachers, trained supervisors, trained tutors, parents
Strauss et al., 2012	44	Age range=26 to 81 months	Autistic Disorder, PDD-NOS	Not reported clearly	6 months	Immediately following intervention	Centre staff, parents, therapists, supervisors

Sources: Anan et al., 2008; Anderson et al., 1987; Baker-Ericzen et al., 2007; Beglinger and Smith, 2005; Ben Itzchak and Zachor, 2007, 2009; Ben Itzchak et al., 2008; Bernard-Opitz et al., 2004; Bibby et al., 2001; Birnbrauer and Leach, 1993; Boyd and Corley, 2001; Cohen et al., 2006; Dawson et al., 2010; Dillenburger et al., 2004; Eikeseth et al., 2002, 2007, 2009, 2012; Eldevik et al., 2006; Farrell et al., 2005; Fava et al., 2011; Fernell et al., 2011; Flanagan et al., 2012; Granpeesheh et al., 2009; Grindle et al., 2012; Harris and Handleman, 2000; Harris et al., 1991; Hayward et al., 2009; Howard et al., 2005; Jocelyn et al., 1998; Koegel et al., 1996; Kovshoff et al., 2011; Lovaas, 1987; Luiselli et al., 2000; Magiati et al., 2007; Matos and Mustaca, 2005; McEachin et al. 1993; Mudford et al., 2001; Perry et al., 2008; Reed et al., 2007a, 2007b, 2012; Remington et al., 2007; Sallows and Graupner, 2005; Sheinkopf and Siegel, 1998; Smith et al., 1997, 2000; Strauss et al., 2012; Weiss, 1999; Zachor et al., 2007.

BENEFIT COVERAGE, UTILIZATION, AND COST IMPACTS

Senate Bill (SB) 126 extends the sunset date of California’s existing behavioral health treatment mandate that requires coverage for intensive behavioral intervention therapies for pervasive developmental disorder or autism (PDD/A) from July 2014 to July 2019. SB 126 would affect benefit coverage for enrollees in California Department of Managed Health Care (DMHC)-regulated health plans and California Department of Insurance (CDI)-regulated policies subject to the proposed benefit mandate. This includes approximately 18.5 million enrollees, including 4.0 million children aged 0–14 years, the age range in which most intensive behavioral intervention therapies are initiated. This number excludes enrollees in Medi-Cal Managed Care and the California Public Employees’ Retirement System (CalPERS), as these groups would not be subject to the mandate.

The California Health Benefits Review Program (CHBRP) estimates that approximately 127,000 enrollees in DMHC-regulated plans and CDI-regulated policies subject to SB 126 are diagnosed with PDD/A. PDD/A includes the five disorders: Autistic Disorder; Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS); Rett’s Disorder; Asperger’s Disorder; and Childhood Disintegrative Disorder.

This section presents the current, or baseline, costs and benefit coverage related to intensive behavioral intervention therapies for PDD/A, and the estimated utilization, cost, and benefit coverage impacts if SB 126 is enacted. For further details on the underlying data sources and methods, please see Appendix D at the end of this document.

Current (Baseline) Benefit Coverage, Utilization, and Cost

Current Coverage of the Mandated Benefit

CHBRP conducts a bill-specific coverage survey of California’s largest health plans and insurers. Responses to this survey represent 80.7% of enrollees in the privately funded, CDI-regulated market and 88.1% of enrollees in the privately funded, DMHC-regulated market. Combined, responses to this survey represent 86.3% of enrollees in the privately funded market subject to state mandates. Based on this bill-specific coverage survey, 100% of enrollees in DMHC-regulated plans and CDI-regulated policies subject to SB 126 have coverage for intensive behavioral intervention therapies as treatment for PDD/A.

The existing behavioral health treatment mandate (for which SB 126 extends the sunset date) requires coverage for intensive behavioral intervention therapies for PDD/A, as does the current California mental health parity law.^{91,92} Therefore, two existing state laws require coverage for intensive behavioral intervention therapies for PDD/A for DMHC-regulated plans and CDI regulated policies subject to SB 126. On the basis of existing law and CHBRP’s survey of health plans and insurers, CHBRP estimates that 100% of enrollees whose health insurance would be

⁹¹ H&SC Section 1374.72; IC Section 10144.5.

⁹² Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

subject to SB 126 currently have coverage for intensive behavioral intervention therapies for PDD/A.

As noted in the *Introduction* and above, this analysis excludes Medi-Cal Managed Care and CalPERS because those plans are not subject to SB 126.

Currently, 100% of enrollees in DMHC-regulated plans and CDI-regulated policies subject to SB 126 have coverage for intensive behavioral intervention therapies for PDD/A under two existing state laws.

Current Utilization Levels

Of the estimated 127,000 enrollees diagnosed with PDD/A in DMHC-regulated plans or CDI-regulated policies subject to SB 126, CHBRP estimates that 12,700 currently use intensive behavioral intervention therapies. CHBRP assumes age-specific utilization rates of intensive behavioral intervention therapy for enrollees with PDD/A (see Appendix D). The age-specific utilization rates are based on a study by Thomas et al. (2007) that estimated the percent of families who use intensive behavioral intervention therapies (applied behavior analysis, Lovaas, Denver Early Start Model) alone or in combination with other intensive behavioral intervention or non-intensive behavioral intervention approaches. This study sample consists of a self-selected sample (98% of whom were insured at the time of the survey) of 383 families with a child aged 11 years and younger with Autistic Disorder residing in North Carolina in 2003–2005. North Carolina is widely considered to have a comprehensive service system for young children with ASD. Therefore, the utilization of intensive behavioral intervention therapies used in the cost model may be an upper bound estimate. CHBRP assumes minimal or no utilization after the age of 14, based on content expert input and a study by Ganz in 2007.

For this analysis, utilization of intensive behavioral intervention therapies is measured as the number of hours per week times the number of weeks in a year. The American Academy of Pediatrics' 2007 guidelines recommend intensive behavioral intervention therapies for PDD/A for 25 hours a week (Myers and Johnson, 2007), but does not provide age-specific guidelines or duration by PDD/A subtypes. Assumed utilization (hours per week) by age group and by PDD/A subtype were developed based on the academic literature and content expert opinion (see Appendix D).

Current Average Annual Cost of Intensive Behavioral Intervention Therapy

There is no definitive estimate of annual cost of intensive behavioral intervention therapies for several reasons: intensive behavioral intervention therapies are either not covered at all or have been just recently covered as a health benefit, and the literature on the cost of services for PDD/A examines cost by broad service delivery benefits (i.e., inpatient, outpatient, pharmacy) (Croen et al., 2006; Flanders et al., 2007; Leslie and Martin, 2007; Liptak et al. 2006; Mandell et al., 2006; Peng et al., 2009; Wang and Leslie, 2010).

CHBRP's estimate of average annual cost is based on the weighted average of annual total hours for intensive behavioral intervention therapies across age groups and across PDD/A diagnostic

subtype (see Appendix D), multiplied by an estimated hourly cost for intensive behavioral intervention therapies in California. CHBRP estimates the weighted average of annual total hours to be 600 (15 hours per week multiplied by 40 weeks per year). CHBRP estimates the hourly cost for intensive behavioral intervention therapies to be \$90. CHBRP estimated this average hourly cost of intensive behavioral intervention therapies in California based on the 2008 Annual Commercial MarketScan claims data for California, trended forward to 2014. Taken together, CHBRP estimates the annual cost of intensive behavioral intervention therapy for a single child to be \$54,000. This is slightly higher than the published national estimates of \$33,000 per year for the 3- to 7-year age group in 2003 U.S. dollars (approximately \$42,000 in 2012 dollars) (Ganz, 2007), but lower than estimated total cost from a Colorado report to its General Assembly which estimates that, in 2009, the “total cost for families for early intensive behavior analytic treatment supervised at the appropriate level is between \$65,400–\$72,720 annually” (Colorado, 2009). This estimate is higher than CHBRP’s estimate because it may have focused only on younger age groups (where utilization is greater than for older age groups), whereas CHBRP models utilization for children and young adults. Current annual expenditures for intensive behavioral intervention therapies among enrollees in health plans subject to SB 126 is estimated to be \$686 million.

Current (Baseline) Premiums and Expenditures

Table 4 (at the end of this section) presents per member per month (PMPM) estimates for premiums and expenditures by market segment.

The Extent to Which Costs Resulting From Lack of Coverage Are Shifted to Other Payers, Including Both Public and Private Entities

Enrollees in DMHC-regulated plans and CDI-regulated policies that would be subject to SB 126 may receive intensive behavioral intervention therapies paid for by families, charities, public programs (including the California Department of Developmental Services and the California Department of Education), or other sources. Although some overlap in services seems likely, as noted in the *Introduction*, CHBRP is unable to quantify the extent to which the public programs provide services that are covered by DMHC-regulated plans and CDI-regulated policies.

Public Demand for Coverage

Considering the criteria specified by CHBRP’s authorizing statute, CHBRP reviews public demand for benefits relevant to a proposed mandate in two ways. CHBRP:

- Considers the bargaining history of organized labor; and
- Compares the benefits provided by self-insured health plans or policies (which are not regulated by DMHC or CDI and so not subject to state-level mandates) with the benefits that are provided by plans or policies that would be subject to the mandate.

Treatment of autism spectrum disorders under terms and conditions in parity with terms and conditions for other covered benefits was a covered benefit for the members of at least one large union in 2011.⁹³

Among publicly funded self-insured health insurance policies, the Preferred Provider Organization (PPO) plans offered by CalPERS currently have the largest number of enrollees. The CalPERS PPOs do not currently provide benefit coverage for intensive behavioral intervention therapies as a treatment for PDD/A.

To further investigate public demand, CHBRP used the bill-specific coverage survey to ask carriers who act as third-party administrators for (non-CalPERS) self-insured group health insurance programs whether the relevant benefit coverage differed from what is offered in group market plans or policies that would be subject to the mandate. The responses indicated that currently, there is a range of coverage for intensive behavioral intervention therapies in the self-insured group health insurance programs for which they act as third-party administrators. Coverage ranged from no coverage for intensive behavioral intervention therapies to coverage for intensive behavioral intervention therapies similar to that required under the existing behavioral health treatment mandate.

Given the varying coverage for intensive behavioral intervention therapies among self-insured plans and the response from large unions, CHBRP concludes that there is some public demand for coverage of intensive behavioral intervention therapies as treatment for PDD/A.

Impacts of Mandated Benefit Coverage

The existing behavioral health treatment mandate (for which SB 126 extends the sunset date) requires coverage for intensive behavioral intervention therapies for PDD/A, as does the current California mental health parity law.^{94,95} Therefore, two existing state laws require coverage for intensive behavioral intervention therapies for PDD/A for DMHC-regulated plans and CDI-regulated policies subject to SB 126, and CHBRP estimates that 100% of enrollees whose health insurance would be subject to SB 126 currently have coverage for intensive behavioral intervention therapies for PDD/A.

How Would Changes in Benefit Coverage Related to the Mandate Affect the Availability of the Newly Covered Treatment/Service, the Health Benefit of the Newly Covered Treatment/Service, and the Per-Unit Cost?

Impact on access and health treatment/service availability

CHBRP does not predict changes in supply or health benefits of intensive behavioral intervention therapies due to SB 126. SB 126 is not expected to change access to intensive behavioral intervention therapies among enrollees with PDD/A in DMHC-regulated plans or CDI-regulated policies.

⁹³ Personal communication, S. Flocks, California Labor Federation, March 2011.

⁹⁴ H&SC Section 1374.72; IC Section 10144.5.

⁹⁵ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

Impact on the health benefit of the newly covered treatment/service

SB 126 would not be expected to change coverage of intensive behavioral intervention therapies since CHBRP estimates that 100% of enrollees in DMHC-regulated plans and CDI-regulated policies subject to SB 126 already have coverage.

Impact on annual cost

CHBRP estimates no measurable effects on annual cost of intensive behavioral intervention therapies since no changes in coverage are anticipated as a result of this mandate.

How Would Utilization Change As a Result of the Mandate?

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

To What Extent Would the Mandate Affect Administrative and Other Expenses?

SB 126 would not be likely to increase administrative costs because 100% of enrollees diagnosed with PDD/A in DMHC-regulated plans and CDI-regulated policies subject to SB 126 already have coverage for intensive behavioral intervention therapies.

Impact of the Mandate on Total Health Care Costs

Changes in total expenditures

SB 126 would not be expected to increase total expenditures of employees with DMHC-regulated plans or CDI-regulated policies. Likewise, SB 126 would not be expected to increase total expenditures of employers in the small-group, large-group, or individual markets.

Potential cost offsets or savings in the short term

SB 126 would not be expected to change coverage of intensive behavioral intervention therapies by a measurable amount because 100% of enrollees in DMHC-regulated plans and CDI-regulated policies subject to the mandate are estimated to be covered. Since no changes in the coverage of intensive behavioral intervention therapies are expected, no cost offsets or savings are expected in the short term.

