



CALIFORNIA
HEALTH BENEFITS REVIEW PROGRAM

Analysis of Assembly Bill 171: Autism

A Report to the 2011-2012 California Legislature
March 26, 2011

CHBRP 11-05



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 Assembly Bill 171: Autism

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Suggested Citation:

California Health Benefits Review Program (CHBRP). (2011). *Analysis of Assembly Bill 171: Autism*. Report to California State Legislature. Oakland, CA: CHBRP. 11-05.

PREFACE

This report provides an analysis of the medical, financial, and public health impacts of Assembly Bill 171. In response to a request from the California Assembly Committee on Health on January 25, 2011, the California Health Benefits Review Program (CHBRP) undertook this analysis pursuant to the program's authorizing statute.

Edward Yelin, PhD, Janet Coffman, MPP, PhD, Mi-Kyung (Miki) Hong, MPH, all of the University of California, San Francisco, prepared the medical effectiveness analysis. Penny Coppernoll-Blach, MLIS, of the University of California, San Diego, conducted the literature search. Diana Cassady, ScD, Dominique Ritley, MPH, all of the University of California, Davis, prepared the public health impact analysis. Ninez Ponce, PhD, of the University of California, Los Angeles, prepared the cost impact analysis. Robert Cosway, FSA, MAAA, of Milliman, provided actuarial analysis. Natacha Akshoomoff, PhD, of the University of California, San Diego, and Renee C. Wachtel, MD, of Children's Hospital & Research Institute, Oakland, California, provided technical assistance with the literature review and expert input on the analytic approach. John Lewis, MPA, of CHBRP staff prepared the introduction and synthesized the individual sections into a single report. A subcommittee of CHBRP's National Advisory Council (see final pages of this report) and a member of the CHBRP Faculty Task Force, Susan L. Ettner, PhD, of the University of California, Los Angeles, reviewed the analysis for its accuracy, completeness, clarity, and responsiveness to the Legislature's request.

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

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EXECUTIVE SUMMARY

California Health Benefits Review Program Analysis of Assembly Bill 171

The California Assembly Committee on Health requested on January 25, 2011, that the California Health Benefits Review Program (CHBRP) conduct an evidence-based assessment of the medical, financial, and public health impacts of Assembly Bill (AB) 171: Autism. In response to this request, CHBRP undertook this analysis pursuant to the provisions of the program's authorizing statute.¹

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.² 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)³ regulates health care service plans, which offer benefit coverage to their enrollees through health plan contracts. The California Department of Insurance (CDI) regulates health insurers,⁴ which offer benefit coverage to their enrollees through health insurance policies.

DMHC-regulated plans and/or CDI-regulated policies would be subject to AB 171. Therefore, the mandate would affect the health insurance of approximately 21.9 million Californians (59%), and this report focuses on that population.⁵

Existing State and Federal Requirements Relevant to AB 171

Current mental health parity law in California⁶ requires coverage for diagnosis and medically necessary treatment of severe mental illnesses (including PDD/A) for persons of any age. Applicable federal law⁷ also addresses parity for mental health benefits.

¹ CHBRP's authorizing statute is available at: http://www.chbrp.org/documents/authorizing_statute.pdf.

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

³ DMHC was established in 2000 to enforce the Knox-Keene Health Care Service Plan of 1975; see Health and Safety Code, Section 1340.

⁴ 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.

⁵ Although CHBRP has no further information, it is possible that AB 171 could have impacts beyond this population, because mental health only plans regulated by DMHC or CDI may be subject to AB 171.

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

⁷ 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 AB 171.

Background on Disorders Relevant to AB 171

AB 171 defines autism spectrum disorders (ASD) as neurobiological conditions inclusive of five conditions/disorders: Asperger's Disorder, Autistic Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified [PPD-NOS], and Rett's Disorder. These five conditions/disorders are referred to in current mental health parity law in California⁸ and DMHC regulation⁹ as pervasive developmental disorders or autism (PDD/A).

This report uses PDD/A as the aggregate term for conditions/disorders relevant to the AB 171 because ASD is not always understood to include two generally less severe disorders (Asperger's Disorder and PDD-NOS) and two less common disorders (Rett's Disorder and Childhood Disintegrative Disorder). AB 171 would affect benefit coverage relevant to all five disorders, and so this report uses the term PDD/A.

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. PDD/A is a chronic condition characterized by impairments in social interactions, communication, sensory processing, stereotypic (repetitive) behaviors or interests, and sometimes impaired 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 AB 171

For enrollees with PDD/A, AB 171 is similar to but would expand coverage as currently required under California's current mental health parity law. This section describes the number of enrollees who have health insurance subject to AB 171, the services and treatments mandated by AB 171 and the terms and conditions of the benefit coverage mandated by the bill. Throughout, comparisons are made to California's current mental health parity law (hereafter referred to as "the current mandate") to clarify where the bill is similar to and where bill's requirements expands coverage beyond the current mandate. In addition, assumptions CHBRP made in order to complete this analysis are described.

Enrollees with health insurance that would be subject to AB 171

AB 171 would be applicable to all DMHC-regulated plans and CDI-regulated policies. The current mandate is not applicable to benefit coverage provided by DMHC-regulated plans to Medi-Cal beneficiaries. Therefore, a greater number of enrollees would have health insurance subject to AB 171 than have health insurance subject to the current mandate.

⁸ California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88).

⁹ California Code of Regulations 1300.74.72(e).

Requirements regarding terms and conditions of benefit coverage

AB 171 would require that benefit coverage be provided under terms and conditions no less favorable than the terms and conditions for benefit coverage provided by the plan or policy for “physical illness.” The current mandate makes a similar requirement, but as the current mandate requires a narrower set of benefits to be covered, AB 171 would apply the parity requirement more broadly. However, AB 171 also contains language that would prohibit limits regarding “age, number of visits, dollar amounts.” For this analysis, CHBRP assumes that benefit coverage would be required to be in parity with terms and conditions applicable to other (medical and mental health) benefits provided by DMHC-regulated plans and CDI-regulated policies.

AB 171 would require that benefit coverage be extended to “all medically necessary services.” The bill repeats the term “medically necessary” and uses the phrases “evidence-based research,” “necessary equipment,” and “best practices.” However, the bill would prohibit denial of coverage based on the treatment being habilitative, nonrestorative, educational, academic, or custodial in nature and would prohibit more than an annual review of treatments. The current mandate requires coverage of medically necessary treatment for PDD/A. For this analysis, CHBRP assumes the mandated benefits would be subject to medical necessity review by plans and insurers and the Independent Medical Review (IMR) process.

Mandated benefit coverage

AB 171 would require coverage for “screening” and “diagnosis” relevant to PDD/A. The current mandate does not require provision of coverage for screening for PDD/A, though it does require that coverage be provided for diagnosis of PDD/A. Therefore, AB 171’s requirement to cover screening would expand coverage beyond the current mandate.

AB 171 would require coverage for treatments relevant to PDD/A. AB 171 defines treatment for PDD/A as inclusive of:

- “Behavioral health treatment,” which the bill defines as including “behavioral intervention therapy, applied behavioral analysis, and other intensive behavioral programs” and which this analysis refers to as intensive behavioral intervention therapy. The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for intensive behavioral intervention therapy as treatment for PDD/A. Therefore, AB 171 could be viewed as exceeding the current mandate.
- Pharmacy care, which AB 171 defines as medications prescribed by a licensed or certified provider. The current mandate explicitly exempts plans and policies that do not provide coverage for prescription drugs from providing coverage for medications relevant to mental health. Any plan or policy that provides coverage for inpatient care provides coverage for prescription medications (when provided in an inpatient setting), since the cost of prescription medications is regularly bundled into inpatient services. For this analysis, because AB 171 makes no explicit exemption, CHBRP assumes that AB 171 would prohibit a currently allowed exclusion (outpatient medications), instead requiring all subject plans and policies to cover outpatient medications relevant to PDD/A.

- Psychiatric care, which the bill defines as direct or consultative services provided by a licensed or certified provider. The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for psychiatric care as treatment for PDD/A. Therefore, by specifying psychiatric care as a treatment for PDD/A, AB 171 could be viewed as an expansion, in terms of mandated benefit coverage.
- Psychological care, which the bill defines as direct or consultative services provided by a licensed or certified provider. The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for psychological care as treatment for PDD/A. Therefore, by specifying psychological care as treatments for PDD/A, AB 171 could be viewed as an expansion, in terms of mandated benefit coverage.
- Therapeutic care, which the bill defines as inclusive of:
 - Occupational therapy provided by a licensed or certified provider;
 - Physical therapy provided by a licensed or certified provider;
 - Speech therapy provided by a licensed or certified provider.

The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for therapeutic care as treatment for PDD/A. Therefore, by specifying these therapies as treatments for PDD/A, AB 171 could be viewed as an expansion, in terms of mandated benefit coverage.

- Equipment, which AB 171 defines as equipment ordered by a licensed or certified provider. For this analysis, CHBRP refers to such equipment as durable medical equipment (DME). The current mandate is silent in regard to DME for the treatment of PDD/A. Therefore, AB 171's requirements may have the effect of expanding coverage for DME that is relevant for the treatment of PDD/A.

Payors Other Than Health Plans and Insurers

Payment for screening, diagnosis, and treatment 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, regional centers contracting with the California Department of Developmental Services (DDS)¹⁰ may pay, as may schools affiliated with the California Department of Education (CDE).¹¹ However, although the population served by DDS and/or CDE would be expected to overlap with enrollees whose health insurance would be subject

¹⁰ 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).

¹¹ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

to AB 171, the populations would not be identical. DDS does not collect¹² information about the sources of health insurance that would allow clients to be identified as having health insurance subject to AB 171, and regional centers may serve persons without health insurance. Similarly, CDE-affiliated schools may serve persons without health insurance, and CDE does not collect information on the health insurance status of public school students.¹³ To further complicate matters, some enrollees with health insurance subject to AB 171 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 AB 171—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.

Medical Effectiveness

Multiple tests have been developed to screen or diagnose children with PDD/A. A national guideline recommends that diagnosis of PDD/A be made by a multidisciplinary team of professionals with expertise in these disorders. Major treatments for PDD/A include behavioral intervention therapies, occupational therapy, physical therapy, speech therapy, psychiatric care, psychological care, and prescription drugs. Persons with Rett's Disorder may also need durable medical equipment to cope with the physical manifestations of their disorder.

Screening and Diagnostic Tests

Universal screening of children at unknown risk for PDD/A

- The preponderance of evidence suggests that the Modified Checklist for Autism in Toddlers (M-CHAT) has high sensitivity (i.e., low false-negative rate) for screening toddlers at unknown risk for PDD/A disorders and that supplementing the M-CHAT with a follow-up telephone call increases the positive predictive value (i.e., the likelihood that a person with a positive test result has a PDD/A disorder).
- The preponderance of evidence from two studies suggests that the Checklist for Autism in Toddlers (CHAT) has high specificity (i.e., low false-positive rate) for screening toddlers at unknown risk for PDD/A.
- Evidence from a single study suggests that the Childhood Asperger's Syndrome Test (CAST) and the Social Communication Questionnaire (SCQ) have high specificity

¹² Personal communication, J Mullen, California Department of Developmental Services, March 2011.

¹³ Personal communication, P Skelton, California Department of Education, March 2011.

(i.e., low false-positive rate) for identifying Asperger's Disorder and related disorders among children at unknown risk for these disorders.

Diagnostic testing for children at risk for or suspected of having a developmental disability

- Findings from a single study suggest that the Autism Diagnostic Observational Schedule–Generic (ADOS-G) has high sensitivity (i.e., low false-positive rate) for diagnosis of toddlers suspected of developmental delay but only fair specificity. The Autism Diagnostic Interview–Revised (ADI-R) had only fair sensitivity and specificity for diagnosis of toddlers. Findings from a study that assessed the joint accuracy of the ADOS-G and the ADI-R for diagnosis of toddlers and preschoolers suspected of PDD/A suggest that joint scores on the ADOS-G and the ADI-R are correlated with clinical diagnosis for Autistic Disorder but not with clinical diagnoses of other PDD/A disorders.
- The preponderance of evidence from three studies suggests that the Childhood Autism Rating Scale (CARS) has a high rate of sensitivity and specificity for diagnosis of PDD/A in children suspected of having a developmental disability.
- Findings from studies that have assessed the accuracy of the M-CHAT for diagnosing children suspected of having PDD/A suggest that the M-CHAT has high sensitivity (i.e., low false-negative rate) but poor specificity and that supplementing the M-CHAT with a follow-up telephone call increases the positive predictive value.
- Evidence from single studies suggests that the Baby and Infant Screen for Children with Autism Traits (BISCUIT) has a high rate of sensitivity and specificity for diagnostic evaluation of toddlers at risk for developmental delay for PDD/A, and that the Autism Behavior Checklist (ABC) and the Social Communication Questionnaire (SCQ) have fair sensitivity for diagnosing children suspected of having a PDD/A disorder or another developmental disability.

Protocols for early detection of PDD/A disorders

- Evidence from a single study suggests that an early detection program that combined screening by primary care providers with a standardized protocol for referring children suspected of PDD/A to a multidisciplinary team for diagnosis decreases the age at which children with PDD/A are diagnosed.

Behavioral Intervention Therapy

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 AB 171 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 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 based 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.

Prescription Drugs

Prescription drugs are prescribed to persons with PDD/A primarily to treat behaviors associated with PDD/A, such as aggression, hyperactivity, and irritability. Risperdal (Risperidone) and Abilify (Aripiprazole), two atypical antipsychotic medications, are the only prescription drugs approved by the U.S. Food and Drug Administration (FDA) for treatment of behavioral symptoms of PDD/A in children and adolescents. Several other classes of prescription drugs are used “off label” to treat behavioral symptoms of PDD/A including selective serotonin reuptake inhibitors (SSRIs, a type of antidepressant), antiepileptic medications, and medications used to treat Attention Deficit/Hyperactivity Disorder.

Evidence regarding the effectiveness of prescription drugs for treatment of behavioral symptoms of PDD/A is limited because only a few RCTs of these medications have been conducted and most of these trials had small sample sizes. Risperdal (Risperidone) is the only medication for which findings from more than two RCTs have been published.

Atypical antipsychotics

- The preponderance of evidence from five RCTs suggests that among children with Asperger's Disorder, Autistic Disorder, and PDD-NOS, relative to a placebo, Risperdal (Risperidone):

- Reduces behavioral symptoms (e.g., hyperactivity, inappropriate speech, irritability, lethargy/social withdrawal, obsessive/compulsive behavior);
 - Is associated with significant side effects, the most prominent of which are tardive dyskinesia (i.e., involuntary movement of parts of the body) and weight gain;
 - Is more effective than Haldol (Haloperidol) in reducing behavioral symptoms; and
 - Is more effective for reducing behavioral symptoms when administered in combination with Topamax (Topiramate), an antiepileptic medication, than when administered alone.
- Evidence from a single RCT suggests that for children and adolescents with Autistic Disorder, Abilify (Aripiprazole) reduces maladaptive behavior relative to a placebo.
 - Evidence from a single RCT suggests that Zyprexa (Olanzapine) does not affect behavioral symptoms of Asperger's Disorder, Autistic Disorder, or PDD-NOS among children and adolescents.

Selective serotonin reuptake inhibitors

- Evidence regarding the effectiveness of SSRIs relative to a placebo differs for children and adults with PDD/A. An RCT that enrolled adults with Autistic Disorder found that Luvox (Fluvoxamine) improves core behaviors associated with PDD/A. In contrast, two RCTs that enrolled children with Asperger's Disorder, Autistic Disorder, or PDD-NOS suggest that Celexa (Citalopram) and Prozac (Fluoxetine) do not improve core behaviors associated with PDD/A.
- Evidence from a single RCT suggests that for children with Asperger's Disorder, Autistic Disorder, or PDD-NOS combining an SSRI with Depakote (Valproate), an antiepileptic medication, reduces irritability relative to an SSRI alone.

Medications used to treat Attention Deficit/Hyperactivity Disorder

- Evidence from two RCTs suggests that for children and adolescents with Autistic Disorder, Ritalin (Methylphenidate) and Strattera (Atomoxetine) reduce hyperactivity, impulsivity, stereotypic behaviors, and inappropriate speech relative to a placebo.

Antiepileptic medications

- Evidence from three RCTs that assessed the effectiveness of antiepileptic medications on maladaptive behaviors associated with Asperger's Disorder, Autistic Disorder, or PDD-NOS is ambiguous. Two RCTs that compared Depakote (Valproate) to a placebo reported reductions in maladaptive behavior, whereas another RCT found no difference. RCTs that compared Keppra (Levetiracetem) and Lamictal (Lamotrogine), respectively, to a placebo also found no difference in maladaptive behavior.

Psychiatric and Psychological Care

- No studies of the effectiveness of psychiatric care or psychological care for PDD/A were identified.
- The lack of studies on psychiatric care and psychological care for PDD/A does not indicate that these treatments are not effective. Psychologists have expertise in assessment of behavior, cognitive function, and social skills that can be helpful in diagnosing PDD/A disorders. Psychiatrists have expertise in prescribing and monitoring psychotropic medications that may be helpful for treating behavioral symptoms of PDD/A disorders.

Occupational Therapy, Physical Therapy, Speech Therapy

- No studies of the effectiveness of occupational therapy, physical therapy, and speech therapy for PDD/A were identified.
- The lack of studies on occupational therapy, physical therapy, or speech therapy for PDD/A does not indicate that these treatments are not effective. Rather, it indicates that there is insufficient evidence to determine whether they are effective.

Durable Medical Equipment

- No studies of the effectiveness of durable medical equipment for PDD/A were identified.
- The lack of studies on durable medical equipment for PDD/A does not indicate that these treatments are not effective. Rather, it indicates that there is insufficient evidence to determine whether they are effective.

Benefit Coverage, Utilization, and Cost Impacts

Approximately 101,000 enrollees in DMHC-regulated plans and/or CDI-regulated policies subject to AB 171 are diagnosed with PDD/A. Table 1 summarizes the expected benefit coverage, cost, and utilization impacts for AB 171.

Critical Caveats, Estimates, and Assumptions

- Although studies on the effectiveness of intensive behavioral intervention therapies is focused on Autistic Disorder and PDD-NOS in preschool- 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 years, 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,¹⁴ 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, the hours per week of intensive behavioral intervention therapy 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 may not be using services since they would have to find another payor or self-pay. CHBRP assumes that utilization in this group would increase, postmandate.
 - 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.

Benefit Coverage Impacts

- If AB 171 were enacted, CHBRP estimates that the percent of enrollees with health insurance that would be subject to AB 171 with benefit coverage for PDD/A relevant intensive behavioral intervention therapies, DME, and prescription drugs would increase to 100%.
 - The number of enrollees covered for intensive behavioral intervention therapies would increase from 3.5 million to 21.9 million: a 520% increase.

¹⁴ 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 16 months and a mode of 2 years.

- The number of enrollees covered for DME would increase from 20.6 million to 21.9 million: a 6% increase.
- The number of enrollees covered for prescription drugs would increase from 21.6 million to 21.9 million: a 1% increase.
- If AB 171 were enacted, CHBRP estimates that there would be no measurable change in benefit coverage for enrollees with health insurance subject to AB 171 for PDD/A relevant speech therapy, physical therapy, occupational therapy, psychological care, or psychiatric care.

Utilization Impacts

- Were AB 171 to be enacted, CHBRP estimates that the mandate would increase the number of enrollees receiving PDD/A-relevant intensive behavioral intervention therapies through their insurance from approximately 1,400 premandate to 12,100 postmandate: a 764% increase. The mandate would be expected to result in 400 new users of intensive behavioral intervention therapies and would prompt 10,300 current users of intensive behavioral intervention therapies to obtain intensive behavioral intervention therapies through their insurance. Premandate, CHBRP estimates that the 10,300 enrollees received intensive behavioral intervention therapy paid for by a source other than health insurance (e.g., families, charities, CDE, and DDS, other).
- Were AB 171 to be enacted,
 - CHBRP would estimate no measurable utilization impact for PDD/A-relevant screening, diagnosis, speech therapy, physical therapy, occupational therapy, psychological care, or psychiatric care.
 - CHBRP would estimate no measurable utilization impact for PDD/A relevant DME.
 - CHBRP would estimate a 1% increase in utilization of PDD/A relevant prescription drugs.

