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CALIFORNIA
HEALTH BENEFITS REVIEW PROGRAM

Analysis of Senate Bill TBD 1:
Health Care Coverage:
Autism

A Report to the 2011-2012 California Legislature
March 20, 2011



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 by statute (California Health and Safety Code, Section 127660, et seq). 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; or (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.

A small 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, as well as Loma Linda University, the University of Southern California, and Stanford University, 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, and 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 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 a small annual assessment on health plans and insurers in California. All CHBRP reports and information about current requests from the California Legislature are available at the CHBRP Web site, www.chbrp.org.

A Report to the 2011-2012 California State Legislature

Analysis of Senate Bill TBD 1: Autism

March 20, 2011

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Additional free copies of this and other CHBRP bill analyses and publications may be obtained by visiting the CHBRP Web site at www.chbrp.org.

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PREFACE

This report provides an analysis of the medical, financial, and public health impacts of Senate Bill SB TBD 1. In response to a request from the California Senate Committee on Health on January 19, 2011 the California Health Benefits Review Program (CHBRP) undertook this analysis pursuant to the program's authorizing statute.

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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 TBD 1

Senate President pro Tempore Darrell Steinberg requested on January 19, 2011, 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) TBD 1 Autism, a bill that would impose a health benefit mandate. The full text of SB TBD 1 is available on CHBRP's Web site.¹ In response to this request, CHBRP undertook this analysis pursuant to the provisions of the program's authorizing statute.²

State-level health insurance benefit mandates

Approximately 21.9 million Californians (59%) 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 is uninsured (and so has no health insurance subject to any benefit mandate) and another portion has 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-level 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 insurers⁵, which offer benefit coverage to their enrollees through health insurance policies.

DMHC-regulated plans and CDI-regulated policies would be subject to SB TBD 1. However, SB TBD 1 is amending current mental health parity law in California⁶ that exempts health insurance provided to Medi-Cal beneficiaries through contracts with the California Department of Health Care Services (DHCS). Therefore, CHBRP assumes, even though the exemption in language of the bill is not perfectly clear,⁷ that current mental health parity law in California SB TBD 1 would not apply to the benefit coverage provided to enrollees in Medi-Cal Managed Care. For this reason, the mandate would affect the health insurance of approximately 18.1 million Californians (48%).⁸

¹ www.chbrp.org.

² CHBRP's authorizing statute is available at: www.chbrp.org/documents/authorizing_statute.pdf.

³ CHBRP's estimates are available at www.chbrp.org/documents/insur_source_est_2011.pdf.

⁴ DMHC was established in 2000 to enforce the Knox-Keene Health Care Service Plan of 1975; see Health and Safety Code, Section 1340.

⁵ 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, Section 106(b) or subdivision (a) of Section 10198.6.

⁶ California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88).

⁷ Personal communication, T. Le Bas, Department of Managed Health Care, February 2011.

⁸ Although CHBRP has no further information, it is possible that SB TBD 1 could have impacts beyond this population, because mental health only plans regulated by DMHC or CDI may be subject to SB TBD1.

Existing state and federal requirements relevant to SB TBD 1

Current California mental health parity law⁹ (referenced by SB TBD 1) requires coverage for diagnosis and medically necessary treatment of severe mental illnesses (including pervasive developmental disorders or autism [PDD/A]) for persons of any age. It does not, however, specify intensive behavioral intervention therapy as a treatment for PDD/A for which benefit coverage is mandated. Applicable federal law¹⁰ also addresses parity for mental health benefits.

Background on disorders relevant to SB TBD 1

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 mental retardation.

Analysis of SB TBD 1

SB TBD 1 would require coverage of intensive behavioral intervention therapy for PDD/A. The bill defines intensive behavioral intervention therapy as including but not being limited to applied behavioral analysis (ABA). Although current mental health parity law in California requires that coverage be provided for medically necessary treatment of PDD/A, including outpatient services, it does not specify that coverage is required for intensive behavioral intervention therapy. Therefore, SB TBD 1 would alter the current mandate.

This report uses the term PDD/A in an effort to make clear that all five disorders are relevant to current mental health parity law in California and to SB TBD 1. The terms autism, Autistic Disorder, or autism spectrum disorders (ASD) are commonly used, but may be used as a synonym for “autism,” not necessarily intending inclusion or exclusion of the two generally less severe disorders (Asperger’s Disorder and Pervasive Developmental Disorder Not Otherwise Specified [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.

SB TBD 1 defines intensive behavioral intervention therapy as inclusive of the following: “design, implementation, and evaluation of environmental modifications, such as ABA, using behavioral stimuli and consequences to produce significant improvement in human health functions and behaviors, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior; and professional services or treatment programs that have been scientifically validated and have demonstrated clinical

⁹ California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88).

¹⁰ Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA); any relevant State Children’s Health Insurance Law (SCHIP), as Healthy Families Program would be subject to SB TBD 1.

efficacy; professional services or treatment programs that have measurable treatment outcomes.” In this report, interventions based on ABA and/or other theories of behavior are referred to as intensive behavioral intervention therapy.

SB TBD 1 would also require 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.

Payors other than health plans and insurers

Payment for intensive behavioral intervention therapy 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) often pay directly for care not covered by health insurance. Charities may also become involved. In addition, for PDD/A-related intensive behavioral intervention therapy, regional centers contracting with the California Department of Developmental Services (DDS)¹¹ may pay, as may schools affiliated with the California Department of Education (CDE).¹² However, while the population served by DDS and/or CDE would be expected to overlap with enrollees whose health insurance would be subject to SB TBD 1, the populations would not be identical. DDS does not collect¹³ information about the sources of health insurance that would allow clients to be identified as having health insurance subject to SB TBD 1 and regional centers may serve persons without health insurance. Similarly, CDE-affiliated schools may serve persons without health insurance, but CDE does not collect information on the health insurance status of public school students.¹⁴ To further complicate matters, some enrollees with health insurance subject to SB TBD 1 may not seek assistance from a regional center or school or may not meet the severity thresholds to qualify for assistance per these programs’ eligibility rules. Therefore, the overlap between the populations with PDD/A—persons served by DDS and/or CDE and enrollees with health insurance that would be subject to SB TBD 1—is not clear.

Requirement in other states

At least 26 states and the District of Columbia have passed health insurance benefit mandates related to autism.

¹¹ 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).

¹² Services provided by public schools are related to Part B of the Federal Individuals with Disabilities Education Act (2004).

¹³ Personal communication, J Mullen, California Department of Developmental Services, March 2011.

¹⁴ Personal communication, P Skelton, California Department of Education, March 2011.

Medical Effectiveness

Many children with PDD/A are treated with intensive (e.g., 25 or more hours per week) interventions based on applied behavioral analysis (ABA) and/or other theories of behavior (hereafter referred to as intensive behavioral intervention therapy) that are aimed at improving behavior and reducing deficits in cognitive function, language, and social skills. The medical effectiveness review focuses on intensive behavioral therapies because SB TBD 1 would specifically require coverage for these and other behavioral intervention therapies.

Methodological Considerations

The literature on the effectiveness of intensive behavioral intervention therapies for PDD/A is difficult to synthesize. ***Most studies compared intensive behavioral intervention therapies of differing duration and intensity or compared interventions based on different theories of behavior.*** Thus, most studies of intensive behavioral intervention therapy cannot answer the question of whether behavioral intervention therapy improves outcomes relative to no treatment. They can only answer the question of whether some behavioral intervention therapies are more effective than others. Even this question is difficult to answer because the characteristics of treatments provided to both intervention and comparison groups vary widely across studies. The outcomes examined by studies of intensive behavioral intervention therapies also differ considerably across studies. Only four outcomes, which are described in greater depth in the *Medical Effectiveness* section of the report, have been measured by a plurality of studies: adaptive behavior, intelligence quotient, language, and academic placement. Findings for these outcomes cannot be easily combined across studies because authors have used different instruments to collect information on these outcomes.

An important limitation of the literature on the effectiveness of intensive behavioral intervention therapies for PDD/A is that 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.

Many studies of intensive behavioral intervention therapies do not assess outcomes over sufficiently long periods of time to determine whether use of these therapies is associated with long-term benefits.

Study Findings

- Six recent meta-analyses and one individual randomized controlled trial (RCT) have assessed the effectiveness of intensive behavioral intervention therapies. Most children enrolled in these studies were treated for 1 to 2 years.
- Studies of intensive behavioral intervention therapies have 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 intelligence quotients (IQs) within the ranges for Mild or Moderate Mental Retardation.

- CHBRP identified no studies regarding effectiveness of intensive behavioral intervention therapy in children younger than 18 months and persons older than 9 years, nor was there direct evidence about this therapy's 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 study populations.
- Outcomes for individual children enrolled in studies of intensive behavioral therapies varied widely. Several meta-analyses have attempted to identify the characteristics of children with who are most likely to benefit from early intensive behavioral therapies. Findings from these studies suggest that children who are younger at initiation of treatment and who have higher IQs and greater adaptive behavior skills (e.g., communication, daily living, motor, and social skills) derive greater benefit from treatment.

Adaptive behavior

- The preponderance of evidence from six meta-analyses of RCTs and nonrandomized studies suggests that intensive behavioral intervention therapy on ABA, is more effective than therapies based on other theories of behavior or less intensive ABA-based therapies in improving adaptive behavior (e.g., communication, daily living, motor, and social skills). However, two RCTs that compared two different types of intensive behavioral intervention therapies based on ABA found no differences in effects on adaptive behavior in the intervention and control groups.
- 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 the Early Start Denver Model was associated with greater improvement in adaptive behavior relative to other interventions available in the community.
- One meta-analysis found that the intensive behavioral intervention therapies of longer duration had more impact on adaptive behavior.

Intelligence quotient

- The preponderance of evidence from six meta-analyses suggests that intensive behavioral intervention therapies based on ABA are more effective than therapies based on other theories of behavior or less intensive ABA-based therapies in increasing intelligence quotient (IQ). Two randomized controlled trials (RCTs) of intensive behavioral intervention therapies based on ABA reached opposite conclusions regarding the impact of these interventions on IQ. The discrepancy between the conclusions of these RCTs may be due to differences in the intensity and duration of the interventions provided to the control groups.

- A single RCT of the Early Start Denver Model found that receipt of this intensive behavioral intervention therapy was associated with greater improvement in IQ relative to other interventions available in the community.
- *Most studies found that the changes in intelligence were not sufficiently large to enable children to achieve levels of intellectual and educational functioning similar to peers without PDD/A.*

Language

- Findings from four meta-analyses that included studies that compared the effects of intensive behavioral intervention therapies based on ABA to therapies based on other theories of behavior or less intensive ABA-based therapies on general language skills and receptive language (i.e., ability to respond to requests from others) are ambiguous.
- The preponderance of evidence from three meta-analyses suggests that intensive behavioral intervention therapies based on ABA are no more effective than therapies based on other theories of behavior or less intensive ABA-based interventions for improving expressive language (i.e., ability to verbally express one's needs and wishes).
- One meta-analysis found that intensive behavioral intervention therapies that provided more total hours of treatment had larger effects on language skills.

Academic placement

- Findings from a systematic review that assessed studies that compared the effects of intensive behavioral intervention therapies based on ABA to therapies based on other theories of behavior or less intensive ABA-based interventions on academic placement are ambiguous.

Benefit Coverage, Utilization, and Cost Impacts

Approximately 77,000 enrollees in DMHC-regulated plans and/or CDI-regulated policies subject to SB TBD 1 are diagnosed with PDD/A. Table 1 summarizes the expected benefit coverage, cost, and utilization impacts for SB TBD 1.

Critical Caveats, Estimates, and Assumptions

- Although studies on the effectiveness of intensive behavioral intervention therapies is focused on Autistic Disorder and PDD-NOS in pre-school- and elementary-aged children, as evaluated in the *Medical Effectiveness* section, this analysis models benefit

coverage, utilization and cost impacts for all five PDD/A subtypes and for all ages. The cost model makes weighted adjustments for age-specific and PDD/A subtype utilization: for example, literature reviewed in the *Medical Effectiveness* section and expert opinion indicate that intensive behavioral intervention utilization is rare for children under age 2, less common for adults, and less common for some PDD/A subtypes, for example Asperger's Disorder.

- Due to variations in severity of PDD/A, circumstances, and/or preferences, not all would get intensive behavioral intervention therapies, even if diagnosed and enrolled in a plan or policy that covers intensive behavioral intervention therapies. Also, treatment, which typically spans 1 to 3 years,¹⁵ may be discontinued if shown to be ineffective for that person.
- In California, intensive behavioral intervention therapies not covered by health plans or insurers may be purchased by other payors, including families, charities, the California Department of Developmental Services (DDS), the California Department of Education (CDE), or other payors.
- CHBRP estimates that the mandate would affect intensive behavioral intervention therapy utilization in two ways: it would add new users of intensive behavioral intervention therapies, and, among newly-covered users, intensive behavioral intervention therapy hours per week would increase.
 - CHBRP estimates that the mandate would add new users of intensive behavioral intervention therapies in the under 3 age group, but for all other age groups, the number of users of intensive behavioral intervention therapies are assumed to be the same pre- and postmandate. This is because some children under the age of 3 years may not qualify for services paid for by DDS (because they have milder forms of PDD/A) and would be too young to receive school-based services paid by CDE. School-aged children and young adults who may not qualify for DDS services (because they have milder forms of PDD/A) could still access services paid for by CDE. Therefore, families of children under age 3 years could may not be using services since they would have to find another payor or self-pay. CHBRP assumes that utilization in this group would be sensitive to coverage as a result of SB TBD 1.
 - CHBRP also estimates that, premandate, enrollees without benefit coverage currently utilizing intensive behavioral intervention therapies are not receiving the full-recommended hours per week. Postmandate, CHBRP estimates that these users would increase their number of hours per week up to the typical recommended hours per week for the user's age and PDD/A disease subtype.

¹⁵ Personal communication, report content expert N Akshoomoff, February 2011. Additionally, as reviewed in the *Medical Effectiveness* section, of the 28 studies that reported the duration of intervention studied, the duration ranged from 3 months to 4 years, with a median of 15 months and a mode of 2 years.

Benefit Coverage Impacts

- CHBRP estimates that 19.5% of enrollees with health plans and policies that would be subject to SB TBD 1 have coverage for intensive behavioral intervention therapies.
- If SB TBD 1 were enacted, 100% of enrollees with health plans and policies that would be subject to SB TBD 1 would have coverage for intensive behavioral intervention therapies, increasing the number of enrollees covered for this benefit from 3.5 million to 18.1 million: a 412% increase.

Utilization Impacts

- Premandate, of the estimated 77,000 enrollees diagnosed with PDD/A in DMHC- or CDI-regulated plans or policies subject to SB TBD 1, an estimated 1,400 enrollees received intensive behavioral intervention therapies covered through their health insurance and 6,900 enrollees received Intensive Behavioral Intervention therapies paid for by another source.
- The mandate is estimated to increase the number of enrollees receiving intensive behavioral intervention therapies through their insurance from approximately 1,400 premandate to 8,700 postmandate: a 521% increase.
- The mandate is estimated to result in 400 new users of intensive behavioral intervention therapies and would shift 6,900 current noncovered users of intensive behavioral intervention therapies to obtain intensive behavioral intervention therapies through their insurance.

Cost Impacts

- SB TBD 1 would increase total expenditures by approximately \$93.3 million, or 0.10%, for plans and policies subject to SB TBD 1. This increase in expenditures results from a \$222.4 million increase in health insurance premiums, a \$17.1 million increase in out-of-pocket expenses for enrollees with PDD/A with newly covered benefits, and a \$146.2 million decrease in expenses for noncovered benefits.
 - The premium impact would range from 0.14% to 0.24% for privately funded health insurance.
 - The premium impact would range from 0.26% to 3.54% for publicly funded health insurance.
 - Because SB TBD 1 contains an exemption, there would be no cost impact for plans providing health insurance to beneficiaries of Medi-Cal enrolled in Medi-Cal Managed Care Plans.

- The \$146.2 million reduction in expenses for noncovered benefits would be a reduction in expenditures for payors other than health plans/insurers. It would be partially offset by the increase in \$17.1 million that enrollees with PDD/A would see in out-of-pocket expenses for newly covered benefits.
- SB TBD 1 would be expected to shift costs to DMHC-regulated plans and CDI-regulated insurers. However, as discussed in *Introduction*, the extent of population overlap is unclear and so it is not possible to calculate what portion of such costs that would be shifted from families, charities, DDS, CDE or other payors.

Impact on Number of Uninsured

As CHBRP estimates premium increases of less than 1% for privately funded health insurance subject to SB TBD 1, no measurable impact on the number of persons who are uninsured would be expected.

Public Health

As noted in the *Medical Effectiveness* section, the preponderance of evidence on the effectiveness and use of intensive behavioral intervention therapy focuses on children aged 18 months to 9 years who are diagnosed with Autistic Disorder and PDD-NOS, many of whom have IQs within the range of mild or moderate mental retardation. CHBRP found no studies regarding effectiveness of intensive behavioral intervention therapy in children younger than 18 months or persons older than 9 years, nor was there direct evidence about this therapy's effectiveness for persons diagnosed with Asperger's, Rett's, or Childhood Disintegrative Disorder. **The absence of evidence is not evidence of no effect, and these therapies may be appropriate for some persons with PDD/A who fall outside the study populations.**

As noted in the *Benefit Coverage, Cost, and Utilization* section, the use of intensive behavioral intervention therapy varies among the five disorders included in PDD/A. Use of the therapy among enrollees with Asperger's Disorder and Rett's is estimated to be less common. While there may be less use among those with Asperger's Disorder or Rett's Disorder, there still may be *some* use.

