# California Health Benefits Review Program

Analysis of California Assembly Bill AB 796 Autism and Pervasive Developmental Disorders

A Report to the 2015-2016 California State Legislature

April 21, 2015



# Key Findings: Analysis of California Assembly Bill AB 796 Autism and Pervasive Developmental Disorders

Summary to the 2015-2016 California State Legislature, April 2015



## AT A GLANCE

AB 796 (introduced February 2015) would alter a current benefit mandate's definitions of qualified autism service (QAS) professional and QAS paraprofessional.

- Enrollees covered. In 2016, approximately 16.3 million Californians will have state-regulated health insurance that would be subject to AB 796.
- **EHBs.** AB 796 would not require new benefit coverage and so AB 796 would not exceed EHBs.
- Medical effectiveness. A preponderance of evidence indicates that intensive behavioral intervention treatments (IBITs) improve outcomes. There is insufficient evidence to indicate optimal staffing for IBIT. A preponderance of evidence indicates that IBIT delivered by personnel trained in IBIT (or supervised by personnel trained in IBIT) improves outcomes.
- **Benefit coverage.** Coverage for IBIT is already 100% among persons whose health insurance would be subject to AB 796.
- **Impact on utilization.** No impact on IBIT utilization is projected.
- Impact on expenditures. As no impact on IBIT benefit coverage or utilization is expected, no impact on expenditures is projected.
- Public health. Because no increase or decrease in IBIT utilization is expected, no impact on the public's health is projected.

BACKGROUND

Pervasive developmental disorders and autism (PDD/A) are neurodevelopmental disorders that typically become symptomatic in children aged 2 to 3 years. They are chronic conditions characterized by impairments in social interactions, communication, sensory processing, repetitive behaviors or interests, and sometimes cognitive

function. Symptoms range from mild to severe, as reflected by the phrase "autism spectrum disorders" (ASD). CHBRP estimates the prevalence of PDD/A in California as 70.9 per 10,000 for persons of all ages. Many persons with PDD/A (primarily children) are treated with intensive behavioral intervention treatments (IBITs), such as applied behavioral analysis (ABA). Other forms of theory-based IBITs include Early Start Denver Model and DIR Floortime. IBIT aims to improve behavior, cognitive function, language, and social skills.

## **BILL SUMMARY**

As noted in Figure 1, AB 796, like the current law it would alter, would affect the health insurance of approximately 16.3 million enrollees.

#### Figure 1. Health Insurance in CA and AB 796



\*Includes federally regulated health insurance, such as Medicare, veterans, or self-insured plans. *Source:* California Health Benefit Review Program, 2015

Like the current health insurance benefit mandate law<sup>1</sup> it would alter, AB 796 would exempt Medi-Cal Managed Care and the health insurance of enrollees associated

<sup>&</sup>lt;sup>1</sup> H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).



with the California Public Employees' Retirement System (CalPERS).

The current law

- Requires coverage for behavioral health treatment for persons with PDD/A;
- Requires plan/policy networks to include qualified autism service (QAS) providers; supervising/employing QAS professionals or QAS paraprofessionals; and
- Offers definitions for QAS providers, QAS professionals, and QAS paraprofessionals.

The phrase behavioral health treatment is inclusive of but not limited to IBITs, which would include ABA and similarly intensive, theory-based treatments. In its analysis of AB 796, CHBRP has focused on coverage of IBITs.

AB 796 would not alter the definition of QAS provider, but would alter the definitions for QAS professionals and QAS paraprofessionals, broadening both definitions and removing the requirement that QAS professionals be both vendors of regional centers associated with the California Department of Developmental Services (DDS) and be trained in ABA.

## **KEY FINDINGS**

AB 796 would not alter benefit coverage for IBIT, which is already 100% due to the current mandate. CHBRP projects no change in utilization for three reasons.

- First, the current law has been in effect since 2012 and CHBRP found no current evidence indicating difficulty in accessing IBIT, which suggests the presence of an extant labor supply of personnel providing IBIT.
- Second, AB 796 affects the definitions of QAS professionals and QAS health professionals that are relevant to health plans and insurers but AB 796 does not directly affect the QAS providers that employ and supervise them. Although AB 796 creates the possibility, it does not require QAS providers to hire either more or different types of QAS professionals or QAS paraprofessionals than they do currently.

 Third, AB 796 creates the possibility but does not require health plans or insurers to modify their current networks and reimbursement arrangements.

As no change in IBIT coverage or utilization is expected, CHBRP projects no impact on expenditures.

## **Medical Effectiveness**

CHBRP found:

- A preponderance of evidence indicates that IBITs improve outcomes.
- There is insufficient evidence to indicate optimal staffing for IBIT. Therefore, it is unknown whether the effectiveness of IBIT varies by the types of personnel delivering the treatment. Note: the absence of evidence is not evidence of no effect.
- A preponderance of evidence indicates that IBIT delivered by personnel trained in IBIT (or supervised by personnel trained in IBIT) improves outcomes.

## **Public Health Impacts**

Although a preponderance of evidence links IBIT to improved outcomes, as no change in utilization or expenditures is expected, no public health impacts are projected.

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# **ABOUT CHBRP**

The California Health Benefits Review Program (CHBRP) was established in 2002 to provide the California Legislature with independent analysis of the medical, financial, and public health impacts of proposed health insurance benefit mandates and repeals, per its authorizing statute. The state funds CHBRP through an annual assessment on health plans and insurers in California.

An analytic staff in the University of California's Office of the President supports a task force of faculty and research staff from several campuses of the University of California to complete each CHBRP analysis. A strict conflict-of-interest policy ensures that the analyses are undertaken without bias. A certified, independent actuary helps to estimate the financial impact, and content experts with comprehensive subject-matter expertise are consulted to provide essential background and input on the analytic approach for each report.

More detailed information on CHBRP's analysis methodology, as well as all CHBRP reports and publications are available at <u>www.chbrp.org</u>.

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# **POLICY CONTEXT**

The California Assembly Committee on Health has requested<sup>2</sup> that the California Health Benefits Review Program (CHBRP)<sup>3</sup> conduct an evidence-based assessment of the medical, financial, and public health impacts of AB 796, Autism and Pervasive Developmental Disorders. AB 796 would alter the definition of professionals and paraprofessionals qualified to provide services to persons with autism.