Impacts on long-term costs

SB 126 would not change PMPM premiums or total expenditures of employers and employees with DMHC-regulated health plans or CDI-regulated health policies. Since no changes in the coverage of intensive behavioral intervention therapies would be expected, no cost offsets or effects on long-term costs are expected.

Impacts for Each Category of Payer Resulting From the Benefit Mandate

Changes in expenditures and PMPM amounts by payer category

SB 126 would not be expected to increase total expenditures and PMPM premiums in the large-group, small-group, or individual markets for DMHC-regulated plans or CDI-regulated policies.

Impacts on the Uninsured and Public Programs as a Result of the Cost Impacts of the Mandate

Changes in the number of uninsured persons as a result of premium increases

Since SB 126 would not be expected to lead to premium increases, CHBRP estimates no measurable loss of health insurance coverage as a result of SB 126.

Impact on public programs as a result of premium increases

Public programs are exempt from SB 126.

Table 4. Baseline Per Member Per Month Premiums and Total Expenditures by Market Segment, California, 2014

	DMHC-Regulated							CDI-Regulated			TOTAL
	Privately Funded Plans (by Market) (a)			Cal-PERS HMOs (b)	Medi-Cal Managed Care Plans			Privately Funded Plans (by Market) (a)			
	Large Group	Small Group	Individual		65 and Over (c)	Under 65	Medi-Cal / Formerly Healthy Families Program (d)	Large Group	Small Group	Individual	
Total enrollees in plans/policies subject to state Mandates (e)	11,289,000	2,479,000	1,029,000	854,000	688,000	5,203,000	626,000	539,000	1,315,000	1,877,000	25,899,000
Total enrollees in plans/policies subject to SB 126	11,289,000	2,479,000	1,029,000	0	0	0	0	539,000	1,315,000	1,877,000	18,528,000
Average portion of premium paid by Employer	\$437.53	\$313.63	\$0.00	\$391.90	\$279.00	\$163.00	\$88.83	\$483.35	\$421.89	\$0.00	\$95,549,186,000
Average portion of premium paid by Employee	\$83.30	\$169.52	\$546.88	\$97.98	\$0.00	\$0.00	\$8.79	\$135.14	\$190.22	\$305.75	\$34,912,666,000
Total Premium	\$520.83	\$483.15	\$546.88	\$489.88	\$279.00	\$163.00	\$97.62	\$618.49	\$612.11	\$305.75	\$130,461,851,000
Enrollee expenses for covered benefits (Deductibles, copays, etc.)	\$28.54	\$46.99	\$109.38	\$25.99	\$0.00	\$0.00	\$4.51	\$87.22	\$209.80	\$163.07	\$14,462,198,000
Enrollee expenses for benefits not covered (f)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0
Total Expenditures	\$549.37	\$530.15	\$656.26	\$515.87	\$279.00	\$163.00	\$102.13	\$705.72	\$821.91	\$468.82	\$144,924,050,000

Source: California Health Benefits Review Program, 2013.

Note: (a) Includes enrollees with grandfathered and nongrandfathered health insurance, inside and outside the exchange.

(b) As of September 30, 2012, 57.5%, or 469,000, CalPERS members were state retirees, state employees, or their dependents. CHBRP assumes the same ratio for 2014.

(c) Medi-Cal Managed Care Plan expenditures for members over 65 include those who also have Medicare coverage.

(d) Children in Healthy Families, California's CHIP, will be moved into Medi-Cal Managed Care by January 1, 2014, as part of the 2012–2013 budget.

(e) This population includes both persons who obtain health insurance using private funds (group and individual) and through public funds (e.g., CalPERS HMOs, Medi-Cal Managed Care Plans). Only those enrolled in health plans or policies regulated by the DMHC or CDI are included. Population includes all enrollees in state-regulated plans or policies aged 0 to 64 years, and enrollees 65 years or older covered by employer-sponsored health insurance.

(f) Includes only those expenses that are paid directly by enrollees or other sources to providers for services related to the mandated benefit that are not currently covered by insurance. This only includes those expenses that will be newly covered, postmandate. Other components of expenditures in this table include all health care services covered by insurance.

Key: CalPERS HMOs=California Public Employees' Retirement System Health Maintenance Organizations; CDI=California Department of Insurance; DMHC=Department of Managed Health Care.

PUBLIC HEALTH IMPACTS

Senate Bill (SB) 126 extends the sunset date of California's existing behavioral health treatment mandate that requires coverage for intensive behavioral intervention therapies for pervasive developmental disorder or autism (PDD/A) from July 2014 to July 2019. Current California mental health parity law⁹⁶ also requires coverage of intensive behavioral intervention therapies for persons with PDD/A⁹⁷ for most California Department of Managed Health Care (DMHC)-regulated plans and California Department of Insurance (CDI)-regulated policies.⁹⁸

PDD/A is a chronic condition for which there is no known cure. Intensive behavioral intervention therapies focus on ameliorating a variety of symptoms common to persons diagnosed with PDD/A. The measurable public health impacts most relevant to SB 126 include changes in intelligence quotient (IQ), language skills, and adaptive behaviors; academic placement in mainstream classrooms; economic loss, including lost productivity of persons diagnosed with PDD/A and their family members; and financial burdens resulting from expenses for noncovered services or treatments.

As described in the *Medical Effectiveness* section, the preponderance of evidence is weak (due to low-quality studies), but does indicate that as compared with usual treatment, intensive behavioral intervention therapies improve adaptive behaviors and IQ (although changes in IQ were not large enough to enable the majority of children with PDD/A to achieve levels of intellectual and educational functioning similar to peers without PDD/A). The evidence is ambiguous with regard to improvements in language and academic placement. Additionally, the California Health Benefits Review Program's (CHBRP's) most recent literature search found no evidence to suggest that harms result from intensive behavioral intervention therapies used by persons with PDD/A.

Estimated Public Health Outcomes

Although evidence shows intensive behavioral intervention therapies to be somewhat medically effective, **CHBRP concludes that passage of SB 126 would produce no overall public health impact due to no measureable change in coverage or utilization. This is because coverage for this therapy is currently required under both the existing behavioral health treatment mandate and the current California mental health parity law.** Additionally, CHBRP estimates SB 126 would have no impact on possible gender and racial/ethnic disparities in health outcomes, economic loss, and no measurable impact on long-term health outcomes because it would neither increase coverage nor utilization.

⁹⁶ H&SC Section 1374.72; IC Section 10144.5.

⁹⁷ Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

⁹⁸ 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).

APPENDICES

Appendix A: Text of Bill Analyzed

On January 23, 2013 the Senate Committee on Health requested that CHBRP analyze SB 126.

SENATE BILL 126

Introduced by Senator Steinberg

JANUARY 22, 2013

An act to amend Section 1374.73 of the Health and Safety Code, and to amend Sections 10144.51 and 10144.52 of the Insurance Code, relating to health care coverage.

LEGISLATIVE COUNSEL'S DIGEST

SB 126, as introduced, Steinberg. Health care coverage: pervasive developmental disorder or autism.

Existing law provides for the licensure and regulation of health care service plans by the Department of Managed Health Care. Existing law provides for the regulation of health insurers by the Department of Insurance. Existing law requires health care service plan contracts and health insurance policies to provide benefits for specified conditions, including coverage for behavioral health treatment, as defined, for pervasive developmental disorder or autism, except as specified. A willful violation of these provisions with respect to health care service plans is a crime. These provisions are inoperative on July 1, 2014, and are repealed on January 1, 2015.

This bill would extend the operation of these provisions until July 1, 2019, and would repeal these provisions on January 1, 2020. By extending the operation of provisions establishing crimes, the bill would impose a state-mandated local program.

The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act for a specified reason.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: yes.

THE PEOPLE OF THE STATE OF CALIFORNIA DO ENACT AS FOLLOWS:

SECTION 1. Section 1374.73 of the Health and Safety Code is amended to read:

1374.73. (a) (1) Every health care service plan contract that provides hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism no later than July 1, 2012. The coverage shall be provided in the same manner and shall be subject to the same requirements as provided in Section 1374.72.

(2) Notwithstanding paragraph (1), as of the date that proposed final rulemaking for essential health benefits is issued, this section does not require any benefits to be provided that exceed the essential health benefits that all health plans will be required by federal regulations to provide under Section 1302(b) of the federal Patient Protection and Affordable Care Act (Public Law 111-148), as amended by the federal Health Care and Education Reconciliation Act of 2010 (Public Law 111-152).

(3) This section shall not affect services for which an individual is eligible pursuant to Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code or Title 14 (commencing with Section 95000) of the Government Code.

(4) This section shall not affect or reduce any obligation to provide services under an individualized education program, as defined in Section 56032 of the Education Code, or an ~~individualized~~ *individual* service plan, as described in Section 5600.4 of the Welfare and Institutions Code, or under the Individuals with Disabilities Education Act (20 U.S.C. Sec. 1400, et seq.) and its implementing regulations.

(b) Every health care service plan subject to this section shall maintain an adequate network that includes qualified autism service providers who supervise and employ qualified autism service professionals or paraprofessionals who provide and administer behavioral health treatment. Nothing shall prevent a health care service plan from selectively contracting with providers within these requirements.

(c) For the purposes of this section, the following definitions shall apply:

(1) "Behavioral health treatment" means 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 and that

meet all of the following criteria:

(A) The treatment is prescribed by a physician and surgeon licensed pursuant to Chapter 5 (commencing with Section 2000) of, or is developed by a psychologist licensed pursuant to Chapter 6.6 (commencing with Section 2900) of, Division 2 of the Business and Professions Code.

(B) The treatment is provided under a treatment plan prescribed by a qualified autism service provider and is administered by one of the following:

- (i) A qualified autism service provider.
- (ii) A qualified autism service professional supervised and employed by the qualified autism service provider.
- (iii) A qualified autism service paraprofessional supervised and employed by a qualified autism service provider.

(C) The treatment plan has measurable goals over a specific timeline that is developed and approved by the qualified autism service provider for the specific patient being treated. The treatment plan shall be reviewed no less than once every six months by the qualified autism service provider and modified whenever appropriate, and shall be consistent with Section 4686.2 of the Welfare and Institutions Code pursuant to which the qualified autism service provider does all of the following:

- (i) Describes the patient's behavioral health impairments to be treated.
- (ii) Designs an intervention plan that includes the service type, number of hours, and parent participation needed to achieve the plan's goal and objectives, and the frequency at which the patient's progress is evaluated and reported.
- (iii) Provides intervention plans that utilize evidence-based practices, with demonstrated clinical efficacy in treating pervasive developmental disorder or autism.
- (iv) Discontinues intensive behavioral intervention services when the treatment goals and objectives are achieved or no longer appropriate.

(D) The treatment plan is not used for purposes of providing or for the reimbursement of respite, day care, or educational services and is not used to reimburse a parent for participating in the treatment program. The treatment plan shall be made available to the health care service plan upon request.

(2) "Pervasive developmental disorder or autism" shall have the same meaning and interpretation as used in Section 1374.72.

(3) "Qualified autism service provider" means either of the following:

(A) A person, entity, or group that is certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies, and

who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the person, entity, or group that is nationally certified.

(B) A person licensed as a physician and surgeon, physical therapist, occupational therapist, psychologist, marriage and family therapist, educational psychologist, clinical social worker, professional clinical counselor, speech-language pathologist, or audiologist pursuant to Division 2 (commencing with Section 500) of the Business and Professions Code, who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the licensee.

(4) "Qualified autism service professional" means an individual who meets all of the following criteria:

(A) Provides behavioral health treatment.

(B) Is employed and supervised by a qualified autism service provider.

(C) Provides treatment pursuant to a treatment plan developed and approved by the qualified autism service provider.

(D) Is a behavioral service provider approved as a vendor by a California regional center to provide services as an Associate Behavior Analyst, Behavior Analyst, Behavior Management Assistant, Behavior Management Consultant, or Behavior Management Program as defined in Section 54342 of Title 17 of the California Code of Regulations.

(E) Has training and experience in providing services for pervasive developmental disorder or autism pursuant to Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code or Title 14 (commencing with Section 95000) of the Government Code.

(5) "Qualified autism service paraprofessional" means an unlicensed and uncertified individual who meets all of the following criteria:

(A) Is employed and supervised by a qualified autism service provider.

(B) Provides treatment and implements services pursuant to a treatment plan developed and approved by the qualified autism service provider.

(C) Meets the criteria set forth in the regulations adopted pursuant to Section 4686.3 of the Welfare and Institutions Code.

(D) Has adequate education, training, and experience, as certified by a qualified autism service provider.

(d) This section shall not apply to the following:

(1) A specialized health care service plan that does not deliver mental health or behavioral health services to enrollees.

(2) A health care service plan contract in the Medi-Cal program

(Chapter 7 (commencing with Section 14000) of Part 3 of Division 9 of the Welfare and Institutions Code).

(3) A health care service plan contract in the Healthy Families Program (Part 6.2 (commencing with Section 12693) of Division 2 of the Insurance Code).

(4) A health care benefit plan or contract entered into with the Board of Administration of the Public Employees' Retirement System pursuant to the Public Employees' Medical and Hospital Care Act (Part 5 (commencing with Section 22750) of Division 5 of Title 2 of the Government Code).