The Public Health section addresses the relevant population as PDD/A, understanding that relevance may be limited for some ages and diagnoses.

- CHBRP estimates SB TBD 1 could produce some improvement in IQ scores and adaptive behaviors for children aged 18 months to 9 years with diagnoses of Autistic Disorder and PDD-NOS due to the effectiveness of intensive behavioral intervention therapy and increased coverage and utilization. The public health impact on persons outside of this age range or with other PDDs is unknown (see the *Medical Effectiveness* and *Benefit Coverage, Cost, and Utilization* sections for supporting detail).

- CHBRP found no literature or data regarding the possible differential use or outcomes by gender of intensive behavioral intervention therapies within the insured population; therefore, the public health impact of SB TBD 1 on reducing the disproportionate burden of PDD/A symptoms experienced by males is unknown.
- CHBRP does not have access to the racial/ethnic distribution of enrollees among plans and policies that would be subject to SB TBD 1 nor did CHBRP find literature about differential use or outcomes of intensive behavioral intervention therapies by race; therefore, the public health impact of SB TBD 1 on reducing potential racial and ethnic disparities of PDD/A symptoms is unknown.
- Although an increased risk of premature death is associated with PDD/A, CHBRP found no evidence about intensive behavioral intervention therapy and its affect on premature death for the PDD/A population; therefore, the public health impact of SB TBD 1 on premature death is unknown.
- Due to lack of evidence, CHBRP concludes the public health impact of SB TBD 1 is unknown regarding the effects of intensive behavioral intervention therapy on lost productivity for persons with PDD/A and their caregivers.
- CHBRP estimates that the postmandate, net decrease in noncovered benefit expenses for the estimated 7,300 newly covered enrollees with PDD/A who use intensive behavioral intervention therapies is about \$146 million. The extent of the reduction in financial burden for enrollees with PDD/A and their families is unknown, as some portion of the shift may be from charities, DDS, CDE, or other payors.

Potential Effects of the Federal Affordable Care Act

The federal “Patient Protection and Affordable Care Act” (P.L.111-148) and the “Health Care and Education Reconciliation Act” (H.R.4872) were enacted in March 2010. These laws (together referred to as the “Affordable Care Act [ACA]”) are expected to dramatically affect the California health insurance market and its regulatory environment, with most changes becoming effective in 2014. How these provisions are implemented in California will largely depend on pending legal actions, funding decisions, regulations to be promulgated by federal agencies, and statutory and regulatory actions to be taken by California state government. The provisions that go into effect during these transitional years would affect the baseline, or current enrollment, expenditures, and premiums. It is important to note that CHBRP’s analysis of specific mandate bills typically address 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 this report.

Essential health benefits for plans sold in the California Exchange and potential interactions with SB TBD 1

As mentioned, EHBs explicitly include “[m]ental health and substance use disorder services, including behavioral health treatment” and “rehabilitative and habilitative services and devices.”¹⁶ The provisions also require that the scope of the EHBs be equal to the scope of benefits provided under a typical employer plan. The ACA requires in 2014 that states “make payments...to defray the cost of any additional benefits” required of Qualified Health Plans (QHPs) sold in the Exchange.¹⁷ SB TBD 1 states, “this section does not require any benefits to be provided that exceed the essential health benefits required to be provided [by QHPs]” Therefore, because of this provision, SB TBD 1 is not expected to incur a fiscal liability for the state as it relates to the QHPs sold in the Exchange.

Whether or not the benefits required by SB TBD 1 would exceed EHBs depend on three factors:

- differences in the scope of mental health and rehabilitative/habilitative benefits in the final EHB package and the scope of mandated benefits in SB TBD 1:
- the number of enrollees in QHPs; and,
- the methods used to define and calculate the cost of additional benefits.

For example, it is unclear whether there will be differences between the mental health and rehabilitative/habilitative benefits included in the EHBs and the benefits required under SB TBD 1. “Behavioral health treatment” may be considered to include forms of “behavioral intervention treatment,” as specified by SB TBD 1. “Habilitative” services may be determined to include forms of therapy that enhance a child’s ability to function.

¹⁶ Affordable Care Act, Section 1302(b)(1)(E) and (G).

¹⁷ Affordable Care Act, 1311(d)(3)(B).

Table 1. SB TBD 1 Autism Impacts on Benefit Coverage, Utilization, and Cost, 2011

	Before Mandate	After Mandate	Increase/ Decrease	Change After Mandate
Benefit Coverage				
Total enrollees with health insurance subject to state-level benefit mandates (a)	21,902,000	21,902,000	0	0.00%
Total enrollees with health insurance subject to SB TBD 1	18,078,000	18,078,000	0	0.00%
Number of enrollees with health insurance coverage subject to SB TBD 1 and having PDD/A	77,000	77,000	0	0.00%
Percentage of enrollees with coverage for the mandated benefit	19.54%	100.00%	80.46%	411.69%
Number of enrollees with coverage for the mandated benefit	3,533,000	18,078,000	14,545,000	411.69%
Utilization and cost				
Number of enrollees using intensive behavioral intervention benefit				
Benefit covered (b)	1,400	8,700	7,300	521.43%
No benefit covered	6,900	—	-6,900	-100.00%
Average annual intensive behavioral intervention cost per member receiving intensive behavioral intervention	\$44,000	\$50,000	\$6,000	13.64%
Expenditures				
Premium expenditures by private employers for group insurance	\$52,713,266,000	\$52,839,042,000	\$125,776,000	0.24%
Premium expenditures for individually purchased insurance	\$6,724,851,000	\$6,734,228,000	\$9,377,000	0.14%
Premium expenditures by persons with group insurance, CalPERS HMOs, Healthy Families Program, AIM, or MRMIP (c)	\$15,173,472,000	\$15,214,727,000	\$41,255,000	0.27%
CalPERS HMO employer expenditures (d)	\$3,465,785,000	\$3,474,645,000	\$8,860,000	0.26%
Medi-Cal Managed Care Plan expenditures (e)	\$8,657,688,000	\$8,657,688,000	\$0	0.00%
MRMIB Plan expenditures (f)	\$1,050,631,000	\$1,087,780,000	\$37,149,000	3.54%
Enrollee out-of-pocket expenses for covered benefits (deductibles, copayments, etc.)	\$7,548,415,000	\$7,565,555,000	\$17,140,000	0.23%
Enrollee expenses for noncovered benefits (g)	\$327,343,000	\$181,116,000	(\$146,227,000)	-44.67%
Total Expenditures	\$95,661,451,000	\$95,754,781,000	\$93,330,000	0.10%

Source: California Health Benefits Review Program, 2011.

Notes: (a) This population includes persons with privately funded and publicly funded (e.g., CalPERS HMOs, Medi-Cal Managed Care plans, Healthy Families Program, AIM, MRMIP) health insurance products regulated by DMHC or CDI. Population includes enrollees aged 0 to 64 years and enrollees 65 years or older covered by employment sponsored insurance.

(b) The postmandate estimate includes three groups of enrollees: users who had premandate benefit coverage (approximately 1,400), new users (approximately 400), and users who had, premandate, accessed the treatment without benefit coverage (approximately 6,900).

(c) Premium expenditures by enrollees include employee contributions to employer-sponsored health insurance and enrollee contributions for publicly purchased insurance.

(d) Of the increase in CalPERS employer expenditures, about 58%, or \$5,139,000, would be expenditures for CalPERS members who are state employees or their dependents.

(e) For this report, CHBRP assumes that SB TBD 1 would exempt Medi-Cal Managed Care from compliance with the mandate.

(f) MRMIB Plan expenditures include expenditures for 874,000 enrollees of the Healthy Families Program, 8,000 enrollees of MRMIP, and 7,000 enrollees of the AIM program.

(g) Includes expenses paid by enrollees and by sources other than enrollees' health insurance to for services related to the mandated benefit when the benefit is not covered by health insurance.

Key: AIM=Access for Infants and Mothers; CalPERS HMOs=California Public Employees' Retirement System Health Maintenance Organizations; CDI=California Department of Insurance; DMHC=Department of Managed Health Care; MRMIB=Managed Risk Medical Insurance Board; MRMIP=Major Risk Medical Insurance Program.

INTRODUCTION

Senate President pro Tempore Darrell Steinberg requested on January 19, 2011, 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) TBD 1: Autism, a bill that would impose a health benefit mandate. The full text of SB TBD 1 is reprinted in Appendix A. In response to this request, CHBRP undertook this analysis pursuant to the provisions of the program's authorizing statute.¹⁸ Following this *Introduction*, successive sections of this report address: medical effectiveness; benefit coverage, cost, and utilization impacts; and public health impacts.

Approximately 21.9 million Californians (59%) have health insurance that may be subject to a health benefit mandate law passed at the state level.¹⁹ Of the rest of the state's population, a portion is uninsured (and so has no health insurance subject to any benefit mandate) and another portion has 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-level benefit mandates. The California Department of Managed Health Care (DMHC)²⁰ regulates health care service plans, which offer benefit coverage to their enrollees through health plan contracts. The California Department of Insurance (CDI) regulates health insurers²¹, which offer benefit coverage to their enrollees through health insurance policies.

DMHC-regulated plans and CDI-regulated policies would be subject to SB TBD 1. However, SB TBD 1 is amending current California code related to mental health benefits²² which exempts health insurance provided to Medi-Cal beneficiaries through contracts with the California Department of Health Care Services (DHCS). Therefore, CHBRP assumes, even though the exemption in the language of the bill is not perfectly clear,²³ that SB TBD 1 would not apply to benefit coverage provided to enrollees in Medi-Cal Managed Care. For this reason, the mandate would affect the health insurance of approximately 18.1 million Californians (48%).²⁴

¹⁸ CHBRP's authorizing statute is available at: www.chbrp.org/documents/authorizing_statute.pdf.

¹⁹ CHBRP's estimates are available at: www.chbrp.org/documents/insur_source_est_2011.pdf.

²⁰ DMHC was established in 2000 to enforce the Knox-Keene Health Care Service Plan of 1975; see Health and Safety Code, Section 1340.

²¹ 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, Section 106(b) or subdivision (a) of Section 10198.6.

²² California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88).

²³ Personal communication, T. Le Bas, Department of Managed Health Care, February 2011.

²⁴ Although CHBRP has no further information, it is possible that SB TBD 1 could have impacts beyond this population, because mental health only plans regulated by DMHC or CDI may be subject to SB TBD1.

Existing state and federal requirements

Current California mental health parity law²⁵ (referenced by SB TBD 1) requires coverage for diagnosis and medically necessary treatment of severe mental illnesses [including pervasive developmental disorders or autism (PDD/A)] for persons of any age. It does not, however, specify behavioral intervention therapy as a treatment for PDD/A for which benefit coverage is mandated. Applicable federal law²⁶ also addresses parity for mental health benefits.

Bill language

The full text of SB TBD 1 can be found in Appendix A.

SB TBD 1 would require coverage of behavioral intervention therapy for pervasive developmental disorders or autism (PDD/A), which could be viewed as an expansion, in terms of mandated benefit coverage.

This report uses the term PDD/A in an effort to make clear all that five disorders are relevant to current mental health parity law in California and to SB TBD 1. The terms autism, Autistic Disorder, or autism spectrum disorders (ASD) are commonly used, but may be used as a synonym for “autism,” 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.

SB TBD 1 defines behavioral intervention therapy as including but not being limited to applied behavioral analysis (ABA). Specifically, it defines behavioral intervention therapy as inclusive of the following: “design, implementation, and evaluation of environmental modifications, such as ABA, using behavioral stimuli and consequences, to produce significant improvement in human health functions and behaviors, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior; professional services or treatment programs that have been scientifically validated and have demonstrated clinical efficacy; professional services or treatment programs that have measurable treatment outcomes.” In this report, interventions based on ABA and/or other theories of behavior are referred to as intensive behavioral intervention therapy.

SB TBD 1 would also require 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.

²⁵ California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88)).

²⁶ Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA); any relevant State Children’s Health Insurance Law (SCHIP), as the Healthy Families Program would be subject to SB TBD 1.

Payors other than health plans and insurers

Payment for intensive behavioral intervention therapy 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) often pay directly for care not covered by health insurance. Charities may also become involved. However, in addition to families and charities, for PDD/A-related intensive behavioral intervention therapy, regional centers contracting with the California Department of Developmental Services (DDS) may pay.²⁷ Schools affiliated with the California Department of Education (CDE),²⁸ may do so as well.

Regional centers with contracts from the DDS are nonprofit, private corporations that contract with the DDS to provide or coordinate services and support for individuals with developmental disabilities.²⁹ 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, 2011). 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 whose health insurance would be subject to SB TBD 1, but the populations would not be identical. DDS does not collect³⁰ information about the sources of health insurance that would allow clients to be identified as having health insurance subject or not subject to SB TBD 1 and regional centers may serve persons without health insurance. In addition, some enrollees with health insurance subject to SB TBD 1 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 the populations with PDD/A—persons served by DDS and enrollees with health insurance that would be subject to SB TBD 1—is not clear.

Public schools provide some services to some persons with PDD/A, including psychological services.³¹ Although CDE does not collect information which allows such specificity, such services may include intensive behavioral intervention therapy. Again, such a population would be expected overlap with enrollees whose health insurance would be subject to SB TBD 1, but the populations would not be identical. CDE does not collect information on the health insurance status of public school students³² and CDE-affiliated schools may serve persons without health insurance. In addition, some enrollees with health insurance subject to SB TBD 1 may attend private schools or may not have impairments sufficient to justify CDE supported services (California Legislature, 2007). Therefore, the overlap between the

²⁷ Personal communication, J Mullen, California Department of Developmental Services, March 2011.

²⁸ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

²⁹ 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).

³⁰ Personal communication, J Mullen, California Department of Developmental Services, March 2011.

³¹ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

³² Personal communication, P Skelton, California Department of Education, March 2011.

populations—those served by CDE and enrollees with health insurance that would be subject to SB TBD 1—is not clear.

Analytic approach and key assumptions

SB TBD 1 would amend current mental health parity law in California.

- Current law does not define PDD/A, but regulations governing health care service plans³³ 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]*). Therefore, CHBRP assumes that SB TBD 1 would require coverage for intensive behavioral intervention therapy for the same set of five disorders.
- Current 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. SB TBD 1 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. Therefore, CHBRP assumes that SB TBD 1 would require that terms and conditions for coverage of intensive behavioral intervention therapy for PDD/A be in parity with benefit coverage provided for physical or mental health.
- Current law specifies that coverage is mandated for “medically necessary” treatment. Therefore, CHBRP assumes that SB TBD 1 would also mandate benefit coverage subject to medical necessity and that the mandated benefits would be subject to the utilization review by the plan or policy and subject to the Independent Medical Review (IMR) process.

SB TBD 1 states “This section shall not be construed as reducing any obligation to provide services to an enrollee under an individualized family service plan, an individualized program plan, a prevention program plan, an individualized education program, or an individualized service plan.” The referenced “plans” are not terms generally associated with health insurance. These types of plans are associated with the regional centers that contract with the California Department of Developmental Services (DDS) or with affiliates of the California Department of Education (CDE). CHBRP assumes the language in SB TBD 1 addressing these types of plans would have no impact on DMHC-regulated plans or CDI-regulated policies.

Requirements in other states

At least 26 states and the District of Columbia have passed health insurance benefit mandates related to autism (BCBSA, 2010).

³³ California Code of Regulations 1300.74.72(e).

Potential Effects of Federal Affordable Care Act

The federal “Patient Protection and Affordable Care Act” (P.L.111-148) and the “Health Care and Education Reconciliation Act” (H.R.4872) were enacted in March 2010. These laws (together referred to as the “Affordable Care Act [ACA]”) are expected to dramatically affect the California health insurance market and its regulatory environment, with most changes becoming effective in 2014. How these provisions are implemented in California will largely depend on pending legal actions, funding decisions, regulations to be promulgated by federal agencies, and statutory and regulatory actions to be taken by California state government.

The provisions that go into effect during the transitional years (2011-2013) would affect the baseline, or current, enrollment, expenditures, and premiums. It is important to note that CHBRP’s analysis of specific mandate bills typically address 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 this report. Each of the provisions that have gone into effect by January 2011 has been considered to determine whether they may affect CHBRP’s 2011 Cost and Coverage Model. There are still a number of provisions that have gone into effect for which data are not yet available. Where data allow, CHBRP has made adjustments to the Cost and Coverage Model to reflect changes in enrollment and/or baseline premiums. These adjustments are discussed in further detail in Appendix D.