If enacted, AB 796 would affect the health insurance of approximately 16.3 million enrollees (43% of all Californians). This represents 66% percent of the 24.6 million Californians who will have health insurance regulated by the state<sup>4</sup> that may be subject to any state health benefit mandate law.<sup>5,6</sup> Specifically, AB 796 would exempt Medi-Cal Managed Care and the health insurance of enrollees associated with the California Public Employees' Retirement System (CalPERS).

It is important to note that CHBRP's analysis of proposal benefit mandate bills typically address the incremental effects of the proposed bills — specifically, how the proposed legislation would impact benefit coverage, utilization, costs, and public health. CHBRP's estimates of these incremental effects are presented in this report.<sup>7</sup>

## **Bill-Specific Analysis of AB 796, Autism and Pervasive Developmental Disorders**

A current health insurance benefit mandate law<sup>8</sup> requires coverage for treatment for persons with pervasive developmental disorder and autism (PDD/A). The current law:

- Requires coverage for behavioral health treatment for persons with PDD/A;
- Requires plan/policy networks to include qualified autism service (QAS) providers supervising/employing QAS professionals or QAS paraprofessionals; and
- References the Business and Professions (B&P) Code and the Welfare and Institutions (W&I) Code, but also offers definitions for QAS providers, QAS professionals, and QAS paraprofessionals. For QAS professionals, the current mandate also references vendor status with regional centers associated with the California Department of Developmental Services (DDS) and California Code of Regulations (CCR) Title 17.

The phrase behavioral health treatment is inclusive of but not limited to intensive behavioral intervention treatments (IBITs), which would include applied behavioral analysis (ABA) and similarly intensive, theory-based treatments. In its analysis of AB 796, in order to complete the analysis within the time permitted,

<sup>&</sup>lt;sup>2</sup> Available at <u>http://www.chbrp.org/</u>.

<sup>&</sup>lt;sup>3</sup> CHBRP is authorized to review legislation affecting health insurance regulated by the state. CHBRP's authorizing statute is available at <u>www.chbrp.org/docs/authorizing\_statute.pdf</u>.

<sup>&</sup>lt;sup>4</sup> State benefit mandates apply to a subset of health insurance in California, those regulated by one of California's two health insurance regulators: the California Department of Managed Health Care (DMHC) and the California Department of Insurance (CDI).

<sup>&</sup>lt;sup>5</sup> CHBRP's estimates of the source of health insurance available at: <u>www.chbrp.org/other\_publications/index.php</u>.

<sup>&</sup>lt;sup>6</sup> Of the rest of the state's population, a portion will be uninsured (and therefore will have no health insurance subject to any benefit mandate), and another portion will have health insurance subject to other state laws or only to federal laws.

<sup>&</sup>lt;sup>7</sup> For CHBRP's technical approach to developing estimates, please see Appendix C.

<sup>&</sup>lt;sup>8</sup> H&SC Section 1374.73 and IC Sections 10144.51 and 10144.52, as enacted by SB 946 (2011).

CHBRP will focus on coverage of IBIT, which is specifically mentioned in the current law (and so in AB 796) rather than the broader category of behavioral health treatment.

#### **Bill Language**

AB 796 would not alter the definition of QAS provider, but AB 796 would alter the definitions for QAS professionals and QAS paraprofessionals.

#### QAS professionals

The current law defines QAS professionals as <u>both</u> meeting the criteria of the W&I Code (4500) or Title 14 (95000) <u>and</u> being a California regional center–approved vendor (through reference to CCR Title 17). CCR Title 17 requires training in ABA but does not mention training for any other form of IBIT. As an alternate for being an approved vendor, AB 796 would define QAS professionals through <u>any</u> of the following:

- Specified training and experience (BA with either 12 semesters relevant credits or 2 years relevant experience);
- Registration as a psychological assistant or psychologist; or
- Registration as an associate clinical social worker.

Therefore, AB 796 would broaden the definition of QAS professional and no longer require that QAS professionals be trained in ABA.

#### QAS paraprofessionals

The current law defines QAS paraprofessionals as meeting the criteria set forth in the W&I Code (4686.3). As an alternate to meeting the W&I Code, AB 796 would define QAS paraprofessionals as meeting <u>all</u> of the following:

- Has a high school diploma or equivalent;
- Has 6 months experience working with persons with developmental disabilities;
- Has 30 hours of relevant training administered by a QAS provider or QAS professional; and
- Has passed a background check by a state-approved agency.

Therefore, AB 796 would broaden the definition of QAS paraprofessionals.

The full text of AB 796 can be found in Appendix A.

#### Analytic Approach and Key Assumptions

The key alteration AB 796 would make to the current law is to broaden the definitions of QAS professional and paraprofessional. In particular, for QAS professionals, AB 796 would remove the requirement for regional center vendor status and for training in ABA.

Current law does not define PDD/A, but regulations governing DMHC-regulated plans<sup>9</sup> define PDD/A as inclusive of Asperger's Disorder, Autistic Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorder Not Otherwise Specified (including atypical autism) (PDD-NOS), and Rett's Disorder, in accordance with the Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition (DSM-IV)–Text Revision (June 2000). CDI also includes these five disorders within PDD/A.<sup>10</sup> This report uses the term "PDD/A" in an effort to make clear that treatment is required for all five disorders.

Payment for IBIT 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 in the case for persons with other disorders. Patients (or their families) may pay directly for care, and charities may also become involved. Moreover, for PDD/A-related behavioral health treatment, regional centers contracting with the California Department of Developmental Services (DDS) generally check for relevant benefit coverage (and ask clients to use it) but may pay,<sup>11</sup> and public schools in California are mandated by state and federal law to provide related services to students that are found eligible by an individualized education program team to receive special education.<sup>12</sup> Schools affiliated with the California Department of Education (CDE)- do not collect information on the health insurance status of public school students<sup>13</sup> and so may serve both persons with and without benefit coverage. Further complicating matters, some enrollees with health insurance subject to the behavioral health treatment mandate may not seek assistance from a regional center or school, may pay directly for care, or may not meet severity threshold criteria to qualify for services per program eligibility rules. Therefore, the overlap between those with PDD/A who are served by DDS and/or CDE and those who are enrollees with health insurance subject to the behavioral health treatment mandate, and thus AB 796, is not clear.

## **Interaction with Existing Requirements**

Health benefit mandates may interact and align with the following state and federal mandates or provisions.