(e) Nothing in this section shall be construed to limit the obligation to provide services under Section 1374.72.

(f) As provided in Section 1374.72 and in paragraph (1) of subdivision (a), in the provision of benefits required by this section, a health care service plan may utilize case management, network providers, utilization review techniques, prior authorization, copayments, or other cost sharing.

(g) This section shall become inoperative on July 1, ~~2014~~ 2019 , and, as of January 1, ~~2015~~ 2020 , is repealed, unless a later enacted statute, that becomes operative on or before January 1, ~~2015~~ 2020 , deletes or extends the dates on which it becomes inoperative and is repealed.

SEC. 2. Section 10144.51 of the Insurance Code is amended to read:

10144.51. (a) (1) Every health insurance policy shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism no later than July 1, 2012. The coverage shall be provided in the same manner and shall be subject to the same requirements as provided in Section 10144.5.

(2) Notwithstanding paragraph (1), as of the date that proposed final rulemaking for essential health benefits is issued, this section does not require any benefits to be provided that exceed the essential health benefits that all health insurers will be required by federal regulations to provide under Section 1302(b) of the federal Patient Protection and Affordable Care Act ~~(P.L.~~

Public Law 111-148), as amended by the federal Health Care and Education Reconciliation Act of 2010 ~~(P.L.~~ *Public Law* 111-152).

(3) This section shall not affect services for which an individual is eligible pursuant to Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code or Title 14 (commencing with Section 95000) of the Government Code.

(4) This section shall not affect or reduce any obligation to provide services under an individualized education program, as defined in Section 56032 of the Education Code, or an

~~individualized~~ *individual* service plan, as described in Section 5600.4 of the Welfare and Institutions Code, or under the Individuals with Disabilities Education Act (20 U.S.C. Sec. 1400 et seq.) and its implementing regulations.

(b) Pursuant to Article 6 (commencing with Section 2240) of Title 10 of the California Code of Regulations, every health insurer subject to this section shall maintain an adequate network that includes qualified autism service providers who supervise and employ qualified autism service professionals or paraprofessionals who provide and administer behavioral health treatment. Nothing shall prevent a health insurer from selectively contracting with providers within these requirements.

(c) For the purposes of this section, the following definitions shall apply:

(1) "Behavioral health treatment" means 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, and that meet all of the following criteria:

(A) The treatment is prescribed by a physician and surgeon licensed pursuant to Chapter 5 (commencing with Section 2000) of, or is developed by a psychologist licensed pursuant to Chapter 6.6 (commencing with Section 2900) of, Division 2 of the Business and Professions Code.

(B) The treatment is provided under a treatment plan prescribed by a qualified autism service provider and is administered by one of the following:

- (i) A qualified autism service provider.
- (ii) A qualified autism service professional supervised and employed by the qualified autism service provider.
- (iii) A qualified autism service paraprofessional supervised and employed by a qualified autism service provider.

(C) The treatment plan has measurable goals over a specific timeline that is developed and approved by the qualified autism service provider for the specific patient being treated. The treatment plan shall be reviewed no less than once every six months by the qualified autism service provider and modified whenever appropriate, and shall be consistent with Section 4686.2 of the Welfare and Institutions Code pursuant to which the qualified autism service provider does all of the following:

- (i) Describes the patient's behavioral health impairments to be treated.
- (ii) Designs an intervention plan that includes the service type, number of hours, and parent participation needed to achieve the plan's goal and objectives, and the frequency at which the patient's

progress is evaluated and reported.

(iii) Provides intervention plans that utilize evidence-based practices, with demonstrated clinical efficacy in treating pervasive developmental disorder or autism.

(iv) Discontinues intensive behavioral intervention services when the treatment goals and objectives are achieved or no longer appropriate.

(D) The treatment plan is not used for purposes of providing or for the reimbursement of respite, day care, or educational services and is not used to reimburse a parent for participating in the treatment program. The treatment plan shall be made available to the insurer upon request.

(2) "Pervasive developmental disorder or autism" shall have the same meaning and interpretation as used in Section 10144.5.

(3) "Qualified autism service provider" means either of the following:

(A) A person, entity, or group that is certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies, and who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the person, entity, or group that is nationally certified.

(B) A person licensed as a physician and surgeon, physical therapist, occupational therapist, psychologist, marriage and family therapist, educational psychologist, clinical social worker, professional clinical counselor, speech-language pathologist, or audiologist pursuant to Division 2 (commencing with Section 500) of the Business and Professions Code, who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the licensee.

(4) "Qualified autism service professional" means an individual who meets all of the following criteria:

(A) Provides behavioral health treatment.

(B) Is employed and supervised by a qualified autism service provider.

(C) Provides treatment pursuant to a treatment plan developed and approved by the qualified autism service provider.

(D) Is a behavioral service provider approved as a vendor by a California regional center to provide services as an Associate Behavior Analyst, Behavior Analyst, Behavior Management Assistant, Behavior Management Consultant, or Behavior Management Program as defined in Section 54342 of Title 17 of the California Code of Regulations.

(E) Has training and experience in providing services for

pervasive developmental disorder or autism pursuant to Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code or Title 14 (commencing with Section 95000) of the Government Code.

(5) "Qualified autism service paraprofessional" means an unlicensed and uncertified individual who meets all of the following criteria:

(A) Is employed and supervised by a qualified autism service provider.

(B) Provides treatment and implements services pursuant to a treatment plan developed and approved by the qualified autism service provider.

(C) Meets the criteria set forth in the regulations adopted pursuant to Section 4686.3 of the Welfare and Institutions Code.

(D) Has adequate education, training, and experience, as certified by a qualified autism service provider.

(d) This section shall not apply to the following:

(1) A specialized health insurance policy that does not cover mental health or behavioral health services or an accident only, specified disease, hospital indemnity, or Medicare supplement policy.

(2) A health insurance policy in the Medi-Cal program (Chapter 7 (commencing with Section 14000) of Part 3 of Division 9 of the Welfare and Institutions Code).

(3) A health insurance policy in the Healthy Families Program (Part 6.2 (commencing with Section 12693)).

(4) A health care benefit plan or policy entered into with the Board of Administration of the Public Employees' Retirement System pursuant to the Public Employees' Medical and Hospital Care Act (Part 5 (commencing with Section 22750) of Division 5 of Title 2 of the Government Code).

(e) Nothing in this section shall be construed to limit the obligation to provide services under Section 10144.5.

(f) As provided in Section 10144.5 and in paragraph (1) of subdivision (a), in the provision of benefits required by this section, a health insurer may utilize case management, network providers, utilization review techniques, prior authorization, copayments, or other cost sharing.

(g) This section shall become inoperative on July 1, ~~2014~~ ~~2019~~, and, as of January 1, ~~2015~~ ~~2020~~, is repealed, unless a later enacted statute, that becomes operative on or before January 1, ~~2015~~ ~~2020~~, deletes or extends the dates on which it becomes inoperative and is repealed.

SEC. 3. Section 10144.52 of the Insurance Code is amended to read:

10144.52. (a) For purposes of this part, the terms "provider,"

"professional provider," "network provider," "mental health provider," and "mental health professional" shall include the term "qualified autism service provider," as defined in subdivision (c) of Section 10144.51.

(b) This section shall become inoperative on July 1, ~~2014~~ 2019 , and, as of January 1, ~~2015~~ 2020 , is repealed, unless a later enacted statute, that becomes operative on or before January 1, ~~2015~~ 2020 , deletes or extends the dates on which it becomes inoperative and is repealed.

SEC. 4. No reimbursement is required by this act pursuant to Section 6 of Article XIII B of the California Constitution because the only costs that may be incurred by a local agency or school district will be incurred because this act creates a new crime or infraction, eliminates a crime or infraction, or changes the penalty for a crime or infraction, within the meaning of Section 17556 of the Government Code, or changes the definition of a crime within the meaning of Section 6 of Article XIII B of the California Constitution.

Appendix B: Literature Review Methods

Appendix B describes methods used in the medical effectiveness literature review for SB 126, a bill that would require all DMHC-regulated health plan contracts and all CDI-regulated policies to provide coverage for intensive behavioral intervention therapies for pervasive developmental disorder or autism (PDD/A). As previously detailed in the *Introduction*, PDD/A includes: Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.

The literature search included studies published in English from 2011 to the present. Because SB 126 is very similar to SB TBD-1, a bill the California Health Benefits Review Program (CHBRP) analyzed in 2011, CHBRP relied on the results of the literature search for that report to identify older literature pertinent to SB 126. The studies included males and females, and study participants could be of any age. The following databases of peer-reviewed literature were searched: MEDLINE (PubMed), the Cochrane Database of Systematic Reviews, the Cochrane Register of Controlled Clinical Trials, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, Web of Science, Business Source Complete, and EconLit. In addition, websites maintained by the following organizations that index or publish systematic reviews and evidence-based guidelines were searched: the Agency for Healthcare Research and Quality, International Network of Agencies for Health Technology Assessment, National Health Service Centre for Reviews and Dissemination, National Institute for Health and Clinical Excellence, and the Scottish Intercollegiate Guideline Network.

Two reviewers screened the title and abstract of each citation retrieved by the literature search to determine eligibility for inclusion. The reviewers acquired the full text of articles that were deemed eligible for inclusion in the review and reapplied the initial eligibility criteria.

Abstracts for 495 publications were identified and reviewed. Three new meta-analyses and systematic reviews and eight new individual articles were included in the review in addition to the six meta-analyses and systematic reviews and one individual article from the SB TBD-1 report.

Evidence Grading System

In making a “call” for each outcome measure, the team and the content expert consider the number of studies as well the strength of the evidence. Further information about the criteria CHBRP uses to evaluate evidence of medical effectiveness can be found in CHBRP’s *Medical Effectiveness Analysis Research Approach*.⁹⁹ To grade the evidence for each outcome measured, the team uses a grading system that has the following categories.

- Research design;
- Statistical significance;
- Direction of effect;
- Size of effect; and

⁹⁹ Available at: www.chbrp.org/analysis_methodology/docs/medeffect_methods_detail.pdf.

- Generalizability of findings.

The grading system also contains an overall conclusion that encompasses findings in these five domains. The conclusion is a statement that captures the strength and consistency of the evidence of an intervention's effect on an outcome. The following terms are used to characterize the body of evidence regarding an outcome:

- 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 large majority 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 majority of the studies reviewed are consistent in their findings that treatment is either effective or not effective. This can be further subdivided into preponderance of evidence from high-quality studies and preponderance of evidence from low-quality 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.

Search Terms

The search terms used to locate studies relevant to SB 126 were as follows:

MeSH terms used to search PubMed:

- Asperger Syndrome
- Autistic Disorder
- Behavior Therapy+
- Child Development Disorders, Pervasive+
- Costs and Cost Analysis+
- Economics+

- Economics (Subheading)
- Rett Syndrome
- Sex Characteristics
- Socioeconomic Factors+
- Vital Statistics+

Keywords used to search PubMed, Cochrane Library, PsycINFO, Web of Science, Business Source Compete, EconLit, and relevant websites:

- ABA
- Applied Behavior Analysis
- Applied Behavior Intervention
- Asperger Syndrome
- Aspergers Syndrome
- Autism
- Autism Spectrum Disorders
- Autistic Disorder
- Behavior Modification
- Behavior Therapy
- Behavior Therapy
- Behavioral Therapy
- Cognitive Therapy
- Cost Containment
- Costs and Cost Analysis
- Denver Early Start Model
- Discreet Trial Training
- Discrete Trial Training
- Early Intensive Behavior Analytic Treatment
- Early Intensive Behavioral Intervention
- Early Start Denver Model
- Economics
- Ethnology

- Financial Strain
- Floortime Therapy
- Greenspan Therapy
- Health Care Costs
- Health Care Economics
- Human Sex Differences
- Intensive Behavior Analytic Treatment
- Long Term Care
- Lovaas Method
- Mortality Rate
- Pervasive Child Development Disorders
- Pervasive Development Disorders
- Pivotal Response Treatment
- Productivity of Racial and Ethnic Attitudes
- Racial and Ethnic Attitudes
- Racial and Ethnic Groups
- Relationship-Based Model
- Relaxation Therapy
- Sociocultural Factors
- UCLA Young Autism Project

Publication types (PubMed):

- Comparative Study
- Controlled Clinical Trial
- Meta-Analysis
- Randomized Controlled Trial
- Review

Appendix C: Description of Studies on Intensive Behavioral Interventions for PDD/A

Appendix C describes the meta-analyses, systematic reviews, and individual studies on intensive behavioral intervention therapies based on applied behavior analysis (ABA) that were included in the medical effectiveness review for SB 126. Table C-1 describes the type of research design, the populations studied, and the intervention and comparison groups. Table C-2 summarizes findings from the studies included in the medical effectiveness review.