A number of ACA provisions will need regulations and further clarity. One example is the ACA’s requirement for certain health insurance to cover “essential health benefits.” Effective 2014, Section 1302(b) will require small-group and individual health insurance, including “qualified health plans” that will be sold in the California Exchange, to cover specified categories of benefits. These essential health benefits (EHBs) are defined as 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. The Secretary of Health and Human Services is charged with defining these categories through regulation, ensuring that the EHB floor “is equal to the scope of benefits provided under a typical employer plan.” In addition, the ACA would allow a state to “require that a qualified health plan offered in [the Exchange] offer benefits in addition to the essential health benefits.” If the state does so, the state must make payments to defray the cost of those additionally mandated benefits, either by paying the individual directly, or by paying the qualified health plan. This ACA requirement could interact with existing and proposed California benefit mandates, especially if California decided to require qualified health plans to cover California-specific mandates, and those mandates were determined to go beyond the EHB floor. Federal regulations regarding which benefits are to be covered under these broad EHB categories and other details, such as how the subsidies for purchasers of qualified health plans are structured, are forthcoming.³⁴

³⁴ For further discussion on EHBs and potential interaction with state mandates, please see, *California's State Benefit Mandates and the Affordable Care Act's "Essential Health Benefits"* available here: www.chbrp.org/documents/ACA-EHB-Issue-Brief-011211.pdf.

Essential health benefits for plans sold in the California Exchange and potential interactions with SB TBD 1

As mentioned, EHBs explicitly include “[m]ental health and substance use disorder services, including behavioral health treatment” and “rehabilitative and habilitative services and devices.”³⁵ The provisions also require that the scope of the EHBs be equal to the scope of benefits provided under a typical employer plan. The ACA requires in 2014 that states “make payments...to defray the cost of any additional benefits” required of Qualified Health Plans (QHPs) sold in the Exchange.³⁶ SB TBD 1 states, “this section does not require any benefits to be provided that exceed the essential health benefits required to be provided [by QHPs].” Therefore, because of this provision, SB TBD 1 is not expected to incur a fiscal liability for the state as it relates to the QHPs sold in the Exchange.

Whether or not the benefits required by SB TBD 1 would exceed EHBs depend on three factors:

- differences in the scope of MH and rehabilitative/habilitative benefits in the final EHB package and the scope of mandated benefits in SB TBD 1;
- the number of enrollees in QHPs; and,
- the methods used to define and calculate the cost of additional benefits.

For example, it is unclear whether there will be differences between the MH and rehabilitative/habilitative benefits included in the EHBs and the benefits required under SB TBD 1. “Behavioral health treatment” may be considered to include forms of “behavioral intervention treatment,” as specified SB TBD 1. “Habilitative” services may be determined to include forms of therapy that enhance a child’s ability to function.

³⁵ Affordable Care Act, Section 1302(b)(1)(E) and (G).

³⁶ Affordable Care Act, 1311(d)(3)(B).

Background on pervasive developmental disorders and 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).

ASD is the common term used to describe Autistic Disorder and two generally less severe disorders (Asperger's Disorder and PDD-NOS) that share some common symptoms (Kogan et al., 2009; Pasco, 2010; Walker et al., 2004).

PDD is frequently used interchangeably with ASD, but PDD is the clinical diagnostic category listed in the DSM-IV and ICD-10 classification systems (Pasco, 2010). Both classification systems identify Autistic Disorder, PDD-NOS, Asperger's Disorder, Rett's Disorder, and Childhood Disintegrative Disorder under the general PDD criteria (APA, 2000).

This report uses "PDD/A" to describe (unless otherwise specified) all five disorders covered by SB TBD 1.

The cause or causes of PDD/A is unknown, and research into genetic etiology as well as environmental factors continue to be explored by researchers. 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 mental retardation. More recent studies about the prevalence of mental retardation (cognitive impairment) in the PDD/A population revealed that nationally, an average of 41% of children aged 8 years with ASD had some cognitive impairment ($IQ \leq 70$) (CDC, 2009). In California, DDS reported that 35.6% of children with ASD who qualify for their services had some form of mental retardation ($IQ \leq 70$), of which approximately 5% were severely or profoundly impaired (DDS, 2009).

Prevalence of PDD/A

Estimates of the prevalence of PDD in the US and worldwide have increased over the last 20 years (Fombonne, 2009a). For example, the number of Californians with autism who were served by DDS increased 12-fold between 1987 and 2007 (DDS, 2009). Researchers frequently note that increasing prevalence rates and variation in published rates 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;
- provider variation in differential diagnosis;
- heterogeneous study methodologies (e.g., sample size, administrative vs. survey data and population demographic characteristics);
- changing PDD definitions; and
- increasing availability or awareness of services for treating PDD/A.

PDD/A prevalence estimates found in the more recent literature range between 60/10,000 (Fombonne, 2009b); 78/10,000 (UCLA, 2006); 90/10,000 (CDC, 2009); and 110/10,000 (Kogan et al., 2009). Additionally, Fombonne (2009b) estimates that the prevalence of PDD/A subcategories to be:

- Autistic Disorder: 20.6/10,000
- PDD-NOS: 37.1/10,000
- Asperger’s Disorder: 6.0/10,000
- Rett’s Disorder: 1.0/10,000-13,000³⁷
- Childhood Disintegrative Disorder: 2.0/100,000

Estimated prevalence of PDD/A in California

Knowing the prevalence of PDD/A is critical to calculating the estimated marginal impact of SB TBD 1 on the cost and utilization of intensive behavioral intervention therapy. The true prevalence of PDD/A is unknown, and CHBRP reviewed multiple sources to determine the best PDD/A prevalence rate for the analysis of SB TBD 1 including epidemiological studies (population- and survey-based), survey data, and California program data from a published report. CHBRP’s estimated prevalence rate was calculated after an analysis of the strengths and limitations of the aforementioned data sources.

For this bill analysis, CHBRP adjusted California DDS data to estimate the prevalence rates by age group and PDD/A subtype based on the literature-supported assumption that use of intensive behavioral intervention therapies varies by age and disorder. For example, literature and claims data available to CHBRP showed that intensive behavioral intervention therapies for PDD/A occurs most frequently in children aged 18 months to 9 years (see the *Medical Effectiveness* section). CHBRP’s analysis applies the age-group prevalence rates, by subtype, as appropriate, in its model to estimate the utilization and cost of services (see the *Benefit Coverage, Utilization, and Cost Impacts* section).

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 2 offers a “snapshot” in time (2007), 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

³⁷ Prevalence of Rett’s Disorder estimated by Kerr, 2002.

risk of PDD/A, changes to diagnostic criteria over time, and/or other factors discussed previously in this section.

The rates in Table 2 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. For many years, California has been among the leaders in offering publicly-supported programs for the developmentally disabled³⁸, 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 and not considered a “payor of last resort”³⁹. 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 2. Estimated Prevalence Rates of Persons Diagnosed with PDD/A in California, 2007

Age Groups (years)	Estimated Prevalence of Autistic Disorder in California (per 10,000)	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	19.8	27.0	46.8
5-9	57.6	91.8	149.3
10-14	35.8	69.0	104.8
15-19	19.5	53.4	72.9
20-24	9.7	35.0	44.7
25-29	5.9	24.8	30.8
30-34	3.7	12.1	15.9
35-39	2.8	8.1	10.9
40-44	3.1	8.0	11.1
45-49	2.5	6.0	8.5
50+	0.7	2.9	3.6

Source: California Health Benefits Review Program, 2011 (based on data from DDS, 2009 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. These estimates are considered valid and appropriate for the analysis of the impact of SB TBD 1 on utilization and cost. This table offers a “snapshot” in time (2007), and does not represent a declining prevalence rate in PDD/A as a cohort ages. Appendix F provides more detail on calculations.

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 have reported a higher PDD/A prevalence rate among males than females with rates three to seven times higher than in females (CDC, 2009; Newschaffer and Curran, 2003; Yeargin-Allsopp et al., 2003). The California DDS reported a ratio of males to females

³⁸ Personal communication, report content expert N. Akshmooff, February 2011.

³⁹ Personal communication, report content expert R. Wachtel, February 2011.

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 the symptoms, but no evidence of differences in treatment patterns and 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; Volkmar et al., 1993; Yeargin-Allsopp et al., 2003). However, the California DDS reported that males with PDD/A had a higher prevalence at every level of severity of mental retardation diagnosis, although the rates varied (5.2:1 for no mental retardation to 2.4:1 for profound mental retardation) (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 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). Additionally, the CDC's more recent study of 11 sites across the United States reported significantly greater pooled prevalence among White children (9.9) than among Black children (7.2) and Hispanic children (5.9) (CDC, 2009), although prevalence by race varied by individual sites.

MEDICAL EFFECTIVENESS

As described in the American Academy of Pediatrics guideline for management of PDD/A, behavioral intervention therapies are a major form of treatment for PDD/A (Myers et al, 2007).⁴⁰ Many children with PDD/A are treated with intensive (e.g., 25 or more hours per week) behavioral interventions based on applied behavioral analysis (ABA) and/or other theories of behavior (hereafter referred to as intensive behavioral intervention therapy) that are aimed at improving behavior and reducing deficits in cognitive function, language, and social skills. The medical effectiveness review focuses on intensive behavioral therapies because SB TBD 1 would specifically require coverage for these and other behavioral intervention therapies.

Literature Review Methods

The literature search was limited to abstracts of peer-reviewed research studies that were published in English from 1990 to present. 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, Web sites 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.

A total of 691 abstracts were retrieved and reviewed. Nine studies were included in the medical effectiveness review. The medical effectiveness review relied heavily on six meta-analyses and systematic reviews of studies of behavioral intervention therapies that were published from 2008 through 2010 (Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Virués-Ortega, 2010). One study published after the studies included in the meta-analyses and systematic reviews was also included (Dawson et al., 2010). 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).

⁴⁰ Other treatments for PDD/A include pharmacotherapy, occupational therapy, physical therapy, speech therapy, psychiatric care, and psychological care. Persons with Rett Syndrome may also need durable medical equipment to cope with the physical manifestations of the disorder. These treatments are discussed in greater depth in CHBRP's report on AB 171 (2011).

Methodological Considerations

Studies of intensive behavioral intervention therapies for PDD/A have several important methodological limitations. **Few studies of these interventions randomly allocate subjects to treatment**, which limits ability to ascertain whether observed differences in outcomes between groups are due to differences in the treatments provided to them (Howlin et al., 2009; Makrygianni and Reed, 2010). Most studies had small sample sizes and, thus, may not have had sufficient statistical power to detect differences between intervention and comparison groups (Makrygianni and Reed, 2010).

In addition, the literature on the effectiveness of intensive behavioral intervention therapies for PDD/A is difficult to synthesize. **Most studies compared therapies of differing duration and intensity or compared therapies based on different theories of behavior**. Ability to generalize findings across studies of the effectiveness of intensive behavioral intervention therapies is limited because the characteristics of treatments provided to both intervention and comparison groups vary widely. CHBRP identified no studies that compared intensive behavioral intervention therapies to no treatment.

The outcomes examined by studies of intensive behavioral intervention therapies also differ considerably across studies. Only four outcomes have been measured by a plurality of studies: adaptive behavior (ie., communication, daily living, motor, and social skills), intelligence quotient (IQ), language, and academic placement. Even findings regarding these outcomes cannot be easily pooled across studies because authors have used different instruments 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 non-verbal measures of intelligence because children with PDD/A tend to perform better on non-verbal tests of intelligence (e.g., visual-spatial tasks) than tests of other types of intelligence (Eldevik et al., 2009).

Finally, many studies of intensive behavioral intervention therapies only assess outcomes immediately following treatment. Improvements achieved in the short-term may not be sustained over the long-term. Because only a limited number of studies collect data on post-treatment outcomes over long periods of time, there is insufficient evidence to determine whether use of intensive behavioral intervention therapies have long-term benefits.

Study Findings

Six meta-analyses of RCTs and nonrandomized studies regarding impact of intensive ABA-based interventions for preschool children were published in 2009 and 2010 (Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Virués-Ortega, 2010). Each of these meta-analyses used different inclusion criteria, resulting in the inclusion of overlapping groups of studies (Table 3). For example, some meta-analyses only included RCTs and nonrandomized studies with comparison groups, whereas others included pre/post studies that did not include a comparison group. The meta-analyses 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 30 studies were included in these meta-analyses. CHBRP also reviewed a randomized controlled trial (RCT) of the Early Start Denver Model (Dawson et al., 2010) that was published after the studies included in the meta-analyses.

Populations studied

Table 4 describes the characteristics of the populations enrolled in the 31 studies of intensive behavioral intervention therapy (i.e., the 30 studies included in the six meta-analyses plus Dawson et al., 2010). 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.

The diagnoses of children enrolled varied across the 31 studies. Fourteen studies enrolled only children with Autistic Disorder. Seven studies enrolled children with either Autistic Disorder or PDD-NOS. Seven studies also enrolled children with unspecified PDD/A diagnoses. Two studies did not report the diagnoses of children enrolled.

Twenty-seven of the thirty-one studies identified by CHBRP reported the degree to which children enrolled in the studies had co-morbid mental retardation as defined in the Diagnostic and Statistical Manual- Version IV.⁴¹ Most studies enrolled children whose mean intelligence quotient (IQ) at baseline was within the range 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). Two studies enrolled children whose mean IQ at enrollment was above the threshold for mental retardation (Anan et al., 2008; Magiati et al., 2007).

CHBRP identified no studies regarding effectiveness of intensive behavioral intervention therapy in children younger than 18 months and persons older than 9 years, nor was there direct evidence about this therapy's 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 study populations.

⁴¹ 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 20-15 to 35-40), Profound Mental Retardation (IQ level below 20-25).

Table 3. Studies of Intensive Behavioral Intervention Therapy for Preschool and Elementary School Children with PDD/A That Are Included in Meta-Analyses Published in 2009 and 2010

	Meta-Analysis					
	Eldevik et al., 2009	Howlin et al., 2009	Reichow and Wolery, 2009	Spreckley and Boyd, 2009	Makrygianni and Reed, 2010	Virués-Ortega, 2010
Individual Study						
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
Jocelyn et al., 1998				X		
Sheinkopf and Siegel, 1998			X	X		X
Weiss et al., 1999					X	X
Smith et al., 2000	X	X	X	X	X	X
Bibby et al., 2001			X			X
Boyd and Corley, 2001			X			
Eikeseth et al., 2002	X	X		X		X
Bernard-Optz et al., 2004				X		
Howard et al., 2005	X	X		X	X	X
Matos and Mustaca, 2005						X
Sallows and Graupner, 2005		X	X	X	X	X
Cohen et al., 2006	X	X	X	X	X	X
Eldevik et al., 2006	X	X	X	X	X	X
Baker-Ericzen et al., 2007						X
Ben-Itzhak and Zachor, 2007					X	X
Eikeseth et al., 2007			X	X		X
Magiati et al., 2007		X	X	X	X	X
Reed et al., 2007a					X	X
Reed et al., 2007b					X	X
Remington et al., 2007	X	X			X	X
Anan et al., 2008						X
Ben-Itzhak et al., 2008						X

Table 4. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in the CHBRP’s Review

Study	Number of Subjects	Age at Entry ⁴²	PDD/A Diagnoses	Degree of Mental Retardation at Entry ⁴³	Duration of Intervention	Length of Follow-Up Treatment
Anderson et al., 1987	14	Mean age = 3.5 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	1 year	Not stated
Lovaas, et al., 1987	59	Mean age 3 years	Autistic Disorder	Mean IQ within ranges for Mild to Moderate Mental Retardation	2 years	Immediately following intervention
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
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
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
Koegel et al., 1996	17	Age range = 3 to 9 years	Autistic Disorder	Not reported	Not stated	Immediately following intervention
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
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
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
Weiss et al., 1999	20	Mean age = 3.5 years	Autistic Disorder, PDD-NOS	Not reported	2 years	Immediately following intervention
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
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
Bibby et al., 2001	22	Mean age = 3.5 years	Autistic Disorder, PDD	Mean IQ at entry was within range for Moderate Mental Retardation ⁴⁴	7 months	Immediately following intervention

⁴² Age at entry = age at which a child was enrolled in a study.

⁴³ 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 20-15 to 35-40), Profound Mental Retardation (IQ level below 20-25).

Table 4. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in the CHBRP’s Review (Cont’d.)

Study	Number of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up Treatment
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)	Varied across subjects
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
Bernard-Opitz et al., 2004	16	Age range = 2 to 3.5 years	Autistic Disorder	Not reported	5 weeks	Immediately following intervention
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
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 stated
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
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
Eldevik et al., 2006	28	Mean age = 4 years	Autistic Disorder	Mean IQ within range for Moderate Mental Retardation	20 months	Immediately following intervention
Baker-Ericzen et al., 2007	158	Age range = 2 to 9 years	Autistic Disorder, PDD-NOS	Not stated	3 months	Immediately following intervention
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

⁴⁴ Pre-treatment IQ scores available for only 22 of 66 subjects.

Table 4. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in the CHBRP’s Review (Cont’d.)

Study	Number of Subjects	Age at Entry	PDD/A Diagnoses	Degree of Mental Retardation at Entry	Duration of Intervention	Length of Follow-Up Treatment
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
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
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 syndrome	Mean IQ within range for Mild to Moderate Mental Retardation	9 to 10 months	Immediately following intervention
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 syndrome	Mean IQ within range for Mild Mental Retardation	9 to 10 months	Nor stated
Remington et al., 2007	44	Mean age = 3 years	Autistic Disorder	Mean IQ within range for Mild Mental Retardation	2 years	2 years
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
Ben-Itzhak 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
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

Types of intensive behavioral intervention therapies studied

Many of the intensive behavioral intervention therapies on which studies have been published are grounded in 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). One of the most well-known intensive behavioral intervention therapies is discrete trials training, which was developed by O. Ivar Lovaas and colleagues at the University of California, Los Angeles (Lovaas, 1987).⁴⁵ 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 Lovaas/UCLA intervention was originally provided to children with Autistic Disorder with a mean age of three years at the time the study began for an average of 40 hours per week for two or more years. Programs based on the Lovaas/UCLA approach have been implemented across the United States but vary in their intensity, duration, and means for providing treatment (e.g., therapists vs. parents with guidance from therapists).