Cost Impacts

- Postmandate, the entirety of the estimated cost impact would result from altered benefit coverage for (and utilization of) PDD/A relevant prescription drugs and intensive behavioral intervention therapies, with intensive behavioral intervention therapies accounting for the vast majority of the mandate's estimated cost impact.¹⁵
- AB 171 would increase total expenditures by \$137.9 million, or 0.14%, for plans and policies subject to AB 171. This increase in expenditures results from a \$338.0 million increase in health insurance premiums, a \$17.4 million increase in out-of-pocket expenses for enrollees with PDD/A with newly covered benefits, and a \$217.6 million decrease in expenses for noncovered benefits.

¹⁵ For comparison, see CHBRP's report on SB TBD 1 (2011), a bill which would not mandate coverage for prescription drugs, available at: http://www.chbrp.org/completed_analyses/index.php

- The premium impact would range by category from 0.14% to 0.24% for privately funded health insurance.
- The premium impact would range by category from 0.26% to 3.54% for publicly funded health insurance.
- The \$217.6 million reduction in expenses for noncovered benefits would be a reduction in expenditures for payors other than health plans/insurers. Costs related to intensive behavioral intervention therapies for PDD/A overwhelmingly account for this shift: such therapies comprise approximately \$216.5 million of the \$217.6 million reduction in expenses for noncovered benefits. Prescription drugs comprise the remaining \$1.1 million decrease in expenses for noncovered benefits.
- AB 171 would be expected to shift costs to DMHC-regulated plans and CDI-regulated insurers. However, as discussed in the *Introduction*, the extent of population overlap is unclear, and so it is not possible to calculate what portion of such costs 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 AB 171, no measurable impact on the number of persons who are uninsured would be expected.

Utilization Impacts

- Were AB 171 to be enacted, CHBRP estimates that the mandate would increase the number of enrollees receiving PDD/A-relevant intensive behavioral intervention therapies through their insurance from approximately 1,400 premandate to 12,100 postmandate: a 764% increase. The mandate would be expected to result in 400 new users of intensive behavioral intervention therapies and would prompt 10,300 current users of intensive behavioral intervention therapies to obtain intensive behavioral intervention therapies through their insurance. Premandate, CHBRP estimates that the 10,300 enrollees received intensive behavioral intervention therapy paid for by a source other than health insurance (e.g., families, charities, CDE, and DDS, other).
- Were AB 171 to be enacted,
 - CHBRP would estimate no measurable utilization impact for PDD/A-relevant screening, diagnosis, speech therapy, physical therapy, occupational therapy, psychological care, or psychiatric care.
 - CHBRP would estimate no measurable utilization impact for PDD/A relevant DME.

- CHBRP would estimate a 1% increase in utilization of PDD/A relevant prescription drugs.

Public Health

- CHBRP estimates that AB 171 would increase benefit coverage for prescription drugs, DME, and intensive behavioral intervention therapies for enrollees with PDD/A, and finds a preponderance of evidence for some effectiveness of prescription drugs and intensive behavioral intervention therapies. Therefore, CHBRP estimates improved outcomes for some PDD/A symptoms (e.g., improved IQ, adaptive behavior, stereotypic or aggressive behavior, etc.) for some enrollees using these treatments.
- No literature or data are available regarding the possible differential use or outcomes by gender or race regarding tests and treatments defined in AB 171. Therefore, the impact of AB 171 on reducing possible gender, racial, or ethnic disparities of symptoms associated with PDD/A is unknown.
- Although an increased risk of premature death is associated with PDD, there is no evidence that tests and treatments defined by AB 171 would reduce premature death for the PDD/A population; therefore, the impact of AB 171 on premature death is unknown.
- CHBRP estimates that the postmandate, net decrease in noncovered benefit expenses for the estimated 10,700 newly covered enrollees with PDD/A who use intensive behavioral intervention therapies is about \$217.6 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. The majority of these savings would be attributable to use of intensive behavioral intervention therapies (about \$215.5 million).

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 addresses the marginal effects of the mandate bill—specifically, how the proposed mandate would impact benefit

coverage, utilization, costs, and public health, holding all other factors constant. CHBRP's estimates of these marginal effects are presented in this report.¹⁶

Essential health benefits offered by qualified health plans in the Exchange and potential interactions with AB 171

As mentioned, EHBs explicitly include “[m]ental health and substance use disorder services, including behavioral health treatment” and “rehabilitative and habilitative services and devices.”¹⁷ 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.¹⁸ AB 171 explicitly states that health plans and policies that are offered through the Exchange would not be required to cover those benefits that are considered to exceed EHBs. Therefore, because of this provision, AB 171 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 AB 171 would exceed EHBs depends 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 AB 171;
- 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 AB 171. “Behavioral health treatment” may be considered to include forms of “behavioral intervention treatment,” as specified AB 171. “Habilitative” services may be determined to include forms of therapy that enhance a child’s ability to function.

How these factors relate to the QHPs and the Exchange is unknown at this time, and is dependent upon the details of pending federal regulations, state legislative and regulatory actions, and enrollment into QHPs after the Exchange is operational.

It is important to note that AB 171 explicitly states that, if any benefits are considered to exceed EHBs, “those specific benefits are required to be provided if offered by a health care service plan contract outside of the Exchange.” Therefore, plans and policies offered outside the Exchange, including those publicly-purchased health plans, would continue to see cost and public health impacts resulting from AB 171.

¹⁶ 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:

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

¹⁷ Affordable Care Act, Section 1302(b)(1)(E) and (G).

¹⁸ Affordable Care Act, 1311(d)(3)(B).

Table 1. AB 171 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 AB 171	21,902,000	21,902,000	0	0.00%
Number of enrollees with health insurance coverage subject to AB 171 and having PDD/A	101,000	101,000	0	0.00%
Percentage of enrollees with coverage for the mandated benefit				
Screenings	100.00%	100.00%	0.00%	0.00%
Diagnostics	100.00%	100.00%	0.00%	0.00%
Intensive behavioral intervention therapies	16.13%	100.00%	83.87%	519.93%
Therapies other than intensive behavioral intervention therapies (b)	100.00%	100.00%	0.00%	0.00%
Prescription drugs (c)	98.78%	100.00%	1.22%	1.23%
DME	94.16%	100.00%	5.84%	6.21%
Number of enrollees with coverage for the mandated benefit				
Screenings	21,902,000	21,902,000	0	0.00%
Diagnostics	21,902,000	21,902,000	0	0.00%
Intensive behavioral intervention therapies	3,533,000	21,902,000	18,369,000	519.93%
Therapies other than intensive behavioral intervention therapies	21,902,000	21,902,000	0	0.00%
Prescription drugs	21,635,000	21,902,000	267,000	1.23%
DME	20,622,000	21,902,000	1,280,000	6.21%
Utilization and cost				
Number of enrollees using outpatient prescription drugs to treat PDD/A				
Benefit covered	52,400	53,000	600	1.15%
Benefit not covered	600	0	-600	
Average annual prescription drug cost for treatment of PDD/A per member using prescription drugs	\$1,850	\$1,850	\$0	0.00%
Number of enrollees using intensive behavioral intervention benefit				
Benefit covered (d)	1,400	12,100	10,700	764.29%
Benefit not covered	10,300	0	-10,300	-100.00%
Average annual intensive behavioral intervention cost per member receiving intensive behavioral intervention	\$44,000	\$50,000	\$6,000	13.64%

Table 1. AB 171 Autism Impacts on Benefit Coverage, Utilization, and Cost, 2011 (Cont'd)

	Before Mandate	After Mandate	Increase/ Decrease	Change After Mandate
Expenditures				
Premium expenditures by private employers for group insurance	\$52,713,266,000	\$52,839,390,000	\$126,124,000	0.24%
Premium expenditures for individually purchased insurance	\$6,724,851,000	\$6,734,813,000	\$9,962,000	0.15%
Premium expenditures by persons with group insurance, CalPERS HMOs, Healthy Families Program, AIM, or MRMIP (e)	\$15,173,472,000	\$15,214,817,000	\$41,345,000	0.27%
CalPERS HMO employer expenditures (f)	\$3,465,785,000	\$3,474,645,000	\$8,860,000	0.26%
Medi-Cal Managed Care Plan expenditures	\$8,657,688,000	\$8,772,338,000	\$114,650,000	1.32%
MRMIB Plan expenditures (g)	\$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	\$7,565,845,000	\$17,430,000	0.23%
Enrollee expenses for noncovered benefits (h)	\$471,358,000	\$253,716,000	-\$217,642,000	-46.17%
Total Expenditures	\$95,805,466,000	\$95,943,344,000	\$137,878,000	0.14%

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 employer-sponsored insurance.

(b) PT/OT/ST are estimated at 100% coverage based on responses from carrier survey, but with a qualification from some carriers that habilitative services are not covered.

(c) Prescription drugs are estimated at 100% coverage: enrollees of large-group health plans with stand-alone drug plans are assumed to already have PDD/A prescription drugs through their stand-alone plan.

(d) 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 10,300).

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

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

(g) 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.

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

Key: AIM=Access for Infants and Mothers; CalPERS HMOs=California Public Employees' Retirement System Health Maintenance Organizations; CDI=California Department of Insurance; DME=Durable Medical Equipment; DMHC=Department of Managed Health Care; MRMIB=Managed Risk Medical Insurance Board; MRMIP=Major Risk Medical Insurance Program; OT=occupational therapy; PT=physical therapy; ST=speech therapy.

INTRODUCTION

The California Assembly Committee on Health requested on January 25, 2011, that the California Health Benefits Review Program (CHBRP) conduct an evidence-based assessment of the medical, financial, and public health impacts of Assembly Bill (AB) 171: Autism. In response to this request, CHBRP undertook this analysis pursuant to the provisions of the program's authorizing statute.¹⁹ Following this *Introduction*, successive sections of this report address: medical effectiveness; benefit coverage, cost, and utilization impacts; and public health impacts.

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.²⁰ 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)²¹ regulates health care service plans, which offer benefit coverage to their enrollees through health plan contracts. The California Department of Insurance (CDI) regulates health insurers,²² which offer benefit coverage to their enrollees through health insurance policies.

DMHC-regulated plans and/or CDI-regulated policies would be subject to AB 171. Therefore, the mandate would affect the health insurance of approximately 21.9 million Californians (59%), and this report focuses on that population.²³

Existing state and federal requirements relevant to AB 171

Current mental health parity law in California²⁴ requires coverage for diagnosis and medically necessary treatment of severe mental illnesses (including PDD/A) for persons of any age. Applicable federal law²⁵ also addresses parity for mental health benefits.

¹⁹ CHBRP's authorizing statute is available at: http://www.chbrp.org/documents/authorizing_statute.pdf.

²⁰ CHBRP's estimates are available at: http://www.chbrp.org/other_publications/index.php

²¹ DMHC was established in 2000 to enforce the Knox-Keene Health Care Service Plan of 1975; see Health and Safety Code, Section 1340.

²² 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.

²³ Although CHBRP has no further information, it is possible that AB 171 could have impacts beyond this population, because mental health-only plans regulated by DMHC or CDI may be subject to AB 171.

²⁴ California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88).

Bill Language and Analytic Approach

The full text of AB 171 can be found in Appendix A.

AB 171 would mandate benefit coverage for screening, diagnosis, and treatment relevant to autism spectrum disorders (ASD). ASD is inclusive of five neurobiological conditions/disorders: Asperger's Disorder, Autistic Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified [PPD-NOS], and Rett's Disorder. These five conditions/disorders are referred to in current mental health parity law in California²⁶ and DMHC regulation²⁷ as pervasive developmental disorders or autism (PDD/A).

This report uses PDD/A as the aggregate term for conditions/disorders relevant to the AB 171 because ASD is not always understood to include two generally less severe disorders (Asperger's Disorder and PDD-NOS) and two less common disorders (Rett's Disorder and Childhood Disintegrative Disorder). AB 171 would affect benefit coverage relevant to all five disorders, and so this report uses the term PDD/A.

For enrollees with PDD/A, AB 171 is similar to but would expand coverage as currently required under California's current mental health parity law. This section describes the number of enrollees who have health insurance subject to AB 171; the services and treatments mandated by AB 171 and the terms and conditions of the benefit coverage mandated by the bill. Throughout, comparisons are made to California's current mental health parity law (hereafter referred to as "the current mandate") to clarify where the bill is similar to and where bill's requirements expands coverage beyond the current mandate. In addition, assumptions CHBRP made in order to complete this analysis are described.

Enrollees with health insurance that would be subject to AB 171

AB 171 would be applicable to all DMHC-regulated plans and CDI-regulated policies. The current mandate is not applicable to benefit coverage provided by DMHC-regulated plans to Medi-Cal beneficiaries. Therefore, a greater number of enrollees would have health insurance subject to AB 171 than have health insurance subject to the current mandate.

Requirements regarding terms and conditions of benefit coverage

AB 171 would require that benefit coverage be provided under terms and conditions no less favorable than the terms and conditions for benefit coverage provided by the plan or policy for "physical illness." The current mandate makes a similar requirement, but as the current mandate requires a narrower set of benefits to be covered, AB 171 would apply the parity requirement more broadly. However, AB 171 also contains language that would prohibit limits regarding "age, number of visits, dollar amounts" For this analysis, CHBRP assumes that benefit coverage would be required to be in parity with terms and conditions applicable

²⁵ 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 AB 171.

²⁶ California Health & Safety Code Section 1374.72 and California Insurance Code Section 10144.5 (also known as AB 88).

²⁷ California Code of Regulations 1300.74.72(e).

to other (medical and mental health) benefits provided by DMHC-regulated plans and CDI-regulated policies.

AB 171 would require that benefit coverage be extended to “all medically necessary services.” The bill repeats the term “medically necessary” and uses the phrases “evidence-based research,” “necessary equipment,” and “best practices.” However, the bill would prohibit denial of coverage based on the treatment being habilitative, nonrestorative, educational, academic, or custodial in nature and would prohibit more than an annual review of treatments. The current mandate requires coverage of medically necessary treatment for PDD/A. For this analysis, CHBRP assumes the mandated benefits would be subject to medical necessity review by plans and insurers and the Independent Medical Review (IMR) process.

Mandated benefit coverage

AB 171 would require coverage for “screening” and “diagnosis” relevant to PDD/A. The current mandate does not require provision of coverage for screening for PDD/A, though it does require that coverage be provided for diagnosis of PDD/A. Therefore, AB 171’s requirement to cover screening would expand coverage beyond the current mandate.

AB 171 would require coverage for treatments relevant to PDD/A. AB 171 defines treatment for PDD/A as inclusive of:

- “Behavioral health treatment,” which the bill defines as including “behavioral intervention therapy, applied behavioral analysis, and other intensive behavioral programs” and which this analysis refers to as intensive behavioral intervention therapy. The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for intensive behavioral intervention therapy as treatment for PDD/A. Therefore, AB 171 could be viewed as an exceeding the current mandate.
- Pharmacy care, which AB 171 defines as medications prescribed by a licensed or certified provider. The current mandate explicitly exempts plans and policies that do not provide coverage for prescription drugs from providing coverage for medications relevant to mental health. Any plan or policy that provides coverage for inpatient care provides coverage for prescription medications (when provided in an inpatient setting), since the cost of prescription medications is regularly bundled into inpatient services. For this analysis, because AB 171 makes no explicit exemption, CHBRP assumes that AB 171 would prohibit a currently allowed exclusion (outpatient medications), instead requiring all subject plans and policies to cover outpatient medications relevant to PDD/A.
- Psychiatric care, which the bill defines as direct or consultative services provided by a licensed or certified provider. The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for psychiatric care as treatment for PDD/A. Therefore, by specifying psychiatric care as a treatment for PDD/A, AB 171 could be viewed as an expansion, in terms of mandated benefit coverage.
- Psychological care, which the bill defines as direct or consultative services provided by a licensed or certified provider. The current mandate requires medically necessary

outpatient treatment but does not specify that coverage is required for psychological care as treatment for PDD/A. Therefore, by specifying psychological care as treatments for PDD/A, AB 171 could be viewed as an expansion, in terms of mandated benefit coverage.

- Therapeutic care, which the bill defines as inclusive of:
 - Occupational therapy provided by a licensed or certified provider;
 - Physical therapy provided by a licensed or certified provider;
 - Speech therapy provided by a licensed or certified provider.

The current mandate requires medically necessary outpatient treatment but does not specify that coverage is required for therapeutic care as treatment for PDD/A. Therefore, by specifying these therapies as treatments for PDD/A, AB 171 could be viewed as an expansion, in terms of mandated benefit coverage.

- Equipment, which the ABA 171 defines as equipment ordered by a licensed or certified provider. For this analysis, CHBRP refers to such equipment as durable medical equipment (DME). The current mandate is silent in regard to DME for the treatment of PDD/A. Therefore, AB 171's requirements may have the effect of expanding coverage for DME that is relevant for the treatment of PDD/A.

AB 171 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 AB 171 addressing these types of plans would have no impact on DMHC-regulated plans or CDI-regulated policies.

Payors other than health plans and insurers

Payment for screening, diagnosis, and treatment relevant to 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 treatments and services, regional centers contracting with the California Department of Developmental Services (DDS) may pay.²⁸ Schools affiliated with the California Department of Education (CDE)²⁹ may do so as well.

²⁸ Personal communication, J. Mullen, California Department of Developmental Services, March 2011.

²⁹ Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

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.³⁰ 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 AB 171, but the populations would not be identical. DDS does not collect³¹ information about the sources of health insurance that would allow clients to be identified as having health insurance subject or not subject to AB 171, and regional centers may serve persons without health insurance. In addition, some enrollees with health insurance subject to AB 171 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 AB 171—is not clear.

Public schools provide some services to some persons with PDD/A.³² Again, such a population would be expected to overlap with enrollees whose health insurance would be subject to AB 171, but the populations would not be identical. CDE does not collect information on the health insurance status of public school students,³³ and CDE-affiliated schools may serve persons without health insurance. In addition, some enrollees with health insurance subject to AB 171 may attend private schools or may not have impairments sufficient to justify CDE supported services (California Legislature, 2007). Therefore, the overlap between the populations—those served by CDE and enrollees with health insurance that would be subject to AB 171—is not clear.

Requirements in other states

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

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

³⁰ 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).

³¹ Personal communication, J. Mullen, California Department of Developmental Services, March 2011.

³² Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004).

³³ Personal communication, P. Skelton, California Department of Education, March 2011.

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

Essential health benefits offered by qualified health plans in the Exchange and potential interactions with AB 171

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 AB 171 explicitly states that health plan and policies that are offered through the Exchange would not be required to cover those benefits that are considered to exceed EHBs. Therefore, because of this provision, AB 171 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 AB 171 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 AB 171;
- 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 AB 171. “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.

All of these factors as it relates to the QHPs and the Exchange are unknown at this time, and are dependent upon the details of pending federal regulations, state legislative and regulatory actions, and enrollment into QHPs after the Exchange is operational.

It is important to note that AB 171 explicitly states that, if any benefits are considered to exceed EHBs, “those specific benefits are required to be provided if offered by a health care service plan contract outside of the Exchange.” Therefore, plans and policies offered outside the Exchange, including those publicly purchased health plans, would continue to face cost and public health impacts resulting from AB 171.

Background on Pervasive Developmental Disorder 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

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

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

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 AB 171.