Table C-1. Studies That Examined the Effectiveness of Intensive Behavioral Intervention Therapies

Type of Intervention	Citation	Type of Trial ¹⁰⁰	Intervention Versus Comparison Group	Population Studied	Location
Intensive behavioral interventions based on ABA	Eldevik et al., 2009	Meta-analysis: 7 level II and level III studies	ABA-based intervention vs. alternative intervention of similar duration and intensity ABA-based intervention vs. no intervention or one considerably less intensive	Children with PDD/A; mean age at enrollment ranged from 30.9 to 66.3 months	N/A
Intensive behavioral interventions based on ABA	Howlin et al., 2009	Systematic review: 8 level II and level III studies	ABA-based intervention vs. comparison group ¹⁰¹	Children with either: (1) autism, (2) ASD, or (3) PDD; mean age of children at enrollment: 40–42 months	N/A
Intensive behavioral interventions based on ABA	Reichow and Worley, 2009	Systematic review: 10 level II and level III studies	ABA-based intervention vs. comparison group ¹⁰²	Children participating had either: (1) ASD, (2) Autism Disorder, (3) PDD-NOS, or (4) PDD; most children aged less than 42 months at enrollment	N/A
Intensive behavioral interventions based on ABA	Spreckley and Boyd 2009	Meta-analysis: 3 level II and level III studies	ABA-based intervention vs. comparison group ¹⁰³	Children diagnosed with PDD/A. One study did not use a standardized diagnostic instrument. Study participants' age at enrollment ranged from 18 months to 6 years	N/A

¹⁰⁰ Level I=well-designed randomized controlled trials, level II=randomized controlled trials with major weaknesses, level III=nonrandomized studies with comparison groups, level IV=case series, level V=case studies.

¹⁰¹ Comparison groups varied from intensive, parent-directed intervention; less intensive ABA-based interventions; eclectic, public schooling; specialist autism school, a mixture of different interventions, or waiting list.

¹⁰² Comparison groups included less intensive ABA-based interventions, other treatments such as usual care, eclectic treatment, specialist nursery school, and service coordination models (i.e., clinic vs. parent-coordination).

¹⁰³ All comparison groups also received intervention (i.e., eclectic treatment, less intensive or less supervised ABA-based intervention).

Table C-1. Studies That Examined the Effectiveness of Intensive Behavioral Intervention Therapies (cont'd)

Type of Intervention	Citation	Type of Trial	Intervention Versus Comparison Group	Population Studied	Location
Intensive behavioral interventions based on ABA	Makrygianni and Reed, 2010	Meta-analysis: 7 level II and level III studies	ABA-based intervention vs. eclectic-control programs ¹⁰⁴	Children participating had either: (1) autism, (2) ASD, (3) Autistic Disorder, (4) PDD-NOS, and/or (5) PDD; mean age at enrollment: 38 months	N/A
Intensive behavioral interventions based on ABA	Virués-Ortega, 2010	Meta-analysis: 10 level II and level III studies	ABA-based intervention vs. control group not receiving ABA-based intervention	Subjects were either diagnosed with autism or PDD-NOS; mean age ranged from 22.6 to 66.3 months	N/A
Early Start Denver Model	Dawson et al., 2010	Level I: randomized controlled trial	Early Start Denver Model vs. community intervention	Children aged between 18 and 30 months of age at enrollment who were diagnosed with Autistic Disorder (PDD-NOS)	Washington, USA
Early intensive behavioral interventions based on ABA	Fava et al., 2011	Level III: nonrandomized study with comparison group	Early intensive behavioral intervention vs. eclectic intervention	22 children diagnosed with autism or PDD-NOS; mean age intervention group: 52 months, eclectic group: 44 months	Italy
Early intensive behavioral interventions based on ABA	Fernell et al., 2011	Level III: nonrandomized study with comparison group	Intensive intervention based on ABA vs. non-intensive targeted intervention based on ABA	208 1.5–4.5 year olds with ASD	Sweden
Early intensive behavioral interventions based on ABA	Fernell et al., 2011	Level III: nonrandomized study with comparison group	Intensive intervention based on ABA vs. non-intensive targeted intervention based on ABA	208 1.5–4.5 year olds with ASD	Sweden

¹⁰⁴ A combination of TEACCH (Treatment and Education of Autistic and Communication Handicapped Children), sensory integration therapy, and some applied behavior analysis methods.

Table C-1. Studies That Examined the Effectiveness of Intensive Behavioral Intervention Therapies (Cont'd)

Type of Intervention	Citation	Type of Trial	Intervention versus Comparison Group	Population Studied	Location
Early intensive behavioral interventions based on ABA	Kovshoff et al., 2011	Level III: nonrandomized study with comparison group, longitudinal follow-up to Remington et al., 2007	Intensive intervention based on ABA (9 were in a university supervised group and 14 were in a professionally trained with parent commissioned group) vs. treatment as usual	44 children with autism including 23 from the intervention group and 18 of the 21 in the comparison group from Remington et al., 2007	UK
Early intensive behavioral interventions based on ABA	Peters-Scheffer et al., 2011	Meta-analysis: 1 level II study, 9 level III studies	ABA-based early intensive behavioral intervention vs. treatment as usual	344 children with ASD; average age ranged from 34 to 66 months.	N/A
Early intensive behavioral and developmental interventions	Warren et al., 2011	Systematic review: level II and level III studies	Early intensive behavioral and developmental interventions vs. comparison groups ¹⁰⁵	Children with ASD; mean age at enrollment ranged from 22 to 66 months	N/A
Early intensive behavioral interventions based on ABA	Eikeseth et al., 2012	Level III: nonrandomized study with comparison group	ABA-based early intensive behavioral intervention (community/school based) vs. treatment as usual	59 children diagnosed with autism (35 in intervention group, 24 in comparison group); age at enrollment ranged from 2 to 7 years	Sweden—intervention group; Norway—comparison group
Early intensive behavioral interventions based on ABA	Flanagan et al., 2012	Level III: nonrandomized study with comparison group	ABA-based intervention vs. (matched pairs) control group not receiving ABA-based intervention	142 children (79 who received intensive behavioral intervention and 63 on the waitlist). All children met diagnostic criteria for ASD towards the severe end of the autism spectrum (50% had autism and 50% had PDD-NOS).	Ontario, Canada

¹⁰⁵ Comparison groups included parent-managed ABA-based interventions, low-intensity ABA-based interventions intervention, high-intensity interventions not based on ABA, eclectic interventions (both high and low intensity), locally available services (not specified).

Table C-1. Studies That Examined the Effectiveness of Intensive Behavioral Intervention Therapies (Cont'd)

Type of Intervention	Citation	Type of Trial	Intervention versus Comparison Group	Population Studied	Location
Early intensive behavioral interventions based on ABA	Grindle et al., 2012	Level III: nonrandomized study with comparison group	ABA-based intervention in a mainstream school setting vs. education as usual	27 children: Intervention group: 9 children 43–68 months; comparison group: 18 children 54–72 months. All children had a clinical diagnosis of autism	UK
Early intensive behavioral interventions based on ABA	Reed et al., 2012	Level III: nonrandomized study with comparison groups	Four interventions were studied: ABA, special nursery, an adapted portage intervention, and a local authority approach	66 children (aged 2.5 years–4 years) diagnosed with autism or PDD-NOS	UK
Early intensive behavioral interventions based on ABA	Reichow et al., 2012	Systematic review: 5 studies, 1 level I, 4 level III studies	ABA-based early intensive behavioral intervention vs. treatment as usual comparison group	203 (116 children in the early intensive behavioral intervention groups and 87 children in the treatment as usual groups) participants under 6 years old at the onset of treatment (mean age 30 to 42 months)	United States and UK
Early intensive behavioral interventions based on ABA	Strauss et al., 2012	Level III: nonrandomized study with comparison group	Staff and parent early intensive behavioral intervention vs. eclectic intervention	44 children with Autistic Disorder or PDD-NOS (24 in intervention group, 20 in comparison group)	Italy

Sources: Dawson et al., 2010; Eikeseth et al., 2012; Eldevik et al., 2009; Fava et al., 2011; Fernell et al., 2011; Flanagan et al., 2012; Grindle et al., 2012; Howlin et al., 2009; Kovshoff et al., 2011; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011. Reed et al., 2012; Reichow and Worley, 2009; Spreckley and Boyd, 2009; Strauss et al., 2012; Virués-Ortega, 2011; Warren et al., 2011.

Key: ABA=applied behavior analysis; ASD=autism spectrum disorders; PDD/A=pervasive developmental disorder or autism; PDD-NOS=pervasive developmental disorder not otherwise specified.

Table C-2. Summary of Findings From Studies of the Effectiveness of Intensive Behavioral Intervention Therapies for PDD/A

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior ¹⁰⁶	Eldevik et al., 2009	Meta-analysis: 7 level II and level III studies ¹⁰⁷	Statistically significant	Favors ABA-based interventions	Effect size=0.66 (95% CI: 0.41, 0.90)	
Adaptive behavior	Howlin et al., 2009	Meta-analysis: 8 level II and level III studies	Statistically significant	Favors ABA-based interventions	Mean difference in mean change score=7.5	
Adaptive behavior	Reichow et al., 2009	Systematic review: 10 level II and level III studies	ABA-based intervention vs. other treatment: statistically significant, 3 of 5 studies; clinical ABA vs. parent ABA: no statistically significant difference, 2 of 2 studies	ABA-based intervention vs. other treatment: 3 of 5 studies found effect favoring ABA; clinical ABA vs. parent ABA: 2 studies found no difference	ABA-based intervention vs. other treatment: no pooled effect size reported; clinical ABA vs. parent ABA: no pooled effect size reported	
Adaptive behavior	Spreckley and Boyd, 2009	Meta-analysis: 3 level II and level III studies	Not statistically significant	No difference	No effect	
Adaptive behavior	Makrygianni and Reed, 2010	Meta-analysis: 7 level II and level III studies	High-quality studies: statistically significant; low-quality studies: statistically significant	High-quality studies: favors EIP; low-quality studies: favors EIP	High-quality studies: weighted mean effect size=0.971 (SE=0.256); low-quality studies: weighted mean effect size=0.656 (SE=0.153)	

¹⁰⁶ Usually measured using the Vineland Adaptive Behavior Scales (VABS, which assesses social, communication, motor, and daily living skills).

¹⁰⁷ Level I=well-designed randomized controlled trials, level II=randomized controlled trials with major weaknesses, level III=nonrandomized studies with comparison groups, level IV=case series, level V=case studies.

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior	Virués-Ortega, 2010	Meta-analysis: 10 Level II and Level III studies	Statistically significant	Favors ABA-based interventions	Effect size=0.81 (95% CI: 0.39, 1.23)	
Adaptive behavior	Fava et al., 2011	Level III: nonrandomized study with comparison group	Not significantly significant—improvements in both groups	No difference	No effect	EIBI and eclectic intervention were equally effective
Adaptive behavior	Fernell et al., 2011	Level III: nonrandomized study with comparison group	Not significantly significant	No difference	No effect	Gains in adaptive behavior were similar for children who received EIBI and children who received a less intensive intervention based on ABA
Adaptive behavior	Kovshoff et al., 2011	Level III: nonrandomized study with comparison group; follow-up to Remington et al., 2007	Intervention vs. comparison: no statistically significant difference; university-based intervention vs. parent-commissioned intervention: statistically significant decrease in university-based group vs. no change in parent-commissioned group	Intervention vs. comparison: no difference; university-based intervention vs. parent-commissioned intervention: worse in university-based group vs. no change in parent-commissioned group	Intervention vs. comparison: no effect; university-based intervention vs. parent-commissioned intervention: 9-point reduction in mean VABS total score in university-based group vs. no change in parent-commissioned group	EIBI and treatment as usual have similar effects on adaptive behavior; parent-commissioned EIBI more effective at maintaining gains in adaptive behavior than university-based intervention

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior	Peters-Scheffer et al., 2011	Meta-analysis	Statistically significant	Favors EIBI	EIBI group scored 5.92 points higher on standardized test $d=0.91$	EIBI associated with higher scores on standardized measures of adaptive behavior relative to treatment as usual
Adaptive behavior	Warren et al., 2011	Systematic review				
Adaptive behavior	Eikeseth et al., 2012	Level III: nonrandomized study with comparison group	Statistically significant	Favors ABA-based EIBI intervention	11-point difference in mean VABS total score; effect size= 0.92	EIBI associated with higher adaptive behavior scores relative to treatment as usual
Adaptive behavior	Flanagan et al., 2012	Level III: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	6-point difference in VABS total score; effect size: $d=0.53$	EIBI associated with higher adaptive behavior scores relative to waitlist comparison group
Adaptive behavior	Grindle et al., 2012	Level III: nonrandomized study with comparison group	Statistically significant	Favors ABA-based EIBI intervention	11-point increase in VABS total score for intervention group vs. 5 point decrease in the comparison group; effect size: $d=2.15$	EIBI associated with higher adaptive behavior scores relative to treatment as usual
Adaptive behavior	Reed et al., 2012	Level III: nonrandomized study with comparison group	No statistically significant difference	No difference	No effect	None of the four interventions compared, including ABA-based EIBI substantially improved adaptive behavior