Other intensive behavioral intervention therapies, such as and the Developmental Individual-difference Relationship-based Intervention, are based on developmental theories of human behavior. The Early Start Denver Model incorporates techniques based on developmental and relationship-based theories of behavior as well as ABA.

Duration of intensive behavioral intervention therapies studied

Twenty-eight studies 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.

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 receive an “eclectic intervention” that combines multiple types of treatments.

⁴⁵ 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.

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 six meta-analyses assessed the impact of intensive behavioral intervention therapies based on ABA on adaptive behavior (Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Virués-Ortega, 2010).⁴⁶ *The preponderance of evidence from these six meta-analyses of RCTs and nonrandomized studies suggests that these interventions are more effective than the other interventions to which they were compared in improving adaptive behavior.*

The only meta-analysis to find 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 the 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 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, 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, parents of children in the intervention groups may have been more motivated to help their children improve, which may have led their children to experience greater improvement than children in the comparison groups.

One RCT assessed the impact of the Early Start Denver Model on adaptive behavior (Dawson et al., 2010). The Early Start Denver Model is 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. The RCT compared the Early Start Denver Model to other behavioral interventions commonly available in the community in which

⁴⁶ 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.

the study took place. The study enrolled children age 18 to 30 months who had been diagnosed with Autistic Disorder or PDD-NOS. The Early Start Denver Model intervention consisted of 20 hours per week of therapy provided by therapists with expertise in providing early intervention to children with PDD/A plus 5 or more hours per week of therapy provided by parents, who were trained to provide treatment in the home that would complement that provided by clinicians. The intervention was provided for 2 years, a length of time consistent with the duration of the original UCLA/Lovaas intervention. Children who received the Early Start Denver Model displayed a steady rate of improvement in adaptive behavior, whereas delays in adaptive behavior increased among children who received standard care.

Intelligence quotient. All six meta-analyses also examined the impact of intensive behavioral intervention therapies on IQ (Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Virués-Ortega, 2010). The studies included in these meta-analyses used a variety of instruments to measure IQ.⁴⁷ ***The preponderance of evidence from these six meta-analyses suggests that intensive behavioral intervention therapies based on ABA are associated with greater increases in IQ than the interventions to which they were compared.*** The only meta-analysis to find 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 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.

One RCT assessed the impact of the Early Start Denver Model on IQ (Dawson et al., 2010). The authors found that children with Autistic Disorder or PDD-NOS who received the Early Start Denver Model experienced a statistically significant increase in IQ relative to children who received standard care available in the community.

It is important to recognize that the reported gains in IQ do not indicate that children who received intensive behavioral intervention therapies were “cured.” ***Most studies found that the increases in intelligence were not sufficiently large to enable the children to achieve levels of intellectual and educational functioning similar to peers without Autistic Disorder, PDD-NOS, or unspecified disorders on the PDD/A spectrum.*** 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’ 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.

⁴⁷ 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.

Language. Five meta-analyses assessed the impact of intensive behavioral intervention therapies based on ABA on language skills (Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Wolery, 2009; Spreckley and Boyd, 2009; Virués-Ortega, 2010). *Findings from four meta-analyses that compared the impact of intensive behavioral intervention therapies to other interventions on general language skills and on receptive language (i.e., ability to respond to verbal requests from others) are ambiguous.* The two meta-analyses that examined effects on general language skills reached opposite conclusions (Spreckley and Boyd, 2009; Virués-Ortega, 2010), perhaps due to differences in the number and characteristics of the studies included in their analyses. Two of the four meta-analyses that compared the effect of intensive behavioral intervention therapies on receptive language found statistically significant differences favoring ABA-based interventions (Howlin et al., 2009; Virués-Ortega, 2010), whereas the other two did not (Reichow and Wolery, 2009; Spreckley and Boyd, 2009). Again, differences in findings may be related to differences in the number and characteristics of studies included in the analyses. The three meta-analyses that evaluated the impact of intensive behavioral intervention therapies on expressive language (i.e., ability to verbalize needs and thoughts) found no statistically significant difference in this outcome between children who received these interventions and the other interventions to which they were compared (Howlin et al., 2009; Reichow and Wolery, 2009; Spreckley and Boyd, 2009).

Academic placement. *Findings from a systematic review of studies that compared the effects of intensive behavioral intervention therapies based on ABA to other interventions or less intensive ABA-based interventions on academic placement 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.⁴⁸ However, no study found that the majority of children receiving intensive behavioral intervention therapies were in unsupported placements in mainstream classrooms.⁴⁹ Two studies reported that children receiving both the intensive behavioral intervention therapy and 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"

⁴⁸ 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.

⁴⁹ 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.

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.

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 behavioral intervention therapies on the likelihood of achieving greater improvement in outcomes relative to the treatments to which they were compared (Virués-Ortega, 2010). The author found that behavioral intervention therapies that were provided for longer periods of time had more impact on adaptive behavior but that gains in IQ and language skills did not differ by duration of treatment. Behavioral intervention therapies that provided more total hours of treatment had larger effects on language skills, but improvements in adaptive behavior and IQ were not associated with total hours of treatment.

Children most likely to benefit from intensive behavioral intervention therapies

Outcomes for individual children enrolled in studies of intensive behavioral intervention therapies varied widely (Howlin et al., 2009). One explanation may be that the characteristics of children enrolled in the studies differed. (see Table 4). 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 co-morbid mental retardation, whereas others enrolled children with moderate, severe, or profound mental retardation.

Several meta-analyses attempted to identify the characteristics children enrolled in the studies who received the greatest benefit from intensive behavioral intervention therapies. Findings from one meta-analysis suggest 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 non-verbal imitation, and daily living experienced greater improvement in IQ, language skills, and social skills. In 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 estimated a multi-variate meta-regression that examine the impact of pretreatment IQ while holding child's age at initiation of treatment and treatment characteristics constant and 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.

Conclusion

- Most studies of intensive behavioral intervention therapies have compared an intensive behavioral intervention therapies based on ABA to another type of behavioral intervention or a less intensive behavioral intervention.
- Studies of intensive behavioral intervention therapy have primarily enrolled children age 2 to 5 years with Autistic Disorder and co-morbid Mild or Moderate Mental Retardation.

- Studies that compared behavioral intervention therapies based on ABA to other behavioral intervention therapies have several important methodological limitations.
 - Only two of these studies are RCTs; in most studies lack of randomization limits ability to ascertain whether observed differences in outcomes between groups are due to differences in the treatments provided to them.
 - Most studies had small sample sizes and, thus, may not have had sufficient statistical power to detect differences between intervention and comparison groups.
 - The outcomes examined by studies of behavioral intervention therapies differ considerably across studies. Only four outcomes have been measured by a plurality of studies: adaptive behavior (i.e., communication, daily living, motor, and social skills), IQ, language, and academic placement.

- CHBRP identified six meta-analyses of RCTs and nonrandomized studies with comparison groups that assessed the effects of intensive behavioral intervention therapies based on ABA and one RCT published after the studies included in the meta-analysis. Findings from these studies suggest the following conclusions.
 - There is a preponderance of evidence that children who receive intensive behavioral intervention therapies based on ABA experience greater improvement in adaptive behavior than children who receive other therapies.
 - There is a preponderance of evidence that children who receive intensive behavioral intervention therapies based on ABA experience greater improvement in IQ than children who receive other therapies.
 - The reported gains in IQ do not indicate that children who received the intensive behavioral interventions were “cured”. Most studies found that the changes in intelligence were not sufficiently large to enable the children to achieve levels of intellectual and educational functioning similar to peers without PDD/A.
 - Findings from studies that compared the impact of intensive behavioral intervention therapies based on ABA to other therapies on general language skills, and receptive language are ambiguous; there is a preponderance of evidence that intensive behavioral intervention therapies are no more effective than the other therapies to which they were compared for improving expressive language.
 - Findings from studies that compared the impact of intensive behavioral intervention therapies based on ABA to other therapies on academic placement are ambiguous.
 - Intensive behavioral intervention therapies of longer duration appear to have greater impact on adaptive behavior, and intensive behavioral intervention

therapies that provided more total hours of treatment had larger effects on language skills.

- Children who are younger at initiation of treatment and who have higher IQs, better adaptive behavior, and better language skills appear to obtain greater benefit from intensive behavioral intervention therapies.

BENEFIT COVERAGE, UTILIZATION, AND COST IMPACTS

Approximately 21.9 million Californians are currently enrolled in health care service plans regulated by the California Department of Managed Health Care (DMHC) and health insurance policies regulated by the California Department of Insurance (CDI). SB TBD 1 would mandate coverage of intensive behavioral intervention therapy for pervasive developmental disorders or autism (PDD/A). SB TBD1 would affect benefit coverage for enrollees in DMHC-regulated health or in CDI-regulated policies. This includes approximately 18.1 million enrollees, including 4.4 million children aged 0-14 years, the age range in which most intensive behavioral intervention therapy is initiated. This number excludes enrollees in Medi-Cal Managed Care as these groups would not be subject to the mandate.

Approximately 77,000 enrollees in DMHC-regulated plans and/or CDI-regulated policies subject to SB TBD 1 are diagnosed with PDD/A. PDD/A includes the subtypes Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder, Asperger's Disorder, and Childhood Disintegrative Disorder.

Critical Caveats, Estimates, and Assumptions

- Although the evidence on the effectiveness of intensive behavioral intervention therapies is focused on Autistic Disorder and PDD-NOS in pre-school- and elementary school-aged children, as evaluated in the *Medical Effectiveness* section, the Cost analysis models benefit coverage, utilization and cost impacts for all five PDD/A subtypes and for all ages. The cost model makes weighted adjustments for age-specific and PDD/A subtype utilization: for example literature reviewed in the *Medical Effectiveness* section and expert opinion indicate that intensive behavioral intervention utilization is rare for children under age 2, less common for adults, and less common for some PDD/A subtypes, for example Asperger's Disorder.
- Due to variations in enrollee severity of PDD/A, circumstances, and/or preferences, not all would get intensive behavioral intervention therapies, even if diagnosed and enrolled in a plan or policy that covers such therapies. Also, treatment, which typically spans 1 to 3 years,⁵⁰ may be discontinued if shown to be ineffective for that person.
- In California, intensive behavioral intervention therapies not covered by health plans or insurers may be purchased by other payors, including families, charities, the California Department of Developmental Services (DDS), the California Department of Education (CDE), or other payors.
- CHBRP estimates that the mandate would affect intensive behavioral intervention utilization in two ways: it would add new users of intensive behavioral intervention therapies, and

⁵⁰ Personal communication, report content expert N Akshoomoff, February 2011. Additionally, as reviewed in the *Medical Effectiveness* section, of the studies that reported duration of intervention studied, duration ranged from 5 weeks to 4 years with a median of 16 months and a mode of 2 years.

among newly covered users, intensive behavioral intervention therapy hours per week would increase.

- CHBRP estimates that the mandate would add new users of intensive behavioral intervention therapies in the under 3 age group, but for all other age groups, the number of users of intensive behavioral intervention therapies are assumed to be the same pre- and postmandate. This is because some children under the age of 3 years may not qualify for services paid for by DDS (because they have milder forms of PDD/A) and would be too young to receive school-based services paid by CDE. School-aged children and young adults who may not qualify for DDS services (because they have milder forms of PDD/A) could still access services paid for by CDE. Therefore, families of children under age 3 years could may not be using services since they would have to find another payor or self-pay. CHBRP assumes that utilization in this group would be sensitive to coverage as a result of SB TBD 1.
- CHBRP also estimates that premandate, current users of intensive behavioral intervention therapies not covered by their health plans and policies are not receiving the full-recommended hours per week of intensive behavioral intervention therapy. CHBRP further assumes that postmandate these users would increase their number of therapy hours per week up to the typical recommended hours per week for the user's age and PDD/A disease subtype. See Appendix D for details of the estimated pre- and postmandate utilization levels.

Current (Baseline) Benefit Coverage, Utilization, and Cost

Current Coverage of the Mandated Benefit

Current coverage of intensive behavioral intervention therapy for enrollees in privately-funded plans and policies regulated by DMHC or CDI was determined by a survey: CHBRP conducts a Bill-Specific Coverage Survey of California's largest health plans and insurers. Responses to this survey represented 85.16% of enrollees in the privately funded, CDI-regulated market and 88.53% of enrollees in the privately funded DMHC-regulated market subject to state mandates.⁵¹ Based on this Bill-Specific Coverage Survey, 16% of enrollees in DMHC-regulated plans and 45% of enrollees in CDI-regulated policies have coverage for intensive behavioral intervention therapies.

Some publicly funded health insurance is also subject to regulation by DMHC or CDI, so would be subject to SB TBD 1. California Public Employees' Retirement System Health Maintenance Organizations (CalPERS HMOs) cover 0% of enrollees for intensive behavioral intervention

⁵¹ CHBRP's analysis of the share of enrollees included in CHBRP's Bill-Specific Coverage Survey of the major carriers in the state is based on "CDI Licenses with HMSR Covered Lives Greater than 100,000" as part of the Accident and Health Covered Lives Data Call, December 31, 2009 by the California Department of Insurance, Statistical Analysis Division, data retrieved from The Department of Managed Health Care's interactive Web site "Health Plan Financial Summary Report," July-September 2010, and CHBRP's Annual Enrollment and Premium Survey.

therapies.⁵² Several of the plans with the largest enrollment of beneficiaries of the Healthy Families Program (HFP), Access for Infants and Mothers (AIM), and the Major Risk Medical Insurance Program (MRMIP) were surveyed to ascertain whether benefit coverage was similar to what is provided to enrollees in privately funded plans and policies. On the basis of survey responses, CHBRP estimates that 0% of beneficiaries of these programs enrolled in DMHC-regulated plans have benefit coverage for intensive behavioral Intervention therapies.

As noted in the Introduction, this analysis excludes Medi-Cal Managed Care since those plans are not subject to SB TBD 1

Among all enrollees whose health insurance would be subject to SB TBD 1, 19.5% currently have coverage for intensive behavioral intervention therapies as treatments for PDD/A.

Current Utilization Levels

Premandate, of the estimated 77,000 enrollees diagnosed with PDD/A in DMHC- or CDI-regulated plans or policies subject to SB TBD 1, CHBRP assumes age-specific utilization rates of intensive behavioral intervention therapies for enrollees with PDD/A, ranging from 0% to 35% premandate and 0% to 40% postmandate. CHBRP assumes that the mandate would increase the utilization rate of intensive behavioral intervention therapies in the under 3 age group, but for all other age groups, the utilization rate of intensive behavioral intervention therapies are assumed to be the same pre- and postmandate (See Appendix D). The age-specific utilization rates are based on a study by Thomas et al. 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 (Thomas et al. 2007). This study sample consisted of a self-selected sample (98% of whom were insured at the time of 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 input¹ and a study by Ganz 2007.

For this analysis, utilization of intensive behavioral intervention therapies is measured as number of hours per week times 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 content expert opinion (see Appendix D).

⁵² Personal communication, P Sherard, CalPERS, March 2011.

Current Average Cost of Intensive Behavioral Intervention Therapies

There is no definitive estimate of cost per hour 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) (Wang and Leslie, 2010; Peng et al. 2009; Mandell et al. 2006; Liptak et al. 2006; Leslie and Martin 2007; Flanders et al. 2007, Croen et al. 2006).

CHBRP estimated an average hourly cost of \$80 per hour for intensive behavioral intervention therapy in California based on the 2008 Annual Commercial MarketScan claims data for California. This \$80 rate is for licensed providers and is within the range of rates for licensed providers (\$75 to \$140 per hour) noted in other benefit mandate reports (Colorado, 2009). This may be a high estimate as it assumes use of licensed providers.

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 \$80 per hour produces an average annual cost of \$50,000 postmandate. This is 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 \$38,000 in 2010 dollars) (Ganz, 2007), but lower than estimated total cost from the Colorado report to the General Assembly referenced above. The report estimates that in 2009 “total cost for families for early intensive behavior analytic treatment supervised at the appropriate level is between \$65,400-\$72,720 annually.” This estimate is higher than CHBRP’s estimate because it may have focused only on younger age groups (where utilization is higher than in older age groups) whereas CHBRP models utilization for children and young adults.

Current (Baseline) Premiums and Expenditures

The current per member per month (PMPM) premiums and expenditures in different market segments are detailed in Table 5. The total population in Table 5 reflects the full 18.1 million enrollees in DMHC- or CDI-regulated plans or policies that would be subject to SB TBD 1, as the premium costs are spread over all enrollees in all plans and policies subject to the mandate. Medi-Cal Managed Care plans would not be subject to SB TBD 1.