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 United States 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 AB 171 on the cost and utilization of tests and treatments identified in the proposed bill. 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 AB 171, 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 tests and treatments 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, and prescription drugs are more frequently used by adults (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 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

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

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 AB 171 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 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

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

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

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 Centers for Disease Control and Prevention's (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

A wide variety of treatments are used to treat PDD/A (Myers and Johnson, 2007). Behavioral therapies are among the most widely used treatments. Occupational, physical, and speech therapy are used to address specific deficits in functioning (e.g., a child with PDD/A who has difficulty speaking would be given speech therapy). Psychiatric care, psychological care, and prescription drugs may be provided to alleviate behavioral symptoms of PDD/A as well as comorbid mental health disorders. (Persons with PDD/A are more likely to be diagnosed with a mood disorder or Attention Deficit/Hyperactivity Disorder than persons without PDD/A). Persons with Rett's Disorder may also need durable medical equipment to cope with the physical manifestations of their disorder.

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 26 studies were included in the medical effectiveness review. 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).

The literature search identified studies on the accuracy of screening and diagnostic tests for autism and on the effectiveness of behavioral intervention therapies and prescription drugs for treatment of PDD/A. ***No studies of the effectiveness of occupational therapy, physical therapy, speech therapy, psychiatric care, psychological care, and durable medical equipment for PDD/A were identified.***

Methodological Issues

The literature review identified a number of important methodological limitations of studies of the effectiveness of treatments for PDD/A.

Screening and Diagnostic Tests

Most studies of screening and diagnostic tests for PDD/A have focused on the reliability and validity of screening instruments administered to persons with PDD/A or their parents/caregivers. Although studies of the accuracy of screening tests are important, they are insufficient to determine whether screening is effective. To draw conclusions about effectiveness, one needs to know whether screening children for PDD/A leads to earlier detection of PDD/A and, in turn, whether early treatment improves health outcomes for persons with PDD/A in the long term. A few studies have examined whether screening children leads to earlier detection of PDD/A, but ***no studies have directly assessed whether early diagnosis is associated with better long-term health outcomes for persons with PDD/A.*** In addition, little is known about the relative effectiveness of screening all children for PDD/A versus screening only children whose parents or caregivers express concern about developmental delay.

A wide variety of screening and diagnostic tests for PDD/A have been evaluated. Synthesizing findings from studies of these tests is difficult because the questions asked, methods of administration (e.g., written, telephone), and respondents (e.g., parents, clinicians) vary widely. In addition, the studies use different “gold standards” for assessing the accuracy of screening tests. For example, the Modified Checklist for Autism in Toddlers (M-CHAT), a recommended screening test for PDD/A, has been compared to three different sets of criteria for diagnosis of PDD/A. Furthermore, some studies have examined the accuracy of screening tests for screening general populations of children at unknown risk for PDD/A, whereas others have assessed accuracy for identifying children suspected of having a developmental delay who would benefit from more comprehensive diagnostic testing to determine whether they have PDD/A or another developmental disorder.

Behavioral Intervention Therapies

Studies of intensive behavioral intervention therapies for PDD/A have several important methodological limitations. ***Few studies of these interventions randomly allocate subjects to intervention and comparison groups,*** 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 (i.e., 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 nonverbal measures of intelligence because children with PDD/A tend to perform better on nonverbal tests of intelligence (e.g., visual-spatial tasks) than tests of other types of intelligence (Eldevik et al., 2009).

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.

Prescription Drugs

The literature on the effectiveness of prescription drugs for PDD/A also has some limitations. Although more randomized controlled trials (RCTs) have been carried out, most have small sample sizes. In addition, only one or two RCTs have been conducted on the effectiveness of most prescription drugs for treatment of PDD/A. ***The conclusions of the review regarding the effectiveness of these drugs are not as strong as they would be if more and larger RCTs had been conducted.***

Study Findings

Findings from the medical effectiveness review are summarized below.

Screening and Diagnostic Tests

The table on epidemiologic terminology below describes the metrics used to assess the accuracy of screening and diagnostic tests. When reviewing studies of screening tests, it is important to consider the tradeoff between sensitivity and specificity. For screening tests that are to be used for universal screening of persons with unknown risk for PDD/A, one may want to place a higher priority on sensitivity to minimize the number of false-negative test results. On the other hand, a test with high sensitivity but low specificity could generate a large number of false-positive results, which could lead to unnecessary follow-up testing and treatment and, given the nature of PDD/A, stigmatization for the affected child. For diagnosis of persons suspected of having a developmental delay, specificity may be as important, if not more important, than sensitivity, because the symptoms of PDD/A can be similar to those of other developmental disorders. Tests used for diagnosis need to be able to distinguish children with PDD/A from children with other developmental disorders to help ensure that children receive appropriate treatment.

Epidemiologic Terminology

Sensitivity is defined as the proportion of PDD/A detected when PDD/A is present, or the true-positive rate. The U.S. Agency for Healthcare Research and Quality (AHRQ) sets the desirable sensitivity rate at greater than 85%.

Specificity is defined as the proportion of negative test results when PDD/A is absent. If the test specificity is low, the test would have a high false-positive rate that could result in unnecessary interventions. The AHRQ sets the desirable specificity rate at greater than 90%.

False-positive rate is defined as the proportion of positive tests that occur in people who do not have the condition. The false-positive rate is equal to $1 - \text{specificity}$.

Positive Predictive Value (PPV) is defined as the proportion of those testing positive that actually have the disorder for which the test is designed to detect. Predictive values are highly dependent upon the prevalence of a disorder in a population.

CHBRP's review of the literature on screening and diagnostic instruments for PDD/A focuses on studies of the accuracy of the tests for identifying persons with PDD/A disorders. For screening, CHBRP examined studies of the accuracy of instruments administered to general populations of children at unknown risk for PDD/A and/or their parents. For

diagnosis, CHBRP reviewed studies of the accuracy of instruments for use in conjunction with other instruments and techniques used to diagnose PDD/A in children suspected of having a developmental disability (including PDD/A) based on the results of a screening test or on parent or clinician concern.

Universal screening of children at unknown risk for PDD/A

The literature review identified four instruments that have been evaluated for accuracy in screening general populations of children at unknown risk for PDD/A (i.e., children not previously identified as having or not having symptoms of PDD/A): the Checklist for Autism in Toddlers (CHAT), the Modified Checklist for Autism in Toddlers (M-CHAT), the Childhood Asperger's Syndrome Test (CAST), and the Social Communication Questionnaire (SCQ). The CHAT and the M-CHAT have been studied in toddlers, and the CAST and SCQ have been studied in preschool and elementary school children.

A systematic review identified two studies of the accuracy of the Checklist for Autism in Toddlers (CHAT) for universal screening of toddlers at unknown risk for PDD/A. The preponderance of evidence from the systematic review suggests that the CHAT has high specificity (i.e., low rate of false positives) for screening toddlers, but that findings regarding sensitivity were ambiguous (Mawle and Griffiths, 2006). A small study (n = 91 children) reported a sensitivity of 100%. In contrast, a much larger study (n = 16,235 children) reported sensitivities of 20% to 38% for Autistic Disorder and of 12% to 35% for any disorder on the PDD/A spectrum.

Three studies have assessed the accuracy of the Modified Checklist for Autism in Toddlers (M-CHAT). The preponderance of evidence from two studies suggests that the M-CHAT has high sensitivity (i.e., a low false-negative rate) and high specificity (i.e., low false-positive rate) for screening toddlers at unknown risk for any diagnosis on the PDD/A spectrum (Mawle and Griffiths, 2006). The preponderance of evidence from two studies suggests that supplementing the M-CHAT with a follow-up telephone interview increases positive predictive value (i.e., the likelihood that a person with a positive test result has a condition) for screening toddlers for PDD/A (Kleinman et al., 2008; Robins, 2008). Evidence from a single study suggests that toddlers' scores on the M-CHAT and Parent's Evaluation of Developmental Status (PEDS), a general screening test for developmental delays, are not well correlated (Pinto-Martin et al., 2008).

One study examined the accuracy of the Social Communication Questionnaire (SCQ) and the Childhood Asperger's Syndrome Test (CAST) for universal screening for Asperger's Disorder (Scott et al., 2002). The authors found that both the SCQ and the CAST have high specificity (i.e., low false-positive rate) and positive predictive value for identifying preschool and elementary school children (ages 4 to 11 years) with Asperger's Disorder (Scott et al., 2002).

Diagnostic testing for children at risk for or suspected of having PDD/A Accuracy for diagnosis of populations of children who are at risk for PDD/A or are suspected of having PDD/A has been evaluated for six instruments: the Autism Behavior Checklist (ABC), the Autism Diagnostic Interview–Revised (ADI-R), the Autism Diagnostic Observational Schedule–Generic (ADOS-G), the Baby and Infant Screen for Children with Autism Traits (BISCUIT), the Childhood Autism Rating Scale (CARS), the M-CHAT, and the SCQ. The ABC, ADI-R, ADOS-G, BISCUIT, CARS, M-CHAT, and SCQ have been studied in toddlers and/or preschoolers. The ABC, CARS, and SCQ have also been studied in older children.

The Autism Diagnostic Observational Schedule–Generic (ADOS-G) and the Autism Diagnostic Interview–Revised (ADI-R) are frequently administered to children suspected of PDD/A.⁴⁰ A study by Ventola et al. (2006) compared scores on the ADI-R and the ADOS-G with diagnoses of Autistic Disorder and PDD-NOS based on criteria from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* for toddlers suspected of developmental delay. The authors found that the ADOS-G had high sensitivity (i.e., low false-negative rate) for diagnosis of both Autistic Disorder and PDD-NOS but only fair specificity. They also found that the sensitivity and specificity of the ADI-R was only fair. Another study compared the accuracy of joint administration of the ADOS-G and ADI-R for diagnosis of PDD/A in toddlers and preschoolers suspected of PDD/A or another developmental disability to a “best estimate” clinical diagnosis based on criteria from the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (Le Couteur et al., 2008)*. Findings suggest that joint assessment with the ADI-R and the ADOS-G correctly identified two-thirds of children with a “best estimate” clinical diagnosis of Autistic Disorder. The ADI-R and ADOS-G were less helpful for identifying children with other PDD/A disorders. The joint agreement of ADI-R and ADOS-G scores with a “best estimate” clinical diagnosis for any PDD/A disorder was only 14%.

The preponderance of evidence from three studies suggests that the Childhood Autism Rating Scale (CARS) has high rates of sensitivity and specificity for diagnosis of Autistic Disorder in children suspected of having a developmental disability and differentiates children with Autistic Disorder from children with PDD-NOS, mental retardation without comorbid PDD/A, and other developmental disabilities (Perry et al., 2005; Rellini et al., 2004; Ventola et al., 2006). Scores on CARS are also highly correlated with PDD/A diagnoses based on criteria from the DSM-IV.

Two studies have examined the effectiveness of the M-CHAT for diagnosis of children suspected of having a developmental disability. One study found that the M-CHAT has high sensitivity (i.e., low false-negative rate) but low specificity (i.e., high false-positive rate) (Eaves et al., 2006a). Evidence from another study suggests that supplementing the M-CHAT with a follow-up telephone interview increases the positive predictive value of the M-CHAT

⁴⁰ See Lord et al., 2000, for a description of the ADOS-G and Lord et al., 1994, for a description of the ADI-R.

for screening children suspected of having developmental delay for PDD/A (Kleinman et al., 2008).

Evidence from two studies suggests that the SCQ has fair sensitivity and specificity for diagnosis of PDD/A among children age 3 to 6 years suspected of having developmental delay (Eaves et al., 2006a, 2006b) and that scores are not highly correlated with scores on the CARS.

Evidence from a single study suggests that the Baby and Infant Screen for Children with Autism Traits (BISCUIT) has high rates of sensitivity and specificity for diagnosis of toddlers at risk for developmental delay for any PDD/A disorder, PDD-NOS, and Autistic Disorder (Matson et al., 2009).

Evidence from a single study suggests that the Autism Behavior Checklist (ABC) has fair sensitivity for diagnosis of children suspected of having PDD/A (Rellini et al., 2004).

Protocols for early detection of PDD/A disorders

One study conducted in the Netherlands assessed the effectiveness of an early detection program for PDD/A (Oosterling et al., 2010). The program used a two-stage screening protocol. Primary care providers were taught to identify the early symptoms of Autistic Disorder and to screen children using a standardized questionnaire. Children who scored positive on the screening test were referred to a multidisciplinary team of experts in PDD/A disorders for further testing and diagnosis. Children with Autistic Disorder in the region of the Netherlands in which the early detection program was implemented were compared to children in another region of the country in which an early detection program was not implemented. The authors found that children with PDD/A who lived in the region in which the early detection program was implemented were diagnosed with Autistic Disorder at a younger age than children in the comparison region.

Evidence from a small number of studies suggests that there are instruments for screening children at unknown risk for PDD/A that have high sensitivity (i.e., low rates of false-negative results) and high specificity (i.e., low rates of false-positive results). There are also instruments for diagnosing PDD/A disorders among children suspected of having a developmental disability that have high rates of sensitivity and specificity, especially for distinguishing between children with Autistic Disorder and children with other developmental disabilities.

Behavioral Intervention Therapies

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 and Johnson, 2007). 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 AB 171 would specifically require coverage for these and other behavioral intervention therapies.

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 (see 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.

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, 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, 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

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 31 studies identified by CHBRP reported the degree to which children enrolled in the studies had comorbid mental retardation as defined in the DSM-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.

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).⁴² 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 3 years at the time the study began for an average of 40 hours per week for 2 or more years. Programs based on the Lovaas/UCLA approach have been implemented across the United States but vary in

⁴² 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.

their intensity, duration, and means for providing treatment (e.g., therapists vs. parents with guidance from therapists).

Other intensive behavioral intervention therapies, such as 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 received an “eclectic intervention” that combined multiple types of treatments.

Table 4. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in the Medical Effectiveness Review

Study	Number of Subjects	Age at Entry ⁴³	PDD/A Diagnoses	Degree of Mental Retardation at Entry ⁴⁴	Duration of Intervention	Length of Follow-Up Post 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, , 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, 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 ⁴⁵	7 months	Immediately following intervention

Table 4. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in the Medical Effectiveness 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 Post 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

Table 4. Characteristics of Populations Enrolled in Studies of Intensive Behavioral Intervention Therapy Included in the Medical Effectiveness 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 Post 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 Disorder	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 Disorder	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

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

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.

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 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’ initial study (1987) of discrete trials training found that 47% of subjects receiving the intervention achieved normal

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.

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.

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 four 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

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.

continued to experience substantial developmental delay following treatment (Eldevik et al., 2006; Smith et al., 1997).

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

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 duration (i.e., 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 with greater intensity (i.e., those 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 comorbid mental retardation, whereas others enrolled children with Moderate, Severe, or Profound Mental Retardation.

Several meta-analyses attempted to identify the characteristics of children enrolled in the studies who received the greatest benefit from intensive behavioral intervention therapies. Findings from one meta-analysis 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 nonverbal 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 multivariate meta-regression that examined 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.

The preponderance of evidence from studies of intensive behavioral interventions provided to preschool and elementary school children with PDD/A suggests that these interventions improve adaptive behavior and increase IQ. Findings regarding effects on language skills and academic placement are ambiguous. Interventions of greater duration and intensity appear to be associated with better outcomes. Findings from studies that have examined the impact of children's characteristics on outcomes of intensive behavioral interventions are also ambiguous.

Prescription Drugs

Prescription drugs are prescribed to persons with PDD/A primarily to treat behaviors associated with PDD/A, such as aggression, hyperactivity, and irritability. Risperdal (Risperidone) and Abilify (Aripiprazole), two atypical antipsychotic medication originally developed to treat schizophrenia, are the only prescription drugs approved by the U.S. Food and Drug Administration (FDA) for treatment of behavioral symptoms of PDD/A in children and adolescents. Several other classes of prescription drugs are used “off label” to treat behavioral symptoms of PDD/A, including selective serotonin reuptake inhibitors (SSRIs, a type of antidepressant), antiepileptic medications, and medications used to treat Attention Deficit/Hyperactivity Disorder. ***Prescription drugs are used to augment other therapies for PDD/A and not as a substitute for them.*** The goal of pharmacotherapy for PDD/A is to alleviate behavioral symptoms of these disorders, which may enable persons with PDD/A to obtain greater benefit from therapies designed to address deficits in cognitive function, language, and social skills (Myers and Johnson, 2007).

Evidence regarding the effectiveness of prescription drugs for treatment of behavioral symptoms of PDD/A is limited because only a few randomized controlled trials (RCTs) of these medications have been conducted, and most of these trials had small sample sizes. Risperdal (Risperidone) is the only medication for which findings from more than two RCTs have been published.

Atypical antipsychotics

Results have been published from five RCTs on the effectiveness of Risperdal (Risperidone) relative to a placebo for alleviating behavioral symptoms among children with Asperger's Disorder, Autistic Disorder, and PDD-NOS. Findings from three of these RCTs were synthesized in a meta-analysis (Jesner et al., 2007). Two additional RCTs (Aman et al., 2008; Pandina et al., 2007) were published after the RCTs included in the systematic review. The preponderance of evidence from the five RCTs suggest that relative to a placebo, Risperdal (Risperidone) reduces hyperactivity, inappropriate speech, irritability, lethargy/social withdrawal, obsessive/compulsive behavior, and stereotypic behavior (e.g., arm flapping). Risperdal (Risperidone) has also been found to improve adaptive behavior (e.g., daily life skills), affect, and sensory motor skills. The

benefits of Risperdal (Risperidone) for improving behavior of persons with PDD/A must be weighed against the medication's harms. Risperdal (Risperidone) is associated with significant side effects, the most prominent of which is weight gain. The meta-analysis of three RCTS found that children treated with Risperdal (Risperidone) gained 1.78 more kilograms (3.7 pounds) more than children treated with placebo (Jesner et al., 2007). A less common but more serious side effect of Risperdal (Risperidone) is tardive dyskinesia, a condition in which the tongue, lips, jaw, face, trunk, limbs, fingers, or toes move involuntarily.

One RCT compared the effectiveness of Risperdal (Risperidone) and Haldol (Haloperidol), an older antipsychotic medication, for alleviating behavioral symptoms among children with Autistic Disorder (Miral et al., 2008). Findings from this RCT suggest that Risperdal (Risperidone) is more effective than Haldol (Haloperidol) in reducing hyperactivity, disruptive behavior, and other maladaptive behaviors.

One RCT compared the effectiveness of combining Risperdal (Risperidone) with Topamax (Topiramate), an antiepileptic medication, to Risperdal (Risperidone) alone for reducing behavioral symptoms among children with Autistic Disorder (Rezaei et al., 2010). The authors reported that adding Topamax (Topiramate) to Risperdal (Risperidone) reduces hyperactivity, irritability, and stereotypic behavior but does not reduce inappropriate speech or lethargy/social withdrawal.

Two RCTS have examined the efficacy of two other atypical antipsychotic medications relative to a placebo for treatment of behavioral symptoms of PDD/A disorders in children and adolescents. One RCT found that among children and adolescents with Autistic Disorder, Abilify (Aripiprazole) reduces maladaptive behavior relative to a placebo (Canitano and Scandurra, 2011). The other RCT found that Zyprexa (Olanzapine) does not alleviate behavioral symptoms among children and adolescents with Asperger's Disorder, Autistic Disorder, or PDD-NOS (Canitano and Scandurra, 2011).

Selective serotonin reuptake inhibitors

Selective serotonin reuptake inhibitors (SSRIs) are a class of antidepressant medications that are widely prescribed for mood disorders. One systematic review (Williams et al., 2010) synthesized findings from studies that have evaluated the efficacy of SSRIs for treatment of behavioral symptoms of PDD/A disorders. The RCTs included in the systematic review reached different conclusions regarding the efficacy of SSRIs for treatment of children and adults. Findings from two RCTs that enrolled children with Asperger's Disorder, Autistic Disorder, or PDD-NOS (one RCT per drug) suggest that Celexa (Citalopram) and Prozac (Fluoxetine) do not improve core behaviors associated with PDD/A. In contrast, findings from a single RCT that enrolled adults with Autistic Disorder suggest that Luvox (Fluvoxamine) improves core behaviors. Generalizing findings across these studies is difficult because none of the three drugs have been studied in both children and adults. In addition, the study of adults only enrolled adults with Autistic Disorder, whereas the studies of children also enrolled children with less severe PDD/A disorders (i.e., Asperger's Disorder and PDD-NOS).