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior	Reichow et al., 2012	Systematic review: 5 studies, 1 level I, 4 level III studies	Statistically significant	Favors EIBI group	EIBI group scored higher on VABS average score $g=0.69$ (95% CI: 0.38 to 1.01)	EIBI associated with higher adaptive behavior scores relative to treatment as usual
Adaptive behavior	Strauss et al., 2012	Level III: nonrandomized study with comparison group	No statistically significance difference	No difference between groups	No effect	Both ABA-based EIBI and eclectic intervention were associated with improvement in adaptive behavior
IQ	Eldevik et al., 2009	Meta-analysis: 9 level II and level III studies	Statistically significant	Favors ABA-based interventions	Effect size=1.103 (95% CI: 0.871, 1.335)	
IQ	Howlin et al., 2009	Meta-analysis: 11 level II and level III studies	Statistically significant	Favors ABA-based interventions	Mean difference in mean change score=12.9	
IQ	Reichow and Wolery, 2009	Systematic review: 10 level II and level III studies	ABA-based intervention vs. minimal treatment: 2 of 2 studies found a statistically significant difference; ABA-based intervention vs. other treatment: 3 of 6 studies found a statistically significant difference, 3 of 6 studies found no statistically significant difference; clinical ABA vs. parent ABA: 1 of 2 studies found a statistically significant difference, 1 of 2 studies found no difference	ABA-based intervention vs. minimal treatment: favors ABA in 2 of 2 studies ABA-based intervention vs. other treatment: favors ABA in 3 of 6 studies, no difference in 3 of 6 studies; clinical ABA vs. parent ABA: favors clinic ABA in 1 of 2 studies, 1 of 2 studies found no difference	ABA-based intervention vs. minimal treatment: no pooled effect size reported; ABA-based intervention vs. other treatment: no pooled effect size reported; clinical ABA vs. parent ABA: no pooled effect size reported	

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
IQ	Spreckley and Boyd, 2009	Meta-analysis: 3 level II and level III studies	EIBI vs. comparison group: not statistically significant	EIBI vs. comparison group: no difference	EIBI vs. comparison group: no effect	
IQ	Makrygianni and Reed, 2010	Meta-analysis: 11 level II and level III studies	High-quality studies: statistically significant; low-quality studies: statistically significant	High-quality studies: favors ABA-based interventions Low-quality studies: ABA-based interventions	High-quality studies: weighted mean effect size=0.568 (SE=0.192); low-quality studies: weighted mean effect size=0.730 (SE = 0.123)	
IQ	Virués-Ortega, 2010	Meta-analysis: 10 level II and level III studies	ABA vs. comparison group: statistically significant	ABA vs. comparison group: favors ABA	ABA vs. comparison group: 1.31 (95% CI: 0.92, 1.70)	
IQ	Kovshoff et al., 2011	Level III—nonrandomized study with comparison group; follow-up to Remington et al., 2007	Intervention vs. comparison: no statistically significant difference; university-based intervention vs. parent-commissioned intervention: statistically significant decrease in university-based group vs. no change in parent-commissioned group	Intervention vs. comparison: no difference; university-based intervention vs. parent-commissioned intervention: worse in university-based group vs. no change in parent-commissioned group	Intervention vs. comparison: no effect; university-based intervention vs. parent-commissioned intervention: 14-point reduction in university-based group vs. no change in parent-commissioned group	EIBI and treatment as usual have similar effects on IQ; parent-commissioned EIBI more effective at maintaining gains in IQ than university-based intervention.

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
IQ	Peters-Scheffer et al., 2011	Meta-analysis	Statistically significant	Favors EIBI group for both full-scale and nonverbal IQ	Full-scale IQ: EIBI group 12 points higher than comparison group d=2.00; nonverbal IQ: EIBI group 11 points higher than comparison group d=0.98	EIBI associated with higher IQ relative to treatment as usual
IQ	Warren et al., 2011	Systematic review				
IQ	Flanagan et al., 2012	Level III: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	16-point difference; effect size d=0.83, p=0.002	EIBI associated with higher IQ relative to waitlist comparison group
IQ	Grindle et al., 2012	Level III: nonrandomized study with comparison group	Not statistically significant	No difference between groups	9-point increase in IQ score for intervention group vs. 1-point increase in the comparison group; effect size: d=0.6	EIBI associated with greater increase in IQ score relative to treatment as usual but difference is not statistically significant
Intellectual functioning (PEP-R) ¹⁰⁸	Reed et al., 2012	Level III: nonrandomized study with comparison group	No statistically significant differences	No difference among groups	ABA-based EIBI associated with greater increase in PEP-R score	EIBI associate with better intellectual functioning but difference was not statistically significant
IQ	Reichow et al., 2012	Systematic review: 4 level III studies	Statistically significant	Favors EIBI	EIBI group scored an average of 11 points higher on IQ test. g=0.76 (95% CI: 0.40 to 1.11)	EIBI associated with higher IQ relative to treatment as usual

¹⁰⁸ Psycho-Educational Profile (PEP-R; Schopler et al.,1990) assesses the typical strengths and weaknesses of children on the autism spectrum. The test measures functioning in seven developmental domains: Imitation, Perception, Fine and Gross Motor Skills, Eye-Hand Coordination, and Nonverbal and Verbal Conceptual Ability.

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Language, expressive	Howlin et al., 2009	Meta-analysis: 7 level II and level III studies	Not statistically significant	No difference	No effect	
Language, expressive	Reichow and Wolery, 2009	Meta-analysis: 10 level II and level III studies	ABA-based intervention vs. other treatment: 4 of 4 studies found no statistically significant difference; clinical ABA vs. parent ABA: 2 of 2 studies found no statistically significant difference	ABA-based intervention vs. other treatment: 4 of 4 studies found no effect; clinical ABA vs. parent ABA: 2 of 2 studies found no effect	ABA-based intervention vs. other treatment: no pooled effect size reported; clinical ABA vs. parent ABA: no pooled effect size reported	
Language, expressive	Spreckley and Boyd, 2009	Meta-analysis: 3 level II and level III studies	Not statistically significant	No difference	No effect	
Language, expressive	Fava et al., 2011	Level III: nonrandomized study with comparison group	Statistical significant	Favors ABA-based intervention	($t(11)=-1.84$ 14 point increase in mean CDI score ¹⁰⁹)	Children who received EIBI intervention experienced larger gains in early language production relative to children who received an eclectic intervention
Language, expressive	Peters-Scheffer et al., 2011	Meta-analysis: 1 level I study, 9 level III studies	Statistically significant	Favors EIBI	Average increase was 15.21 points more than comparison group $d=1.10$	EIBI associated with larger gains in expressive language relative to treatment as usual

¹⁰⁹ MacArthur Communications Development Inventories.

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Language, expressive	Reichow et al., 2012	Systematic review: 3 level III studies	Statistically significant	Favors EIBI	$g=0.50$ (95% CI 0.05 to 0.95 ¹¹⁰)	EIBI associated with larger gains in expressive language relative to treatment as usual
Language, expressive	Strauss et al., 2012	Level III: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	17-point increase in mean CDI score	EIBI associated with greater gains in expressive language than eclectic treatment
Language, receptive	Howlin et al., 2009	Meta-analysis: 7 level II and level III studies	Statistically significant	Favors ABA-based intervention	Mean difference in mean change score=11.2	
Language, receptive	Reichow and Wolery, 2009	Meta-analysis: 10 level II and level III studies	ABA-based intervention vs. other treatment: 1 of 4 studies found a statistically significant difference, 3 of 4 studies found no statistically significant difference Clinical ABA vs. parent ABA: 2 of 2 studies found no statistically significant difference	ABA-based intervention vs. other treatment: 1 of 4 studies favored ABA, 3 of 4 studies found no effect Clinical ABA vs. parent ABA: 2 of 2 studies found no effect	ABA-based intervention vs. other treatment: no pooled effect size reported Clinical ABA vs. parent ABA: no pooled effect size reported	

¹¹⁰ Scores on Reynell Developmental Language Scales.

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Language, receptive	Spreckley and Boyd, 2009	Meta-analysis: 3 level II and level III studies	Not statistically significant	No difference	No effect	
Language, receptive	Virués-Ortega, 2010	Meta-analysis: 7 level II and level III studies	Statistically significant	Favors ABA-based intervention	Effect size=0.99 (95% CI: 0.56, 1.42)	
Language, receptive	Fava et al., 2011	Level II: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	10 -point increase in scores on CDI ¹¹¹	Children who received EIBI intervention had gains in early language comprehension relative to children who received an eclectic intervention
Language, receptive	Peters-Scheffer et al., 2011	Meta-analysis: 1 level I study, 9 level III studies	Statistically significant	Favors ABA-based intervention	13.94 points higher than comparison group d=2.91	EIBI associated with larger gains in receptive language relative to treatment as usual
Language, receptive	Reichow et al., 2012	Systematic review: 3 level III studies	Statistically significant	Favors ABA-based intervention	g=0.57 (95% CI: 0.20 to 0.94) ¹¹²	EIBI associated with larger gains in receptive language relative to treatment as usual
Language, receptive	Strauss et al., 2012	Level III: nonrandomized study with comparison group	No statistically significant difference	No difference between groups	No effect	Both EIBI and eclectic intervention were associated with increase in receptive language

¹¹¹ MacArthur Communications Development Inventories.

¹¹² Scores on Reynell Developmental Language Scales

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Language, general	Makrygianni and Reed, 2010	Meta-analysis: 6 level II and level III studies	High-quality studies: statistically significant; low-quality studies: statistically significant	High-quality studies: favors ABA-based interventions; low-quality studies: favors ABA-based interventions	High-quality studies: weighted mean effect size=0.534 (SE= 0.244); low-quality studies: weighted mean effect size=0.910 (SE=0.177)	
Language, general	Virués-Ortega, 2010	Meta-analysis: 4 level II and level III studies	Statistically significant	Favors ABA-based intervention	Effect size=1.20 (95% CI: 0.22, 2.17)	
Autism severity	Fava et al., 2011	Level II: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	4-point decrease in ADOS ¹¹³ score	EIBI associated with reduction in autism severity relative to an eclectic intervention
Autism severity	Flanagan et al., 2012	Level II: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	3-point difference in CARS ¹¹⁴ score; effect size: d=0.053	EIBI associated with lower autism severity relative to a waitlist comparison group
Autism severity	Strauss et al., 2012	Level II: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	3-point reduction in ADOS score	EIBI associated with reduction in autism severity relative to eclectic intervention

¹¹³ Autism Diagnostic Observation Scale.

¹¹⁴ Childhood Autism Rating Score.

Table C2-a. Early Intensive Behavioral Intervention Based on Applied Behavior Analysis vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Mental developmental state	Fava et al., 2011	Level II: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	14-point increase in GMDS score ¹¹⁵	Children who received EIBI intervention experienced improvement in general developmental quotient relative to children who received an eclectic intervention
Mental developmental state	Strauss et al., 2012	Level II: nonrandomized study with comparison group	Statistically significant	Favors ABA-based intervention	13-point increase in GMDS score	Children who received EIBI intervention experienced improvement in general developmental quotient relative to children who received an eclectic intervention
Comorbid psychopathology	Fava et al., 2011	Level III: nonrandomized study with comparison group	Not statistically significant except for ADHD ¹¹⁶ scores	No difference except ADHD scores which favored EIBI intervention group	No effect, except for ADHD 3 point decrease in CBCL score ¹¹⁷	EIBI associated with reduction in challenging behaviors associated with ADHD relative to eclectic intervention

Sources: Eikeseth et al., 2012; Eldevik et al., 2009; Fava et al., 2011; Fernell et al., 2011; Flanagan et al., 2012; Grindle et al., 2012; Howlin et al., 2009; Kovshoff et al., 2011; Makrygianni and Reed, 2010; Peters-Scheffer et al., 2011; Reichow and Worley, 2009; Reed et al., 2012; Spreckley and Boyd, 2009; Strauss et al., 2012; Virués-Ortega, 2010; Warren et al., 2011.

Key: ABA=applied behavior analysis; CI=confidence interval; EIBI=early intensive behavioral intervention; IQ=intelligence quotient; SE=standard error.

¹¹⁵ Griffith Mental Development Scales.

¹¹⁶ Attention deficit hyperactivity disorder

¹¹⁷ Measured by the Child Behavior Checklist

Table C2-b. Early Start Denver Model vs. Community Intervention

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior .	Dawson et al., 2010	Level II: randomized controlled trial with major weaknesses	Statistically significant	Better	Same score for VABS ¹¹⁸ across 2 years for intervention group (steady rate of development). Lower VABS scores across 2 years for comparison group (11.2 average decline)	Single study suggests that children who receive treatment with the Early Start Denver Model experience a steady rate of development compared to children who receive community interventions
IQ	Dawson et al., 2010	Level II: randomized controlled trial with major weaknesses	Statistically significant	Better	Improvement in MSEL ¹¹⁹ composite scores: 17.6 points in intervention group vs. 7 points in the comparison group	Single study suggests that children who receive treatment with the Early Start Denver Model improve in IQ compared to children who receive community interventions.
Autism severity ¹²⁰	Dawson et al., 2010	Level II: randomized controlled trial with major weaknesses	Statistically significant	Better	Not reported	Single study suggests that severity of autism decreases among children who receive treatment with the Early Start Denver Model compared to children who receive community interventions.