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

Enrollees in DMHC-regulated plans and CDI-regulated policies that would be subject to SB TBD 1 may receive intensive behavioral intervention therapies paid for by families, charities, public programs (including DDS and CDE), or other sources. Although some shifting seems likely, as noted in the *Introduction*, CHBRP is unable to quantify the extent to which the public programs have been impacted by the lack of benefit coverage in 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 the DMHC or CDI and therefore 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 is a covered benefit the members of at least one large union.⁵³

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 excludes coverage for intensive behavioral intervention therapies as a treatment for PDD/A.

To further investigate public demand, CHBRP used the bill-specific coverage survey. In the survey, CHBRP asked 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 there were no substantive differences.

Based on coverage levels of self-insured plans and responses from large unions, CHBRP concludes that there may be some public demand for intensive behavioral intervention therapy benefits as a treatment for PDD/A by collective bargaining agents and insufficient demand by self-insured plans.

Impacts of Mandated Benefit Coverage

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

The estimated increase in new users and the hours/week of therapy is likely to require plans and insurers to alter their provider contracts and networks to provide these additional services. There appears to be an adequate supply of providers to meet the increased demand as a result of the mandate for two reasons. First, payors other than health insurance currently pay providers for intensive behavioral intervention therapy (including DDS⁵⁴) or treatments that may include

⁵³ Personal communication, S Flocks, California Labor Federation, March 2011.

⁵⁴ Personal communication, J Mullen, California Department of Developmental Services, March 2011.

intensive behavioral intervention therapy (including CDE⁵⁵) and this suggests the presence of an extant labor supply of intensive behavioral intervention providers. Second, SB TBD 1 is silent as to the use of licensed intensive behavioral intervention therapy providers. Depending on other provider contracting and licensing rules and regulations, plans and insurers may have the flexibility to expand their provider networks in more than one manner—for example, they may be able to contract with unlicensed providers that are supervised by a licensed provider. For these reasons, CHBRP assumes there to be an adequate supply of providers.

Impact on per-unit cost

Since the provider-supply bottlenecks are assumed to be minimal, CHBRP assumes that the unit cost of intensive behavioral intervention services would not increase were SB TBD 1 to be enacted.

How Would Utilization Change as a Result of the Mandate?

Postmandate, CHBRP estimates that the total number of enrollees receiving intensive behavioral intervention therapies would increase and that enrollees would use more hours a week of intensive behavioral intervention therapies when they gain coverage for the benefit (see Appendix D). The mandate would increase the number of enrollees receiving intensive behavioral intervention therapies through their insurance from approximately 1,400 premandate to 8,700 postmandate: a 521% increase.

The mandate would result in approximately 400 new users of intensive behavioral intervention therapies and would result in approximately 6,900 current users of intensive behavioral intervention therapies to obtain such therapies through their health insurance.

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

CHBRP assumes that if health care costs increase as a result of increased utilization or changes in unit costs, there is a corresponding proportional increase in administrative costs. CHBRP assumes that the administrative cost proportion of premiums would be unchanged, postmandate. All health plans and insurers include a component for administration and profit in their premiums. CHBRP estimates that the increase in administrative costs of DMHC-regulated plans and/or CDI-regulated policies would remain proportional to the increase in premiums.

CHBRP assumes that the mandate could increase costs related to expanding provider networks for intensive behavioral intervention therapies, but not out of proportion to the current ratio of administrative overhead to premiums.

⁵⁵ Personal communication, P Skelton, California Department of Education, March 2011.

Impact of the Mandate on Total Health Care Costs

Changes in total expenditures

SB TBD 1 would increase total expenditures by \$93.3 million, or 0.10%, for this insured population. This increase in expenditures results from a \$222.4 million increase in health insurance premiums, and a \$17.1 million increase in out-of-pocket expenses for enrollees with PDD/A with newly covered benefits

The \$146.2 million reduction in expenses for noncovered benefits would be a reduction in expenditures for payors other than DMHC-regulated plans and CDI-regulated insurers. It would be partially offset by the increase in \$17.1 million that enrollees with PDD/A would see in out-of-pocket expenses for newly covered benefits.

Since, as noted, other payors pay, premandate, for some portion of intensive behavioral intervention therapy for enrollees with PDD/A, SB TBD 1 would be expected to result in a shift of costs to DMHC-regulated plans and CDI-regulated policies from other payors. However, for the reasons discussed in the *Introduction*, it is not possible to calculate what portion of such costs that would be shifted from which other payors (enrollees, families, charities, DDS, CDE, other).

Potential cost offsets or savings in the short-term

In some cases, an increase in cost due to an expansion in benefit coverage is accompanied by a decrease in the cost for other health care services, known as a “cost offset.” There is no evidence to prove or disprove health cost savings within the 1-year time frame of this cost analysis. Therefore, CHBRP does not estimate a cost offset in the first year following implementation.

Impacts for Each Category of Payor Resulting From the Benefit Mandate

Changes in expenditures and PMPM amounts by payor category

Table 6 shows the estimated impacts of SB TBD 1 on premiums and expenditures by each payor category. Note that the total population in Table 6 reflects the full 18.1 million enrollees in DMHC- or CDI-regulated plans or policies that would be subject to SB TBD 1. The premium increases are estimated to be spread among all enrollees in all plans or policies, whether the enrollees would possibly use the benefits for PDD/A mandated by SB TBD 1.

Increases in per member per month (PMPM) premiums for the newly mandated benefit coverage vary by market segment (Table 6). Increases as measured by percentage changes in PMPM premiums are estimated from an average of 0.14% (for CDI-regulated individual market policies) to 3.54% (for MRMIB plans) in the market segments subject to SB TBD 1. Increases as measured by percentage changes in PMPM total expenditures are estimated to range from an average of 0.057% (for CDI-regulated individual market policies) to 1.30% (for MRMIB plans).

In the privately funded large-group market, postmandate, the premiums increase by an average of \$0.81 PMPM among CDI-regulated policies and \$0.97 PMPM among DMHC-regulated plan contracts (Table 6). For enrollees with privately funded small-group insurance policies, health insurance premiums are estimated to increase by an average of \$0.51 PMPM for CDI-regulated

policies and \$0.96 PMPM for DMHC-regulated contracts. In the privately funded individual market, the health insurance premiums are estimated to increase by an average of \$0.28 PMPM and by \$0.56 PMPM in CDI- and DMHC-regulated markets, respectively.

Among publicly funded DMHC-regulated health plans, CHBRP estimates an impact on premiums of 0.26% (\$1.11) PMPM for CalPERS HMOs and 3.54% (\$3.97) PMPM for MRMIB plans

Increases as measured by percentage changes in PMPM premiums are estimated to range from an average of 0.14% (for CDI-regulated individual market policies) to 3.54% (for MRMIB plans) in the market segments subject to SB TBD 1. Increases as measured by PMPM premiums are estimated to range from an average of \$0.28 (for CDI-regulated individual market policies) to \$3.97 (for MRMIB plans).

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

CHBRP estimates premium increases of less than 1% for the privately funded insurance market. Due to the small size of the increase in premiums after the mandate, CHBRP does not anticipate loss of health insurance, changes in availability of the benefit beyond those subject to the mandate, changes in offer rates of health insurance, changes in employer contribution rates, changes in take-up of health insurance by employees, or purchase of individual market policies. This premium increase would not have a measurable impact on number of persons who are uninsured.

Impact on public programs

Since, as noted, other payors pay, premandate, for some portion of intensive behavioral intervention therapy for enrollees with PDD/A, SB TBD 1 would be expected to result in a shift of costs to DMHC-regulated plans and CDI-regulated policies from other payors. However, for the reasons discussed in the *Introduction*, it is not possible to calculate what portion of such costs that would be shifted from which other payors (enrollees, families, charities, DDS, CDE, other).

Table 5. Baseline (Premandate) Per Member Per Month Premiums and Total Expenditures by Market Segment, California, 2011

	DMHC-Regulated							CDI-Regulated			Total
	Privately Funded Plans (by Market)			CalPERS HMOs (b)	Medi-Cal Managed Care Plans		MRMIB Plans (d)	Privately Funded Policies (by Market)			
	Large Group	Small Group	Individual		65 and Over (c)	Under 65		Large Group	Small Group	Individual	
Total enrollees in plans/policies subject to state mandates (a)	10,526,000	2,241,000	733,000	831,000	285,000	3,539,000	889,000	397,000	1,118,000	1,343,000	21,902,000
Total enrollees in plans/policies subject to SB TBD 1	10,526,000	2,241,000	733,000	831,000	0	0	889,000	397,000	1,118,000	1,343,000	18,078,000
Average portion of premium paid by employer	\$317.59	\$267.09	\$0.00	\$347.55	\$346.00	\$176.00	\$98.48	\$375.44	\$270.30	\$0.00	\$65,887,370,000
Average portion of premium paid by employee	\$82.91	\$83.47	\$399.69	\$86.89	\$0.00	\$0.00	\$13.79	\$122.08	\$64.15	\$199.13	\$21,898,323,000
Total Premium	\$400.51	\$350.57	\$399.69	\$434.44	\$346.00	\$176.00	\$112.27	\$497.52	\$334.45	\$199.13	\$87,785,693,000
Enrollee expenses for covered benefits (deductibles, copays, etc.)	\$21.82	\$32.63	\$84.77	\$22.41	\$0.00	\$0.00	\$4.68	\$63.15	\$123.11	\$58.53	\$7,548,415,000
Enrollee expenses for benefits not covered (e)	\$1.40	\$1.38	\$0.97	\$1.42	\$0.00	\$0.00	\$5.18	\$1.32	\$1.20	\$0.78	\$327,343,000
Total Expenditures	\$423.73	\$384.58	\$485.43	\$458.26	\$346.00	\$176.00	\$122.13	\$562.00	\$458.76	\$258.44	\$95,661,451,000

Source: California Health Benefits Review Program, 2011.

Notes: (a) This population includes persons insured with private funds (group and individual) and insured with public funds (e.g., CalPERS HMOs, Medi-Cal Managed Care Plans, Healthy Families Program, AIM, MRMIP) enrolled in health plans or policies regulated by the DMHC or CDI. Population includes enrollees aged 0 to 64 years and enrollees 65 years or older covered by employment-sponsored insurance.

(b) Of these CalPERS HMO members, about 58% or 482,000 are state employees or their dependents.

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

(d) MRMIB Plan expenditures include expenditures for 874,000 enrollees of the Healthy Families Program, 8,000 enrollees of MRMIP, and 7,000 enrollees of the AIM program.

(e) Includes expenses paid by enrollees and by sources other than enrollees' health insurance to for services related to the mandated benefit when the benefit is not covered by health insurance.

Key: AIM=Access for Infants and Mothers; CalPERS HMOs=California Public Employees' Retirement System Health Maintenance Organizations; CDI=California Department of Insurance; DMHC=Department of Managed Health; MRMIB=Managed Risk Medical Insurance Board; MRMIP=Major Risk Medical Insurance Program.

Table 6. Impacts of the Mandate on Per Member Per Month Premiums and Total Expenditures by Market Segment, California, 2011

	DMHC-Regulated							CDI-Regulated			Total
	Privately Funded Plans (by Market)			CalPERS HMOs (b)	Medi-Cal Managed Care Plans		MRMIB Plans (d)	Privately Funded Policies (by Market)			
	Large Group	Small Group	Individual		65 and Over (c)	Under 65		Large Group	Small Group	Individual	
Total enrollees in plans/policies subject to state mandates (a)	10,526,000	2,241,000	733,000	831,000	285,000	3,539,000	889,000	397,000	1,118,000	1,343,000	21,902,000
Total enrollees in plans/policies subject to SB TBD 1	10,526,000	2,241,000	733,000	831,000	0	0	889,000	397,000	1,118,000	1,343,000	18,078,000
Average portion of premium paid by employer	\$0.7723	\$0.7337	\$0.0000	\$0.8885	\$0.0000	\$0.0000	\$3.4822	\$0.6126	\$0.4155	\$0.0000	\$171,785,000
Average portion of premium paid by employee	\$0.2016	\$0.2270	\$0.5582	\$0.2221	\$0.0000	\$0.0000	\$0.4875	\$0.1992	\$0.0982	\$0.2772	\$50,632,000
Total Premium	\$0.9739	\$0.9608	\$0.5582	\$1.1107	\$0.0000	\$0.0000	\$3.9697	\$0.8118	\$0.5137	\$0.2772	\$222,417,000
Enrollee expenses for covered benefits (deductibles, copays, etc.)	\$0.0530	\$0.0937	\$0.1210	\$0.0573	\$0.0000	\$0.0000	\$0.1656	\$0.1072	\$0.2010	\$0.0815	\$17,140,000
Enrollee expenses for benefits not covered (e)	-\$0.6375	-\$0.6063	-\$0.3955	-\$0.6978	\$0.0000	\$0.0000	-\$2.5486	-\$0.5555	-\$0.4264	-\$0.2113	-\$146,227,000
Total Expenditures	\$0.3894	\$0.4482	\$0.2837	\$0.4702	\$0.0000	\$0.0000	\$1.5867	\$0.3635	\$0.2883	\$0.1474	\$93,329,000

Table 6. Impacts of the Mandate on Per Member Per Month Premiums and Total Expenditures by Market Segment, California, 2011

	DMHC-Regulated							CDI-Regulated			Total
	Privately Funded Plans (by Market)			CalPERS HMOs (b)	Medi-Cal Managed Care Plans		MRMIB Plans (d)	Privately Funded Plans (by Market)			
	Large Group	Small Group	Individual		65 and Over (c)	Under 65		Large Group	Small Group	Individual	
Percentage Impact of Mandate											
Insured premiums	0.2432%	0.2741%	0.1397%	0.2557%	0.0000%	0.0000%	3.5358%	0.1632%	0.1536%	0.1392%	0.2534%
Total Expenditures	0.0919%	0.1165%	0.0584%	0.1026%	0.0000%	0.0000%	1.2991%	0.0647%	0.0628%	0.0570%	0.0976%

Source: California Health Benefits Review Program, 2011.

Notes: (a) This population includes persons insured with private funds (group and individual) and insured with public funds (e.g., CalPERS HMOs, Medi-Cal Managed Care Plans, Healthy Families Program, AIM, MRMIP) enrolled in health plans or policies regulated by the DMHC or CDI. Population includes enrollees aged 0 to 64 years and enrollees 65 years or older covered by employment-sponsored insurance.

(b) Of these CalPERS HMO members, about 58% or 482,000 are state employees or their dependents.

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

(d) MRMIB Plan expenditures include expenditures for 874,000 enrollees of the Healthy Families Program, 8,000 enrollees of MRMIP, and 7,000 enrollees of the AIM program.

(e) Includes expenses paid by enrollees and by sources other than enrollees' health insurance to for services related to the mandated benefit when the benefit is not covered by health insurance.

Key: AIM=Access for Infants and Mothers; CalPERS HMOs=California Public Employees' Retirement System Health Maintenance Organizations; CDI=California Department of Insurance; DMHC=Department of Managed Health; MRMIB=Managed Risk Medical Insurance Board; MRMIP=Major Risk Medical Insurance Program.

PUBLIC HEALTH IMPACTS

SB TBD 1 would require coverage of behavioral intervention therapy for pervasive developmental disorders or autism (PDD/A). For purposes of this analysis, CHBRP focuses on intensive (e.g., 25 or more hours per week) interventions based on applied behavioral analysis (ABA) and/or other theories of behavior (hereafter referred to as intensive behavioral intervention therapy) that are aimed at improving symptoms of PDD/A. SB TBD 1 would also require that benefits be subject to the same requirements as provided in current code related to mental health benefits, which mandates parity with other benefits in terms of lifetime maximums, copayments, and deductibles.

As noted earlier in this report enrollees in DMHC-regulated plans and CDI-regulated policies may obtain intensive behavioral intervention therapy through payment from various sources and that the population benefiting most often from this therapy are preschool and elementary-aged children. Health insurance plans and policies, California Department of Education (CDE), the California Department of Developmental Services (DDS), charities, or families may pay for therapies. Services obtained vary in intensity and duration due to PDD/A typology, disorder severity, geographic location, age of patient—even parental/guardian preference may influence the distribution of services. Additionally, the financial burden for intensive behavioral intervention therapy born by families or by the third party payors mentioned above.

As noted in the *Medical Effectiveness* section, the preponderance of studies on the effectiveness and use of intensive behavioral intervention therapy focuses on children aged 18 months to 9 years who are diagnosed with Autistic Disorder and PDD-NOS, many of whom have IQs within the range of mild or moderate mental retardation. CHBRP found no evidence regarding effectiveness of intensive behavioral intervention therapy in children younger than 18 months or persons older than 9 years, nor was there direct evidence about this therapy's effectiveness for persons diagnosed with Asperger's, Rett's, or Childhood Disintegrative Disorder. **The absence of evidence is not evidence of no effect and these therapies may be appropriate for some persons with PDD/A who fall outside the study populations.**

Also, as noted in the *Benefit Coverage, Utilization, and Cost Impacts* section, the use of intensive behavioral intervention therapy varies among the five disorders included in PDD/A. Use of the therapy among enrollees with Asperger's Disorder and Rett's is estimated to be less common. While there may be less use among those with Asperger's Disorder or Rett's Disorder, there still may be *some* use.

The Public Health section addresses the relevant population as PDD/A with the understanding that relevance may be limited for some ages and diagnoses.

Public Health Outcomes

PDD/A is 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 public health impacts most relevant to SB TBD 1 include improvements in IQ, language skills, and adaptive behaviors; academic placement in mainstream classrooms;

premature mortality; and economic loss, including lost productivity of persons diagnosed with PDD/A and their family members and financial burdens resulting from expenses for noncovered benefits.