#### **State Requirements**

#### California law and regulations

In addition to the current law that AB 796 would alter, the current California mental health parity law<sup>14</sup> requires coverage for the diagnosis and medically necessary treatment of severe mental illnesses, including for PDD/A, for persons of any age. The current California mental health parity law applies to most DMHC-regulated plans and CDI-regulated policies; it exempts Medi-Cal Managed Care Plans.<sup>15</sup> Coverage for IBIT for persons with PDD/A is required under the current California mental health parity law.<sup>16</sup>

<sup>&</sup>lt;sup>9</sup> California Code of Regulations, (Vol. 38), Title 28, Managed Health Care, Section 1300.74.72(e).

<sup>&</sup>lt;sup>10</sup> Personal communication, J. Figueroa, CDI, March 2013.

<sup>&</sup>lt;sup>11</sup> Personal communication, E. Gelber and P. Choate, California Department of Developmental Services (DDS), March 2015.

<sup>&</sup>lt;sup>12</sup> Services provided by public schools are related to Part B of the federal Individuals with Disabilities Education Act (2004). <sup>13</sup> Personal communication, A. Smith, California Department of Education, March 2013.

<sup>&</sup>lt;sup>14</sup> H&SC Section 1374.72 and IC Section 10144.5.

<sup>&</sup>lt;sup>15</sup> The current California mental health parity law discussed here exempts Medi-Cal Managed Care (H&SC Section

<sup>1374.72</sup> and IC Section 10144.5), as does the existing behavioral health treatment mandate, and thus SB 126.

<sup>&</sup>lt;sup>16</sup> Personal communication, S. Lowenstein, DMHC, and J. Figueroa, CDI, February 2013.

#### *Similar requirements in other states*

At least 37 states and the District of Columbia (BCBSA, 2014) have passed health insurance benefit mandates related to autism. Some states identify treatments for which coverage is specifically required. Over half of the states with health insurance benefit mandates related to autism specifically require coverage for ABA. CHBRP is unaware, however, of any state with a mandate that defines QAS providers, professionals, and paraprofessionals in the way the current mandate does (and which AB 796 would alter).

#### **Federal Requirements**

#### Affordable Care Act

The Affordable Care Act (ACA) has profoundly impacted health insurance, its financing, and regulation in California. As of January 2014, an expansion of the Medi-Cal program, California's Medicaid program,<sup>17</sup> and the availability of subsidized and nonsubsidized health insurance purchased through Covered California,<sup>18</sup> the state's health insurance marketplace,<sup>19</sup> significantly increased the number of people with health insurance in California.

A number of ACA provisions have the potential to or do interact with state benefit mandates. Below is an analysis of how AB 796 may interact with requirements of the ACA, including the requirement for certain health insurance to cover "essential health benefits" (EHBs).<sup>20</sup>

#### **Essential Health Benefits**

State health insurance marketplaces, such as Covered California, are responsible for certifying and selling qualified health plans (QHPs) in the small-group and individual markets.<sup>21</sup> Health insurance offered in Covered California is required to at least meet the minimum standard of benefits as defined by the ACA as essential health benefits (EHBs), and available in the Kaiser Foundation Health Plan Small Group Health Maintenance Organization (HMO) 30 plan, the state's benchmark plan for EHBs through December 31, 2016.22,23

<sup>&</sup>lt;sup>17</sup> The Medicaid expansion, which California will pursue, is to 133% of the federal poverty level (FPL) — 138% with a 5% income disregard.

<sup>&</sup>lt;sup>18</sup> The California Health Benefits Exchange (Covered California) Authorizing Statute is available here:

www.healthexchange.ca.gov/Documents/California%20Codes%20Governing%20the%20Health%20Benefit%20Exch ange.pdf.

<sup>&</sup>lt;sup>19</sup> The ACA requires the establishment of health insurance exchanges in every state, now referred to as health insurance marketplaces.

<sup>&</sup>lt;sup>20</sup> The ACA requires nongrandfathered small-group and individual market health insurance — including but not limited to QHPs sold in Covered California - to cover 10 specified categories of EHBs. Resources on EHBs and other ACA impacts are available on the CHBRP website: http://www.chbrp.org/other\_publications/index.php.

<sup>&</sup>lt;sup>21</sup> Effective 2017, states may allow large-group purchasing through health insurance marketplaces, which may make some large-group plans and policies subject to the requirement to provide essential health benefits [ACA Section 1312(f)(2)(B)].

<sup>&</sup>lt;sup>22</sup> The U.S. Department of Health and Human Services (HHS) has allowed each state to define its own EHBs for 2016 by selecting one of a set of specified benchmark plan options. CCIIO, Essential Health Benefits Bulletin. Available at: cciio.cms.gov/resources/files/Files2/12162011/essential health benefits bulletin.pdf.

<sup>&</sup>lt;sup>23</sup> H&SC Section 1367.005; IC Section 10112.27.

States may require such QHPs to offer benefits that exceed EHBs.<sup>24</sup> However, a state that chooses to do so must make payments to defray the cost of those additionally mandated benefits, either by paying the purchaser directly or by paying the QHP.<sup>25,26</sup> On the other hand, "state rules related to provider types, cost-sharing, or reimbursement methods" would *not meet* the definition of state benefit mandates that could exceed EHBs.<sup>27</sup>

#### AB 796 and EHBs

For two reasons, AB 796 would not exceed EHBs. First, AB 796 alters the terms and conditions of an existing benefit mandate, but does not require benefit coverage. Second, the current law that AB 796 would alter expressly indicates that it ceases to function if it exceeds EHBs.

#### Federal Mental Health Parity and Addiction Equity Act

Although neither the current law nor AB 796 would interact directly with it, it is worth noting that the federal Mental Health Parity and Addiction Equity Act (MHPAEA) address parity for mental health benefits.<sup>28</sup> The MHPAEA requires that if mental health or substance use disorder services are covered, cost-sharing terms and treatment limits be no more restrictive than the predominant terms or limits applied to medical/surgical benefits. The MHPAEA applies to the large group, but starting in 2014, the ACA requires small group and individual market plans and policies purchased through a state health insurance marketplace to comply with the MHPAEA. This federal requirement is similar to the California mental health parity law, although the state law applies to some plans and policies not captured in the MHPAEA.

<sup>&</sup>lt;sup>24</sup> ACA Section 1311(d)(3).

<sup>&</sup>lt;sup>25</sup> State benefit mandates enacted on or before December 31, 2011, may be included in a state's EHBs for 2016, according to the U.S. Department of Health and Human Services (HHS). Patient Protection and Affordable Care Act: Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation. Final Rule. Federal Register, Vol. 78, No. 37. February 25, 2013. Available at: <a href="http://www.gpo.gov/fdsys/pkg/FR-2013-02-25/pdf/2013-04084.pdf">www.gpo.gov/fdsys/pkg/FR-2013-02-25/pdf/2013-04084.pdf</a>.