Source: Dawson et al., 2010.

Key: IQ=intelligence quotient.

¹¹⁸ Vineland adaptive behavior scales: assesses social, communication, motor and daily living skills.

¹¹⁹ Mullen Scales of Early Learning: standardized developmental test for children from birth to 68 months of age.

¹²⁰ Defined as change in diagnosis from Autistic Disorder to PDD-NOS.

Appendix D: Cost Impact Analysis: Data Sources, Caveats, and Assumptions

This appendix describes data sources, estimation methodology, as well as general and mandate-specific caveats and assumptions used in conducting the cost impact analysis. For additional information on the cost model and underlying methodology, please refer to the California Health Benefits Review Program (CHBRP) website at www.chbrp.org/analysis_methodology/cost_impact_analysis.php.

The cost analysis in this report was prepared by the members of the cost team, which consists of CHBRP task force members and contributors from the University of California, San Diego, the University of California, Los Angeles, the University of California, Davis, and University of California, Berkeley, as well as the contracted actuarial firm, Milliman, Inc. (Milliman).¹²¹

Data Sources

In preparing cost estimates, the cost team relies on a variety of data sources as described below.

Baseline model

1. The California Simulation of Insurance Markets (CalSIM) is used to project health insurance status of Californians aged 64 and under in 2014. CalSIM is a microsimulation model that projects the effects of the Affordable Care Act on firms and individuals.¹²² CalSIM relies on national Medical Expenditure Panel Survey (MEPS) Household Component and Person Round Plan, California Health Interview Survey (CHIS) 2009, and California Employer Health Benefits Survey data.
2. California Health Interview Survey (2011) data are used to estimate the number of Californians aged 65 and older, and the number of Californians dually eligible for both Medi-Cal and Medicare coverage. CHIS 2011 is also used to determine the number of Californians with incomes below 400% of the federal poverty level. CHIS is a continuous survey that provides detailed information on demographics, health insurance coverage, health status, and access to care. CHIS 2011 surveyed approximately 23,000 households and is conducted in multiple languages by the UCLA Center for Health Policy Research. More information on CHIS is available at www.chis.ucla.edu.
3. The latest (2012) California Employer Health Benefits Survey is used to estimate:
 - a. Size of firm
 - b. Percentage of firms that are purchased/underwritten (versus self-insured)
 - c. Premiums for health care service plans regulated by the Department of Managed Health Care (DMHC) (primarily health maintenance organizations [HMOs] and point of service [POS] plans)

¹²¹ CHBRP's authorizing legislation requires that CHBRP use a certified actuary or "other person with relevant knowledge and expertise" to determine financial impact (www.chbrp.org/docs/authorizing_statute.pdf).

¹²² UC Berkeley Center for Labor Research and Education and UC Los Angeles Center for Health Policy Research. *Methodology & Assumptions, California Simulation of Insurance Markets (CalSIM) Version 1.7*, June 2012. Available at www.healthpolicy.ucla.edu/pubs/files/calsim_methods.pdf. Accessed October 19, 2012.

- d. Premiums for health insurance policies regulated by the California Department of Insurance (CDI) (primarily preferred provider organizations [PPOs] and fee-for-service [FFS] plans)

This annual survey is currently released by the California Health Care Foundation/National Opinion Research Center (CHCF/NORC) and is similar to the national employer survey released annually by the Kaiser Family Foundation and the Health Research and Educational Trust. Information on the CHCF/NORC data is available at: www.chcf.org/publications/2010/12/california-employer-health-benefits-survey.

4. Milliman data sources are relied on to estimate the premium impact of mandates. Milliman's projections derive from the Milliman Health Cost Guidelines (HCGs). The HCGs are a health care pricing tool used by many of the major health plans in the United States. See www.milliman.com/expertise/healthcare/products-tools/milliman-care-guidelines/index.php. Most of the data sources underlying the HCGs are claims databases from commercial health insurance plans. The data are supplied by health insurance companies, HMOs, self-funded employers, and private data vendors. The data are mostly from loosely managed health care plans, generally those characterized as preferred provider organization (PPO) plans. The HCGs currently include claims drawn from plans covering 37 million members. In addition to the Milliman HCGs, CHBRP's utilization and cost estimates draw on other data, including the following:
 - a. The MarketScan databases, which reflects the healthcare claims experience of employees and dependents covered by the health benefit programs of large employers. These claims data are collected from approximately 100 different insurance companies, Blue Cross Blue Shield plans, and third party administrators. These data represent the medical experience of insured employees and their dependents for active employees, early retirees, individuals with COBRA continuation coverage, and Medicare-eligible retirees with employer-provided Medicare Supplemental plans. No Medicaid or Workers Compensation data are included.
 - b. An annual survey of HMO and PPO pricing and claim experience. The most recent survey (2010 Group Health Insurance Survey) contains data from seven major California health plans regarding their 2010 experience.
 - c. Ingenix MDR Charge Payment System, which includes information about professional fees paid for healthcare services, based upon approximately 800 million claims from commercial insurance companies, HMOs, and self-insured health plans.
 - d. These data are reviewed for applicability by an extended group of experts within Milliman but are not audited internally.
5. Premiums and enrollment in DMHC-regulated health plans and CDI-regulated policies by self-insured status and firm size are obtained annually from CalPERS for active state and local government public employees and their dependents who receive their benefits through CalPERS. Enrollment information is provided for DMHC-regulated health care service plans covering non-Medicare beneficiaries—about 74% of CalPERS total

enrollment. CalPERS self-funded plans—approximately 26% of enrollment—are not subject to state mandates. In addition, CHBRP obtains information on current scope of benefits from evidence of coverage (EOC) documents publicly available at www.calpers.ca.gov. For the 2013 model, CHBRP assumes CalPERS’s enrollment in 2014 will not be affected by the ACA.

6. Enrollment in Medi-Cal Managed Care (beneficiaries enrolled in Two-Plan Model, Geographic Managed Care, and County Operated Health System plans) is estimated based on data maintained by the Department of Health Care Services (DHCS). CHBRP assesses enrollment information online at: www.dhcs.ca.gov/dataandstats/statistics/Pages/RASB_Medi-Cal_Enrollment_Trends.aspx. Starting with the 2013 model, the most recent Medi-Cal enrollment data from DHCS is projected to 2014 based on CalSIM’s estimate of the impact of the Medi-Cal expansion in 2014.

Estimate of Premium Impact of Mandates

7. CHBRP’s Annual Enrollment and Premium Survey collects information from the seven largest providers of health insurance in California (Aetna, Anthem Blue Cross of California, Blue Shield of California, CIGNA, Health Net, Kaiser Foundation Health Plan, and United Healthcare/PacifiCare) to obtain estimates of baseline enrollment by purchaser (i.e., large and small group and individual), type of plan (i.e., DMHC-regulated or CDI-regulated), grandfathered and nongrandfathered status, and average premiums. Enrollment in plans or policies offered by these seven insurers represent an estimated 97.5% of the persons with health insurance subject to state mandates. This figure represents an estimated 97.9% of enrollees in full-service (nonspecialty) DMHC-regulated health plans and an estimated 96.1% of enrollees in full-service (nonspecialty) CDI-regulated policies.

For CHBRP reports analyzing specific benefit mandates, CHBRP surveys the seven major carriers on current coverage relevant to the benefit mandate. CHBRP reports the share of enrollees—statewide and by market segment—reflected in CHBRP’s bill-specific coverage survey responses. The proportions are derived from data provided by CDI and DMHC. CDI provides data by market segment (large, small, and individual) based on “CDI Licenses With HMSR Covered Lives Greater Than 100,000” as part of the Accident and Health Covered Lives Data Call September 30, 2011, by the California Department of Insurance, Statistical Analysis Division. The Department of Managed Health Care’s interactive website “Health Plan Financial Summary Report,” July–September 2012, provides data on DMHC-regulated plans by segment.¹²³

The following table describes the data sources mentioned above, and the data items that they inform.

¹²³ CHBRP assumes DMHC-regulated PPO group enrollees and POS enrollees are in the large-group segment. <http://wpsso.dmhc.ca.gov/flash/>.

Table D-1. Population and Cost Model Data Sources and Data Items

Data Source	Items
California Simulation of Insurance Markets (CalSIM)	Uninsured, age: 0–17; 18–64 Medi-Cal (non-Medicare) (a), age: 0–17; 18–64 Other public (b), age: 0–64 Individual market, age: 0–17; 18–64 Small group, age: 0–17; 18–64 Large group, age: 0–17; 18–64
California Health Interview Survey, 2011 (CHIS, 2011)	Uninsured, age: 65+ Medi-Cal (non-Medicare), age: 65+ Other public, age: 65+ Employer-sponsored insurance, age: 65+
CalPERS data, annually, enrollment as of September 30	CalPERS HMO and PPO enrollment 1. Age: 0–17; 18–64; 65+ HMO premiums
California Employer Survey, conducted annually by NORC and funded by CHCF	Enrollment by HMO/POS, PPO/indemnity self-insured, fully insured, Premiums (not self-insured) by: <ul style="list-style-type: none"> • Size of firm (3–25 as small group and 25+ as large group) • Family vs. single • HMO/POS vs. PPO/indemnity vs. HDHP employer vs. employer premium share
DHCS administrative data for the Medi-Cal program, annually, 11-month lag from the end of November	Distribution of enrollees by managed care or FFS distribution by age: 0–17; 18–64; 65+ Medi-Cal Managed Care premiums
CMS administrative data for the Medicare program, annually (if available) as of end of September	HMO vs. FFS distribution for those 65+ (noninstitutionalized)
CHBRP enrollment survey of the seven largest health plans in California, annually as of end of September	Enrollment by: <ul style="list-style-type: none"> • Size of firm (2–50 as small group and 51+ as large group), • DHMC vs. CDI regulated • Grandfathered vs. nongrandfathered Premiums for individual policies by: <ul style="list-style-type: none"> • DMHC vs. CDI regulated • Grandfathered vs. nongrandfathered
Department of Finance population projections, for intermediate CHIS years	Projected civilian, noninstitutionalized CA population by age: 0–17; 18–64; 65+
Medical trend influencing annual premium increases	Milliman estimate

Source: California Health Benefits Review Program, 2013.

Notes: (a) Includes children previously enrolled in Healthy Families, California’s CHIP. By January 1, 2014, children enrolled in Healthy Families will be transitioned into Medi-Cal as required in the 2012–2013 state budget agreement.

(b) Includes individuals dually eligible for Medi-Cal and Medicare.

Key: CDI=California Department of Insurance; CHCF=California HealthCare Foundation; CHIS=California Health Interview Survey; CMS=Centers for Medicare & Medicaid Services; DHCS=Department of Health Care Services; DMHC=Department of Managed Health Care; FFS=fee-for-service; HMO=health maintenance organization; NORC=National Opinion Research Center; PPO=preferred provider organization.

Projecting the Effects of the Affordable Care Act in 2014

This subsection discusses adjustments made to CHBRP's Cost and Coverage Model to account for the potential impacts of the ACA effective January 2014. It is important to emphasize that CHBRP's analysis of specific mandate bills typically addresses the marginal effects of the mandate bill—specifically, how the proposed mandate would impact benefit coverage, utilization, costs, and public health, *holding all other factors constant*. CHBRP's estimates of these marginal effects are presented in the *Benefit Coverage, Utilization, and Cost Impacts* section of this report.

Baseline premium rate development methodology—2014 post-ACA

Mandate bills introduced during 2013 would, if passed, become effective in 2014. Many significant provisions of the Affordable Care Act also become effective in 2014. In many cases, provisions required in the ACA would become effective on the same date as a mandate proposed to California law.

CHBRP's analyses of mandates effective in 2014 assume that carriers implement the new ACA provisions first. The baseline premiums reflect the estimated 2014 premium levels costs *after* carriers have implemented the 2014 ACA provisions. The estimated cost impact of a proposed mandate is then calculated relative to this post-ACA baseline.

The key components of the baseline model for utilization and expenditures are estimates of the per member per month (PMPM) values for each of the following:

- Insurance premiums PMPM;
- Gross claims costs PMPM;
- Member cost sharing PMPM; and
- Health care costs paid by the health plan.

For each plan type, we first obtained an estimate of the insurance premium PMPM by taking the 2012 reported premium from the above-mentioned data sources and trending that value to 2014. CHBRP uses trend rates published in the Milliman Health Cost Guidelines to estimate the health care costs for each plan segment in 2014.

In 2014, 4 plan segments in the previous CHBRP model¹²⁴ were split into 12 segments. Each of the two small-group segments (CDI-regulated and DMHC-regulated), and individual segments (CDI-regulated and DMHC-regulated) were split into: grandfathered non-exchange, nongrandfathered non-exchange, and exchange groups in order to separately calculate the impact of ACA and specific mandates that may apply differently to these three subgroups. The premium rate information received from NORC did not split the premiums based on grandfathered or exchange status. The 2012 CHBRP Annual Enrollment and Premium Survey asked the seven

¹²⁴ In the past, CHBRP's model has reflected large-group, small-group, and individual market segments. These market segments were further subdivided by regulator: DMHC-regulated and CDI-regulated. The four plan segments refer to the small and individual market subdivisions by regulator.

largest insurance carriers in California to provide their average premium rates separately for grandfathered and nongrandfathered plans. The ratios from the carrier survey data are then applied to the NORC aggregate premium rates, to estimate premium rates for grandfathered and nongrandfathered plans that were consistent with the NORC results.