In brief, it appears that there is a preponderance of evidence that intensive behavioral intervention therapies produce favorable effects on improving IQ and adaptive behaviors for children with PDD/A aged 18 months to 9 years. Evidence regarding improvements in language skills for persons diagnosed with PDD/A was ambiguous. As noted in the *Medical Effectiveness* section, the findings from studies on the effects of intensive behavioral intervention therapies on academic placement are ambiguous. CHBRP found no evidence to suggest that harms result from intensive behavioral intervention therapies used by persons with PDD/A.

As presented in the *Benefit Coverage, Utilization, and Cost Impacts* section, CHBRP assumes that enrollees with new benefit coverage resulting from SB TBD 1 would increase their use of intensive behavioral intervention therapies, resulting in an overall average utilization increase of 13.6%, and a \$6,000 cost increase to \$50,000 per user per year. The duration of therapy is usually one to 3 years, with a median of 16 months.

CHBRP estimates SB TBD 1 could produce some improvement in IQ and adaptive behaviors for children aged 18 months to 9 years with diagnoses of Autistic Disorder and PDD-NOS due to the effectiveness of intensive behavioral intervention therapy and increased benefit coverage and utilization. The public health impact on persons outside of this age range or with other PDDs is unknown.

Impact on Gender and Racial Disparities

Several competing definitions of “health disparities” exist. CHBRP relies on the following definition: *A health disparity/inequality is a particular type of difference in health or in the most important influences of health that could potentially be shaped by policies; it is a difference in which disadvantaged social groups (such as the poor, racial/ethnic minorities, women or other groups that have persistently experienced social disadvantage or discrimination) systematically experience worse health or greater health risks than more advantaged groups* (Braveman, 2006).

CHBRP investigated the effect that SB TBD 1 would have on health disparities by gender, race, and ethnicity. Evaluating the impact on racial and ethnic disparities is particularly important because racial and ethnic minorities report having poorer health status and worse health indicators (KFF, 2007). One important contributor to racial and ethnic health disparities is differential rates of insurance, where minorities are more likely than whites to be uninsured; however, disparities still exist within the insured population (Kirby et al, 2006; Lillie-Blanton and Hoffman, 2005). Since SB TBD 1 would only affect the insured population, a literature review was conducted to determine whether there are gender, racial, or ethnic disparities associated with treatment of PDD/A outside of disparities attributable to differences between insured and uninsured populations.

Impact on Gender Disparities

As discussed in the *Introduction*, there is evidence of gender differences in the prevalence rate and symptoms of PDD/A in California, with the rate of PDD/A four times higher in males than in females (DDS, 2009). There is a small body of literature that investigated disparities in symptoms between males and females, and reported conflicting results (see the Introduction). Specifically, Hartley and Sikora summarized conflicting results from previous studies that controlled for cognitive function; two studies found no difference in autistic symptoms, whereas three studies 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). They noted that if true differences exist, modifying diagnostic and treatment protocols for sex-specific differences could improve health outcomes for both males and females (Hartley and Sikora, 2009). However, CHBRP found no evidence of differences by gender in treatment patterns or health outcomes related to PDD/A.

CHBRP found no literature or data regarding the possible differential use or outcomes by gender of intensive behavioral intervention therapies within the insured population; therefore, the public health impact of SB TBD 1 on reducing the disproportionate burden of PDD/A symptoms experienced by males is unknown.

Impact on Racial and Ethnic Disparities

Review of the literature reveals ambiguous evidence (see the *Introduction*) regarding differences in the prevalence of PDD/A by race and ethnicity. Some studies indicate no significant differences in PDD/A prevalence by race (Bertrand, et al., 2001; Dyches et al., 2004; Fombonne, 2003b; Yeargin-Allsopp et al., 2003; Newschaffler et al., 2007), whereas a study on the California population found higher rates among Blacks (Croen et al., 2002). Additionally, the CDC's more recent study of 11 sites across the United States reported significantly greater pooled prevalence among White children (9.9) than among Black children (7.2) and Hispanic children (5.9), although prevalence by race varied by individual sites (CDC, 2009). No studies were found discussing racial or ethnic disparities with regard to use or effectiveness of Intensive behavioral intervention therapies.

CHBRP does not have access to the racial/ethnic distribution of enrollees among plans and policies that would be subject to SB TBD 1 nor is there literature available about differential use or outcome of intensive behavioral intervention therapies by race; therefore, the public health impact of SB TBD 1 on reducing potential racial and ethnic disparities of PDD/A symptoms is unknown.

Impacts on Premature Death and Economic Loss

Premature death is often defined as death before the age of 75 (Cox, 2006). The overall impact of premature death due to a particular disease can be measured in “years of potential life lost” prior to age 75 years and summed for the population (generally referred to as “YPLL”) (Cox, 2006;

Gardner and Sanborn, 1990). In California, it is estimated that there are nearly 102,000 premature deaths each year accounting for more than 2 million YPLL (Cox, 2006). In order to measure the impact of premature mortality across the population impacted by a proposed mandate, CHBRP first collects baseline mortality rates. Next, the medical effectiveness literature is examined to determine whether the proposed mandated benefit impacts mortality. In cases where a reduction in mortality is projected, a literature review is conducted to determine whether the YPLL has been established for the given condition. Some diseases and conditions do not result in death, and therefore, a mortality outcome is not relevant.

Premature Death

Persons with PDD/A experience premature mortality about two times more often than the general population, but CHBRP found no studies that directly attributed PDD/A to an increased risk of premature death. However, comorbidities that often accompany PDD/A (such as epilepsy) and accidents are often cited as causes of death for this population. Four studies found standardized mortality rates varied between 1.9 and 2.6 (Isager et al., 1999; Mouridsen et al., 2008; Pickett et al., 2006; Shavelle et al., 2001). One study, which used a Swedish registry to follow children diagnosed with autism/atypical autism into early adulthood (mean age, 33 years), reported that of the 120 autistic persons (total population sample), nine died during the follow-up time period for a rate 5.6 times higher than expected, with females significantly more at risk (Gillberg et al., 2010). Mouridsen et al. and Pickett et al. also found significant increased risk of premature death for females. In all studies, the most common causes of death were attributed to epilepsy and accidents. CHBRP found no studies that examined the impact of Intensive behavioral intervention therapy on premature mortality.

Although an increased risk of premature death is associated with PDD/A, CHBRP found no evidence that intensive behavioral intervention therapies would reduce premature death for the PDD/A population; therefore, the public health impact of SB TBD 1 on premature death is unknown.

Economic Loss

Economic loss associated with disease is generally presented in the literature as an estimate of the value of the YPLL in dollar amount (i.e. valuation of a population's lost years of work over a lifetime), but can also include direct medical costs, including the insureds' expenses for noncovered benefits.

Lost productivity associated with PDD/A

For CHBRP analyses, a literature review is conducted to determine whether lost productivity has been established in the literature. In addition, morbidity associated with the disease or condition of interest can also result in lost productivity; either by causing the worker to miss days of work due to their illness or due to their role as a caregiver for someone else who is ill.

In an economic analysis using the human capital approach, Ganz estimated that the largest component of societal cost to caring for persons diagnosed with PDD/A is lost productivity of persons diagnosed with PDD/A and their caregivers. This accrues to about 60% (\$1.87 million) of the per capita societal costs (\$3.2 million) over the lifetime of a person with PDD/A (Ganz,

2007). The total lost productivity was split between PDD/A persons and their caregivers. A survey based on parent-report found that more than half of parents of children with ASD had to curtail or stop work to care for their child as compared with about one-third of parents of children with other emotional or behavioral problems (Kogan et al., 2009).

Using a subsample of a longitudinal study of families of ASD children and adults, researchers reported that very low employment rates of adults with PDD/A are common, with few persons earning a living wage (Taylor and Seltzer, 2010). CHBRP found no studies assessing the effects of intensive behavioral intervention therapies on lost-productivity or self-sustaining employment related to PDD/A.

Due to lack of evidence, CHBRP concludes the public health impact of SB TBD 1 is unknown regarding the effects of intensive behavioral intervention therapy on lost productivity for persons with PDD/A and their caregivers.

Financial burden of PDD/A

Other important costs to caring for persons with PDD/A include expenses directly paid for noncovered treatments and services. A study of the National Survey of Children with Special Health Care Needs (NS-CSHCN) found a disproportionate number of families of children with ASD encumbering “large” expenses related to noncovered benefits (>\$1,000), financial strain, and need for additional income (Kogan, et al., 2008). Another study (using results from the National Household Education Survey–After School Programs and Activities Survey 2005) estimated that families with autistic children lost 14% of their reported annual household income (\$6,200). The authors associated higher expenses for behavioral and educational treatments based on earlier studies of disproportionate burden of direct medical costs on families with children with PDD/A (Montes and Halterman, 2008).

CHBRP estimates that the postmandate, new benefit coverage would result in a net decrease in expenses for noncovered benefits for an estimated 7,300 enrollees with PDD/A (who use intensive behavioral intervention therapies) of about \$146 million. CHBRP assumes this postmandate shift would represent a savings for enrollees, their families, charities, DDS, CDE, and other payors. The extent to which the shift would result in a reduction in financial burden for enrollees with PDD/A (and their families) is unknown.

Long-Term Public Health Impacts

Long-term public health impacts consider both the financial burden on enrollees and the health outcomes related to the condition and its treatments. It has been estimated that the direct and indirect (medical and nonmedical) costs to care for persons with PDD/A each year over their lifetime is about \$35 billion, or a lifetime per capital incremental social cost of \$3.2 million per year (Ganz, 2007). Another study estimated the average lifetime public expenditure for a person with PDD/A as exceeding \$4.7 million (Newschaffer, 2007).

The longest term studies considering outcomes related to intensive behavioral intervention therapies were measured by two randomized controlled trials that looked at the 4- and 5-year outcomes of intensive behavioral intervention therapies (see the *Medical Effectiveness* section). Each found that intensive behavioral intervention therapies varied in effectiveness, with some children achieving mainstream classroom placement (McEachin et al., 1993; Sallows and Graupner, 2005). CHBRP found no studies of long-term outcomes (into adolescence or adulthood) for children receiving intensive behavioral intervention therapy.

SB TBD 1 would require DMHC-regulated plans and CDI-regulated policies to establish or expand networks of qualified autism providers. To the extent that SB TBD 1 would increase coverage for and use of intensive behavioral intervention therapies, it should be noted that supply of such therapies may be overcome by demand at some point in the future. Montes et al. analyzed results from the National Survey of Children with Special Health Care Needs (NS-CSHCN) and found parents of children with autism were three times more likely to have difficulty obtaining services than families with nonautistic children (odds ratio [OR]: 3.39 [confidence interval [CI]: 2.78-4.14]). In comparison with families with nonautistic children, these parents reported “no providers with skills child needed” (59.3% vs. 39.5%; $p < 0.01$), “services not available in my area” (56.3% vs. 39.1%; $p < 0.01$), and “long waiting lists” (55.1% vs. 44.5%; $p < 0.05$) (Montes et al., 2009), regardless of insurance status. The study did not specify type of providers or services needed, but these findings could indicate a problematic provider supply for intensive behavioral intervention therapies premandate.

Due to the lack of evidence of long-term impacts on the outcomes and behaviors relevant to this report, CHBRP concludes that the long-term public health impacts of SB TBD 1 are unknown.

APPENDICES

Appendix A: Text of Bill Analyzed

On January 19, 2011, Senate President pro Tempore Darrell Steinberg requested that CHBRP analyze SB TBD 1.

An act to add Section 1374.73 to the Health and Safety Code, and to add Section 10144.51 to the Insurance Code, relating to health care coverage.

LEGISLATIVE COUNSEL'S DIGEST

Bill No.

as introduced, ---

General Subject: Health care coverage: mental illness: autism.

(1) Existing law provides for licensing and regulation of health care service plans by the Department of Managed Health Care. A willful violation of these provisions is a crime. Existing law provides for licensing and regulation of health insurers by the Insurance Commissioner. Existing law requires health care service plan contracts and health insurance policies to provide benefits for specified conditions, including certain mental health conditions.

This bill would require health care service plan contracts and health insurance policies to also provide coverage for behavioral intervention therapy, as defined, for pervasive developmental disorder or autism. The bill would, however, provide that no benefits are required to be provided that exceed the essential health benefits required under federal law. Because the bill would change the definition of a crime with respect to health care service plans, it would thereby impose a state-mandated local program.

(2) 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. The Legislature finds and declares all of the following:

(a) During the past decade, scientific research has established that behavioral intervention therapy can significantly improve the cognitive function and emotional capabilities of, and reduce self-injurious behaviors of, a significant number of individuals with pervasive developmental disorders or autism.

(b) Scientists, physicians, and other autism experts now consider that behavioral intervention therapy is an important and medically necessary treatment for a significant number of individuals with pervasive developmental disorder or autism.

(c) Controversy, uncertainty, and disparities currently exist among some health

care service plans and health insurers as to whether behavioral intervention therapy should be a covered benefit for pervasive developmental disorder or autism. • e

(d) It is the intent of this act to provide clarification of existing laws requiring mental health parity and to provide for coverage of behavioral intervention therapy with regard to pervasive developmental disorder or autism.

SEC. 2. Section 1374.73 is added to the Health and Safety Code, to read:

1374.73. (a) (1) Every health care service plan contract issued, amended, or renewed on or after January 1, 2012, that provides hospital, medical, or surgical coverage pursuant to Section 1374.72 shall provide coverage for behavioral intervention therapy for pervasive developmental disorder or autism. 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), this section does not require any benefits to be provided that exceed the essential health benefits required to be provided 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 be construed as reducing any obligation to provide services to an individual under an individualized family service plan, an individualized program plan, a prevention program plan, an individualized education program, or an individualized service plan.

(b) (1) For the purposes of this section, "behavioral intervention therapy" shall be defined to include, but not be limited to, the following:

(A) The design, implementation, and evaluation of environmental modifications, such as applied behavioral analysis, using behavioral stimuli and consequences, to produce significant improvement in human health functions and behaviors, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.

(B) Professional services or treatment programs that have been scientifically validated and have demonstrated clinical efficacy.

(C) Professional services or treatment programs that have measurable treatment outcomes.

(2) For the purposes of this section, "pervasive developmental disorder or autism" shall have the meaning as used in Section 1374.72.

SEC. 3. Section 10144.51 is added to the Insurance Code, to read:

10144.51. (a) (1) Every health insurance policy issued, amended, or renewed on or after January 1, 2012, that provides hospital, medical, or surgical coverage pursuant to Section 10144.5 shall provide coverage for the behavioral intervention therapy for pervasive developmental disorder or autism. 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), this section does not require any benefits to be provided that exceed the essential health benefits required to be provided 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 be construed as reducing any obligation to provide services to an individual under an individualized family service plan, an individualized program plan, a prevention program plan, an individualized education program, or an individualized service plan.

(b) (1) For the purposes of this section, "behavioral intervention therapy" shall be defined to include, but not be limited to, the following:

(A) The design, implementation, and evaluation of environmental modifications, such as applied behavioral analysis, using behavioral stimuli and consequences, to produce significant improvement in human health functions and behaviors, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.

(B) Professional services or treatment programs that have been scientifically validated and have demonstrated clinical efficacy.

(C) Professional services or treatment programs that have measurable treatment outcomes.

(2) For the purposes of this section, "pervasive developmental disorder or autism" shall have the meaning as used in Section 10144.5.

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 TBD 1 Autism, a bill that would require all DMHC-regulated health plan contracts and all CDI-regulated policies to provide coverage for intensive behavioral intervention therapy for 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 1990 to the present. 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, Web sites 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 691 publications were identified. Twenty-five publications were retrieved for further examination. Six meta-analyses and one individual study were included in the literature review.

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. 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
- 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
- Insufficient evidence

The conclusion states that there is “clear and convincing” evidence that an intervention has a favorable effect on an outcome if most of the studies included in a review are well-implemented, randomized controlled trials and report statistically significant and clinically meaningful findings that favor the intervention.

The conclusion characterizes the evidence as “preponderance of evidence” that an intervention has a favorable effect if most but not all five criteria are met. For example, for some interventions, the only evidence available is from nonrandomized studies or from small RCTs with weak research designs. If most such studies that assess an outcome have statistically and clinically significant findings that are in a favorable direction and enroll populations similar to those covered by a mandate, the evidence would be classified as a “preponderance of evidence favoring the intervention.” In some cases, the preponderance of evidence may indicate that an intervention has no effect or has an unfavorable effect.

The evidence is presented as “ambiguous/conflicting if their findings vary widely with regard to the direction, statistical significance, and clinical significance/size of the effect.

The category “insufficient evidence” of an intervention’s effect indicates that available evidence is not sufficient to determine whether or not a health care service is effective. It is used when no research studies have been completed or when only a small number of poorly designed studies are available. It is not the same as “evidence of no effect.” A health care service for which there is insufficient evidence might or might not be found to be effective if more evidence were available.