<sup>&</sup>lt;sup>26</sup> However, as laid out in the Final Rule on EHBs HHS released in February 2013, state benefit mandates enacted on or before December 31, 2011, would be included in a state's EHBs for 2016 and there would be no requirement that the state defray the costs of those state mandated benefits. For state benefit mandates enacted after December 31, 2011, that are identified as exceeding EHBs, the state would be required to defray the cost.

<sup>&</sup>lt;sup>27</sup> Essential Health Benefits. Final Rule. A state's health insurance marketplace would be responsible for determining when a state benefit mandate exceeds EHBs, and QHP issuers would be responsible for calculating the cost that must be defrayed.

<sup>&</sup>lt;sup>28</sup> Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), as amended by the ACA.

# BACKGROUND ON PERVASIVE DEVELOPMENTAL DISORDERS AND AUTISM

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

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 796.

The cause (or causes) of PDD/A is unknown, and research into genetic etiology as well as environmental factors continues to be explored. There is no cure for PDD/A; however, there is some evidence that treatment, such as speech therapy, pharmacotherapy, and behavioral treatments, may improve symptoms (see the *Medical Effectiveness* section, page 15).

PDD/A is associated with other comorbidities, such as epilepsy and intellectual disability. The Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network reports that 38% of their network's PDD/A population (children aged 8 years) are classified as intellectually disabled (intelligence quotient [IQ]  $\leq$ 70) and 24% are classified as borderline status (IQ 71–85) with the remaining 38% scoring in the average to above-average IQ range (CDC, 2012). The CDC collects this data through the 11 ADDM Network sites around the country (but not in California). For each surveillance year, the CDC conducts medical chart reviews for 8-year-olds, as most children with autism and PDD/A would be diagnosed by that age. In 2014, the California Department of Developmental Services (DDS) reported that 23% of its clients with PDD/A had some form of intellectual disability (mild, moderate, severe, or profound), of which 4.3% were severely or profoundly impaired.<sup>29</sup>

## **PDD/A Prevalence in California**

Estimates of prevalence of PDD/A in the United States and worldwide have been increasing over the last 20 years (Fombonne, 2009a). For example, the number of Californians with autism served by DDS increased 33-fold between 1987 and 2014.<sup>30</sup> The overall PDD/A prevalence estimates found in the more recent literature range from 78/10,000 (UCLA, 2006) to 114/10,000 (CDC, 2012; Kogan et al., 2009). For children aged 6 to 17 years, the CDC released a report in 2013 showing the national prevalence to be 200/10,000 (1 in 50 children) in 2011-2012 (Blumberg et al., 2013). Researchers frequently note that

<sup>&</sup>lt;sup>29</sup> Personal Communication, P. Choate, DDS. March 2015

<sup>&</sup>lt;sup>30</sup> Personal Communication, P. Choate, DDS. March 2015

increasing prevalence rates and variation in published rates over time may be attributable to multiple reasons (Charman et al., 2009; Croen et al., 2006 Leonard et al., 2010; Williams et al., 2006) such as:

- Increased absolute risk for PDD/A;
- Health care provider variation in diagnosis over time;
- Variety of study methodologies (e.g., sample size, administrative vs. survey data, and population demographic characteristics);
- Reliability and sensitivity of screening tests;
- Changing PDD/A definitions; and
- Increasing awareness of PDD/A (as a condition) or increasing availability of services used to treat PDD/A.

PDD/A is not a reportable condition nor are there registries established in the United States; therefore, the true prevalence of PDD/A is unknown. CHBRP reviewed multiple sources to determine the best estimated PDD/A prevalence rate in California for the analysis of AB 796. Data sources include epidemiological studies (population- and survey-based), survey data, and California program data generated by analysts from DDS.

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

- Autistic Disorder: 20.6/10,000
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS): 37.1/10,000
- Asperger's Disorder: 6.0/10,000
- Rett's Disorder: 1.0/10,000–13,000<sup>31</sup>
- Childhood Disintegrative Disorder: 2.0/100,000

#### **Estimated Prevalence of PDD/A in California**

After an analysis of the strengths and limitations of the aforementioned data sources, CHBRP chose to adjust 2014 DDS data to estimate California-specific prevalence rates by age group and PDD/A subtype. This level of specificity recognizes the variation in PDD/A prevalence by age group. **Understanding the differences in prevalence rates by age group are useful to this analysis since AB 796 focuses on intensive behavioral treatment therapies, which are generally administered to younger children.** 

These estimated rates use baseline data about Californians with PDD/A who are eligible for services from DDS, and use assumptions from the literature to capture the extant population that is ineligible for DDS services (generally, those persons with less severe PDD/A). See Appendix D for further description of calculations and rationale. Table 1 offers a "snapshot" in time (2014), 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.

<sup>&</sup>lt;sup>31</sup> Prevalence of Rett's Disorder estimated by Kerr, 2002.

The estimated rates in Table 1 for California are higher than national estimates, but the estimates are based on adjustments to the actual number of Californians known to be served by DDS rather than a national, population-based surveillance prevalence rate (see Appendix D for rate calculation methodology). For many years, California has been among the leaders in offering publicly supported programs for the developmentally disabled,<sup>32</sup> 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. For the purposes of this analysis, it is assumed that representation of the PDD/A population is similar between the insured and uninsured populations.

Age Groups (years)	Estimated Prevalence of Autistic-Only Disorder in California (per 10,000)	Estimated Prevalence of "Other" PDD in California (per 10,000)	Estimated Prevalence of All PDD/A in California (per 10,000)
0-4	36.6	29.6	66.2
5-9	101.1	155.1	265.1
10-14	78.7	140.5	219.2
15-19	49.0	122.7	171.7
20-24	30.9	101.9	132.8
25-29	13.8	54.8	68.6
30-34	6.8	28.4	35.2
35-39	4.6	19.6	24.1
40-44	3.3	13.0	16.4
45-49	3.4	13.0	16.4
50+	1.5	5.1	6.6
TOTAL	22.7	48.2	70.9

Table 1. Estimated Prevalence Rates of Persons (All Ages) Diagnosed with PDD/A in California, 2014

*Source:* California Health Benefits Review Program, 2015 (based on 2014 data from DDS,<sup>33</sup> and Appendix D). *Note:* These estimated prevalence rates are based on persons with PDD/A who are eligible for DDS services rather than a surveillance of the population for those medically diagnosed with PDD/A. This table offers a "snapshot" in time (2014), and does not represent a declining prevalence rate in PDD/A as a cohort ages. Appendix D provides more details on calculation methodology.