The marginal impact of ACA on 2014 premiums was established as follows:

- For nongrandfathered small-group and individual market segments, a 3% increase in medical costs is applied to reflect the total cost of requiring each plan to cover the essential health benefits.
- For nongrandfathered small-group plans, a 5% increase in medical costs is applied to reflect the other additional costs of ACA (e.g., age rating, health status, increased premium taxes and fees, change in actuarial value, etc.).
- For DMHC-regulated individual plans and CDI-regulated individual policies, an increase of 20% and 31%, respectively, in medical costs is applied to reflect the other additional costs of ACA.

The remaining three values were then estimated by the following formulas:

- Health care costs paid by the health plan = insurance premiums PMPM \times (1 – profit/administration load).
- Gross claims costs PMPM = health care costs paid by the health plan \div percentage paid by health plan
- Member cost sharing PMPM = gross claims costs \times (1 – percentage paid by health plan)

In the above formulas, the quantity “profit/administration load” is the assumed percentage of a typical premium that is allocated to the health plan’s administration and profit. These values vary by insurance category, and under the ACA, are limited by the minimum medical loss ratio requirement. CHBRP estimated these values based on Milliman’s knowledge of the health care market.

In the above formulas, the quantity “percentage paid by health plan” is the assumed percentage of gross health care costs that are paid by the health plan, as opposed to the amount paid by member cost sharing (deductibles, copays, etc.). In ACA terminology, this quantity is known as the plan’s “actuarial value.” These values vary by insurance category. For each insurance category, Milliman estimated the member cost sharing for the average or typical plan in that category. Milliman then priced these plans using the Milliman Health Cost Guidelines to estimate the percentage of gross healthcare costs that are paid by the carrier.

General Caveats and Assumptions

The projected cost estimates are estimates of the costs that would result if a certain set of assumptions were exactly realized. Actual costs will differ from these estimates for a wide variety of reasons, including:

- Prevalence of mandated benefits before and after the mandate may be different from CHBRP assumptions.
- Utilization of mandated benefits (and, therefore, the services covered by the benefit) before and after the mandate may be different from CHBRP assumptions.
- Random fluctuations in the utilization and cost of health care services may occur.
- The impact of ACA on the mandated benefit cost may be different from CHBRP assumptions.

Additional assumptions that underlie the cost estimates presented in this report are:

- Cost impacts are shown only for plans and policies subject to state benefit mandate laws.
- Cost impacts are only for the first year after enactment of the proposed mandate.
- Employers and employees will share proportionately (on a percentage basis) in premium rate increases resulting from the mandate. In other words, the distribution of the premium paid by the subscriber (or employee) and the employer will be unaffected by the mandate.
- For state-sponsored programs for the uninsured, the state share will continue to be equal to the absolute dollar amount of funds dedicated to the program.
- When cost savings are estimated, they reflect savings realized for 1 year. Potential long-term cost savings or impacts are estimated if existing data and literature sources are available and provide adequate detail for estimating long-term impacts. For more information on CHBRP's criteria for estimating long-term impacts, please see: http://chbrp.org/documents/longterm_impacts08.pdf.
- Several studies have examined the effect of private insurance premium increases on the number of uninsured (Chernew et al., 2005; Glied and Jack, 2003; Hadley, 2006). Chernew et al. (2005) estimate that a 10% increase in private premiums results in a 0.74 to 0.92 percentage point decrease in the number of insured, whereas Hadley (2006) and Glied and Jack (2003) estimate that a 10% increase in private premiums produces a 0.88 and a 0.84 percentage point decrease in the number of insured, respectively. Because each of these studies reported results for the large-group, small-group, and individual insurance markets combined, CHBRP employs the simplifying assumption that the elasticity is the same across different types of markets. For more information on CHBRP's criteria for estimating impacts on the uninsured, please see: http://chbrp.org/documents/uninsured_010109.pdf.

There are other variables that may affect costs, but which CHBRP did not consider in the cost projections presented in this report. Such variables include, but are not limited to:

- Population shifts by type of health insurance: If a mandate increases health insurance costs, some employer groups and individuals may elect to drop their health insurance. Employers may also switch to self-funding to avoid having to comply with the mandate.

- Changes in benefit plans: To help offset the premium increase resulting from a mandate, subscribers/policyholders may elect to increase their overall plan deductibles or copayments. Such changes would have a direct impact on the distribution of costs between the health plan and policies and enrollees, and may also result in utilization reductions (i.e., high levels of patient cost sharing result in lower utilization of health care services). CHBRP did not include the effects of such potential benefit changes in its analysis.
- Adverse selection: Theoretically, individuals or employer groups who had previously foregone health insurance may now elect to enroll in a health plan or policy, postmandate, because they perceive that it is to their economic benefit to do so.
- Medical management: Health plans and insurers may react to the mandate by tightening medical management of the mandated benefit. This would tend to dampen the CHBRP cost estimates. The dampening would be more pronounced on the plan types that previously had the least effective medical management (i.e., PPO plans).
- Geographic and delivery systems variation—Variation in existing utilization and costs, and in the impact of the mandate, by geographic area and delivery system models: Even within the health insurance types CHBRP modeled (HMO—including HMO and POS plans—and non-HMO—including PPO and FFS policies), there are likely variations in utilization and costs by type. Utilization also differs within California due to differences in the health status of the local population, provider practice patterns, and the level of managed care available in each community. The average cost per service would also vary due to different underlying cost levels experienced by providers throughout California and the market dynamic in negotiations between providers and health plans or insurers. Both the baseline costs prior to the mandate and the estimated cost impact of the mandate could vary within the state due to geographic and delivery system differences. For purposes of this analysis, however, CHBRP has estimated the impact on a statewide level.
- Compliance with the mandate: For estimating the postmandate coverage levels, CHBRP typically assumes that plans and policies subject to the mandate will be in compliance with the coverage requirements of the bill. Therefore, the typical postmandate coverage rates for populations subject to the mandate are assumed to be 100%.

Bill Analysis-Specific Caveats and Assumptions

For this analysis, CHBRP makes the following assumptions:

- The percentage of enrollees receiving intensive behavioral intervention therapies varies by age, as shown in Table D-1.
- Utilization (hours per week) of intensive behavioral intervention therapies varies between age groups and by diagnosis, as shown in Table D-2.
- Persons with PDD/A receiving intensive behavioral intervention therapies would receive this treatment for 40 weeks a year. This figure assumes treatment lasting a full year, less vacation-related breaks.

The age-specific utilization rates in Table D-1 are based on a study detailed in the *Benefit Coverage, Utilization, and Cost Impacts* section (Thomas et al., 2007). CHBRP assumes assumption of minimal or no utilization after the age 14 on available literature (Ganz, 2007) and content expert opinion. The diagnosis specific utilization rates in Table D-2 are based on review of the academic literature and expert opinion. For this analysis, CHBRP assumes that utilization by persons with Asperger’s Disorder is approximately 60% of the utilization rate of persons with PDD/A other than Asperger’s Disorder. CHBRP has made the simplifying assumption of zero utilization for enrollees aged 20 years and older across all PDD/A subtypes. The utilization rate in terms of weeks per year is based on expert opinion.

Table D-2. Intensive Behavioral Intervention Therapy Utilization Assumptions—Percent of Enrollees Utilizing

Age Groups (years)	Percent Users of Intensive Behavioral Intervention Therapy
0–4	40%
5–9	20%
10–14	10%
15–19	1%
20+	0%

Source: California Health Benefits Review Program, 2013.

Table D-3. Intensive Behavioral Intervention Therapy Utilization Assumptions—Hours per Week Utilized

Age Groups (years)	PDD/A Other Than Asperger’s Disorder	Asperger’s Disorder
0–4	25	15
5–9	15	9
10–14	5	3
15–19	5	3
20+	0	0

Source: California Health Benefits Review Program, 2013.

Key: PDD/A=pervasive developmental disorders or autism.

Appendix E: Information Submitted by Outside Parties

In accordance with the California Health Benefits Review Program (CHBRP) policy to analyze information submitted by outside parties during the first 2 weeks of the CHBRP review, the following parties chose to submit information.

The following information was submitted by Senate President Pro Tem Steinberg's Office in February 2013.

Behavioral Analyst Certification Board. Guidelines. Health Plan Coverage of Applied Behavioral Analysis Treatment for Autism Spectrum Disorder. 2012. Available at: http://bacb.com/Downloadfiles/ABA_Guidelines_for_ASD.pdf. Accessed February 11, 2013.

California Legislative Blue Ribbon Commission on Autism. Available at: <http://senweb03.senate.ca.gov/autism/index.html>. Accessed February 11, 2013.

Center for Consumer Information and Insurance Oversight. Additional Information on Essential Health Benefits Benchmark Plans. Available at: <http://cciio.cms.gov/resources/data/ehb.html#california>. Accessed February 11, 2013.

Submitted information is available upon request.

Appendix F: Public Health Calculations

For this analysis, the California Health Benefits Review Program (CHBRP) calculated an estimated prevalence rate of pervasive developmental disorder or autism (PDD/A) for Californians, based on a study cited by the California Department of Developmental Services (DDS) in their 2007 report and adjustments to the report's 2007 data updated by DDS in 2013.¹²⁵ The following explains the rationale and adjustments related to the DDS data.

PDD/A prevalence rates have been increasing during the last 20 years for yet to be determined reasons (Charman et al., 2009; Croen et al., 2002; Williams et al., 2006). CHBRP reviewed several recent estimates of prevalence rates for its cost, utilization and public health impact analysis of SB 126. The decision criteria used to choose the most appropriate rates are: California data preferred over national data (to reflect California population characteristics); studies using multiple ages, with access to age distribution, rather than a single age (to analyze the more intensive use and cost of services at younger ages when screening, diagnosis, and treatment begin); and robust sample size. All sources of data had strengths and limitations. Based on these criteria and CHBRP's analytic needs, the California DDS data are used in this report because of its presentation of California-specific data and distribution of ages diagnosed with PDD/A. Furthermore, requisite data are available from the literature to make necessary adjustments to the undercounts in the California data, considered a potential limitation to the data. CHBRP's estimated prevalence rates are based on the number of people receiving treatment from DDS at a point in time, rather than on survey data or a review of medical or school records. The appearance of declining prevalence of PDD/A in the older age groups is assumed to be a combination of fewer PDD/A persons seeking services through DDS as they age, and a true lower prevalence rate (due to longitudinal differences in diagnostic criteria or actual changes in incidence during the last two decades).

The sources reviewed by CHBRP estimated prevalence rates from 110/10,000 (CDC, 2012) to 132/10,000 (Kogan et al., 2009) with large variation in ages studied, and study methodology (including measurement years).¹²⁶ An analysis of CHBRP's estimated prevalence rates shows that using the higher CHBRP estimate of 240/10,000 (ages 5–9 years) would yield about 17,500 California children aged 5–9 years diagnosed with PDD/A in 2012. The difference in prevalence estimates is due in part to the data's different baseline years (2008 vs. 2012). Clearly, prevalence rates have been increasing over time and a five-year gap explains some of the difference. Additionally, CDC notes a 23% increase in prevalence between 2006 and 2008 (9.0/1,000 vs. 11.0/1,000) and CHBRP estimates a 38% increase between 2007 and 2012 (14.9/1,000 vs. 24.0/1,000)—an additional 3 years of data likely explains the larger increase in the CHBRP estimates. Furthermore, differences may be attributable to California's public diagnostic and support service system, which may be more comprehensive than many other states (King and Bearman, 2009), and may identify PDD/A more accurately. CHBRP's estimate may be closer to the true prevalence rate in 2012 given the accelerated, increasing rates in the last 10 years.

¹²⁵ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

¹²⁶ The CDC's March 20, 2013 report on the prevalence of autism, which estimates 200/10,000 (1 in 50 children ages 6-17 yrs), was not available for review during the writing of this report; however, this new 2012 estimate closely aligns with CHBRP's estimates for that age group (Table 1).

Description and Rationale for Use of California Department of Developmental Services

Data

To provide the best estimate, CHBRP uses data from DDS, which is the primary state agency that serves residents with developmental disabilities, including 75%-80% of persons diagnosed with Autism Disorder (Croen et al., 2002). Updates to the 2007 report data by DDS show that, in 2012, DDS served 60,550 persons with PDD/A who met the service eligibility criteria (defined as those who are diagnosed by a qualified provider with full spectrum, suspected or residual autism [56,309] and “Other ASD” [4,241] [DDS, 2013]). This administrative data appears to be the most comprehensive accounting of California cases of PDD/A.