A single RCT examined the effectiveness of combining an SSRI with Depakote (Valproate), an antiepileptic medication, relative to treatment with an SSRI alone in children with Asperger's Disorder, Autistic Disorder, or PDD-NOS (Anagnostou et al., 2006). The authors found that combining an SSRI with Depakote (Valproate) reduces irritability relative to an SSRI alone.

Medications used to treat Attention Deficit/Hyperactivity Disorder

A recent systematic review by Canitano and Scandurra (2011) identified two RCTs that have assessed the effectiveness of two medications used to treat Attention Deficit/Hyperactivity Disorder relative to a placebo for treatment of behavioral symptoms in children and adolescents with Autistic Disorder. The authors of one RCT reported that Ritalin (Methylphenidate) reduces hyperactivity, stereotypic behaviors, and inappropriate speech relative to a placebo. Another RCT found that Strattera (Atomoxetine) reduces hyperactivity and impulsivity relative to a placebo.

Antiepileptic medications

The systematic review by Canitano and Scandurra (2011) identified five placebo-controlled RCTs of antiepileptic medications. All five RCTs enrolled children and adolescents with PDD/A disorders. Findings from three RCTs that compared Depakote (Valproate) to a placebo for treatment of children and adolescents with Asperger's Disorder, Autistic Disorder, or PDD-NOS were ambiguous. Two RCTs reported reductions in maladaptive and repetitive behaviors among subjects who received Depakote (Valproate), but the other found no difference between the treatment and control groups. One of the RCTs with favorable findings was a 12-week trial, whereas the RCT that found no difference was only an 8-week trial, suggesting the drug's effects on behavior depend in part on the duration of treatment. Findings from a single RCT that compared Keppra (Levetiracetem) to a placebo suggest that for children and adolescents with Asperger's Disorder, Autistic Disorder, or PDD-NOS, Keppra does not reduce affective disturbances, aggression, hyperactivity, impulsivity, and repetitive behaviors. Findings from a single RCT that compared Lamictal (Lamotrogine) to a placebo suggest that for children and adolescents with Autistic Disorder, Lamictal does not reduce maladaptive behaviors or severity of PDD/A. Findings from the RCT that assessed the effectiveness of combining Risperdal (Risperidone) with another antiepileptic medication, Topamax (Topiramate), to treat children with Autistic Disorder suggested that the combination may be more effective than treatment with Risperdal (Risperidone) alone (Rezaei et al., 2010).

The preponderance of evidence from five RCTs suggests that Risperdal (Risperidone), an atypical antipsychotic medication, reduces behavioral symptoms among children with PDD/A disorders. Evidence from single RCTs (one study per drug) suggests that Ritalin (Methylphenidate) and Strattera (Atomoxetine) reduce hyperactivity among children and adolescents with Autistic Disorder and that Luvox (Fluvoxamine) improves behavioral symptoms among adults with Autistic Disorder.

Psychiatric and Psychological Care

No studies of the effectiveness of psychiatric care or psychological care for PDD/A were identified. The lack of studies on psychiatric care and psychological care for PDD/A does not indicate that these treatments are not effective. Psychologists have expertise in assessment of behavior, cognitive function, and social skills that can be helpful in diagnosing PDD/A disorders. Psychiatrists have expertise in prescribing and monitoring psychotropic medications that may be helpful for treating behavioral symptoms of PDD/A disorders.

Occupational Therapy, Physical Therapy, and Speech Therapy

No studies of the effectiveness of occupational therapy, physical therapy, and speech therapy for PDD/A were identified. The lack of studies on occupational therapy, physical therapy, and speech therapy for PDD/A does not indicate that these treatments are not effective. Rather, it indicates that there is insufficient evidence to determine whether they are effective.

Durable Medical Equipment

No studies of the effectiveness of durable medical equipment for PDD/A were identified. The lack of studies on durable medical equipment for PDD/A does not indicate that these treatments are not effective. Rather, it indicates that there is insufficient evidence to determine whether they are effective. It seems likely that certain forms of durable medical equipment, such as wheelchairs, may assist persons in coping with the physical manifestations of Rett's Disorder.

BENEFIT COVERAGE, UTILIZATION, AND COST IMPACTS

Over 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). AB 171 would mandate coverage of screening, diagnostics, therapies based on intensive behavioral intervention, therapies other than intensive behavioral intervention therapy (speech therapy, physical therapy, occupational therapy, psychological care, psychiatric care), prescription drugs, and durable medical equipment (DME) for pervasive developmental disorders or autism (PDD/A). AB 171 would affect those enrolled in DMHC-regulated health plans or in CDI-regulated policies.

Approximately 101,000 enrollees in DMHC-regulated plans and/or CDI-regulated policies subject to AB 171 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.

Because over 90% of enrollees subject to AB 171 are covered for mandated benefits other than intensive behavioral intervention therapies, CHBRP estimates that intensive behavioral intervention therapies would account for most of the impact on utilization of AB 171.

Critical Caveats, Estimates, and Assumptions

- Although studies on the effectiveness of intensive behavioral intervention therapies is focused on Autistic Disorder and PDD-NOS in preschool- 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 years, 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,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

⁵⁰ 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 16 months and a mode of 2 years.

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, the hours per week of intensive behavioral intervention therapy 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 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 AB 171.
 - 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.

This section will first present the current (baseline) benefit coverage, utilization, and costs related to intensive behavioral intervention therapy and prescription drugs for PDD/A persons, and then provide estimates of the impacts on coverage, utilization, and cost if AB 171 is enacted. For further details on the underlying data sources and methods, please see Appendix D at the end of this document.

Current (Baseline) Benefit Coverage, Utilization, and Cost

Current Coverage of the Mandated Benefit

Current benefit coverage for enrollees with privately-funded health insurance that would be subject to AB 171 was determined through surveys of California's largest health plans and insurers. A Bill-Specific Coverage Survey for AB 171 determined current coverage of benefits other than outpatient prescription drugs and DME. Responses to this survey represent an estimated 71.77% of enrollees in the CDI-regulated market and 84.88% of enrollees in the privately funded, DMHC-regulated market (82.15% of the whole privately funded market

subject to state-level mandates).⁵¹ Coverage of PDD/A-related outpatient prescription drugs was determined through responses to CHBRP's Annual Enrollment and Premium Survey. Responses represent an estimated 94.4% of enrollees in DMHC-regulated health plans and 90.1% of enrollees in CDI-regulated policies. Coverage of PDD/A-related DME was determined from CHBRP's 2010 Bill-Specific Coverage survey for Assembly Bill 754. Responses represent an estimated 82.37% of enrollees in CDI-regulated policies and 92.03% of enrollees in DMHC-regulated plans.

DMHC-regulated publicly funded insurance is subject to AB 171. Several of the DMHC-regulated plans with the largest enrollment of beneficiaries of public programs [Medi-Cal Managed Care, the Healthy Families Program (HFP), Access for Infants and Mothers (AIM), and the Major Risk Medical Insurance Program (MRMIP)], were surveyed to ascertain the benefit coverage of beneficiaries of these public programs. Confirmation of plan responses was requested from the California Department of Health Care Services (DHCS), which administers the Medi-Cal program, and the Major Risk Medical Insurance Board (MRMIB), which administers HFP, AIM, and MRMIP. Queries were also made of the California Public Employees' Retirement System (CalPERS) as to benefit coverage for CalPERS Health Maintenance Organizations (HMOs) enrollees.

From the information gathered, CHBRP estimates:

- 16.1% of enrollees in plans and policies that would be subject to AB 171 have benefit coverage for intensive behavioral intervention therapies for PDD/A.
- 98.8% of enrollees in plans and policies that would be subject to AB 171 have benefit coverage for outpatient prescription drugs, including prescriptions drugs for PDD/A (current law allows plan contracts and policies to exclude all coverage for outpatient prescription drugs).
- 94.2% of enrollees in plans and policies that would be subject to AB 171 have benefit coverage for durable medical equipment (DME), including DME related to PDD/A (current law allows plan contracts and policies to exclude all coverage for DME).
- 100% of enrollees in plans and policies that would be subject to AB 171 have benefit coverage for PDD/A-related psychiatric care, psychological care, occupational therapy (OT), physical therapy (PT), and speech therapy (ST). Some responses indicated that habilitative services are not covered and expert opinion suggests that there may be unmet demand for PDD/A-related ST/PT/OT services. However, without sufficient data to quantify the extent of unmet demand, CHBRP assumes 100% coverage for these benefits.

⁵¹ 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.

Current Utilization Levels and Average Costs

Current utilization and average costs are presented below for the benefits for which AB 171 is expected to impact coverage.

Premandate, of the estimated 101,000 enrollees diagnosed with PDD/A in DMHC- or CDI-regulated plans or policies subject to AB 171, 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 percentage 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 autism spectrum disorder (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 was developed based on content expert opinion (see Appendix D).

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) (Croen et al., 2006; Flanders et al., 2007; Leslie and Martin, 2007; Liptak et al., 2006; Mandell et al., 2006; Peng et al., 2009; Wang and Leslie, 2010).

CHBRP 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 the estimated total cost from the Colorado report to the General Assembly referenced above. That 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.

CHBRP assumes that 45% of enrollees with PDD/A aged 19 years and younger and 75% of enrollees with PDD/A aged 20 years and older use PDD/A-specific outpatient prescription drugs. This assumption is based on studies that indicate that approximately 45% of children and adolescents (Aman et al., 2003; Langworthy-Lam et al., 2002; Witwer and Lecavalier, 2005) and up to 75% of adults (Seltzer et al., 2004; Tsakanikos et al., 2006) with PDD/A are treated with psychotropic medication.

CHBRP used 2008 MarketScan claims data for individuals with a PDD/A diagnosis to determine the average annual cost of drugs that are used to treat PDD/A. From this data, CHBRP estimates that the average annual prescription drug cost for treatment of PDD/A per user is \$1850 and that approximately 10% of enrollees with PDD/A who use prescription drugs have prescription drug costs estimated to be more than \$8000 per year.

Based on content expert opinion, CHBRP assumes no measurable use of DME specifically associated with the PDD/A diagnosis.⁵²

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 21.9 million enrollees in DMHC- or CDI-regulated plans or policies that would be subject to AB 171, as the premium costs are spread over all enrollees in all plans and policies subject to the mandate.

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 AB 171 may receive tests or treatments paid for by families, charities, public programs (including DDS

⁵² Notable exceptions are braces to arrest scoliosis and splints to modify hand movements for people with Rett’s Disorder. Rett’s Disorder, however, is a rare disease (see prevalence estimates in the *Introduction*).

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 so not subject to state-level mandates) with the benefits that are provided by plans or policies that would be subject to the mandate.

Based on response from unions, one large union reported the treatment of PDD/A may be covered under the same terms and conditions as other mental health services are covered (e.g. in parity).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 exclude coverage from intensive behavioral intervention therapy as a treatment for PDD/A, a stance similar to that taken by many group health insurance plans and policies that would be subject to the mandate.

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.

On the basis of coverage levels of self-insured plans and responses from large unions, CHBRP concludes that there may be some public demand for ABA-based therapy benefits as a treatment for PDD/A by collective bargaining agents and insufficient demand by self-insured plans.

Impacts of Mandated Benefit Coverage

Postmandate, CHBRP projects increases in the percentage of enrollees in DMHC-regulated plans and CDI-regulated policies with benefit coverage for PDD/A related intensive behavioral intervention therapy (see Table 1). CHBRP assumes this to be true for DMHC-regulated plans that enroll Medi-Cal beneficiaries despite the current contractual carve-out of mental health services. Although the surveyed plans noted the carve-out and DHCS confirmed that DDS is responsible for delivery of PDD/A-related services for Medi-Cal beneficiaries,⁵⁴ AB 171 does not exempt any DMHC-regulated plans from the mandate. Therefore, despite the current

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

contractual carve-outs, AB 171 would be expected to impact the DMHC-regulated plans that enroll Medi-Cal beneficiaries.

Postmandate, CHBRP also projects an increase in the percentages of enrollees in privately funded DMHC-regulated plans and CDI-regulated policies with benefit coverage for outpatient prescription drugs, and DME (see Table 1). No increase is expected for beneficiaries of public programs enrolled in DMHC-regulated plans, as these enrollees have benefit coverage for outpatient prescription drugs and DME.

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 PDD/A-related intensive behavioral intervention therapy is likely to require plans and insurers to alter their provider contracts and networks. However, 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 DDS⁵⁵) or treatments that may include intensive behavioral intervention therapy (including CDE⁵⁶) and this suggests the presence of an extant labor supply of intensive behavioral intervention providers. Second, AB 171 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.

CHBRP assumes that the estimated increase of enrollees with coverage for PDD/A-related outpatient prescription drugs and DME will not impact access because the number of enrollees with PDD/A expected to gain benefit coverage is relatively small in comparison to the total number of users (which would include users with other health conditions) of these medications and of DME.

Impact on per-unit cost

Since the provider/supply bottlenecks are assumed to be minimal, CHBRP assumes that the unit cost of intensive PDD/A-related behavioral intervention therapy, outpatient prescription medication, and DME would not increase were AB 171 to be enacted. CHBRP assumes that AB

⁵⁴ Personal communication, T Stratton, California Department of Health Care Services, March 2011.

⁵⁵ Personal communication, J. Mullen, California Department of Developmental Services, March 2011.

⁵⁶ Personal communication, P. Skelton, California Department of Education, March 2011.

171 would not have an impact on per-unit cost of the other mandated benefits because no measurable utilization change is expected for PPD/A-related screening, diagnosis, speech therapy, physical therapy, occupational therapy, psychological care, and psychiatric care.

CHBRP assumes that the impact on per-unit cost of prescriptions drugs and DME would be not be measurable because the number of enrollees with PDD/A who are expected to gain benefit coverage is relatively small in comparison to the total number of users (which would include other health conditions) of these medications and DME.

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 covered by their health insurance from approximately 1,400, premandate, to 12,100, postmandate: a 521% increase. The mandate would also add approximately 400 new users of intensive behavioral intervention therapies and would result in approximately 10,300 current users of intensive behavioral intervention therapies to obtain such therapies covered by their health insurance.

Findings from the literature suggest that demand for prescription drugs is likely to increase as enrollees gain coverage for this benefit. However, because 98.8% of enrollees with health insurance subject to AB 171 have coverage for prescription drugs (including PDD/A-related drugs) a limited utilization or cost impact is expected as a result of the mandate. CHBRP has made the simplifying assumption of no change in PDD/A-related prescription drugs utilization, postmandate, but projects that costs for these medications would shift to DMHC-regulated plans and CDI-regulated insurers.

Although the percentage of enrollees with coverage for PDD/A-related DME would increase, based on content expert opinion, CHBRP assumes no measurable use of DME specifically associated with the PDD/A diagnosis, either pre- or postmandate.⁵⁷

Although CHBRP assumes 100% coverage of psychiatric care, psychological care, occupational therapy (OT), physical therapy (PT), and speech therapy (ST), surveys of DDS and CDE indicate that some level of ST, PT, and OT are provided by these payors and content experts indicate that there may be unmet demand for these services. Thus, the mandate could increase the utilization of OT, PT, or ST, but, absent data to measure this unmet demand, the extent that post mandate utilization would increase is unknown.

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 is 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 will 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.

Impact of the Mandate on Total Health Care Costs

Postmandate, the entirety of the estimated cost impact would result from altered benefit coverage for (and utilization of) PDD/A relevant prescription drugs and intensive behavioral intervention therapies, with intensive behavioral intervention therapy utilization accounting for the vast majority of the mandate's estimated cost impact.⁵⁸

Changes in total expenditures

AB 171 would increase total expenditures by \$137.9 million, or 0.14%, for this insured population. This increase in expenditures results from a \$338.1 million increase in health insurance premiums, a \$17.4 million increase in out-of-pocket expenses for enrollees with PDD/A with newly covered benefits, and a \$217.6 million decrease in expenses for noncovered benefits.

⁵⁷ Notable exceptions are braces to arrest scoliosis and splints to modify hand movements for people with Rett's Disorder. Rett's Disorder, however, is a rare disease (see prevalence estimates in the *Introduction*).

⁵⁸ For comparison, see CHBRP's report on SB TBD 1 (2011), a bill which would not mandate coverage for prescription drugs, available at: http://www.chbrp.org/completed_analyses/index.php.

- The premium impact would range by market segments from 0.14% to 0.24% for privately funded health insurance.
- The premium impact would range by market segments from 0.26% to 3.54% for publicly funded health insurance.

The \$217.6 million reduction in expenses for noncovered benefits would be a reduction in expenditures for payors other than health plans/insurers. Costs related to intensive behavioral intervention therapies for PDD/A overwhelmingly account for this shift: such therapies comprise approximately \$216.5 million of the \$217.6 million reduction in expenses for noncovered benefits. Prescription drugs comprise the remaining \$1.1 million decrease in expenses for noncovered benefits.

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 AB 171 on premiums and expenditures by each payor category. Note that the total population in Table 6 reflects the full 21.9 million enrollees in DMHC- or CDI-regulated plans or policies that would be subject to AB 171. The premium increases are estimated to be spread among all enrollees in a plan or policy, whether enrollees would possibly use the benefits for PDD/A mandated by AB 171. CHBRP estimates no increase in PMPM premiums for Medi-Cal Managed Care plans for enrollees over age 65, as CHBRP assumes no measureable utilization for this older age group.

In market segments subject to AB 171, increases in per member per month (PMPM) premiums and total expenditures are expected to vary by market segment (Table 6). The mandate is estimated to increase PMPM premiums, ranging by category from an average of 0.14% (for DMHC-regulated individual market policies) to 3.54% (for MRMIB plans). Increases in PMPM total expenditures are estimated to range by category from an average of 0.059% (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 \$0.54 PMPM for CDI-regulated policies and \$0.97 PMPM for DMHC-regulated contracts. In the privately funded individual market, the health insurance premiums are estimated to increase by an average of \$0.30 PMPM and by \$0.58 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, 1.53% (\$2.70) PMPM for Medi-Cal Managed Care Plans for persons under age 65, and 3.54% (\$3.97) PMPM 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 the 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, AB 171 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 AB 171	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
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	\$0.98	\$1.42	\$0.00	\$3.36	\$5.18	\$1.32	\$1.22	\$0.81	\$471,358,000
Total Expenditures	\$423.73	\$384.58	\$485.44	\$458.26	\$346.00	\$179.36	\$122.13	\$562.00	\$458.78	\$258.47	\$95,805,466,000

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 state expenditures for members over 65 years of age include those who also have Medicare coverage.

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

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 AB 171	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
Average portion of premium paid by employer	\$0.7723	\$0.7377	\$0.0000	\$0.8885	\$0.0000	\$2.6997	\$3.4822	\$0.6126	\$0.4335	\$0.0000	\$286,783,000
Average portion of premium paid by employee	\$0.2016	\$0.2283	\$0.5753	\$0.2221	\$0.0000	\$0.0000	\$0.4875	\$0.1992	\$0.1024	\$0.3041	\$51,306,000
Total Premium	\$0.9739	\$0.9660	\$0.5753	\$1.1107	\$0.0000	\$2.6997	\$3.9697	\$0.8118	\$0.5359	\$0.3041	\$338,089,000
Enrollee expenses for covered benefits (deductibles, copays, etc.)	\$0.0530	\$0.0942	\$0.1247	\$0.0573	\$0.0000	\$0.0000	\$0.1656	\$0.1072	\$0.2097	\$0.0894	\$17,430,000
Enrollee expenses for benefits not covered (e)	-\$0.6375	-\$0.6110	-\$0.4129	-\$0.6978	\$0.0000	-\$1.6555	-\$2.5486	-\$0.5555	-\$0.4529	-\$0.2408	-\$217,642,000

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

	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 Expenditures	\$0.3894	\$0.4492	\$0.2871	\$0.4702	\$0.0000	\$1.0442	\$1.5867	\$0.3635	\$0.2927	\$0.1528	\$137,878,000
Percentage Impact of Mandate											
Insured premiums	0.2432%	0.2755%	0.1439%	0.2557%	0.0000%	1.5339%	3.5358%	0.1632%	0.1602%	0.1527%	0.3851%
Total expenditures	0.0919%	0.1168%	0.0592%	0.1026%	0.0000%	0.5822%	1.2991%	0.0647%	0.0638%	0.0591%	0.1439%

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. This 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 state expenditures for members over 65 years of age include those who also have Medicare coverage.