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

<sup>&</sup>lt;sup>32</sup> Personal communication, report content expert N. Akshoomoff, March 2015.

<sup>&</sup>lt;sup>33</sup> Personal communication, P. Choate, DDS, March 2015.

In 2016, CHBRP estimates that half of Californians aged 0 through 19 will be Medi-Cal beneficiaries. Children and teens comprise a significant proportion of persons with PDD/A (Blumberg, 2013). As Medi-Cal is exempt from the current mandate and so from AB 796 (as is health insurance purchased by CalPERS), a portion of PDD/A patients potentially eligible for IBIT would not be affected AB 796 (see Table 2).

	State- Regulated Health Insurance Subject to AB 796	State- Regulated Health Insurance Exempt from AB 796 <sup>(1)</sup>	Health Insurance Not Subject to State Mandates <sup>(2)</sup>	Total (All of California)
Population	16,297,000	8,260,000	13,348,000	37,905,000
Population aged 0-19	3,929,000	5,077,000	1,787,000	10,793,000
Population aged 0-19 with PDD/A <sup>(3)</sup>	70,000	90,000	32,000	192,000

Table 2. Estimate of Californians (All Ages) with PDD/A and Health Insurance Subject to AB 796, 2016

Source: California Health Benefits Review Program, 2015.

*Note:* (1) The current mandate and AB 796 exempt the health insurance of Medi-Cal beneficiaries enrolled in DMHCregulated plans and enrollees associate with CalPERS; (2) Includes Medicare, self-insured plans, etc.; (3) A large portion of the population aged 0 to 20, including those diagnosed with PDD/A, is comprised of children and teens who are beneficiaries of Medi-Cal, which is exempt from the current mandate and so from AB 796 as well.

Key: PDD/A = pervasive developmental disorder / autism

# **Disparities**<sup>34</sup> in Pervasive Developmental Disorders and Autism

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

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

<sup>&</sup>lt;sup>34</sup> Several competing definitions of "health disparities" exist. CHBRP relies on the following definition: "Health disparities are potentially avoidable differences in health (or health risks that policy can influence) between groups of people who are more or less advantaged socially; these differences systematically place socially disadvantaged groups" at risk for worse health outcomes (Braveman, 2006).

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). By contrast, the CDC's more recent study of 14 sites across the United States reported significantly greater pooled prevalence among white children (12.0/1,000) than among black children (10.2/1,000) and Hispanic children (7.9/1,000) (CDC, 2012), although prevalence by race varied by individual sites. Among those provided PDD/A services by California's DDS, the four largest race/ethnic groups were distributed as follows: Whites accounted for 36% of the clients, Hispanics 31%, Asians 9%, and blacks 8%. The remaining 17% were "other," Filipino, Native American, and Polynesian (DDS, 2012).

# **MEDICAL EFFECTIVENESS**

## **Research Approach and Methods**

#### **Analytic Approach and Key Assumptions**

As discussed previously in the *Policy Context* section (page 5), AB 796 would expand the definition of a QAS professional and QAS paraprofessional to include persons who have a specified levels education and experience. AB 796 does not make modifications to the definition of a QAS provider, who is a person or entity responsible for the design and supervision of the behavioral health treatment that is delivered by the QAS professional or paraprofessional.

Many children with PDD/A are treated with intensive behavioral health treatment<sup>35</sup> based on ABA and/or other theories of behavior. These treatments are aimed at improving behavior, cognitive function, language, and social skills. The medical effectiveness review focuses on the effectiveness of IBIT. In particular, the review examines whether the effectiveness of IBIT varies by the types of personnel delivering the treatment.

Studies of IBIT for PDD/A were identified through searches of 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. The following Web sites were also 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. Because CHBRP's medical effectiveness review had previously conducted thorough literature searches on this topic in 2014 for a report on a bill relevant to PPD/A, the search was limited to studies published from 2014 to present. Of the 278 articles found in the literature review, 18 were reviewed for potential inclusion in this report on AB 796, and nine studies were included in the medical effectiveness review for this report. The medical effectiveness review also presents findings from the studies that were previously included in the CHBRP AB 2041 report.

#### **Methodological Considerations**

The literature on the effectiveness of IBIT for PDD/A is limited in several respects. An important limitation of the literature on the effectiveness of IBIT 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. Descriptions of the credentials of personnel providing behavioral health treatments was inconsistent across studies, which limit the ability to determine which treatments utilized personnel similar to QAS professional or QAS paraprofessional as defined in AB 796. The sample sizes of most studies are small, often less than 50 children. Small sample size limits the precision with which the effects of treatments can be estimated.

<sup>&</sup>lt;sup>35</sup> In addition to behavioral health treatments, children with PDD/A often receive other treatments such as psychological care, pharmacotherapy, physical therapy, speech therapy, and occupational therapy.

## Guidelines on the Treatment of Children and Adolescents with PDD/A

The American Academy of Child and Adolescent Psychiatry (AACAP) and the American Academy of Pediatrics (AAP) have developed recommendations for evidence-based behavioral and education treatments (which would include treatments CHBRP is terming IBIT) for children and adolescents with PDD/A (Myers, 2007; Volkmar at el., 2014). The primary goals of treatment are to maximize independence, learning, and quality of life by minimizing the core autism disorder attributes. IBIT is recommended for children upon PDD/A diagnosis.

Behavioral interventions such ABA draw upon the theories of B.F. Skinner and emphasize using reinforcement to teach children with PDD/A basic social skill skills such as attention, compliance, and imitation. There are different types of ABA-based programs, such as the Discrete Trial Training, Early Intensive Behavioral Intervention, and Pivotal Response Training.

Educational interventions, such as the Early Start Denver Model, combine ABA-based and developmental approaches. An individualized education plan developed by an interdisciplinary team of personnel and parents explicitly describes intensive services to be provided with the goal of enhancing communication, motor, and academic skills.

Other IBIT models are based on developmental theory of behavior change, such as the Developmental, Individual Difference, Relationship-based Floortime model (DIR/Floortime). The DIR/Floortime method is relationship-based and emphasizes emotionally meaningful exchanges with the goal to increase skills in the processes of social engagement and communicating.