Search Terms

The search terms used to locate studies relevant to SB TBD 1 Autism were as follows:

MeSH Terms Used to Search PubMed

Asperger Syndrome

Asperger Syndrome/Diagnosis, Economics, Epidemiology, Therapy

Autistic Disorder

Autistic Disorder/ Diagnosis, Economics, Epidemiology, Therapy

Behavior Therapy+

Child Development Disorders, Pervasive+

Child Development Disorders, Pervasive+/ Diagnosis, Economics, Epidemiology, Therapy

Continental Population Groups+

Economics+

Rett Syndrome

Rett Syndrome/ Diagnosis, Economics, Epidemiology, Therapy

Sex Characteristics

Vital Statistics+

Keywords used to search PubMed, Cochrane Library, CINAHL, PsycInfo and relevant Web sites

ABA
Applied Behavior Analysis
Asperger Syndrome
Aspergers Syndrome
Autism
Autism Spectrum Disorders
Autistic Children
Autistic Disorder
Behavior Modification
Behavior Therapy
Behavioral Therapy
Cognitive Therapy
Cost Containment
Costs and Cost Analysis
Denver Early Start Model
Diagnosis
Differential Diagnosis
Disease Management
Discrete Trial Training
Economics
Educational Diagnosis
Ethnology
Financial Strain
Florentine Therapy
Greenspan Therapy
Health Care Costs
Health Care Economics
Health Screening
Human Sex Differences
Long Term Care
Medical Diagnosis
Mortality Rate
Pervasive Child Development Disorders
Pervasive Developmental Disorders
Productivity
Psychodiagnosis
Quality of Life
Racial and Ethnic Attitudes
Racial and Ethnic Groups
Relaxation Therapy
Screening
Sociocultural Factors

Publication Types:

Comparative Study
Controlled Clinical Trial
Evaluation Studies
Meta-Analysis
Practice Guideline
Randomized Control Trial
Review
Systematic Reviews

Appendix C: Summary Findings on Medical Effectiveness

Appendix C describes the studies of therapies for PDD/A based on behavioral intervention therapies included in the medical effectiveness review for SB TBD 1. Table C-1 describes the characteristics of the studies included in the review. The review focuses on intensive behavioral intervention therapies based on applied behavioral analysis (ABA) or other theories of behavior because they are specifically referenced in the bill and because they are the behavioral intervention therapies on which the largest amount of literature has been published. Table C-2 summarizes findings from the studies included in the review. Where available, the review relied on systematic reviews and meta-analyses.

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

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Intensive behavioral interventions based on ABA	Eldevik et al., 2009	Meta-analysis	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 30.9-66.3 months	N/A
Intensive behavioral interventions based on ABA	Howlin et al., 2009	Systematic Review	ABA-based intervention vs. comparison group ⁵⁶	Children with either: (1) autism, (2) autism spectrum disorders, or (3) pervasive developmental disorders: mean age of children at enrollment: 40-42 months	N/A
Intensive behavioral interventions based on ABA	Reichow and Worley, 2009	Meta-analysis	ABA-based intervention vs. comparison group ⁵⁷	Children participating had either: (1) ASD, (2) AD, (3) PDD-NOS, or (4) PDD: most children aged less than 42 months at enrollment	N/A

⁵⁶ 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.

⁵⁷ 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)

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

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Intensive behavioral interventions based on ABA	Spreckley et al., 2009	Meta-analysis	ABA-based intervention vs. comparison group ⁵⁸	Children diagnosed with PDD/A ⁵⁹ according to the criteria based on the DSM IV ⁶⁰ . One study did not use a standardized diagnostic instrument. Study participants' age ranged from 18 months to 6 years	N/A
Intensive behavioral interventions based on ABA	Makrygianni and Reed, 2010	Meta-analysis	ABA-based intervention vs. eclectic-control programs ⁶¹	Children participating had either: (1) autism, (2) autistic spectrum disorders (ASD), (3) Autistic Disorder (AD), (4) Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and/or (5) pervasive developmental disorders (PDD): mean age at enrollment: 38 months	N/A

⁵⁸ All comparison groups also received intervention (i.e., eclectic treatment, less intensive or less supervised ABA-based intervention).

⁵⁹ PDD/A = Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (including atypical autism).

⁶⁰ *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.

⁶¹ 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 Interventions (cont'd.)

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Intensive behavioral interventions based on ABA	Virués-Ortega, 2010	Meta-analysis	ABA-based intervention vs. control group not receiving ABA-based intervention	Subjects were either diagnosed with autism or PDD-NOS ⁶² . Mean age ranged from 22.6 to 66.3 months	N/A
Early Start Denver Model	Dawson et al., 2010	Randomized controlled trial	Early Start Denver Model (ESDM) vs. community intervention	Children aged between 18 and 30 months of age at enrollment who were diagnosed with AD (PDD-NOS)	Washington, USA

Sources: Dawson et al., 2010; Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Worley, 2009; Spreckley et al., 2009; Virués-Ortega, 2010.

⁶² Pervasive Developmental Disorder Not Otherwise Specified (including atypical autism)

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

Table C2-a. Early intensive behavioral intervention based on Applied Behavior Analysis (ABA) vs. comparison group⁶³

Outcome	Citation	Research Design ⁶⁴	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior ⁶⁵	Eldevik et al., 2009;	Meta-analysis: 7 Level II and Level III studies	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	Makrygianni and Reed, 2010	Meta-analysis: 7 Level II and Level III studies	High-quality studies: ⁶⁶ 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)	
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	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)	

⁶³ Comparison groups varied widely across studies and included less intensive versions of the same intervention, parent-led versions of the same intervention, eclectic treatment (i.e., mix of other treatments commonly provided to children with autism), and standard care in the community in which a child resided

⁶⁴ 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.

⁶⁵ Usually measured using the Vineland adaptive behavior scales (VABS, which assesses social, communication, motor, and daily living skills.)

⁶⁶ Based on 11 criteria specified by the authors (Makrygianni and Reed, 2010).

Table C2-a. Early intensive behavioral intervention based on Applied Behavior Analysis (ABA) vs. comparison group

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
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	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	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	
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	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)	

Table C2-a. Early intensive behavioral intervention based on Applied Behavior Analysis (ABA) 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, 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	

Table C2-a. Early intensive behavioral intervention based on Applied Behavior Analysis (ABA) 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, 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: 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)	

Sources: Eldevik et al., 2009; Howlin et al., 2009; Makrygianni and Reed, 2010; Reichow and Worley, 2009; Spreckley et al., 2009; Virués-Ortega, 2010.

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	1 Level II study ⁶⁷	Statistically significant	Better	Same score for VABS ⁶⁸ 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 (intelligence quotient)	Dawson et al., 2010	1 Level II study	Statistically significant	Better	Improvement in MSEL ⁶⁹ 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.
Reduction of severity of ASD ⁷⁰	Dawson et al., 2010	1 Level II study	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,

⁶⁷ Randomized controlled trial with major weaknesses.

⁶⁸ Vineland adaptive behavior scales: assesses social, communication, motor and daily living skills.

⁶⁹ Mullen Scales of Early Learning: standardized developmental test for children from birth to 68 months of age.

⁷⁰ 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, 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 CHBRP Web site at www.chbrp.org/costimpact.html.

The cost analysis in this report was prepared by the members of cost team, which consists of CHBRP task force members and contributors from the University of California, San Diego, and the University of California, Los Angeles, as well as the contracted actuarial firm, Milliman, Inc. (Milliman). Milliman provides data and analyses per the provisions of CHBRP's authorizing legislation.

Data Sources

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

Health insurance

1. The latest (2009) California Health Interview Survey (CHIS), which is used to estimate health insurance for California's population and distribution by payor (i.e., employment-based, individually purchased, or publicly financed). The biennial CHIS is the largest state health survey conducted in the United States, collecting information from approximately 50,000 households. More information on CHIS is available at www.chis.ucla.edu.
2. The latest (2010) California Employer Health Benefits Survey is used to estimate:
 - size of firm,
 - percentage of firms that are purchased/underwritten (versus self-insured),
 - premiums for health care service plans regulated by the Department of Managed Health Care (DMHC) (primarily health maintenance organizations [HMOs] and Point of Service Plans [POS]),
 - premiums for health insurance policies regulated by the California Department of Insurance (CDI) (primarily preferred provider organizations [PPOs] and fee-for-service plans [FFS]), and
 - premiums for high deductible health plans (HDHPs) for the California population with employment-based health insurance.
 - 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.

3. 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, Blues plans, HMOs, self-funded employers, and private data vendors. The data are mostly from loosely managed health care plans, generally those characterized as preferred provider plans, or PPOs. The HCGs currently include claims drawn from plans covering 4.6 million members. In addition to the Milliman HCGs, CHBRP’s utilization and cost estimates draw on other data, including the following:
 - The MarketScan Database, which includes demographic information and claim detail data for approximately 13 million members of self-insured and insured group health plans.
 - 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.
 - 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.
 - These data are reviewed for applicability by an extended group of experts within Milliman but are not audited externally.
4. An annual survey by CHBRP of 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 PacifiCare) to obtain estimates of baseline enrollment by purchaser (i.e., large and small group and individual), type of plan (i.e., DMHC- or CDI-regulated), cost-sharing arrangements with enrollees, and average premiums. Enrollment in plans or policies offered by these seven firms represents an estimated 93.7% of the persons with health insurance subject to state mandates. This figure represents an estimated 94.4% of enrollees in full service (nonspecialty) DMHC-regulated health plans and an estimated 90.1% of enrollees in full service (nonspecialty) CDI-regulated policies.⁷¹

⁷¹ CHBRP analysis of the share of enrollees included in CHBRP’s Bill-Specific Coverage Survey of the major carriers in the state is based on “CDI Licenses with HMSR Covered Lives Greater than 100,000” as part of the Accident and Health Covered Lives Data Call, December 31, 2009, by the California Department of Insurance, Statistical Analysis Division, data retrieved from The Department of Managed Health Care’s interactive Web site “Health Plan Financial Summary Report,” July-September 2010,” and CHBRP’s Annual Enrollment and Premium Survey.

Publicly funded insurance subject to state benefit mandates

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 (EOCs) documents publicly available at www.calpers.ca.gov.
6. Enrollment in Medi-Cal Managed Care (DMHC-regulated health plans) is estimated based on CHIS and data maintained by the Department of Health Care Services (DHCS). DHCS supplies CHBRP with the statewide average premiums negotiated for the Two-Plan Model, as well as generic contracts that summarize the current scope of benefits. CHBRP assesses enrollment information online at www.dhcs.ca.gov/dataandstats/statistics/Pages/RASS_General_Medi_Cal_Enrollment.aspx.
7. Enrollment data for other public programs—Healthy Families Program (HFP), Access for Infants and Mothers (AIM), and the Major Risk Medical Insurance Program (MRMIP)—are estimated based on CHIS and data maintained by the Managed Risk Medical Insurance Board (MRMIB). The basic minimum scope of benefits offered by participating health plans under these programs must comply with all requirements for DMHC-regulated health plans, and thus these plans are affected by state-level benefit mandates. CHBRP does not include enrollment in the Post-MRMIP Guaranteed-Issue Coverage Products as these persons are already included in the enrollment for individual market health insurance offered by DMHC-regulated plans or CDI-regulated insurers. Enrollment figures for AIM and MRMIP are included with enrollment for Medi-Cal in presentation of premium impacts. Enrollment information is obtained online at www.mrmib.ca.gov/. Average statewide premium information is provided to CHBRP by MRMIB staff.

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 would 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.

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 would only be for the first year after enactment of the proposed mandate.
- Employers and employees would share proportionately (on a percentage basis) in premium rate increases resulting from the mandate. In other words, the distribution of premium paid by the subscriber (or employee) and the employer would be unaffected by the mandate.
- For state-sponsored programs for the uninsured, the state share would continue to be equal to the absolute dollar amount of funds dedicated to the program.
- When cost savings are estimated, they reflect savings that would be 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 recent 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, while Hadley (2006) and Glied and Jack (2003) estimate that a 10% increase in private premiums produces a 0.88 and 0.84 percentage point decrease in the number of insured, respectively. The price elasticity of demand for insurance can be calculated from these studies in the following way. First, take the average percentage point decrease in the number of insured reported in these studies in response to a 1% increase in premiums (about -0.088), divided by the average percentage of insured persons (about 80%), multiplied by 100%, i.e., ($\{-0.088/80\} \times 100 = -0.11$). This elasticity converts the *percentage point* decrease in the number of insured into a *percentage* decrease in the number of insured persons for every 1% increase in premiums. 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%.

Potential Effects of the Federal Affordable Care Act

As discussed in the *Introduction*, there are a number of the ACA provisions that have already gone into or will go into effect over the next 3 years. Some of these provisions affect the baseline or current enrollment, expenditures, and premiums. This subsection discusses adjustments made to the 2011 Cost and Coverage Model to account for the potential impacts of the ACA that have gone into effect by January, 2011. It is important to emphasize that CHBRP's analysis of specific mandate bills typically address 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.

CHBRP reviewed the ACA provisions and determined whether and how these provisions might affect:

1. The number of covered lives in California, and specifically the makeup of the population with health insurance subject to state mandates;
2. Baseline premiums and expenditures for health insurance subject to state mandates; and
3. Benefits required to be covered in various health insurance plans subject to state mandates.

There are still a number of provisions that have gone into effect for which data are not yet available. Where data allows, CHBRP has made adjustments to the 2011 Cost and Coverage model to reflect changes in enrollment and/or baseline premiums and these are discussed here.

Coverage for adult children

PPACA Section 2714, modified by HR 4872, Section 2301, requires coverage for adult children up to age 26 as dependants to primary subscribers on all individual and group policies, effective September 23, 2010. California's recently enacted law, SB 1088 (2010) implements this provision. This could potentially affect both premiums and enrollment in 2011. According to the California Health Interview Survey (CHIS) approximately 22% of Californians aged 19-25 years (1,063,000) were estimated to be uninsured at some point in 2009. As a result of the ACA, many of these young adults will likely gain access to health insurance through a parent. This dynamic may diminish the number of uninsured and may also shift some young adults from the individually-purchased health insurance market into the group market. The Departments of Treasury, Labor, and Health and Human Services estimate, for 2011, the number of young adults newly covered by his/her parent's plan would be about 0.78 to 2.12 million (using high and low take-up rate assumptions, respectively). Of these young adults, about 0.2 to 1.64 million would have previously been uninsured. The corresponding incremental cost impact to group insurance policies is estimated to be a premium increase of 0.5% to 1.2%. Based on the responses to the Annual Enrollment and Premium survey, there has been an increase of 1% to 1.5% in enrollment for the 19-25 year olds and the increase varies depending on whether the parents were enrolled in the large group, small group or individual markets. Based on analysis of the estimates from the Departments of Treasury, Labor, and Health and Human Services as well as CHIS 2009 data, approximately 25% of the increase in enrollment represents a shift from the individual market and approximately 75% were previously uninsured. CHBRP took these estimates into account and adjusted underlying population data since source data did not reflect the effects of this provision, because shift in populations were expected to be significant, and to account for potential lags in enrollment (e.g., due to awareness).

Minimum medical loss ratio requirement

PPACA Section 2718 requires health plans offering health insurance in group and individual markets to report to the Secretary of Health and Human Services the amount of premium revenue spent on clinical services, activities to improve quality, and other non-claim costs. Beginning in 2011, large group plans that spend less than 85% of premium revenue and small group/individual market plans that spend less than 80% of premium revenue on clinical services and quality must provide rebates to enrollees. According to the Interim Final Rule, (45 CFR Part 158) "Issuers will provide rebates to enrollees when their spending for the benefit of policyholders on reimbursement for clinical services and quality improvement activities, in relation to the premiums charged, is less than the MLR standards established pursuant to the statute."⁷² The requirement to report medical loss ratio is effective for the 2010 plan year, while the requirement to provide rebates is effective January 1, 2011. The MLR requirement, along with the rebate payment requirement, will affect premiums for 2011, but the effects are unknown, and data are

⁷² Department of Health and Human Services, *Interim Final Rule: Health Insurance Issuers Implementing Medical Loss Ratio (MLR) Requirements Under the Patient Protection and Affordable Care Act*. 45 CFR Part 158. December 1, 2010.

not yet available. There is potential for substantial impact on markets with higher administrative costs, including the small and individual group markets. Responses to CHBRP's Annual Enrollment and Premiums Survey indicate that carriers intend to be in compliance with these requirements. For those that may not be in compliance, the requirement to pay rebates is intended to align the MLR retrospectively. Therefore for modeling purposes, CHBRP has adjusted administrative and profit loads to reflect MLRs that would be in compliance with this provision.

Pre-Existing Condition Insurance Plan

PPACA Section 1101 establishes a temporary high-risk pool for individuals with pre-existing medical conditions, effective 90 days following enactment until January 1, 2014. In 2010, California enacted AB 1887 and SB 227, providing for the establishment of the California Pre-existing Conditions Insurance Plan (PCIP) to be administered by the Managed Risk Medical Insurance Board (MRMIB) and federally funded per Section 1101. MRMIB has projected average enrollment of 23,100 until the end of 2013, when the program will expire. As of December 2010, there were approximately 1,100 subscribers.⁷³ The California PCIP is not subject to state benefit mandates,⁷⁴ and therefore, this change does not directly affect CHBRP's Cost and Coverage Model. CHBRP has revised its annual update of *Estimates of the Sources of Health Insurance in California*.⁷⁵ to reflect that a slight increase in the number of those who are insured under other public programs that are not subject to state-level mandates.