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

PUBLIC HEALTH IMPACTS

AB 171 would require coverage of screening, diagnosis, and treatment of pervasive developmental disorders or autism (PDD/A). AB 171 would also require that benefits be subject to the same requirements as provided in current mental health parity law in California related to mental health benefits, which mandates parity with other benefits in terms of lifetime maximums, copayments, and deductibles.

As noted in the *Introduction*, persons with PDD/A may obtain these types of care through a variety of sources. For example, plans and policies, the California Department of Education, the California Department of Developmental Services, charities, and direct payment for services by families may provide access to one or more of the above types of care. The provision of such care varies due to PDD/A typology, disorder severity, geographic location, age of patient—even parental/guardian preference may influence the distribution of services.

Public Health Outcomes

Screening and diagnostic tests

The term “screening” generally indicates testing of a population that is asymptomatic for a condition of interest, and “diagnostic” testing, a more in-depth process that requires a team of experts, occurs for individuals who exhibit symptoms of a condition. One study relying on health and school records found that children with PDD/A were initially evaluated at a mean age of 48 months, and diagnosed with ASD at a mean age of 61 months (Wiggins et al., 2006).

The screening process in California and across the United States is disjointed; although many tests are administered by health care providers, schools and DDS regional centers also administer screening and diagnostic tests. Because there are several “points of entry,” persons with PDD/A are usually diagnosed by the time they reach early elementary school, but for those relying on school-based diagnosis, this results in the late initiation of treatment. Although the American Academy of Pediatrics supports universal screening, only about 8% of pediatricians in the United States screen regularly, but 44% report treating at least 10 children with PDD/A (Johnson and Meyers, 2007). One study found that 70% of practitioners did not use a diagnostic tool when assigning initial PDD/A diagnosis. Most cases of PDD/A were identified through clinics or hospitals, but 24% of diagnoses were identified through schools (Wiggins et al., 2006). This uneven approach to PDD/A screening and diagnosis has led to public awareness campaigns by the American Academy of Pediatrics, the CDC’s “Learn the Signs. Act Early” program, and the National Medical Home Autism Initiative program to heighten awareness of parents and health care providers of the benefits of earlier screening and diagnosis (Shattuck et al., 2009).

The evidence of effectiveness of screening and diagnostic tests for PDD/A is limited. CHBRP’s review of the evidence (for those at risk of developmental delay and PDD/A) found a preponderance of evidence that these tests are generally accurate in identifying those with and without developmental disabilities and PDD/A. See the *Medical Effectiveness* section for more detail. Additionally, the *Benefit Coverage, Utilization, and Cost Impacts* section reports that 100% of enrollees in plans and policies subject to AB 171 are assumed to have coverage premandate for screening and diagnostic testing.

Other forms of therapy

CHBRP found no evidence of the effectiveness of occupational therapy, physical therapy, speech therapy, or psychiatric or psychological care on treating symptoms of PDD/A. *The lack of studies does not indicate that these treatments are not effective. Rather, the lack of studies suggests that there is insufficient evidence to determine whether these therapies are effective.* Additionally, as shown in the *Benefit Coverage, Utilization, and Cost Impacts* section, 100% of enrollees in plans and policies subject to AB 171 are covered premandate for these treatments.

Prescription drugs and DME

As cited in the *Medical Effectiveness* section, CHBRP finds Risperidone, Methylphenidate, and Atomoxetine to be effective in treating symptoms; however, antiepileptics did not effectively treat PDD/A symptoms. SSRIs were found to be effective in treating symptoms of PDD/A in adults, but not children. As noted in the *Benefit Coverage, Utilization, and Cost Impacts* section, an estimated 98.2% of enrollees in plans and policies subject to AB 171 have premandate coverage for outpatient prescription drugs. Postmandate, all enrollees with health insurance subject to AB 171 would have coverage for PDD/A-related outpatient drugs. Therefore, CHBRP estimates that 600 enrollees with PDD/A would gain coverage for PDD/A-related outpatient prescription drugs, were AB 171 to be enacted.

Although AB 171 would mandate coverage for DME for the remaining 6% of enrollees in plans or policies that did not provide DME coverage premandate, CHBRP does not estimate a measurable increase in utilization of DME for persons with PDD/A postmandate. However, for those persons diagnosed with Rett's Disorder or another disorder requiring use of DME, coverage of such equipment would likely reduce financial burdens and improve quality of life for those users.

Behavioral intervention therapies

CHBRP's analysis of the effectiveness of behavioral intervention therapies for PDD/A focuses on therapies that are grounded in applied behavior analysis (ABA) because AB 171 specifically references this type of behavioral intervention therapy. Although studies demonstrate effectiveness of intensive behavioral intervention therapy for some children with PDD/A, the improvements from this therapy are not universal for all children and are unknown for adults. See the *Medical Effectiveness* section for more detail. Additionally, CHBRP estimates that AB 171 would increase coverage for intensive behavioral intervention therapies for 10,700 enrollees with PDD/A (including 400 new users) (see the *Benefit Coverage, Utilization, and Cost Impacts* section). CHBRP estimates that utilization of such therapies would increase because of new users *and* increased therapy intensity by those who were already assumed to be using therapy funded by other sources.

CHBRP estimates that AB 171 would increase coverage for prescription drugs, DME, and intensive behavioral intervention therapies for persons with PDD/A, and finds a preponderance
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of evidence for some effectiveness of prescription drugs and intensive behavioral intervention therapies. Therefore, CHBRP estimates improved public health outcomes for some PDD/A symptoms (e.g., improved IQ, adaptive behavior, stereotypic or aggressive behavior, etc.) for some persons using these treatments. The majority of these gains accrue through increased use and intensity of intensive behavioral intervention therapies.

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 great health risks than more advantaged groups* (Braveman, 2006).

CHBRP investigated the effect that AB 171 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 AB 171 would only affect the insured population, a literature review was conducted to determine whether there are gender, racial, or ethnic disparities associated with the prevalence and treatment of PDD/A outside of disparities attributable to differences between insured and uninsured populations.

Impact on Gender Disparities

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, which 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).

No literature or data are available regarding the possible differential use by gender of the types of care defined in AB 171 within the insured population with PDD/A. Therefore, the impact of AB

171 on reducing possible proportional gender disparities in the treatment of symptoms associated with PDD/A 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, 2003; Newschaffer et al., 2007; Yeargin-Allsopp et al., 2003), 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).

There are inconsistent findings regarding delayed diagnosis of PDD/A by race or ethnicity. For example, one study using CDC Autism and Developmental Disabilities Monitoring (ADDM) Network data found no statistical difference between races, although a racial difference existed in whether children meeting diagnostic criteria were ever diagnosed by a health or education professional (Shattuck et al., 2009). Another analysis of CDC ADDM data found no differences in timing of diagnosis based on race or ethnicity (Wiggins et al., 2006). Conversely, an older study of the Pennsylvania Medicaid system found Blacks receiving a diagnosis of PDD/A an average of 18 months later than White children. Once in treatment, Blacks required three times the number of visits over a period three times longer than Whites to confirm diagnosis (Mandell et al., 2002).

No studies were found discussing racial or ethnic disparities with regard to use or effectiveness of DME, prescription drugs, psychological care, psychiatric care, or behavioral interventions for treating symptoms of PDD/A.

CHBRP does not have access to the racial/ethnic distribution of enrollees among commercial plans subject to California health benefit mandates nor is there literature available about differential use or outcome of treatments in AB 171 by race. Therefore, the impact of AB 171 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 years (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 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 a premature mortality rate about two times greater 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 cause 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 that 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. (2008) and Pickett et al. (2006) also found significant increased risk of premature death for females. In all studies, many causes of death were attributed to epilepsy and accidents. CHBRP found no literature studying the effects of AB 171–defined treatments on premature death.

Although an increased risk of premature death is associated with PDD, there is no evidence that the types of care defined by AB 171 would reduce premature death for the PDD/A population; therefore, the impact of AB 171 on premature death is unknown.

Economic Loss

Economic loss associated with disease is generally presented in the literature as an estimation 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 enrollees’ expenses for noncovered benefits. 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.

Direct medical expenditures associated with PDD/A

A handful of studies about direct medical costs associated with PPD/A indicate that families experience expenses greater than those without PDD/A or with other conditions. Shimabukuro et al. reported privately insured children with PDD/A had average medical expenditures \$4,000 to \$6,000 greater, or 8.4 to 9.5 times greater, than those without PDD/A; however, the study did not indicate the extent that intensive behavioral intervention therapies were covered (Shimabukuro et al., 2008). Similarly, several other studies reached similar conclusions that medical expenditures were about two times higher for persons diagnosed with PDD/A than non-PDD/A persons (Croen et al., 2006; Flanders et al., 2007; Leslie and Martin, 2007; Liptak et al., 2006; Mandell et

al., 2006). With the exception of Liptak et al. (2006), these studies do not specifically identify use or associated cost of intensive behavioral intervention therapies. A systematic review of medical costs associated with PDD/A reports that families of children with PDD/A experience medical costs two to nine times more than families of children with no PDD/A (Young et al., 2009).

Financial burden of noncovered treatments

Other important costs to caring for persons with PDD/A include expenses incurred 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 encumbered by “large” noncovered expenses (\$1,000+), financial strain, and need for additional income as compared with families with other children with special needs (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 had a loss of 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).

The *Benefit Coverage, Utilization, and Cost Impacts* section estimates that the postmandate net decrease in noncovered expenses for the estimated 101,000 newly covered PDD/A enrollees using intensive behavioral intervention therapies is about \$217.6 million dollars. This decrease may be realized in part by other payors such as CDE, DDS, or charities, as well as enrollees and their families.

CHBRP estimates AB 171 would produce a cost shift of \$217.6 million from sources paying for premandate, noncovered treatments to plans and policies subject to AB 171. CHBRP assumes this postmandate savings would be shared between multiple payors, other than plans and policies, and would reduce financial burdens borne by users of the covered treatments. The majority of this savings would be attributable to use of intensive behavioral intervention therapies (about \$216.5 million) and the remaining proportion attributable to prescription drugs (about \$1.1 million). Savings from DME may be realized on an individual basis, and reduce financial burdens for individual families, but remains unmeasurable at the population level.

Long-Term Public Health Impacts

The lifetime per capita incremental societal cost of autism in the United States was estimated by Ganz at \$3.2 million, in which behavioral therapies comprised 6.5% of the cost, or approximately \$200,000 (Ganz, 2007). In this study, these costs are largely represented by productivity loss and cost of adult care and minimally by costs incurred by the health system, for example in increased inpatient care. Another study estimated the average lifetime public expenditure for a person with PDD/A as exceeding \$4.7 million (Newschaffer et al., 2007).

AB 171 would require plans and policies to establish a network of qualified autism providers. To the extent that AB 171 would increase coverage and use of intensive behavioral intervention therapies, it should be noted that supply of such therapies may be overcome by demand sometime 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 (OR: 3.39 [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. Although the study did not specify type of providers or services needed, these findings could indicate a problematic provider supply for intensive behavioral intervention therapies premandate. However, CHBRP estimates an adequate supply of licensed and unlicensed providers overall; the distribution of providers is unknown in California and may not be equal among geographic areas. This could result in a temporary delay in diagnosis and treatment of PDD/A.

Additionally, CHBRP estimates less than a 1% impact on total expenditures as a result of the mandate. CHBRP, therefore, estimates that AB 171 has no measurable impact on increasing the uninsured population.

CHBRP found no longitudinal studies into adulthood regarding the outcomes of intensive behavioral intervention therapy. Due to the lack of evidence of long-term impacts by types of care defined in AB 171, CHBRP concludes that the long-term impacts of AB 171 on the public health of California are unknown.

APPENDICES

Appendix A: Text of Bill Analyzed

On January 25, 2011, the Assembly Committee on Health requested that CHBRP analyze AB 171.

ASSEMBLY BILL No. 171

Introduced by Assembly Member Beall

January 20, 2011

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.

AB 171, as introduced, Beall. Autism spectrum disorder.

(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 provide coverage for the screening, diagnosis, and treatment of autism spectrum disorders. The bill would, however, provide that no benefits are required to be provided by a health benefit plan offered through the California Health Benefit Exchange that exceed the essential health benefits required under federal law. The bill would prohibit coverage from being denied for specified reasons. 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.

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

Vote: majority. Appropriation: no. Fiscal committee: yes.

State-mandated local program: yes.

The people of the State of California do enact as follows:

SECTION 1. Section 1374.73 is added to the Health and Safety Code, to read:

1374.73. (a) Every health care service plan contract issued,

amended, or renewed on or after January 1, 2012, that provides hospital, medical, or surgical coverage shall provide coverage for the screening, diagnosis, and treatment of autism spectrum disorders. A health care service plan shall not terminate coverage, or refuse to deliver, execute, issue, amend, adjust, or renew coverage, to an enrollee solely because the individual is diagnosed with, or has received treatment for, an autism spectrum disorder.

(b) Coverage required to be provided under this section shall extend to all medically necessary services and shall not be subject to any limits regarding age, number of visits, or dollar amounts. Coverage required to be provided under this section shall not be subject to provisions relating to lifetime maximums, deductibles, copayments, or coinsurance or other terms and conditions that are less favorable to an enrollee than lifetime maximums, deductibles, copayments, or coinsurance or other terms and conditions that apply to physical illness generally under the plan contract.

(c) Coverage required to be provided under this section is a health care service and a covered health care benefit for purposes of this chapter. Coverage shall not be denied on the basis that the treatment is habilitative, nonrestorative, educational, academic, or custodial in nature.

(d) A health care service plan may request, no more than once annually, a review of treatment provided to an enrollee for autism spectrum disorders. The cost of obtaining the review shall be borne by the plan. This subdivision does not apply to inpatient services.

(e) A health care service plan shall establish and maintain an adequate network of qualified autism service providers with appropriate training and experience in autism spectrum disorders to ensure that enrollees have a choice of providers, and have timely access, continuity of care, and ready referral to all services required to be provided by this section consistent with Sections 1367 and 1367.03 and the regulations adopted pursuant thereto.

(f) (1) 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.

(2) This section shall not be construed as limiting benefits that are otherwise available to an enrollee under a health care service plan.

(3) This section shall not be construed as affecting litigation that is pending on January 1, 2012.

(g) On and after January 1, 2014, to the extent that this section requires health 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) by qualified health plans offering those benefits in the California Health Benefit Exchange pursuant to Title 22 (commencing with Section 100500) of the Government Code, the specific benefits that exceed the federally required essential health benefits are not required to be provided when offered by a health care service plan contract through the Exchange. However, those specific benefits are required to be provided if offered by a health care service plan contract outside of the Exchange.

(h) As used in this section, the following terms shall have the following meanings:

(1) “Autism spectrum disorder” means a neurobiological condition that includes autistic disorder, Asperger’s disorder, Rett’s disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.

(2) “Behavioral health treatment” means professional services and treatment programs, including behavioral intervention therapy, applied behavioral analysis, and other intensive behavioral programs, that have demonstrated efficacy to develop, maintain, or restore, to the maximum extent practicable, the functioning or quality of life of an individual and that have been demonstrated to treat the core symptoms associated with autism spectrum disorder.

(3) “Behavioral intervention therapy” means the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in behaviors, including the use of direct observation, measurement, and functional analyses of the relationship between environment and behavior.

(4) “Diagnosis of autism spectrum disorders” means medically necessary assessment, evaluations, or tests to diagnose whether an individual has one of the autism spectrum disorders.

(5) “Evidence-based research” means research that applies rigorous, systematic, and objective procedures to obtain valid knowledge relevant to autism spectrum disorders.

(6) “Pharmacy care” means medications prescribed by a licensed physician and surgeon or other appropriately licensed or certified provider and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

(7) “Psychiatric care” means direct or consultative psychiatric services provided by a psychiatrist or any other appropriately licensed or certified provider.

(8) “Psychological care” means direct or consultative psychological services provided by a psychologist or any other appropriately licensed or certified provider.

(9) “Therapeutic care” means services provided by licensed or certified speech therapists, occupational therapists, or physical therapists or any other appropriately licensed or certified provider.

(10) “Treatment for autism spectrum disorders” means all of the following care, including necessary equipment, prescribed or ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician and surgeon or a licensed psychologist or any other appropriately licensed or certified provider who determines the care to be medically necessary:

(A) Behavioral health treatment.

(B) Pharmacy care.

(C) Psychiatric care.

(D) Psychological care.

(E) Therapeutic care.

(F) Any care for individuals with autism spectrum disorders that is demonstrated, based upon best practices or evidence-based research, to be medically necessary.

SEC. 2. Section 10144.51 is added to the Insurance Code, to read:

10144.51. (a) Every health insurance policy issued, amended, or renewed on or after January 1, 2012, that provides hospital, medical, or surgical coverage shall provide coverage for the screening, diagnosis, and treatment of autism spectrum disorders. A health insurer shall not terminate coverage, or refuse to deliver, execute, issue, amend, adjust, or renew coverage, to an insured solely because the individual is diagnosed with, or has received treatment for, an autism spectrum disorder.

(b) Coverage required to be provided under this section shall extend to all medically necessary services and shall not be subject to any limits regarding age, number of visits, or dollar amounts. Coverage required to be provided under this section shall not be subject to provisions relating to lifetime maximums, deductibles, copayments, or coinsurance or other terms and conditions that are less favorable to an insured than lifetime maximums, deductibles, copayments, or coinsurance or other terms and conditions that apply to physical illness generally under the policy.

(c) Coverage required to be provided under this section is a health care service and a covered health care benefit for purposes of this part. Coverage shall not be denied on the basis that the treatment is habilitative, nonrestorative, educational, academic, or custodial in nature.

(d) A health insurer may request, no more than once annually, a review of treatment provided to an insured for autism spectrum disorders. The cost of obtaining the review shall be borne by the insurer. This subdivision does not apply to inpatient services.

(e) A health insurer shall establish and maintain an adequate network of qualified autism service providers with appropriate training and experience in autism spectrum disorders to ensure that insureds have a choice of providers, and have timely access, continuity of care, and ready referral to all services required to be provided by this section consistent with Sections 10133.5 and 10133.55 and the regulations adopted pursuant thereto.

(f) (1) This section shall not be construed as reducing any obligation to provide services to an insured under an individualized family service plan, an individualized program plan, a prevention program plan, an individualized education program, or an individualized service plan.

(2) This section shall not be construed as limiting benefits that are otherwise available to an enrollee under a health insurance policy.

(3) This section shall not be construed as affecting litigation that is pending on January 1, 2012.

(g) On and after January 1, 2014, to the extent that this section requires health 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) by qualified health plans offering those benefits in the California Health Benefit Exchange pursuant to Title 22 (commencing with Section 100500) of the Government Code, the specific benefits that exceed the federally required essential health benefits are not required to be provided when offered by a health insurance policy through the Exchange. However, those specific benefits are required to be provided if offered by a health insurance policy outside of the Exchange.

(h) As used in this section, the following terms shall have the following meanings:

(1) "Autism spectrum disorder" means a neurobiological condition that includes autistic disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.

(2) "Behavioral health treatment" means professional services and treatment programs, including behavioral intervention therapy, applied behavioral analysis, and other intensive behavioral programs, that have demonstrated efficacy to develop, maintain, or restore, to the maximum extent practicable, the functioning or quality of life of an individual and that have been demonstrated to treat the core symptoms associated with autism spectrum disorder.