While there is evidence that IBITs are associated with better outcomes (see Overall Study Findings section below), the consensus across the AAP and AACAP is that the quality of research in the area is variable (Volkmar et a., 2014). Among the different IBIT models, none has been clearly identified as superior (Myers, 2007). Neither the AACAP nor the AAP have developed recommendations on the optimal personnel for delivering IBIT for children with PPD/A.

## **Characteristics of Included Studies**

#### **Characteristics of Populations Studied**

Studies of behavioral health treatments enrolled children who range in age from 18 months to 11 years. Most of the children enrolled had Autistic Disorder or PDD-NOS and had IQs within the ranges for Mild or Moderate Mental Retardation.

#### **Characteristics of Treatments and Comparison**

Most studies of IBIT identified by CHBRP assessed behavioral treatments based on ABA. Some studies compared more intensive to less intensive behavioral health treatments. Other studies compared IBIT to treatment as usual, which typically consists of a mix of interventions. In recent years, some studies compared different treatments based on ABA (e.g., Mohammadzaheri et al., 2014). Recent studies also investigated whether behavioral health treatments are effective for children with PPD/A who have severe impairments in communication and other areas of development (e.g., Goods et al., 2013). Two recent studies investigated whether behavioral health treatments may improve social function, an outcome that has been less studied in the past (Camargo et al., 2014; Locke et al., 2014). In addition, a growing number of studies assessed the Early Start Denver Model (Dawson et al., 2010; Eapen et al., 2013).

#### **Characteristics of Personnel Providing Treatments**

The IBITs assessed in the studies identified by CHBRP were provided by a wide range of personnel including certified applied behavioral therapists, child care workers, early childhood educators, nurses, occupational therapists, psychologists, speech and language therapists, students, teachers, teachers' aides, and parents. Descriptions of the credentials of personnel providing behavioral health treatments were inconsistent across studies, which limits the ability to determine which treatments utilized personnel similar to QAS professional or QAS paraprofessionals. None of the studies included in CHBRP's review compared the provision of IBIT by personnel similar to QAS professional or QAS paraprofessionals to other IBIT personnel.

Treatments were often provided by multiple personnel with different types and levels of training. Persons who did not have graduate degrees in behavior analysis or a related field were typically supervised by personnel with graduate degrees.

#### **Overall Study Findings**

In summary, as noted in

**Figure 2**, CHBRP found a preponderance of evidence that IBIT is more effective than other treatments in improving behavioral outcomes, and a preponderance of evidence that IBIT delivered by persons who are trained or supervised by experienced IBIT providers are effective in improving outcomes. CHBRP found insufficient evidence to directly compare the provision of IBIT by different personnel.

Figure 2. Summary of Medical Effectiveness Findings

Treatment			Conclusion				
Intensive Behavioral Intervention Treatments			The preponderance of evidence suggests that intensive behavioral intervention treatments (IBITs) are more effective than usual treatment in improving some behavioral outcomes and for some patients.				that intensive are more g some ts.
Not Effective					•		Effective
Clear and Convincing	High Moderate Preponderance of Evi	Low dence	Ambiguous	Low Preponde	Moderate erance of Evi	High dence	Clear and Convincing
Staffing			Conclusion				
Optimal Staffing for Delivering Intensive Behavioral Intervention Treatments			CHBRP found insufficient evidence directly comparing the provision of IBIT by different personnel. Thus, the optimal staffing for delivering these interventions is unknown.				

Training			Conclusion					
Intensive Behavioral Intervention Treatments Delivered by Persons who are Trained or Supervised by Experienced Providers		The preponderance of evidence suggests that IBITs that are delivered by persons who are trained or supervised by experienced IBIT providers are effective in improving outcomes.				a that IBITs ined or are		
Not Effective					₽			Effective
Clear and Convincing	High Prepon	Moderate derance of Evi	Low dence	Ambiguous	Low Prepon	Moderate derance of Ev	High idence	Clear and Convincing

Source: California Health Benefits Review Program, 2015.

#### **Effectiveness of Intensive Behavioral Intervention Treatments**

The preponderance of evidence, which comes primarily from studies with moderately strong research designs, suggests that IBITs are more effective than usual treatments in increasing IQ and improving adaptive behaviors, such as communication, daily living, motor, and social skills (Camargo et al., 2015; CHBRP, 2014; Kogel et al., 2015; Locke et al., 2015). Behavioral health treatments that are more intensive and longer in duration have greater impact on IQ and adaptive behavior. However, findings are ambiguous as to the effect that IBITs have on academic placement and on expressive language (i.e., ability to verbally express one's needs and wishes) and receptive language (i.e., ability to respond to requests from others) relative to usual treatment (CHBRP, 2014).

Outcomes for individual children enrolled in studies of IBIT vary widely, with some children showing dramatic gains while other children show little to no gains. Current evidence of which children would gain the most from which intervention is limited (Vivanti et al., 2014). Findings from some studies suggest that children who are younger, start treatment early, or who have higher IQ and greater adaptive behaviors may derive greater benefit, yet other studies come to different conclusions (CHBRP, 2014; Orinstein et al., 2014; Vivanti et al., 2014).

#### **Effects of IBIT by Different Personnel on Behavioral Health Outcomes**

**CHBRP found no studies that directly compared the provision of IBIT by different personnel.** Moreover, descriptions of the credentials of personnel providing behavioral health treatments were inconsistent across studies, making it difficult to determine which treatments were provided by personnel similar to QAS professionals or QAS paraprofessionals, as defined in AB 796. Thus, the optimal staffing for delivering these interventions is unknown.

#### **IBIT Delivered by Persons Who Are Trained or Supervised**

The preponderance of evidence suggests that IBITs that are delivered by persons who are trained or supervised by experienced IBIT providers are effective in improving outcomes. Two recent systematic reviews and one RCT examined the impact of behavioral health program by persons who had been trained or supervised by persons with experience with IBIT (Reichow et al., 2013; Shire and Kasari, 2014; Tonge et al., 2014). A recent systematic review concluded that behavioral health treatments based on ABA that were delivered by "nonspecialized" personnel (e.g., nurse practitioner, teacher, teacher's aide, parent) who were trained and supervised by persons with expertise in ABA improved IQ, language,

daily living skills, and motor skills among lower functioning children with autism relative to usual care (Reichow et al., 2013).

Another recent systematic review summarized the evidence of Train the Trainer (TTT) trials of behavioral interventions for children with PPD/A. TTT requires that community clinicians experienced in the interventions (e.g., clinic supervisor) train the personnel who deliver the services in the community (e.g., home interventionist). Of the 12 articles included in the review, one was a randomized controlled trial while the others had moderate to low experimental designs, such as a pre-post design. Overall, the authors report that these treatments delivered by the trained community personnel result in positive outcomes in cognition, language, and autism symptoms, particularly among higher functioning children (Shire and Kasari, 2014).