Prohibition of pre-existing condition exclusion for children

PPACA Sections 1201& 10103(e): Prohibits pre-existing condition exclusions for children. This provision was effective upon enactment). California's recently enacted law, AB 2244 (2010) implements this provision. AB 2244 also prohibits carriers that sell individual plans or policies from refusing to sell or renew policies to children with pre-existing conditions. Carriers that do not offer new plans for children are prohibited from offering for sale new individual plans in California for 5 years.⁷⁶ This provision could have had significant premium effects, especially for the DMHC- and CDI-regulated individual markets. The premium information is included in the responses to CHBRP's Annual Enrollment and Premium Survey. Thus the underlying data used in CHBRP annual model updates captured the effects of this provision.

Prohibition of lifetime limits and annual benefit limit changes

PPACA Section 2711 prohibits individual and group health plans from placing lifetime limits on the dollar value of coverage, effective September 23, 2010. Plans may only impose annual limits on coverage and these annual limits may be no less than \$750,000 for "essential health benefits." The minimum annual limit will increase to \$1.25 million on Sept. 23, 2011, and to \$2 million September 23, 2012. Earlier in 2010, CHBRP conducted an analysis of SB 890 which sought to prohibit lifetime and annual limits for "basic health care services" covered by CDI-regulated

⁷³ Enrollment report presented at the Managed Risk Medical Insurance Board Meeting, January 19, 2010. Available at:

www.mrmib.ca.gov/MRMIB/Agenda_Minutes_011911/Agenda_Item_9.a_PCIP_Board_Report_for_Dec_2010_FI_NAL.pdf.

⁷⁴ Correspondence with John Symkowitz, Legislative Coordinator, MRMIB, October 19, 2010.

⁷⁵ See: www.chbrp.org/documents/insur_source_est_2010.pdf.

⁷⁶ See enacted language at: www.leginfo.ca.gov/pub/09-10/bill/asm/ab_2201-2250/ab_2244_bill_20100930_chaptered.pdf.

policies. CHBRP's indicated that DMHC-regulated plans were generally prohibited from having annual or lifetime limits. The analysis also indicated that less than 1% of CDI-regulated policies in the state had annual benefit limits and of those, the average annual benefit limit was approximately \$70,000 for the group market and \$100,000 for the individual market. Almost all CDI-regulated policies had lifetime limits in place, and the average lifetime limit was \$5 million. After the effective date of the PPACA Section 2711, removal of these limits may have had an effect on premiums. As mentioned, premium information is included in the responses to CHBRP's Annual Enrollment and Premium Survey. Thus, the underlying data used in CHBRP's annual model updates captured the effects of this provision to remove lifetime limits and to increase annual limits for those limited number of policies that had annual limits that fell below \$750,000.

Medi-Cal Managed Care enrollment: Seniors and persons with disabilities

Although the PPACA allows states the option to expand coverage to those not currently eligible for Medicaid (Medi-Cal in California), large-scale expansions are not expected to be seen during 2011. However, as a result of the 2010-2011 California Budget Agreement, there are expected to be shifts in coverage for seniors and persons with disabilities. Specifically, "Seniors and persons with disabilities who reside in certain counties which have managed care plans, and who are not also eligible to enroll in Medicare, will be required to enroll in a managed care plan under a phased-in process."⁷⁷ The Medi-Cal Managed Care enrollment in CHBRP's 2011 Cost and Coverage Model has been adjusted to reflect this change. Baseline premium rates have also been adjusted to reflect an increase in the number of seniors and persons with disabilities in Medi-Cal Managed Care. Information from DHCS indicate these changes will go into effect July 1, 2011, and would affect approximately 427,000 Medi-Cal beneficiaries.⁷⁸ CHBRP used data from DHCS to adjust enrollment in Medi-Cal Managed Care, and to adjust premiums to account for the change in acuity in the underlying populations.⁷⁹

Bill Analysis-Specific Caveats and Assumptions

For this analysis, CHBRP makes the following assumptions:

- The percentage of enrollees receiving intensive behavioral intervention therapy varies by age, as shown in Table D-1.
- Utilization (hours per week) of intensive behavioral intervention therapy varies between age groups and by diagnosis, as show in Table D-2.

⁷⁷ Taylor, M. Legislative Analyst, *The Budget Package 2010-11 California Spending Plan*. LAO: November, 2010. Available at:

www.lao.ca.gov/reports/2010/bud/spend_plan/spend_plan_110510.pdf

⁷⁸ Data from the Department of Health Care Services, Medi-Cal Managed Care Division. Received January 14, 2011.

⁷⁹ See the study conducted for DHCS by Mercer on this topic: Mercer, *Medi-Cal Acuity Study: Seniors and Persons with Disabilities*. September 28, 2010. Available at

www.dhcs.ca.gov/provgovpart/Documents/Waiver%20Renewal/SPD_Study_092810.pdf

- 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 bases an assumption of minimal or no utilization after the age 14 on available literature (Ganz, 2007) and content expert opinion. For enrollees aged 3 or less, CHBRP assumes that there would be a postmandate increase in the utilization rate. The elasticity assumption used to estimate this increased utilization rate was the RAND chronic mental health outpatient elasticity of approximately 0.23, rounded 0.20 in the cost model. (Newhouse, 1993). The diagnosis specific utilization rates in Table D-2 are based on 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. Persons aged 20 years and older with Autistic Disorder and PDD NOS are assumed to typically utilize 0 hours per week of intensive behavioral intervention therapies. Persons aged 20 and older with Asperger’s Disorder could use intensive behavioral intervention therapies 0-2 hours per week (more than would typically be assumed for PDD/A other than Asperger’s Disorder). However, since Asperger’s Disorder is estimated to comprise less than 10% of all PDD/A cases in the U.S. population (see Appendix F and Fombonne 2009), 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-1. Intensive Behavioral Intervention Therapy Utilization Assumptions – Percent of Enrollees Utilizing

	Premandate	Postmandate
Age 0-4	35%	40%
Age 5-9	20%	20%
Age 10-14	10%	10%
Age 15-19	1%	1%
Age 20+	0%	0%

Source: CHBRP, 2011

Table D-2. Intensive Behavioral Intervention Therapy Utilization Assumptions – Hours per Week Utilized

	PDD/A Other Than Asperger’s Disorder	Asperger’s Disorder
Age 0-4	25	15
Age 5-9	15	9
Age 10-14	5	3
Age 15-19	5	3
Age 20+	0	0

Source: CHBRP, 2011

Appendix E: Information Submitted by Outside Parties

In accordance with 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 Autism Speaks on February 9, 2011.

Autism Speaks. *Back to the Envelope Economic Impact of Autism Specific Health Insurance Reform SB TBD*. February 9, 2011.

The following information was submitted by the Office of Senator Darrell Steinberg in February, 2011.

California Legislative Blue Ribbon Commission on Autism Web site. Available at: <http://senweb03.senate.ca.gov/autism/index.html>. Accessed March 8, 2011.

Bouder JN, Stuart S, Mandell DS. Brief report: Quantifying the impact of autism coverage on private insurance premiums. *Journal of Autism Developmental Disorders*. 2009.

Office of the President pro Tempore. *A Consumer's Perspective: Health Insurance Coverage of Individuals with Autism Spectrum Disorders – Issues for Discussion*. Sacramento, CA: 2009.

Department of Managed Health Care. *Improving Plan Performance to Address Autism Spectrum Disorders*. Sacramento, CA: 2009.

Consumer Watchdog; Anshu Batra, MD v. California Department of Managed Health Care; Lucinda Ehnes. Lawsuit Brief. Sacramento, CA: 2010.

California Senate Select Committee on Autism. *Health Insurance Coverage of Behavioral Intervention Therapy for Autism Spectrum Disorders (ASD)*. June 10, 2010.

United Healthcare. Intensive Behavioral Therapy for the Treatment of Autism Spectrum Disorders. Medical Policy; 2010.

For information on the processes for submitting information to CHBRP for review and consideration please visit: www.chbrp.org/requests.html.

Appendix F: Public Health Calculations

For this analysis, CHBRP calculated an estimated prevalence rate of PDD/A for Californians, based on adjustments to data from a 2007 report by the California Department of Developmental Services and a study cited by DDS in the 2007 report. 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 TBD 1. 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. It is noted that CHBRP's estimated prevalence rates are based on 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 90/10,000 (CDC, 2009) to 132/10,000 (Kogan et al., 2009) with large variation in ages studied and study methodology. A sensitivity analysis CHBRP's estimated prevalence rates shows that using the higher CHBRP estimate of 149/10,000 (ages 5-9 years) would yield about 15,000 California children aged 5-9 years diagnosed with PDD/A, whereas 90/10,000 yields about 9,000 children in that same age bracket. This difference 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. This estimate may be closer to the true prevalence rate given the accelerated increasing rates in the last 10 years.

Description and Rationale for Use of California Department of Developmental Services Data

To provide the best estimate, CHBRP uses data from the California Department of Developmental Services (DDS), which is the primary state agency that serves residents with developmental disabilities, including 75%-80% of persons diagnosed with Autistic Disorder (Croen et al, 2002). The 2007 DDS report stated that it served 38,084 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 [34,656] and "Other ASD" [3,428] DDS, 2009). This administrative data appears to be the most comprehensive accounting of California cases of

PDD/A and includes details on gender and racial subpopulations as well as distribution by age categories (Croen et al., 2002; DDS, 2009).

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. These adjusted rates generally align with other published rates. For example, the adjusted prevalence rate for the 5- to 9-year age group (149/10,000) appears to be comparable to the National Survey of Children’s Health 6- to 8-year age group (132/10,000). Another potential limitation to DDS data relate to an estimated 20%-25% undercount of the total DDS caseload of those diagnosed with Autistic 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: Autistic Disorder and “other” PDD. Both require some adjustment to estimate the total number of Californians with PDD/A.

To calculate the prevalence of Autistic Disorder in California:

In Table F-1b, DDS reported that it served an estimated 75%-80% of Autistic Disorder diagnoses in California. To find the total persons diagnosed with Autistic Disorder, the reported caseload is divided by the midpoint between 75% and 80% ($34,656/0.775 = 44,717$). DDS also provided the distribution of its Autistic Disorder population by age group, which CHBRP used to estimate the California Autistic Disorder prevalence rates by age using the following steps in Table F-1a:

1. “Number of people with Autistic Disorder served by DDS”: Multiply the percentage distribution reported by DDS by 34,656.
2. “Estimated number of people with Autistic Disorder in California”: Divide “number of people with autism disorder served by DDS” by 0.775 (to adjust by age category).
3. “Estimated prevalence of Autistic Disorder in California (per 10,000)”: Divide “estimated number of people with Autistic Disorder in California” by 2007 California population (from California Department of Finance) and multiply by 10,000.

To calculate the 2007 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 June 2007, DDS reported serving 3,428 Californians with “ASD other than Autistic Disorder” (DDS, 2009). CHBRP adjusted the second half of the table for the “other PDDs” using prevalence rates from literature, 2007 DDS data, and 2007 state population estimates (the numerator and denominator data years must match to properly estimate the 2007

prevalence rate). Table F-1a estimates distribution of PDD/A subtypes using prevalence rates taken from Fombonne (2009) in which Autistic Disorder represents 32% of all PDD and "other" represents 68% of all PDD. To find "percentage and number of PDD subtypes," CHBRP divides 32% by total Autistic Disorder population (44,717), which equals 139,741; the "estimated total number of Californians with PDD/A." CHBRP subtracts "number of Autistic Disorder subtypes" from "estimated total number of Californians with PDD/A" to determine "estimated number of people with "other" PDD in California" ($139,741 - 44,717 = 95,024$).

Using baseline data from Tables F-1a and F-1b, CHBRP applied the same logic used in the Autistic 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 Autistic 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 (CHIS)

The 2005 CHIS (a telephone-based survey) dataset was queried to double check CHBRP's methodology for determining prevalence of PDD/A in California. Results from the query yielded 40 cases of parent-reported autism diagnosis in children aged 0-11 years out of 11,358 child surveys (CHIS, 2005). These results represent about a 0.8% prevalence rate among children 0-11, which is close to the CDC's estimate of a 1% prevalence rate nationwide (CDC, 2009). CHIS 2005 (unlike more recent years) allowed parents to specify autism as a condition that prevented their child from doing age-appropriate activities and/or schoolwork. This analysis does not use the CHIS data in this analysis due to the following limitations: small number of cases, a narrower age-interval than other studies, and limited questions discerning differences among types of PDDs.

National Survey on Child Health

Kogan et al. published an estimated prevalence of 110/10,000 based on parent-reported diagnosis of "autism spectrum disorders" in children aged 3-17 years in 2007. 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 (Kogan et al., 2009). 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). Despite this study's strengths, CHBRP relies on California-specific data rather than national estimates, as the California experience may be different than other locales (see the CDC study).

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

The CDC's ADDM Network coordinated a multisite (10 states) surveillance of prevalence, population characteristics, and public health impacts of ASDs and other developmental disabilities. The CDC derived the overall ASD prevalence rate of 90/10,000 from a retrospective review of medical and school records of 8-year-olds. The CDC reported that age 8 is "a reasonable index age at which to monitor peak prevalence" (CDC, 2009). 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 states, (42/10,000 to 121/10,000) and conformed to other study findings of a male-to-female prevalence ratio of 4:1. 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 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. Although the CDC study is widely cited, one of the study's strengths (elimination of early misdiagnosis for the 8-year-old population in the CDC study) may not benefit this analysis as, presumably, these children still would use screening, diagnostic, and perhaps some treatment services before being re-categorized. Additionally, the absence of California involvement in the study and the wide variation in prevalence rates between the 10 participating states support CHBRP's use of state-specific data when possible.

Table F-1a. Calculations for Estimating California PDD/A Prevalence Rates Using Adjusted 2007 California DDS Data

Age Groups (years)	DDS Reported Age Group Distribution of Persons with Autistic Disorder Served by DDS (a)	DDS Reported Number of People with Autistic Disorder Served by DDS (a)	Estimated Number of People with Autistic Disorder in California (b)	California Population (c)	Estimated Prevalence of Autistic 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	12.0%	4,159	5,366	2,710,425	19.8	7.7%	7,317	2,710,425	27.0	46.8
5-9	34.0%	11,783	15,204	2,640,636	57.6	25.5%	24,231	2,640,636	91.8	149.3
10-14	22.8%	7,902	10,196	2,849,005	35.8	20.7%	19,670	2,849,005	69.0	104.8
15-19	12.9%	4,471	5,769	2,955,147	19.5	16.6%	15,774	2,955,147	53.4	72.9
20-24	5.8%	2,010	2,594	2,686,442	9.7	9.9%	9,407	2,686,442	35.0	44.7
25-29	3.3%	1,144	1,476	2,487,338	5.9	6.5%	6,177	2,487,338	24.8	30.8
30-34	2.1%	728	939	2,507,943	3.7	3.2%	3,041	2,507,943	12.1	15.9
35-39	1.8%	624	805	2,827,954	2.8	2.4%	2,281	2,827,954	8.1	10.9
40-44	2.0%	693	894	2,865,786	3.1	2.4%	2,281	2,865,786	8.0	11.1
45-49	1.6%	554	715	2,849,634	2.5	1.8%	1,710	2,849,634	6.0	8.5
50+	1.7%	589	760	10,430,272	0.7	3.2%	3,041	10,430,272	2.9	3.6
Total		34,656	44,717	37,810,582	11.8		95,024	37,810,582	25.1	37.0

Source: California Health Benefits Review Program, 2011 (based on data from a report by DDS, 2009).

(a) CHBRP uses the DDS caseload percentage and number by age category as reported in the 2007 DDS report.

(b) The DDS report cited a study by Croen et al. that estimated DDS served 75%-80% of the total Autistic Disorder population in California. The DDS Autistic 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 2007 California population as the denominator to correspond with the DDS June 2007 numerator to capture the prevalence rate (point in time) in 2007.

"California population" by age category obtained from: "California Population, 2007" Prepared by California Department of Health Services, EPIC Source: California Department of Finance, Race/Ethnic Population with Age and Sex Detail Branch, EPICenter Web site (www.dhs.ca.gov/epicenter). Table created on February 1, 2011.

http://apps.cdph.ca.gov/epicdata/content/st_population.htm.

Key: DDS=California Department of Developmental Services.

Table F-1b. Determining Distribution of PDD/A Subtypes Within the California PDD/A Population in 2007

PDD and Its Subtypes	Epidemiology of PDD: Prevalence Rates (a)	Percentage and Number of PDD Subtypes (b)	
Autistic Disorder	20.6/10,000	32%	44,717
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%	95,024
Estimated total number of Californians with any PDD/A diagnosis (2007)	NA	100%	139,741

Source: California Health Benefits Review Program, 2011 (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: Autistic Disorder represents 32% of all PDD and "Other" represents 68% of all PDD.

(b) "Percentage and number of PDD subtypes" are derived from Fombonne prevalence rates and DDS data for Autistic Disorder-only population. Divide "estimated number of people with Autistic 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 PDD/A" (44,717/0.32=139,741). Subtract 44,717 from 139,741 to determine "Other" PDD population (95,024).

(c) Childhood Disintegrative Disorder and Rett's Disorder not included in "other PDDs."

Key: NOS=not otherwise specified; PDD=pervasive developmental disorders.

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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 and three private universities in California. 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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