(3) "Behavioral intervention therapy" means the design,

implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in behaviors, including the use of direct observation, measurement, and functional analyses of the relationship between environment and behavior.

(4) “Diagnosis of autism spectrum disorders” means medically necessary assessment, evaluations, or tests to diagnose whether an individual has one of the autism spectrum disorders.

(5) “Evidence-based research” means research that applies rigorous, systematic, and objective procedures to obtain valid knowledge relevant to autism spectrum disorders.

(6) “Pharmacy care” means medications prescribed by a licensed physician and surgeon or other appropriately licensed or certified provider and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

(7) “Psychiatric care” means direct or consultative psychiatric services provided by a psychiatrist or any other appropriately licensed or certified provider.

(8) “Psychological care” means direct or consultative psychological services provided by a psychologist or any other appropriately licensed or certified provider.

(9) “Therapeutic care” means services provided by licensed or certified speech therapists, occupational therapists, or physical therapists or any other appropriately licensed or certified provider.

(10) “Treatment for autism spectrum disorders” means all of the following care, including necessary equipment, prescribed or ordered for an individual diagnosed with one of the autism spectrum disorders by a licensed physician and surgeon or a licensed psychologist or any other appropriately licensed or certified provider who determines the care to be medically necessary:

(A) Behavioral health treatment.

(B) Pharmacy care.

(C) Psychiatric care.

(D) Psychological care.

(E) Therapeutic care.

(F) Any care for individuals with autism spectrum disorders that is demonstrated, based upon best practices or evidence-based research, to be medically necessary.

SEC. 3. 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 AB 171, a bill that would require all DMHC-regulated health plan contracts and all CDI-regulated policies to provide coverage for screening, diagnosis, and treatment of 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 (PDD-NOS).

The literature search included studies published in English from 2001 to 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, Scopus, 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 2,786 publications were identified. One hundred five publications were retrieved for further examination.

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 AB 171 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
Asperger's 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
Discreet Trial Training
Disparity
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
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 screening, diagnostics, and treatments for PDD/A included in the medical effectiveness review for AB 171. Tables C-1a through C-1c describe the characteristics of the studies included in the review. Tables C-2a through C-2c summarize findings from these studies. Where available, the review relied on systematic reviews and meta-analyses.

Table C-1a. Characteristics of Published Studies on the Accuracy of Screening and Diagnostic Tests in the Detection of PDD/A

Type of Intervention	Citation	Type of Trial	Screening or Diagnostic Test vs. Diagnostic Reference Standard	Population Studied	Location
<i>Screening</i>					
Checklist for Autism in Toddlers (CHAT)	Mawle and Griffiths, 2006	Systematic Review	CHAT vs. DSM III ⁵⁹ criteria or ICD-10 ⁶⁰ plus clinician judgment	16,326 children aged 16 to 21 months screened by general practitioners or health visitors	United Kingdom
Childhood Asperger's Syndrome Test (CAST)	Scott et al., 2002	Validation study	CAST and SCQ ⁶¹ vs. assessment by the ADI-R or ADOS-G ⁶²	199 primary school-age children in mainstream classrooms, aged 4-11 years	Cambridgeshire, U.K.
Modified Checklist for Autism in Toddlers (M-CHAT)	Mawle and Griffiths, 2006	Systematic Review	M-CHAT vs. assessments based on DSM IV, CARS, ⁶³ Communication and Symbolic Behavior Scale, and Vineland Adaptive Behavior Scales	1293 children aged 18 or 24 months screened during well-child visits	Atlanta, Georgia
M-CHAT and M-CHAT follow up interview	Kleinman et al., 2008	Validation study	M-CHAT vs. clinician judgment based on DSM-IV ⁶⁴ criteria	3,309 children aged 16-30 months screened in pediatricians' office	Connecticut, Massachusetts, Rhode Island
M-CHAT and M-CHAT follow up interview	Robins, 2008	Validation study	M-CHAT vs. clinician judgment based on DSM-IV criteria	4,797 children aged 14 to 27 months screened during well-child visits	Atlanta, Georgia

⁵⁹ *Diagnostic and Statistical Manual of Mental Disorders, 3rd. Edition (DSM-III).*

⁶⁰ *International Statistical Classification of Diseases and Related Health Problems* 10th Revision (ICD-10).

⁶¹ Social Communication Questionnaire (SCQ).

⁶² The Autism Diagnostic Interview-Revised (ADI-R) is a structured interview conducted with the parents of individuals who have been referred for the evaluation of possible autism or autism spectrum disorders. The interview can be used for diagnostic purposes for anyone with a mental age of at least 18 months and measures behavior in the areas of reciprocal social interaction, communication and language, and patterns of behavior. The Autism Diagnostic Observational Schedule-Generic (ADOS-G) is a semistructured assessment of communication, social interaction, and play for individuals suspected of having autism or another pervasive developmental disorder (PDD).

⁶³ Childhood Autism Rating Scale (CARS) was designed to help differentiate children with autism from those with other developmental delays, such as mental retardation.

⁶⁴ *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV).*

Table C-1a. Characteristics of Published Studies on the Accuracy of Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Type of Intervention	Citation	Type of Trial	Screening or Diagnostic Test vs. Diagnostic Reference Standard	Population Studied	Location
Screening					
M-CHAT and the Parent's Evaluation of Developmental Status (PEDS)	Pinto-Martin et al., 2008	Validation study	M-CHAT vs. PEDS	152 children aged 18-30 months screened during well-child visits	Philadelphia, Pennsylvania
Social Communication Questionnaire (SCQ)	Scott et al., 2002	Validation study	CAST and SCQ vs. clinical diagnosis and assessment by the ADI-R or ADOS-G ⁶⁵	139 primary school-age children in mainstream classrooms, aged 4-11 years	Cambridgeshire, U.K.
Diagnostic					
Autism Behavior Checklist (ABC)	Rellini et al., 2004	Validation study	ABC vs. DSM-IV diagnostic criteria	65 children aged 18 months to 11 years who had been diagnosed with Autistic Disorder or were suspected of having Autistic Disorder	Italy
Autism Diagnostic Interview-Revised (ADI-R)	Ventola et al., 2006	Validation study	ADI-R vs. clinician judgment based on DSM-IV criteria	45 children age 16 to 30 months with suspected PDD/A based on M-CHAT scores	Connecticut
Autism Diagnostic Observational Schedule- Generic (ADOS-G)	Ventola et al., 2006	Validation study	ADOS-G vs. clinician judgment based on DSM-IV criteria	45 children age 16 to 30 months with suspected PDD/A based on M-CHAT scores	Connecticut
ADI-R and ADOS	Le Couteur et al., 2008	Validation study	ADI-R and ADOS vs. clinician judgment based on ICD-10 diagnostic criteria	101 children aged 24- 49 months suspected of having developmental delay	United Kingdom

⁶⁵ Autism Diagnostic Interview-Revised (ADI-R); Autism Diagnostic Observational Schedule-Generic (ADOS-G).

Table C-1a. Characteristics of Published Studies on the Accuracy of Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Type of Intervention	Citation	Type of Trial	Screening or Diagnostic Test vs. Diagnostic Reference Standard	Population Studied	Location
<i>Diagnostic</i>					
Baby and Infant Screen for Children with Autism Traits (BISCUIT)	Matson et al., 2009	Validation study	BISCUIT vs. diagnoses based on psychological evaluation using M-CHAT ⁶⁶ scores, scores from the BDI-2 ⁶⁷ and DSM IV criteria for Autistic Disorder and PDD-NOS ⁶⁸	1,007 children ranging in age from 17 to 37 months enrolled in a state-funded program that provides services to the families of infants and children who either have a developmental delay or have a medical condition that is likely to result in a developmental delay.	Louisiana
Childhood Autism Rating Scale (CARS)	Rellini et al., 2004	Validation study	CARS vs. clinical judgment based on DSM-IV diagnostic criteria	65 children aged 18 months to 11 years who had been diagnosed with Autistic Disorder or were suspected of having Autistic Disorder	Italy
CARS	Perry et al., 2005	Validation study	CARS vs. clinical judgment based on DSM-IV criteria	274 children aged 2-6 years suspected of developmental delay	Canada
CARS	Ventola et al., 2006	Validation study	CARS vs. clinician judgment based on DSM-IV criteria	45 children age 16 to 30 months with suspected PDD/A based on M-CHAT scores	Connecticut
Modified Checklist for Autism in Toddlers (M-CHAT)	Eaves et al., 2006a	Validation study	M-CHAT or SCQ vs. multidisciplinary team assessment based on CARS scores, DSM-IV criteria and clinical judgment	84 children aged 2 to 3 years suspected of PDD/A	Canada

⁶⁶ Modified Checklist for Autism in Toddlers (M-CHAT).

⁶⁷ Battelle Developmental Inventory (BDI-2).

⁶⁸ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Table C-1a. Characteristics of Published Studies on the Accuracy of Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Type of Intervention	Citation	Type of Trial	Screening or Diagnostic Test vs. Diagnostic Reference Standard	Population Studied	Location
<i>Diagnostic</i>					
M-CHAT	Kleinman et al., 2008	Validation study	M-CHAT vs. clinician judgment based on DSM-IV criteria	484 children aged 16-30 months suspected of developmental delay	Connecticut, Massachusetts
Social Communication Questionnaire (SCQ)	Eaves et al., 2006a	Validation study	SCQ vs. multidisciplinary team assessment based on CARS scores, DSM-IV criteria and clinical judgment	94 children aged 4 to 6 years suspected of PDD/A	Canada
SCQ	Eaves et al., 2006b	Validation study	SCQ vs. multidisciplinary team assessment based on CARS scores, DSM-IV criteria and clinical judgment	151 children age 36 to 82 months suspected of PDD/A	Canada

Table C-1b. Characteristics of Studies on the Effectiveness of Intensive Behavioral Intervention Therapies Based on Applied Behavior Analysis

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Early 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
Early intensive behavioral interventions based on ABA	Howlin et al., 2009	Systematic review	ABA-based intervention vs. comparison group ⁶⁹	Children with either (1) autism, (2) autism spectrum disorder, or (3) pervasive developmental disorder: mean age of children at enrollment: 40-42 months	N/A
Early intensive behavioral interventions based on ABA	Reichow and Worley, 2009	Meta-analysis	ABA-based intervention vs. comparison group ⁷⁰	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
Early intensive behavioral interventions based on ABA	Spreckley et al., 2009	Meta-analysis	ABA-based intervention vs. comparison group ⁷¹	Children diagnosed with PDD/A ⁷² according to the criteria based on the DSM-IV ⁷³ . One study did not use a standardized diagnostic instrument. Study participants' age ranged from 18 months to 6 years	N/A

⁶⁹ Comparison groups included intensive, parent-directed intervention, less intensive ABA-based interventions, eclectic treatments, public schooling, specialist autism school, a mixture of different interventions, and waiting list.

⁷⁰ 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)

⁷¹ All comparison groups also received intervention (i.e., eclectic treatment, less intensive or less supervised ABA-based intervention).

⁷² PDD/A=Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism).

⁷³ *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)*.

Table C-1b. Characteristics of Studies on the Effectiveness of Intensive Behavioral Intervention Therapies Based on Applied Behavior Analysis (Cont'd)

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Early intensive behavioral interventions based on ABA	Makrygianni and Reed, 2010	Meta-analysis	ABA-based intervention vs. eclectic-control programs ⁷⁴	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 disorder (PDD): mean age at enrollment: 38 months	N/A
Early 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 ⁷⁵ . Mean age ranged from 22.6 to 66.3 months	N/A

Table C-1b. Characteristics of Studies on the Effectiveness of the Early Start Denver Model (Cont'd)

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
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 State

⁷⁴ A combination of TEACCH (Treatment and Education of Autistic and Communication Handicapped Children), sensory integration therapy, and some applied behavior analysis methods.

⁷⁵ Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism).

Table C-1c. Characteristics of Studies on the Effectiveness of Prescription Drugs for Controlling Behavioral Symptoms of PDD/A

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Risperdal (risperidone)	Aman et al., 2008	Randomized controlled trial	Risperdal (risperidone) vs. placebo	38 children with Autistic Disorder (based on DSM-IV criteria) and severe behavioral disturbances, ages 5-17 years at enrollment	United States (multisite)
Risperdal (risperidone)	Jesner et al., 2007	Meta-analysis	Risperdal (risperidone) vs. placebo	Participants of any age with a diagnosis of PDD/A using either a standardized diagnostic instrument or established criteria	N/A
Risperdal (risperidone)	Pandina et al., 2007	Randomized controlled trial	Risperdal (risperidone) vs. placebo	80 children ages 5-12 years (mean age: 7.4 years) with Autistic Disorder based on DSM- IV criteria	Canada
Risperdal (risperidone) Haldol (haloperidol)	Gencer et al., 2008	Randomized controlled trial	Risperdal (risperidone) vs. Haldol (haloperidol)	28 children with Autistic Disorder (based on DSM-IV criteria) ages 8-18 years at study enrollment	Turkey
Risperdal (risperidone) Haldol (haloperidol)	Miral et al., 2008	Randomized controlled trial	Risperdal (risperidone) vs. Haldol (haloperidol)	30 children ages 8-18 years with Autistic Disorder based on DSM-IV criteria	Turkey
Risperdal (risperidone) + Topamax (topiramate)	Rezaei et al., 2010	Randomized controlled trial	Risperdal (risperidone) + Topamax (topiramate) vs. placebo + Risperdal (risperidone)	40 children ages 3 through 12 years with Autistic Disorder based on DSM-IV criteria	Iran

Table C-1c. Characteristics of Studies on the Effectiveness of Prescription Drugs for Controlling Behavioral Symptoms of PDD/A (Cont'd)

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Selective serotonin reuptake inhibitors (SSRIs) ⁷⁶⁷⁷	Williams et al., 2010	Meta-analysis	SSRI vs. placebo	Individuals diagnosed with Asperger's Disorder, or PDD-NOS (based on either a standardized diagnostic instrument or established criteria, such as the DSM-IV.) Individuals with Rett's Disorder and Childhood Disintegrative Disorder were excluded.	N/A
SSRIs	Anagnostou et al., 2006	Randomized controlled trial	SSRI vs. SSRI + Depakote (valproate)	13 children with Autistic Disorder, Asperger's Disorder, or PDD-NOS (based on DSM-IV criteria and Autism Diagnostic Interview) Mean age at study enrollment: 9.5 years	New York State

⁷⁶ DSM IV=*Diagnostic and Statistical Manual of Mental Disorder, 4th Edition.*

⁷⁷ fluoxetine, fluvoxamine, fenfluramine, and citalopram or any composite thereof.

Table C-1c. Characteristics of Studies on the Effectiveness of Prescription Drugs for Controlling Behavioral Symptoms of PDD/A (Cont'd)

Type of Intervention	Citation	Type of Trial	Intervention vs. Comparison Group	Population Studied	Location
Abilify (aripiprazole) Depakote (valproate) Keppra (levetiracetem) Lamictal (lamotrogine) Risperdal (risperidone) Ritalin (methylphenidate) SSRIs Strattera (atomoxetine) Zyprexa (olanzepine)	Canitano and Scandurra, 2011	Systematic review	Abilify (aripiprazole) vs. placebo Depakote (valproate) vs. placebo Keppra (levetiracetem) vs. placebo Lamictal (lamotrogine) vs. placebo Risperdal (risperidone) vs. placebo Ritalin (methylphenidate) vs. placebo SSRIs vs. placebo Strattera (atomoxetine) vs. placebo Zyprexa (olanzepine) vs. placebo	Abilify (aripiprazole) vs. placebo = Autistic Disorder Depakote (valproate) vs. placebo = Asperger's, autism, PDD-NOS Keppra (levetiracetem) vs. placebo = Asperger's, autism, PDD-NOS Lamictal (lamotrogine) vs. placebo = Autistic Disorder Ritalin (methylphenidate) vs. placebo = autism Strattera (atomoxetine) vs. placebo = autism Zyprexa (olanzepine) vs. placebo = Asperger's, autism, PDD-NOS	N/A

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A

Checklist for Autism in Toddlers (CHAT) Screening vs. DSM-IV⁷⁸ and/or ICD-10⁷⁹ Diagnostic Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Screening</i>				
Screening test accuracy of CHAT to detect autism in children under age 4 years	Mawle and Griffiths, 2006	1 systematic review of Level I-II studies: 2 studies of CHAT	<u>Range of findings reported</u> Sensitivity: 12%-100% Specificity: 97.6%-100% PPV: 4.7%-100% NPV: 99%-100%	Preponderance of evidence suggests that the CHAT screen has high specificity (low false-positive rate) and high negative predictive value, but findings regarding the sensitivity and positive predictive value are ambiguous

Childhood Asperger's Syndrome Test (CAST) vs. assessment by the ADI-R or ADOS-G⁸⁰

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Screening</i>				
Screening test accuracy of CAST to detect Asperger's syndrome and related social communication conditions in elementary school children	Scott et al., 2002	Validation study	Specificity = 99% Positive predictive value = 82%	Findings from a single study suggest that screening with the CAST high specificity (low false-positive rate) and high positive predictive value for Asperger's syndrome and related social communication conditions

⁷⁸ DSM IV=*Diagnostic and Statistical Manual of Mental Disorder, 4th Edition.*

⁷⁹ ICD 10 = *International Statistical Classification of Diseases and Related Health Problems, 10th Revision.*

⁸⁰ Autism Diagnostic Interview–Revised (ADI-R); Autism Diagnostic Observational Schedule–Generic (ADOS-G).

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Modified Checklist for Autism in Toddlers (M-CHAT) vs. Clinician Judgment Based on DSM-IV Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Screening</i>				
Screening test accuracy of M-CHAT to detect autism in children under age 4 years	Mawle and Griffiths, 2006	1 systematic review of Level I-II studies: 1 study	Sensitivity: 100% Specificity: 98% PPV: 62%	Evidence from a single study suggests that screening with the M-CHAT can detect autism earlier than can be detected in the absence of screening
Screening test accuracy of M-CHAT and follow-up telephone call for children with suspected PDD/A aged 16-30 months screened during a well-child visit	Kleinman et al., 2008	Validation study	M-CHAT alone: Positive Predictive Value = 11% (95% CI, 6% to 15%) M-CHAT with telephone interview: Positive Predictive Value = 65% (95% CI, 48% to 81%)	Findings from a single study suggest that M-CHAT is not an effective screening test for PDD/A, unless there is a protocol for a follow-up telephone interview with parents of children who failed the written screening test
Screening test accuracy of M-CHAT to detect PDD/A in children aged 14-27 months (M-CHAT alone vs. M-CHAT plus follow-up telephone interview)	Robins, 2008	Validation study	M-CHAT alone: Positive Predictive Value = 5.8% M-CHAT with telephone interview: Positive Predictive Value = 57%	Findings from a single study suggest that M-CHAT is not an effective screen for detecting PDD/A, unless there is a protocol for a follow-up telephone interview with parents of children who failed the written screening test

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Modified Checklist for Autism in Toddlers (M-CHAT) vs. Parent's Evaluation of Developmental Status (PEDS)

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Screening</i>				
Screening test accuracy and agreement of M-CHAT and PEDS to detect PDD/A in children aged 18-30 months	Pinto-Martin et al., 2008	Validation study	Of those that screened positive on PEDS for developmental concerns, 16% screened positive for PDD/A on the M-CHAT. Of those that did not screen positive on PEDS for developmental concerns, 14% screened positive for PDD/A on the M-CHAT.	Evidence from a single study suggests that scores on the M-CHAT and PEDS are not well correlated (i.e., that the two screening tools measure different domains relating to developmental disabilities.