Tonge and collogues (2014) examined the impact of providing a parent education and skills training intervention on behavioral outcomes. Psychologists or special educators who had experience working with children with autism provided a 20-week intervention to two groups of parents of young children receiving PPD/A early intervention services. One group of parents was randomized to receive a parent education and counseling training intervention, and the second group received a parent education and behavioral management intervention. The parent education and behavioral management intervention resulted in a significant improvement in adaptive behaviors and autism symptoms for lower-functioning children.

#### **Generalizability of Findings to AB 796**

The generalizability of findings from studies included in the Medical Effectiveness review to AB 796 is unknown. Descriptions of the credentials of personnel providing behavioral health treatments were inconsistent across studies resulting in insufficient evidence to determine which treatments utilized personnel similar to QAS professional or QAS paraprofessional as defined in AB 796.

## **BENEFIT COVERAGE, UTILIZATION, AND COST IMPACTS**

AB 796 would expand the definition of a QAS professional and QAS paraprofessional to include persons who have a specified levels education and experience, but would not alter benefit coverage for IBIT, which is already 100% due to the current mandate.

This section reports the potential incremental impact of AB 796 on estimated baseline benefit coverage, utilization, and overall cost. CHBRP projects no change in benefit coverage, utilization, or unit cost of IBIT within the first 12-month timeframe after the enactment of AB 796. Since utilization and unit cost are not expected to change, CHBRP estimates no impact of AB 796 on premiums and expenditures.

## **Benefit Coverage**

#### Premandate (Baseline) and Postmandate Benefit Coverage

CHBRP estimates that 100% of the 16.3 million enrollees in DMHC-regulated plans or CDI-regulated policies that would besubject to AB 796 have coverage for behavioral health treatment for PDD/A due to the current law (H&S Code 1374.73 and Ins Code 10144.51). The term behavioral health treatment includes but is not limited to IBITs, which would include ABA and similarly intensive, theory-based treatments. In this analysis, CHBRP has focused on coverage of IBIT. If AB 796 were enacted, CHBRP estimates that the percent of enrollees with benefit coverage for IBIT would remain the same due to the existence of the current law.

## Utilization

#### Premandate (Baseline) and Postmandate Utilization

Current law requires health plan and insurer networks to include QAS providers supervising/employing QAS professionals or QAS paraprofessionals. With current law requiring coverage for IBIT and with the understanding that school-based programs and the regional centers associated with DDS also engage personnel to deliver IBIT, CHBRP estimates an adequate supply of QAS professionals and paraprofessionals. CHBRP assumes an adequate supply of QAS personnel for the following reasons:

- First, the current law has been in effect since 2012 and CHBRP found no current evidence indicating difficulty in accessing IBIT, which suggests the presence of an extant labor supply of personnel providing IBIT.
- Second, AB 796 affects the definitions of QAS professionals and QAS health paraprofessionals that are relevant to health plans and insurers, but AB 796 does not directly affect the QAS providers that employ and supervise them. Although AB 796 creates the possibility, it does not require QAS providers to hire either more or different types of QAS professionals or QAS paraprofessionals than they do currently.
- Third, AB 796 creates the possibility but does not require health plans or insurers to modify their current networks and reimbursement arrangements.

#### Impact on access and health treatment/service availability

By altering the training requirements for QAS professionals and QAS paraprofessionals, AB 796 could encourage access to a wider range of treatments (by expanding access to personnel trained in forms of

IBIT other than ABA). However, AB 796 does not change current law that requires health plan and insurer networks to include qualified QAS providers supervising/employing QAS professionals or QAS paraprofessionals, so the care will remain limited by the choices made by the QAS providers who employ QAS professionals and QAS paraprofessionals and who supervise delivery of IBIT.

## **Per-Unit Cost**

#### **Premandate (Baseline) and Postmandate Per-Unit Cost**

CHBRP assumes that the unit cost will not change in the first 12 months postmandate due to the limited number of enrollees with PDD/A that will need IBIT, plus the sufficient supply of personnel, and current law requiring QAS providers to supervise and employ QAS professionals or QAS paraprofessionals. In future years, it is possible that the unit cost could decrease if demand for IBIT increases while payments for IBIT remain constrained. In such a circumstance, QAS providers might seek to expand their pool of QAS professionals and QAS paraprofessionals, whose services may be less costly than the services of QAS providers (so potentially lowering overall unit cost for IBIT). AB 796, which would expand the definitions of QAS professionals and QAS paraprofessionals, would enable but not compel such actions on the part of QAS providers. Because AB 796 would enable but not compel, the future proportion of care delivered by various personnel (and the resulting impact on unit cost) are unknown.

## **Premiums and Expenditures**

#### **Premandate (Baseline) and Postmandate Premiums and Expenditures**

#### Changes in total expenditures

Because CHBRP estimates no change in utilization or unit cost, CBHRP projects no postmandate impact on expenditures.

#### Postmandate administrative expenses and other expenses

CHBRP estimates that the increase in administrative costs of DMHC-regulated plans and/or CDIregulated policies will remain proportional to the increase in premiums. 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 portion of premiums is unchanged. All health plans and insurers include a component for administration and profit in their premiums.

## **Related Considerations for Policymakers**

#### Cost of exceeding essential health benefits (EHB)

Because coverage for behavioral health treatments (including IBI) for persons with PDD/A is already covered as an EHB in California and because AB 796 would affect the terms and conditions of benefit coverage but would not affect whether there is coverage (altering the QAS professional and paraprofessional definitions), AB 796 would not exceed EHBs.

#### Postmandate Changes in Uninsured and Public Program Enrollment

#### Changes in the number of uninsured persons

CHBRP estimates no premium increases related to AB 796 and so projects no impact on the number of persons who are uninsured. Postmandate, CHBRP does not anticipate loss of health insurance or changes in any of the following: offer rates of health insurance; employer contribution rates; take-up of health insurance by employees; or purchase of individual market policies.

#### Changes in public program enrollment

As does the current mandate, AB 796 would exempt Medi-Cal Managed Care and the health insurance of enrollees associated with the California Public Employees' Retirement System (CalPERS). Therefore, CHBRP projects no measurable impact on enrollment in publicly funded insurance programs or on utilization of covered benefits.