Limitations to the DDS data may be attenuated through several adjustments (described in Adjustments to DDS Data). The limitations include an undercount of the “Other” PDD category (Asperger’s, Rett’s, and PDD–Not Otherwise Specified [PDD-NOS]) because persons with these diagnoses are less likely to qualify for DDS services due to these usually milder forms of PDD/A (CDC, 2009). Several studies indicated that these two subtypes of PDD/A represent close to double the number of diagnoses than that of autism diagnosis (21/10,000 vs. 43/10,000 [Fombonne, 2009b]; 7.1/10,000 vs. 20/10,000, [Williams et al., 2006]; and 39/10,000 vs. 77/10,000, [Baird et al., 2006]). CHBRP adjusted the DDS data to obtain a more accurate estimate of California’s “other” PDD population. Another potential limitation to DDS data relate to an estimated 20%–25% undercount of the total DDS caseload of those diagnosed with Autism Disorder (estimated after matching DDS records with California Special Education school records [Croen et al., 2002]), for which CHBRP made a simple adjustment.

Adjustments to DDS data

There are two primary categories of diagnoses available in the DDS data: Autism Disorder and “other” PDD. Both require some adjustment to estimate the total number of Californians with PDD/A.

To calculate the prevalence of Autism Disorder in California in 2012:

In Table F-1b, DDS reported that it served an estimated 75%-80% of Autism Disorder diagnoses in California. To find the total persons diagnosed with Autism Disorder, the reported caseload is divided by the midpoint between 75% and 80% ($56,309/0.775=72,657$). DDS also provided the distribution of its Autism Disorder population by age group, which CHBRP used to estimate the California Autism Disorder prevalence rates by age using the following steps in Table F-1a:

1. “DDS reported number of people with Autism Disorder served by DDS”: Multiply the percentage distribution reported by DDS (column B) by 56,309.
2. “Estimated number of people with Autism Disorder in California”: Divide “DDS reported number of people with Autism Disorder served by DDS” by 0.775 (to adjust by age category).
3. “Estimated prevalence of Autism Disorder in California (per 10,000)”: Divide “estimated number of people with Autism Disorder in California” by 2011 California population (CDPH, 2013) and multiply by 10,000.

To calculate the 2012 estimated prevalence rate of “other” PDDs in California:

DDS undercounts “other PDD” diagnoses because this population generally does not qualify for DDS services, although in 2012, DDS reported serving 4,241 Californians with “ASD other than Autism Disorder” (DDS, 2013). CHBRP adjusted the second half of the table for the “other PDDs” using prevalence rates from literature, 2012 DDS data, and 2011 state population estimates (the most recent year for data from the California Department of Public Health). Table F-1b estimates the distribution of PDD/A subtypes using prevalence rates taken from Fombonne (2009b) in which Autism Disorder represents 32% of all PDD and “other” represents 68% of all PDD. To estimate the number of persons diagnosed with PDD subtypes, CHBRP divides (from Table F-1a) the “estimated number of people with Autism Disorder in California” (which has already been adjusted to account for DDS undercount by 23%) by 0.32, which equals the “Estimated total number of Californians with any PDD/A diagnosis” ($72,657/0.32=227,053$). CHBRP subtracts 72,657 from 227,053 to determine the “Other” PDD population (154,396).

Using baseline data from Tables F-1a and F-1b, CHBRP applied the same logic used in the Autism Disorder calculations (steps 1–3) to calculate the age group–specific estimates for the “other” PDD columns.

To find the “estimated prevalence of all PDD/A in California by age category (per 10,000),” CHBRP added “estimated prevalence of ‘other’ PDD in California (per 10,000)” and “estimated prevalence of Autism Disorder in California (per 10,000).”

Review of Other Sources for Prevalence Rates

CHBRP evaluated other sources for data, and concludes that DDS data are more complete for the California population than other national data and permit more accurate estimates of prevalence by age categories, which are most relevant to this analysis.

California Health Interview Survey

The most recent CHIS to collect data on PDD/prevalence was administered in 2005 (CHIS, 2013). CHBRP considers this information out of date for the SB 126 analysis. A prior report by CHBRP for SB TBD-1 in 2011 (CHBRP, 2011) declined to use CHIS 2005 data due to a small number of cases, a narrower age interval than other studies, and limited questions discerning differences among types of PDDs.

National Survey of Children’s Health¹²⁷

CHBRP performed a data query of the 2009–2010 National Survey of Children’s Health, which recorded that 1% of children aged 2–17 years are currently diagnosed with PDD/A (CAHMI, 2013). The second-most recent source for PDD/A prevalence comes from a 2007 National Survey on Child Health. Using these data, Kogan et al. (2009) published an estimated prevalence

¹²⁷ **Update to National Survey on Children’s Health:** On March 20, 2013, the CDC released the results of the 2011-2012 National Survey of Children’s Health, which showed a significant increase in the prevalence of parent-reported autism spectrum disorder (ASD) in children aged 6-17 years (from 116/10,000 to 200/10,000) (Blumberg et al, 2013). Report authors note limitations to the survey including a lower-than-desired response rate (23%); however non-response bias analysis showed that nonrespondents should not have a major impact on the conclusions. The CDC numbers reported for children ages 6-17 appear to correspond to CHBRP estimates (Table F-1); however, the prevalence by specific age interval varies. For example, CHBRP reports the prevalence for ages 5-9 as 240/10,000 and ages 10-14 as 180/10,000 while CDC reports 180/10,000 for ages 6-9 and 239/10,000 for ages 10-13.

of 110/10,000 based on parent-reported diagnosis of “autism spectrum disorders” in children aged 3–17 years. The survey sample size was 78,037 parents, and the study included analysis of prevalence by age category, gender, race, education status, family income, and geographic region. This study reported the highest overall prevalence rate of the studies reviewed by CHBRP (and rates of 132/10,000 and 138/10,000 for children aged 6–8 years and 9–11 years, respectively). CHBRP considers this information out of date for the SB 126 analysis and prefers to use California-specific data when available as the California experience may differ from that of other locales.

Centers for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring Network (ADDM)

The CDC’s ADDM Network coordinated a multisite (14 ADDM sites) surveillance of prevalence, population characteristics, and public health impacts of ASDs and other developmental disabilities. The CDC derived the overall ASD prevalence rate of 113/10,000 from a retrospective review of medical and school records of 8-year-olds. The CDC reported that surveying 8-year olds is optimal as the CDC has “demonstrated that this is the age of identified peak prevalence” (CDC, 2012). Study authors noted that, by age 8, children who were misdiagnosed will be categorized appropriately. Study results showed a wide variation in prevalence rates among sites, (48/10,000 to 212/10,000) and conformed to other study findings of almost five times as many males diagnosed with PDD/A as females. This study was not nationally representative of 8-year-olds and relied on a retrospective review of records (which may have compromised the quantity and quality of data therein). However, the large sample size (more than 300,000, or 8%, of U.S. children aged 8 years), the standardized training of abstractors and clinician reviewers who confirmed cases according to standardized definitions, and the use of multiple sources of administrative data provided a sound methodology for estimating the prevalence of PDD/A. However, the lag in data collection (2008) and the absence of California involvement in the study and the wide variation in prevalence rates between the 14 participating sites support CHBRP’s use of state-specific data when possible.

Table F-1. Calculations for Estimating California PDD/A Prevalence Rates Using Adjusted 2012 California DDS Data

Age Groups (years)	DDS Reported Age Group Distribution of Persons With Autism Disorder Served by DDS (a)	DDS Reported Number of People With Autism Disorder Served by DDS (a)	Estimated Number of People with Autism Disorder in California (b)	California Population (c)	Estimated Prevalence of Autism Disorder in California (per 10,000)	DDS Reported Age Group Distribution of Persons With "Other" PDD Served by DDS (a)	Estimated Number of People With "Other" PDD in California (c)	California Population (c)	Estimated Prevalence of "Other" PDD in California (per 10,000)	Estimated Prevalence of All PDD/A in California by Age Category (per 10,000)
0-4	10.6%	5,948	7,675	2,442,453	31.4	6.3%	9,684	2,442,453	39.6	71.1
5-9	31.0%	17,464	22,534	2,437,539	92.4	23.3%	35,969	2,437,539	147.6	240.0
10-14	22.7%	12,760	16,465	2,575,961	63.9	19.5%	30,071	2,575,961	116.7	180.7
15-19	15.2%	8,565	11,052	2,804,618	39.4	17.1%	26,358	2,804,618	94.0	133.4
20-24	9.0%	5,082	6,557	2,853,312	23.0	14.5%	22,389	2,853,312	78.5	101.4
25-29	3.7%	2,111	2,724	2,849,911	9.6	6.6%	10,121	2,849,911	35.5	45.1
30-34	2.1%	1,157	1,493	2,703,431	5.5	3.8%	5,898	2,703,431	21.8	27.3
35-39	1.4%	766	988	2,538,450	3.9	2.3%	3,531	2,538,450	13.9	17.8
40-44	1.2%	648	836	2,613,424	3.2	2.1%	3,240	2,613,424	12.4	15.6
45-49	1.2%	695	897	2,612,047	3.4	1.7%	2,585	2,612,047	9.9	13.3
50+	2.0%	1,113	1,436	11,129,629	1.3	2.9%	4,551	11,129,629	4.1	5.4
Total	100.0%	56,309	72,657	37,560,775	19.3	100.0%	154,396	37,560,775	41.1	60.4

Source: California Health Benefits Review Program, 2013; DDS.¹²⁸

(a) CHBRP uses the 2012 DDS caseload percentage and number by age category as reported by DDS.

(b) The DDS 2007 report cited a study by Croen et al. (2002) that estimated DDS served 75%–80% of the total Autism Disorder population in California. The DDS Autism Disorder numbers are divided by 0.775 as a midpoint of their estimate to adjust for the DDS undercount. "Other" PDDs are *not* adjusted by the 0.775.

(c) CHBRP uses the 2011 California population (California Department of Public Health: <http://epicenter.cdph.ca.gov/ReportMenus/PopulationTable.aspx>) as the denominator to correspond with the 2012 DDS to capture the prevalence rate (point in time) in 2012.

Key: DDS=California Department of Developmental Services.

¹²⁸ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

Table F-2. Determining Distribution of PDD/A Subtypes in the California PDD/A Population in 2007

PDD and Its Subtypes	Epidemiology of PDD: Prevalence Rates (a)	Percentage and Number of PDD Subtypes (b)	
Autism Disorder	20.6/10,000	32%	72,657
PDD-NOS	37.1/10,000	NA	NA
Asperger’s Disorder	6/10,000	NA	NA
Childhood Disintegrative Disorder/Rett’s Disorder (c)	1/100,000 1/50,000	NA	NA
“Other PDDs” (defined as total of PDD-NOS and Asperger’s)	43.1/10,000	68%	154,396
Estimated total number of Californians with any PDD/A diagnosis (2007)	NA	100%	227,053

Source: California Health Benefits Review Program, 2013 (based on data from a report by DDS, 2009, and Fombonne, 2009b).

Notes: Table F-1b explains the underlying calculations to estimating “Other PDD” numbers (in Table F-1a) for the California population. The “other PDD” estimates are not available through DDS or other state agencies, thus the estimation by CHBRP.

(a) Prevalence rates are taken from Fombonne, 2009b: Autism Disorder represents 32% of all PDD, and “Other PDDs” represents 68% of all other PDD categories—those that are grouped in the shaded area.

(b) “Percentage and number of PDD subtypes” are derived from Fombonne prevalence rates and 2012 DDS data for Autism Disorder—only population. From Table F-1a, divide “estimated number of people with Autism Disorder in California” (which has already been adjusted to account for DDS undercount by 23%) by 0.32, which equals the “Estimated total number of Californians with any PDD/A diagnosis” (72,657/0.32=227,053). Subtract 72,657 from 227,053 to determine “Other” PDD population (154,396).

(c) Childhood Disintegrative Disorder and Rett’s Disorder not included in “other PDDs.”

Key: NOS=not otherwise specified; PDD/A=pervasive developmental disorders or autism.

Table F-3. 2012 PDD/A Population Served by DDS—Data Used to Inform Table F-1a

Age	Autism	UCD Calculation	Other ASD	UCD Calculation
Statewide	56,309		4,241	
00–04	10.6%	5,948	6.3%	266
05–09	31.0%	17,464	23.3%	988
10–14	22.7%	12,760	19.5%	826
15–19	15.2%	8,565	17.1%	724
20–24	9.0%	5,082	14.5%	615
25–29	3.7%	2,111	6.6%	278
30–34	2.1%	1,157	3.8%	162
35–39	1.4%	766	2.3%	97
40–44	1.2%	648	2.1%	89
45–49	1.2%	695	1.7%	71
50–99	2.0%	1,113	2.9%	125

Source: California Health Benefits Review Program, 2013; DDS.¹²⁹

Note: These data were used to inform columns B and G in Table F-1a. These data support calculations in Table F-1a to estimate the prevalence of PDD/A in California by age category.

Key: ASD=autism spectrum disorders; UCD=University of California, Davis.

¹²⁹ Personal communication, E. Gelber and P. Choate, DDS, February 2013.

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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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