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Social Communication Questionnaire (SCQ) vs. assessment by the ADI-R or ADOS-G

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Screening</i>				
Screening test accuracy of SCQ to detect Asperger's syndrome and related social communication conditions in elementary school children	Scott et al., 2002	Validation study	Specificity = 99% PPV = 75%	Findings from a single study suggest that screening with the CAST high specificity (low false-positive rate) and high positive predictive value for Asperger's syndrome and related social communication conditions

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Autism Behavior Checklist (ABC) vs. Clinician Judgment Based on DSM-IV Diagnostic Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnostic</i>				
Diagnostic accuracy of ABC to correctly identify Autistic Disorder in children aged 18 months to 11 years	Rellini et al., 2004	Validation study	Sensitivity=54%	Findings from a single study suggest that the ABC has fair sensitivity for diagnosis of Autistic Disorder

Autism Diagnostic Interview-Revised vs. Clinician Judgment Based on DSM-IV Diagnostic Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnostic</i>				
Diagnostic accuracy of ADI-R to detect PDD/A in children aged 16-30 suspected of PDD/A	Ventola et al., 2006	Validation study	<u>Autistic Disorder</u> Sensitivity = 55.6% Specificity = 61.1% Positive Predictive Value = 68.2% <u>Autistic Disorder or PDD-NOS</u> Sensitivity = 52.8% Specificity = 66.7% Positive Predictive Value = 86.4%	Findings from a single study suggest that the ADI-R has fair sensitivity and specificity for distinguishing children with Autistic Disorder and PDD-NOS from children with other developmental disabilities

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Autism Diagnostic Observation Schedule-Generic (ADOS-G) vs. Clinician Judgment Based on DSM-IV Diagnostic Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnostic</i>				
Diagnostic accuracy of the ADOS-G to detect PDD/A in children aged 24- 49 months suspected of developmental delay	Ventola et al., 2006	Validation study	<u>Autistic Disorder</u> Sensitivity = 97.2% Specificity = 66.7% Positive Predictive Value = 92.1% <u>Autistic Disorder or PDD-NOS</u> Sensitivity = 89.9% Specificity = 66.7% Positive Predictive Value = 80.0%	Findings from a single study suggest that the ADOS-G has a high rate of sensitivity (i.e., low false negative rate) but only fair specificity for distinguishing children with Autistic Disorder or PDD-NOS from children with other developmental disabilities.

ADI-R and ADOS vs. Clinician Judgment Based on ICD-10 Diagnostic Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnostic</i>				
Diagnostic accuracy of ADI-R and ADOS to detect PDD/A in children aged 24- 49 months	Le Couteur et al., 2008	Validation study	Joint agreement of ADI-R and ADOS with a “best estimate” of clinical diagnosis of Autistic Disorder = 67% Joint agreement of ADI-R and ADOS with a BECD (“best estimate” clinical diagnosis) of any PDD/A disorder = 14%	Findings from a single study suggest that joint administration of the ADI-R and the ADOS yields accurate diagnoses of Autistic Disorder in two-thirds of cases but that these tests are not very accurate for diagnosis of other PDD/A disorders.

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Baby and Infant Screen for Children with Autism Traits (BISCUIT) vs. DSM IV and BDI-2⁸¹ and M-CHAT⁸²

Outcome	Citation	Research Design ⁸³	Findings (Size of Effect)	Conclusion
<i>Diagnosis</i>				
Accuracy of BISCUIT to detect PDD/A disorders in children aged 17-37 months at risk for developmental delay	Matson et al., 2009	Validation study	<p><u>PDD/A</u> Sensitivity: 93.4%</p> <p>Specificity: 86.6%</p> <p>Overall correct classification rate: 88.8%</p> <p><u>Autistic Disorder</u> Sensitivity: 84.4%</p> <p>Specificity: 83.3%</p> <p>Overall correct classification rate: 83.9%</p> <p><u>PDD-NOS</u> Sensitivity: 84.7%</p> <p>Specificity: 86.4%</p> <p>Overall correct classification rate: 86.1%</p>	Findings from a single validation study suggest that the BISCUIT has high sensitivity (i.e., low false negative rate) and high specificity (i.e., low false positive rate) for identifying children with any PDD/A disorder, PDD-NOS, or Autistic Disorder and children among a population of children at risk for developmental delay.

⁸¹ BDI-2 = Battelle Developmental Inventory-Second Edition.

⁸² M-CHAT = Modified Checklist for Autism in Toddlers.

⁸³ Level I=well-implemented RCTs and cluster RCTs; Level II=RCTs and cluster RCTs with major weaknesses; Level III=nonrandomized studies that include an intervention group and one or more comparison groups and time series analyses; Level IV=case series and case reports; and Level V=clinical/practice guidelines based on consensus or opinion.

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Childhood Autism Rating Scale vs. Clinical Judgment based on DSM-IV Diagnostic Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnostic</i>				
Diagnostic accuracy of the CARS correctly identify Autistic Disorder in children aged 18 months to 11 years	Rellini et al., 2004	Validation study	Sensitivity=100%	Findings from a single study suggest that CARS has high sensitivity (i.e., low rate of false negatives) for diagnosis of Autistic Disorder.
Diagnostic accuracy of the CARS to detect Autistic Disorder, PDD-NOS, mental retardation, language delay, and other conditions (ADHD, behavior problems) in children aged 2-6 years	Perry et al., 2005	Validation study	Agreement between CARS and diagnosis of Autistic Disorder based on the DSM-IV = 88% Sensitivity = 94% Specificity = 85%	Findings from a single study suggest that CARS has high accuracy in diagnosing Autistic Disorder and in differentiating Autistic Disorder from PDD-NOS, mental retardation, and other developmental disabilities.
Diagnostic accuracy of the the CARS to detect PDD/A in children aged 24- 49 months suspected of developmental delay	Ventola et al., 2006	Validation study	<u>Autistic Disorder</u> Sensitivity = 88.9% Specificity = 100% Positive Predictive Value = 100% <u>Autistic Disorder or PDD-NOS</u> Sensitivity = 96.3% Specificity = 66.7% Positive Predictive Value = 81.3%	Findings from a single study suggest that the CARS has a high rate of sensitivity and specificity (i.e., low false negative rate and low false positive rate) for distinguishing children with Autistic Disorder from children with other developmental disabilities Specificity is not as strong for PDD-NOS.

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Modified Checklist for Autism in Toddlers (M-CHAT) vs. DSM IV Criteria

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnosis</i>				
Accuracy of M-CHAT and follow-up telephone call for children with suspected PDD/A to detect PDD/A in children aged 16-30 months suspected of having developmental delay	Kleinman et al., 2008	Validation study	M-CHAT alone: Positive Predictive Value = 60% (95% CI, 53% to 67%) M-CHAT with telephone interview: Positive Predictive Value = 76% (95% CI, 69% to 83%)	Findings from a single study suggest that M-CHAT is not an effective test for identifying PDD/A in children suspected of developmental delay, unless there is a protocol for a follow-up telephone interview for children who failed the written screening test

Modified Checklist for Autism in Toddlers (M-CHAT) vs. CARS, DSM IV Criteria and Clinician Judgment

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnosis</i>				
Accuracy of the M-CHAT for diagnosis of PDD/A among children age 2 to 3 years suspected of developmental delay	Eaves et al., 2006a	Validation study	Sensitivity: 92% Specificity: 27% Positive Predictive Value = 68% Correlation with CARS score (r) = 0.37	Evidence from a single study suggests that screening with the M-CHAT has high sensitivity to detect PDD/A (i.e., low rate of false negatives) but poor specificity (i.e., high rate of false positives).

Table C-2a. Summary of Published Studies on the Accuracy of PDD/A Screening and Diagnostic Tests in the Detection of PDD/A (Cont'd)

Social Communication Questionnaire (SCQ) vs. CARS, DSM IV Criteria and Clinician Judgment

Outcome	Citation	Research Design	Findings (Size of Effect)	Conclusion
<i>Diagnosis</i>				
Accuracy of the SCQ for diagnosis of PDD/A among children age 4 to 6 years suspected of developmental delay	Eaves et al., 2006a	Validation study	Sensitivity: 74% Specificity: 54% PPV= 65% Correlation with CARS score (r) = 0.42	Evidence from a single study suggests that screening with the SCQ has fair sensitivity and specificity for diagnosis of PDD/A among children suspected of developmental delay.
Accuracy of SCQ to detect PDD/A in children aged 36-82 months who were suspected of having autism (autism clinic subsample) and not suspected of developmental delay	Eaves et al., 2006b	Validation study	<u>Entire sample</u> Sensitivity = 71% Specificity = 79% <u>Autism clinic</u> Sensitivity = 71% Specificity = 53% <u>Preschool clinic</u> Sensitivity = 71% Specificity = 76%	Findings from a single study suggest that the SCQ has fair sensitivity and specificity for diagnosis of PDD/A among children suspected of developmental delay.

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A

Intensive Behavioral Intervention Therapies based on Applied Behavior Analysis (ABA) vs. Comparison Group⁸⁴

Outcome	Citation	Research Design ⁸⁵	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Adaptive behavior ⁸⁶	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)	Intensive ABA-based therapies are more effective than other treatments for improving adaptive behavior
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	Intensive ABA-based therapies are more effective than other treatments for improving adaptive behavior
Adaptive behavior	Makrygianni and Reed, 2010	Meta-analysis: 7 Level II and Level III studies	High-quality studies: ⁸⁷ 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)	Intensive ABA-based therapies are more effective than other treatments for improving adaptive behavior

⁸⁴ 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.

⁸⁵ 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.

⁸⁶ Usually measured using the Vineland Adaptive Behavior Scales (VABS, which assesses social, communication, motor, and daily living skills).

⁸⁷ Based on 11 criteria specified by the authors (Makrygianni and Reed, 2010).

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A

Intensive Behavioral Intervention Therapies based on Applied Behavior Analysis (ABA) vs. Comparison Group

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
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	Intensive ABA-based therapies are more effective than other treatments at improving adaptive behavior; therapies provided primarily by parents appear to be as effective as therapies provided by clinicians.
Adaptive behavior	Spreckley and Boyd, 2009	Meta-analysis: 3 Level II and Level III studies	Not statistically significant	No difference	No effect	Intensive ABA-based therapies are no more effective than other treatments for improving adaptive behavior
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)	Intensive ABA-based therapies are more effective than other treatments for improving adaptive behavior

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A (Cont'd)

Intensive Behavioral Intervention Therapies based on Applied Behavior Analysis (ABA) vs. Comparison Group (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
IQ (intelligence quotient)	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)	Intensive ABA-based therapies are more effective than other treatments at improving IQ
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	Intensive ABA-based therapies are more effective than other treatments at improving IQ
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)	Intensive ABA-based therapies are more effective than other treatments for improving IQ

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A (Cont'd)

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
IQ	Reichow and Wolery, 2009	Systematic review: 10 Level II and Level III studies	<p>ABA-based intervention vs. minimal treatment: 2 of 2 studies found a statistically significant difference</p> <p>ABA-based intervention vs. other treatment: 3 of 6 studies found a statistically significant difference, 3 of 6 studies found no statistically significant difference</p> <p>Clinical ABA vs. parent ABA: 1 of 2 studies found a statistically significant difference, 1 of 2 studies found no difference</p>	<p>ABA-based intervention vs. minimal treatment: favors ABA in 2 of 2 studies</p> <p>ABA-based intervention vs. other treatment: favors ABA in 3 of 6 studies, no difference in 3 of 6 studies</p> <p>Clinical ABA vs. parent ABA: Favors clinic ABA in 1 of 2 studies, 1 of 2 studies found no difference</p>	<p>ABA-based intervention vs. minimal treatment: no pooled effect size reported</p> <p>ABA-based intervention vs. other treatment: no pooled effect size reported</p> <p>Clinical ABA vs. parent ABA: no pooled effect size reported</p>	Intensive ABA-based therapies are more effective than minimal interventions at improving IQ. Findings from studies that compared ABA-based interventions to other treatments and studies that compared therapies provided primarily by parents to therapies provided by clinicians are ambiguous.
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	Intensive ABA-based therapies are no more effective than other treatments for improving IQ

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A (Cont'd)

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
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)	Intensive ABA-based therapies are more effective than other treatments for improving IQ
Language, expressive	Howlin et al., 2009	Meta-analysis: 7 Level II and Level III studies	Not statistically significant	No difference	No effect	Intensive ABA-based therapies are no more effective than other treatments for improving expressive language.
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	Intensive ABA-based therapies are no more effective than other treatments for improving expressive language.

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A (Cont'd)

Intensive Behavioral Intervention Therapies 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	Spreckley and Boyd, 2009	Meta-analysis: 3 Level II and Level III studies	Not statistically significant	No difference	No effect	Intensive ABA-based therapies are no more effective than other treatments for improving expressive language.
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	Intensive ABA-based therapies are more effective than other treatments for improving receptive language
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	Intensive ABA-based therapies are no more effective than other treatments for improving receptive language. ABA-based therapies led by clinicians are no more effective than ABA-based therapies led by parents for improving receptive language.

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A (Cont'd)

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	Intensive ABA-based therapies are more effective than other treatments for improving receptive language
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)	Intensive ABA-based therapies are more effective than other treatments for improving receptive language
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)	Intensive ABA-based therapies are more effective than other treatments for improving general language skills
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)	Intensive ABA-based therapies are more effective than other treatments for improving general language skills

Table C-2b. Summary of Findings From Studies of the Effectiveness of Therapies Based on Applied Behavior Analysis for PDD/A (Cont'd)

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 ⁸⁸	Statistically significant	Better	Same score for VABS ⁸⁹ across 2 years for intervention group (steady rate of development). Lower VABS scores across 2 years for comparison group (11.2 average decline)	Single study suggests that children who receive treatment with the Early Start Denver Model experience a steady rate of development compared to children who receive community interventions
IQ	Dawson et al., 2010	1 Level II study	Statistically significant	Better	Improvement in MSEL ⁹⁰ 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 ⁹¹	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

⁸⁸ Randomized controlled trial with major weaknesses.

⁸⁹ Vineland Adaptive Behavior Scales: assesses social, communication, motor, and daily living skills.

⁹⁰ Mullen Scales of Early Learning: standardized developmental test for children from birth to 68 months of age.

⁹¹ Defined as change in diagnosis from Autistic disorder to PDD-NOS.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy)

Risperdal (Risperidone) vs. Placebo

Outcome	Citation	Research Design ⁹²	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Cognitive function: Cancellation Task (test of attention span) ⁹³	Aman et al., 2008	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Not reported	Evidence from 1 RCT suggests that Risperdal improves correct detection on test of attention span relative to placebo
Cognitive function: Verbal Learning Task	Aman et al., 2008	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Not reported	Evidence from 1 RCT suggests that Risperdal improves word recognition relative to placebo
Obsessive-compulsive behavior: Yale-Brown Obsessive Compulsive Scale	Jesner et al., 2007	1 meta-analysis: 1 RCT	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean and SD ⁹⁴ at end of trial Risperdal: 12.77 ± 3.63 Placebo: 14.35 ± 3.02	Evidence from 1 RCT suggests that Risperdal reduces obsessive-compulsive behavior relative to placebo

⁹² Level I=well-implemented RCTs and cluster RCTs; Level II=RCTs and cluster RCTs with major weaknesses; Level III=nonrandomized studies that include an intervention group and one or more comparison groups and time series analyses; Level IV=case series and case reports; and Level V=clinical/practice guidelines based on consensus or opinion.

⁹³ Only 38 of 101 subjects enrolled in the trial were able to complete the Cancellation Task and the Verbal Learning Task.

⁹⁴ SD = standard deviation.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Placebo (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Sensory motor—Ritvo-Freeman Real Life Rating Scale ⁹⁵	Jesner et al., 2007	1 meta-analysis: 2 Level II studies	Statistically significant: 2 out of 2 RCTs	Better: 1 of 1 meta-analysis	Mean and SD at end of trial <u>RCTa</u> ⁹⁶ Risperdal: 0.38 ± 0.38 Placebo: 0.64 ± 0.49 <u>RCTb</u> ⁹⁷ Risperdal: 0.59 ± 0.42 Placebo: 0.91 ± 0.60	Evidence from 1 meta-analysis suggests that Risperdal improves sensory motor skills relative to placebo
Social—Ritvo-Freeman Real Life Rating Scale	Jesner et al., 2007	1 meta-analysis: Level II studies (RCTa ¹⁰ , RCTb ¹¹)	Not statistically significant: 2 of 2 RCTs	No effect: 2 of 2 RCTs	No difference: 2 of 2 RCTs	The evidence of the effect of Risperdal treatment in improving social skills is ambiguous

⁹⁵ Ritvo-Freeman Real Life Rating Scale, a scale that evaluates effects of treatment on symptomatic behaviors in patients with PDD/A.

⁹⁶ McDougle et al., 1998.

⁹⁷ McDougle et al., 2005.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Placebo (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Affect—Ritvo-Freeman Real Life Rating Scale	Jesner et al., 2007	1 meta-analysis: Level II studies (RCTa, RCTb)	Statistically significant: 2 RCTs out of 2 RCTs	Better: 1 of 1 meta-analysis	Mean and SD at end of trial <u>RCTa</u> Risperdal: 0.35 ± 0.37 Placebo: 0.82 ± 0.57 <u>RCTb</u> Risperdal: 0.88 ± 0.56 Placebo: 1.6 ± 0.71	Evidence from 1 meta-analysis suggests that Risperdal improves affect vs. placebo
Sensory responses—Ritvo-Freeman Real Life Rating Scale	Jesner et al., 2007	1 meta-analysis: Level II studies (RCTa, RCTb)	Statistically significant: 1 RCT out of 1 RCT Not statistically significant: 1 RCT out of 1 RCT	Better: 1 RCT included in 1 meta-analysis No effect: 1 RCT included in 1 meta-analysis	Mean and SD at end of trial <u>RCTa</u> No difference <u>RCTb</u> Risperdal: 0.60 ± 0.38 Placebo: 1.07 ± 0.54	The evidence of the effect of Risperdal treatment in improving sensory skills is ambiguous
Language—Ritvo-Freeman Real Life Rating Scale	Jesner et al., 2007	1 meta-analysis: Level II studies (RCTa ¹⁰ , RCTb ¹¹)	Not statistically significant: 1 out of 1 meta-analysis	No effect: 1 out of 1 meta-analysis	No difference: 1 out of 1 meta-analysis	Evidence from 1 meta-analysis suggests that Risperdal does not improve language abilities vs. placebo

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd.)

Risperdal (Risperidone) vs. Placebo (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Irritability—Aberrant Behavior Checklist	Jesner et al., 2007	1 meta-analysis: 2 Level II studies	Statistically significant: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean difference: -8.09 (95% CI: -12.99, -3.19)	Evidence from 1 meta-analysis of 2 RCTs suggests that Risperdal reduces irritability relative to placebo
Social Withdrawal/Lethargy—Aberrant Behavior Checklist	Jesner et al., 2007	1 meta-analysis: 2 Level II studies	Statistically significant: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean difference: -1.00 (95% CI: -5.03, -0.97)	Evidence from 1 meta-analysis of 2 RCTs suggests that Risperdal reduces social withdrawal/lethargy relative to placebo
Hyperactivity—Aberrant Behavior Checklist	Jesner et al., 2007	1 meta-analysis: 2 Level II studies	Statistically significant: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean difference: -8.98 (95% CI: -12.01, -5.94)	Evidence from 1 meta-analysis of 2 RCTs suggests that Risperdal reduces hyperactivity relative to placebo
Stereotypy—Aberrant Behavior Checklist	Jesner et al., 2007	1 meta-analysis: 2 Level II studies	Statistically significant: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean difference: -1.71 (95% CI: -2.97, -0.45)	Evidence from 1 meta-analysis of 2 RCTs suggests that Risperdal reduces stereotypy relative to placebo

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Placebo (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Inappropriate speech—Aberrant Behavior Checklist	Jesner et al., 2007	1 meta-analysis: 2 Level II studies	Approaching significance: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean difference: -1.93 (95% CI: -3.79, -0.07)	Evidence from 1 meta-analysis of 2 RCTs suggests that Risperdal reduces inappropriate speech relative to placebo
Behavior (multiple dimensions)—Nisonger Child Behavior Rating form	Jesner et al., 2007	1 meta-analysis: 1 Level II study	Statistically significant: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean change in score from baseline to end of trial Risperdal: -10.4 Placebo: -6.6	Evidence from 1 RCT suggests that Risperdal improves behavior relative to placebo
Maladaptive Behavior ⁹⁸	Jesner et al., 2007	1 meta-analysis: 1 Level II study	Statistically significant: 1 out of 1 meta-analysis	Better: 1 of 1 meta-analysis	Mean and SD ⁹⁹ at end of trial Risperdal: 20.34 ± 7.93 Placebo: 30.27 ± 8.87	Evidence from 1 RCT suggests that Risperdal improves adaptive behavior relative to placebo
Irritability ¹⁰⁰	Pandina et al., 2007	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean ± SD Risperdal: -13.4 (1.5) Placebo: -7.2 (1.4)	Evidence from 1 RCT suggests that Risperdal reduces irritability relative to placebo

⁹⁸ As measured by the Vineland Adaptive Behavior Scales, domains I and II.

⁹⁹ SD = standard deviation.

¹⁰⁰ As measured by the Aberrant Behavior Checklist–Irritability subscale.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Haldol (Haloperidol)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Social skills—Ritvo-Freeman Real Life Rating Scale	Miral et al., 2008	Randomized controlled trial	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Mean ± SD ¹⁰¹ at end of trial Risperdal: -0.11 ± 0.38 Haldol: 0.02 ± 0.57	Evidence from 1 RCT suggests that Risperdal does not improve social skills relative to Haldol treatment
Sensory motor skills—Ritvo-Freeman Real Life Rating Scale	Miral et al., 2008	Randomized controlled trial	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Mean ± SD at end of trial Risperdal: 0.36 ± 0.34 Haldol: 0.50 ± 0.44	Evidence from 1 RCT suggests that Risperdal does not improve sensory motor skills relative to Haldol treatment
Affect—Ritvo-Freeman Real Life Rating Scale	Miral et al., 2008	Randomized controlled trial	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Mean ± SD at end of trial Risperdal: 0.54 ± 0.34 Haldol: 0.64 ± 0.48	Evidence from 1 RCT suggests that Risperdal does not improve affect relative to Haldol treatment
Sensory—Ritvo-Freeman Real Life Rating Scale	Miral et al., 2008	Randomized controlled trial	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Mean ± SD at end of trial Risperdal: 0.51 ± 0.25 Haldol: 0.58 ± 0.49	Evidence from 1 RCT suggests that Risperdal does not improve sensory function relative to Haldol treatment

¹⁰¹ SD = standard deviation

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Haldol (Haloperidol) (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Language—Ritvo-Freeman Real Life Rating Scale	Miral et al., 2008	Randomized controlled trial	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Mean \pm SD at end of trial Risperdal: 0.04 \pm 0.25 Haldol: 0.05 \pm 0.5	Evidence from 1 RCT suggests that Risperdal does not improve language skills relative to Haldol treatment
Maladaptive behavior ¹⁰²	Miral et al., 2008	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean \pm SD at end of trial Risperdal: 36.8 \pm 13.8 Haldol: 45.8 \pm 20.2	Evidence from 1 RCT suggests that Risperdal reduces maladaptive behavior relative to Haldol treatment
Hyperactivity and disruptive behavior ¹⁰³	Miral et al., 2008	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean \pm SD at end of trial Risperdal: 53.5 \pm 9.6 Haldol: 59.6 \pm 21.3	Evidence from 1 RCT suggests that Risperdal reduces hyperactivity and disruptive behavior relative to Haldol treatment

¹⁰² As measured by the Aberrant Behavior Checklist

¹⁰³ As measured by the Turgay DSM-IV scale, which measures hyperactivity and disruptive behavior

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Risperdal (Risperidone) + Topamax (Topiramate)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Irritability—ABC-C rating scale (Aberrant Behavior Checklist–Community) ¹⁰⁴	Rezaei et al., 2010	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean ± SD ¹⁰⁵ Risperdal + Topamax=8.20 ± 2.44 Risperdal + placebo=15.30 ± 4.64	Single RCT suggests that the combination of Topamax with Risperdal reduces irritability relative to Risperdal alone
Stereotypic behavior—ABC-C rating scale	Rezaei et al., 2010	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean ± SD Risperdal + Topamax=3.40 ± 1.04 Risperdal + placebo=8.09 ± 3.04	Single RCT suggests that the combination of Topamax with Risperdal reduces stereotypic behaviors relative to Risperdal alone
Hyperactivity—ABC-C rating scale	Rezaei et al., 2010	Randomized controlled trial	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Mean ± SD Risperdal + Topamax=7.60 ± 2.37 Risperdal + placebo=19.25 ± 8.30	Single RCT suggests that the combination of Topamax with Risperdal reduces hyperactivity relative Risperdal alone

¹⁰⁴ ABC-C is a scale that was developed for assessing treatment effects and for assessing behavior problems in people with developmental disabilities for those in community settings (i.e., not institutionalized).

¹⁰⁵ SD = standard deviation

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Risperdal (Risperidone) vs. Risperdal (Risperidone) + Topamax (Topiramate) (Cont'd)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
ABC-C rating scale Lethargy/social withdrawal	Rezaei et al., 2010	Randomized controlled trial	Not statistically significant: 1 out of 1 RCT	No effect: 1 out of 1 RCT	No difference: 1 out of 1 RCT	Single RCT suggests that Topamax plus Risperdal treatment does not improve lethargy and social withdrawal symptoms relative to Risperdal alone
ABC-C rating scale Inappropriate speech	Rezaei et al., 2010	Randomized controlled trial	Not statistically significant: 1 out of 1 RCT	No effect: 1 out of 1 RCT	No difference: 1 out of 1 RCT	Single RCT suggests that Topamax plus Risperdal treatment does not reduce inappropriate speech relative to Risperdal alone

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Abilify (Aripiprazole) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Maladaptive behaviors ¹⁰⁶	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 2 RCTs	No formal test of statistical significance	Favors Abilify (aripiprazole)	Not stated	Preponderance of evidence suggests that treatment with Abilify reduces maladaptive behavior vs. placebo

Table C2. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Zyprexa (Olanzapine) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
CGI-I ¹⁰⁷	Canitano and Scandurra, 2011	1 RCT from 1 systematic review of Level II-III studies	Not statistically significant: 1 out of 1 RCT	No effect: 1 out of 1 RCT	No difference: 1 out of 1 RCT	Single RCT suggests that Zyprexa does not improve symptoms of PDD/A vs. placebo

¹⁰⁶ As assessed by the Clinical Global Impression-Improvement (CGI-I) scale, the CY-BOCS=Children's Yale-Brown Obsessive Compulsive Scale and the Aberrant Behavior Checklist (ABC). The ABC measures the emotional and behavioral symptoms of irritability in autistic disorder, including aggression towards others, deliberate self-injuriousness, temper tantrums, and quickly changing moods.

¹⁰⁷CGI-I=Clinical Global Impression-Improvement scale

Tale C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Selective Serotonin Reuptake Inhibitors (SSRIs¹⁰⁸) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Repetitive behaviors ¹⁰⁹ (child data only)	Williams et al., 2010	1 meta-analysis of Level I-II studies: 1 RCT	Citalopram—not statistically significant: 1 of 1 RCT	Citalopram—no effect: 1 of 1 RCT	Citalopram—no difference: 1 of 1 RCT	The preponderance of evidence suggests that citalopram does not improve core behaviors associated with PDD/A among children
Behavior-General ¹¹⁰ (child data only)	Williams et al., 2010	1 meta-analysis of Level I-II studies: 1 RCT	Fenfluramine—not statistically significant: 1 of 1 RCT	Fenfluramine—no effect: 1 of 1 RCT	Fenfluramine—no difference: 1 of 1 RCT	The preponderance of evidence suggests that fenfluramine does not improve core behaviors associated with PDD/A among children
Clinical impression ¹¹¹ (child data only)	Williams et al., 2010	1 meta-analysis of Level I-II studies: 1 RCT	Citalopram—not statistically significant: 1 of 1 RCT	Citalopram—no effect: 1 of 1 RCT	Citalopram—no difference (RR, 0.96: 95% CI; 0.61-1.51)	The preponderance of evidence suggests that citalopram does not improve clinical features associated with PDD/A among children.

¹⁰⁸ Fluoxetine, fluvoxamine, fenfluramine, and citalopram or any composite thereof.

¹⁰⁹ As measured by the Repetitive Behavior Scale–Revised (RBS-R), a rating tool that captures the breadth of repetitive behavior in autism.

¹¹⁰ As measured by the Behavior Summarized Evaluation Scale (BSE), which measures changes in behavioral parameters in autistic children over time and treatments.

¹¹¹ As measured by the Clinical Global Impression-Improvement scale.

Tale C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Selective Serotonin Reuptake Inhibitors (SSRIs) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Clinical impression ¹¹² (child data only)	Williams et al., 2010	1 meta-analysis of Level I-II studies: 1 RCT	Fluoxetine—not statistically significant: 1 of 1 RCT	Fluoxetine—no effect: 1 of 1 RCT	Fluoxetine—not stated	The preponderance of evidence suggests that fluoxetine does not improve clinical features associated with PDD/A among children
Clinical impression ¹¹³ (adult data only)	Williams et al., 2010	1 meta-analysis of Level I-II studies	Fluvoxamine—Statistically significant: 1 of 1 RCT	Fluvoxamine—Better: 1 of 1 RCT	Fluvoxamine—53% of subjects improved in the treatment arm, compared to no improvement among subjects in the placebo arm	Single RCT from a meta-analysis suggests that fluvoxamine improves clinical features associated with PDD/A among adults

¹¹² As measured by the Clinical Global Impression Scale Global Autism Score.

¹¹³ As measured by the Clinical Global Impression-Improvement scale.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

SSRIs¹¹⁴ vs. SSRIs + Depakote (Valproate)

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Irritability ¹¹⁵	Anagnostou et al., 2006	Randomized controlled trial	Statistically significant: 1 out of 1 RCT	Better: 1 out of 1 RCT	Worsening of irritability for those only on SSRI vs. those on Depakote + SSRI (d = 3.1)	Single RCT suggests that combined treatment with SSRI and Depakote improves irritability vs. SSRI treatment alone
CGI-I ¹¹⁶	Anagnostou et al., 2006	Randomized controlled trial	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	No difference: 1 of 1 RCT	Single RCT suggests that combined treatment with SSRI and Depakote does not improve illness severity/global well-being ³ vs. treatment with SSRI alone

¹¹⁴ Fluoxetine.

¹¹⁵ As measured by OAS-M (Overt Aggression Scale-Modified), which contains items that address subjective irritability and overt irritability.

¹¹⁶ CGI-I=Clinical Global Impression-Improvement scale.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Ritalin (Methylphenidate) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Hyperactivity ¹¹⁷	Canitano and Scandurra., 2011	1 systematic review of Level I-II studies: 1 RCT	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	$d^{118} = 0.02-0.54$	Single RCT suggests that treatment with Ritalin improves hyperactivity vs. placebo
Inappropriate speech	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 1 RCT	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Not stated	Single RCT suggests that treatment with Ritalin improves inappropriate speech vs. placebo
Stereotypy	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 1 RCT	Statistically significant: 1 of 1 RCT	Better: 1 of 1 RCT	Not stated	Single RCT suggests that treatment with Ritalin improves stereotypy vs. placebo

¹¹⁷ As measured by the Aberrant Behavior Checklist.

¹¹⁸ Cohen's *d* is an effect size used to indicate the standardized difference between two means.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Strattera (Atomoxetine) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Hyperactivity	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 1 RCT	Statistically significant: 1 out of 1 RCT	Better: 1 out of 1 RCT	Children were more likely to experience 25 % or greater improvement on the ABC ¹¹⁹ hyperactivity subscale and on CGI ¹²⁰ scale when taking Strattera vs. placebo (43% vs. 25% of children)	Single RCT suggests that Strattera improves hyperactivity and impulsivity vs. placebo

¹¹⁹ Aberrant Behavior Checklist.

¹²⁰ CGI = Clinical Global Impression-Improvement scale.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Depakote (Valproate) vs. Placebo

Outcome	Citation	Research Design ¹	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Maladaptive behaviors	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 2 RCTs	Statistically significant: 1 of 2 RCTs Not statistically significant: 1 of 2 RCTs	Better: 1 of 2 RCTs No effect: 1 of 2 RCTs	1 study found that children receiving Depakote were more likely to experience a reduction in irritability ¹²¹ (62.5% vs. 9.0%). No difference: 1 of 2 RCTs	The evidence regarding the impact of Depakote on maladaptive behavior vs. placebo is ambiguous
Repetitive behaviors	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 2 RCTs	Statistically significant: 1 of 2 RCTs Not statistically significant: 1 of 2 RCTs	Better: 1 of 2 RCTs No effect: 1 of 2 RCTs	1 RCT showed significant improvement with the CY-BOCS ¹²² scale between 2 treatment groups ($d^5=1.616$) No difference: 1 of 2 RCTs	The evidence regarding the impact of Depakote on maladaptive behavior vs. placebo is ambiguous

¹²¹ As assessed by the Clinical Global Impression-Improvement (CGI-I) scale. CGI is a scale that measures illness severity, global improvement or change and a therapeutic response.

¹²² CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale. The CY-BOCS is used with children and adolescents ages 6-14 years to assess obsessive-compulsive behavior.

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Keppra (Levetiracetem) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Aggression and affective disturbances ¹²³	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 1 RCT	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	No difference: 1 of 1 RCT	Single RCT suggests that Keppra does not reduce aggression or affective disturbances vs. placebo
Repetitive behavior	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 1 RCT	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Not stated	Single RCT suggests that Keppra does not reduce repetitive behavior vs. placebo
Impulsivity and hyperactivity	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies: 1 RCT	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	Not stated	Single RCT suggests that Keppra does not reduce impulsivity or hyperactivity vs. placebo

¹²³ As assessed by the Aberrant Behavior Checklist

Table C-2c. Summary of Findings From Studies of the Effectiveness of Interventions for PDD/A (Pharmacotherapy) (Cont'd)

Lamictal (Lamotrogine) vs. Placebo

Outcome	Citation	Research Design	Statistical Significance	Direction of Effect	Size of Effect	Conclusion
Maladaptive behavior as rated by the ABC	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	No difference: 1 of 1 RCT	Single RCT suggests that lamotrogine does not improve maladaptive behavior vs. placebo
Adaptive Behavior as rated by the VABS ¹²⁴	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	No difference: 1 of 1 RCT	Single RCT suggests that lamotrogine does not improve adaptive behavior vs. placebo
Severity of PDD/A as rated by the ADOS ¹²⁵ or the CARS ¹²⁶	Canitano and Scandurra, 2011	1 systematic review of Level I-II studies	Not statistically significant: 1 of 1 RCT	No effect: 1 of 1 RCT	No difference: 1 of 1 RCT	Single RCT suggests that lamotrogine does not reduce symptoms associated with PDD/A vs. placebo

¹²⁴ VABS=Vineland Adaptive Behavior Scales.

¹²⁵ The Autism Diagnostic Observation Schedule (ADOS) is the "gold standard" for assessing and diagnosing autism and pervasive developmental disorder (PDD) across ages, developmental levels, and language skills.

¹²⁶ Childhood Autism Rating Scale (CARS): This 15-item behavior rating scale helps to identify children with autism and to distinguish them from developmentally disabled children who are not autistic.

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 http://www.chbrp.org/analysis_methodology/cost_impact_analysis.php.

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 over 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 healthcare 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.¹²⁷

¹²⁷ 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 (beneficiaries enrolled in Two-Plan Model, Geographic Managed Care, and County Operated Health System 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 will differ from these estimates for a wide variety of reasons, including:

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

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

- Cost impacts are shown only for plans and policies subject to state benefit mandate laws.
- Cost impacts are only for the first year after enactment of the proposed mandate.
- Employers and employees will share proportionately (on a percentage basis) in premium rate increases resulting from the mandate. In other words, the distribution of premium paid by the subscriber (or employee) and the employer will be unaffected by the mandate.
- For state-sponsored programs for the uninsured, the state share will continue to be equal to the absolute dollar amount of funds dedicated to the program.
- When cost savings are estimated, they reflect savings realized for 1 year. Potential long-term cost savings or impacts are estimated if existing data and literature sources are available and provide adequate detail for estimating long-term impacts. For more information on CHBRP's criteria for estimating long-term impacts, please see: http://www.chbrp.org/analysis_methodology/cost_impact_analysis.php.
- 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, whereas 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://www.chbrp.org/analysis_methodology/cost_impact_analysis.php.

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 point of service [POS] plans—and non-HMO—including PPO and fee for service [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 three 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 Impact* 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 years 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 (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- to 25-year-olds, and the increase varies depending on whether the parents were enrolled in the large-group, small-group, or individual market. 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 shifts 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."¹²⁸ The requirement to report medical loss ratio is effective for the 2010 plan year, whereas 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

¹²⁸ 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.

unknown, and data are 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 (PCIP)

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.¹²⁹ The California PCIP is not subject to state benefit mandates,¹³⁰ 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*.¹³¹ to reflect 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.¹³² 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 September 23, 2011, and to \$2 million September 23, 2012. Earlier in 2010, CHBRP conducted an analysis of SB 890 that sought to prohibit lifetime and annual limits for "basic health care services" covered by CDI-

¹²⁹ 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.

¹³⁰ Correspondence with John Symkowick, Legislative Coordinator, MRMIB, October 19, 2010.

¹³¹ See: http://www.chbrp.org/other_publications/index.php.

¹³² See enacted language at: www.leginfo.ca.gov/pub/09-10/bill/asm/ab_2201-2250/ab_2244_bill_20100930_chaptered.pdf.

regulated 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 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."¹³³ 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.¹³⁴ 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.¹³⁵

¹³³ 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.

¹³⁴ Data from the Department of Health Care Services, Medi-Cal Managed Care Division. Received January 14, 2011.

¹³⁵ 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.

Bill Analysis-Specific Caveats and Assumptions

For this analysis, CHBRP makes the following assumptions:

Intensive behavioral intervention therapy

- 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 shown in Table D-2.
- Persons with PDD/A receiving intensive behavioral intervention therapies would receive this treatment for 40 weeks a year. This figure assumes treatment lasting a full year, less vacation-related breaks.

The age-specific utilization rates in Table D-1 are based on a study detailed in the *Benefit Coverage, Utilization, and Cost Impacts* section (Thomas et al., 2007). CHBRP 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 years 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, 2009b), 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—Percentage 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

CHBRP 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 (as shown in Table D-2).

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 two weeks of the CHBRP review, the following parties chose to submit information.

The following information was submitted by Alliance of California Autism Organizations (ACAO).

Alliance of California Autism Organizations (ACAO). *Back of the Envelope Economic Impact of Autism Specific Health Insurance Reform AB 171*. February 9, 2011.

Blue Cross Blue Shield of Minnesota. *Informational Presentation on Autism for the Honorable Kim Norton*; February 13, 2009.

Chasson GS, Harris GE, Neely WJ. Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies*. 2007;16:401–413.

Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*. 2007;161:343-349.

Howard JS, Sparkman CR, Cohen HG, Green G, Stanislaw H. A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*. 2005;26:359–383.

Jacobson JW, Mulick JA, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism–: General model and single state case. *Behavioral Interventions*. 1998;13:201-226.

Maximus Center for Health Dispute Resolution. *Considerations in the Treatment of Autism Spectrum Disorders*. Report prepared for the State of California Department of Managed Health Care. May 20, 2008.

Sallows GO, Graupner TD. Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*. 2005;110:417-438.

For information on the processes for submitting information to CHBRP for review and consideration please visit: http://www.chbrp.org/recent_requests/index.php.

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 2009 report by the California Department of Developmental Services and a study cited by DDS in the 2009 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 AB 171. 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 age 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 2009 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” PDD 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 (2009b) 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, 2009). 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" PDD 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
Pervasive Developmental Disorder Not Otherwise Specified (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” PDD.

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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