#### How Lack of Coverage Results in Cost Shifts to Other Payers

Because AB 796 would alter training requirements for QAS professionals and QAS paraprofessionals but not compel changes in staffing among personnel being reimbursed by health plans and insurers, CHBRP assumes that the mandate would produce no measurable impact on enrollment in or utilization of publicly funded programs, such as PDD/A-related behavioral health treatment provided by regional centers or school-based special education.

#### **AB 796 and Actuarial Value**

Benefit mandates can affect actuarial value (AV).<sup>36</sup> However, because AB 796 does not alter coverage or cost sharing for IBIT, AB 796 would not impact AV for plans and policies associated with Covered California.

<sup>&</sup>lt;sup>36</sup> See Criteria and Methods for Estimating the Impact of Benefit Mandates on Actuarial Value, Available at: <u>http://www.chbrp.org/analysis\_methodology/cost\_impact\_analysis.php</u>.

# **PUBLIC HEALTH IMPACTS**

As discussed previously in the *Policy Context* section (page 5), AB 796 would expand the criteria for qualified autism service (QAS) professional and QAS paraprofessional to include persons who have specified levels of education and experience. AB 796 does not make modifications to the definition of a QAS provider, who is a person or entity responsible for the design and supervision of the behavioral health treatment that is delivered to persons with PDD/A diagnoses by the QAS professional or paraprofessional.PDD/A is a chronic condition for which there is no known cure. Intensive behavioral intervention treatments (IBITs), delivered by QAS personnel, focus on ameliorating a variety of symptoms common to persons diagnosed with PDD/A. The measurable public health impacts most relevant to AB 796 include changes in IQ, language skills, and adaptive behaviors; economic loss, including lost productivity of persons diagnosed with PDD/A and their family members; and financial burdens resulting from expenses for noncovered services or treatments.

## **Estimated Public Health Outcomes**

As presented in the *Medical Effectiveness* section (page 15), there is a preponderance of evidence that IBITs are effective in improving behavioral outcomes, such as IQ and adaptive behaviors among children and adolescents with PDD/A when delivered by personnel trained and supervised by experienced IBIT providers. In addition, evidence suggests that, when delivered at an earlier age with greater intensity and duration, IBIT may have a greater positive impact on behavioral outcomes. CHBRP found no studies comparing the differential effectiveness of IBIT when delivered by personnel with varying levels experience and training; therefore, the optimal staffing for delivering behavioral interventions is unknown.

As presented in the *Benefit Coverage, Utilization, and Cost Impacts* section (page 20), 100% of the 16.3 million enrollees in DMHC-regulated plans and CDI-regulated policies have coverage for PDD/A-related IBIT delivered by in-network QAS personnel under the current law. Therefore, although AB 796 would expand the definition of QAS professionals and paraprofessionals, CHBRP estimates that AB 796 will not alter coverage for IBIT services received by QAS personnel. Given that AB 796 does not compel QAS providers to contract with the newly defined QAS professionals and paraprofessionals, nor does it require health plans or insurers to modify their networks or reimbursement arrangements, CHBRP assumes that the supply of IBIT personnel in the current market is sufficient to meet the current demand. Considering these factors, CHBRP estimates that AB 796 would not change the current utilization of IBIT services. Finally, CHBRP estimates no changes in per-unit cost due to the limited number of new enrollees who would require IBIT in a market with an adequate supply of QAS personnel.

Although evidence shows that trained and supervised QAS personnel are effective in delivering intensive behavioral intervention therapies in a manner that improves behavioral outcomes among children and adolescents with PDD/A, CHBRP concludes that passage of AB 796 would have no short-term<sup>37</sup> public health impact due to no change in coverage, utilization, or unit cost. This is because coverage for IBIT services delivered by QAS personnel is already required under the current law and AB 796 does not compel IBIT providers or markets to alter their current staffing and or reimbursement arrangements. Furthermore, CHBRP estimates AB 796 would have no impact on gender and racial/ethnic disparities in behavioral outcomes, and no impact on financial burden, premature death, or societal economic losses because it would not increase coverage or utilization.

<sup>&</sup>lt;sup>37</sup> CHBRP defines short-term impacts as changes occurring within 12 months of bill implementation.

# APPENDIX A TEXT OF BILL ANALYZED

On March 3, 2015, the California Assembly Committee on Health requested that CHBRP analyze AB 796.

ASSEMBLY BILL No. 796

Introduced by Assembly Member Nazarian (Coauthor: Assembly Member Rendon)

February 26, 2015

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

legislative counsel's digest AB 796, as introduced, Nazarian. Health care coverage: autism and pervasive developmental disorders.

Existing law provides for the licensure and regulation of health care service plans by the Department of Managed Health Care. A violation of those provisions is a crime. Existing law provides for the licensure and regulation of health insurers by the Department of Insurance. Existing law requires every health care service plan contract and health insurance policy to provide coverage for behavioral health treatment for pervasive developmental disorder or autism. Existing law requires every health care service plan and health insurance policy to maintain an adequate network that includes qualified autism service providers who supervise and employ qualified autism service professionals or paraprofessionals who provide and administer behavioral health treatment. Existing law defines "qualified autism service professional" and "qualified autism service paraprofessional" for this purpose to mean a person who meets specified educational and training requirements. This bill would expand the eligibility for a person to be a qualified autism service professional to include a person who possesses a bachelor 99 of arts or science degree and meets other specified requirements, a registered psychological assistant, a registered psychologist, or an associate clinical social worker. The bill would also expand the eligibility for a person to be a qualified autism service paraprofessional to include a person with a high school diploma or equivalent and, among other things, 6 months experience working with persons with developmental disabilities. Vote: majority. Appropriation: no. Fiscal committee: no. State-mandated local program: no.

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

SECTION 1. The Legislature finds and declares all of the following:

(a) Autism and other pervasive developmental disorders are complex neurobehavioral disorders that include impairments in social communication and social interaction combined with rigid, repetitive behaviors, interests, and activities.

(b) Autism covers a large spectrum of symptoms and levels of impairment ranging in severity from somewhat limiting to a severe disability that may require institutional care.

(c) One in 68 children born today will be diagnosed with autism or another pervasive developmental disorder.

(d) Research has demonstrated that children diagnosed with autism can often be helped with early administration of behavioral health treatment.

(e) There are several forms of evidence-based behavioral health treatment, including, but not limited to, applied behavioral analysis.

(f) Children diagnosed with autism respond differently to behavioral health treatment.

(g) It is critical that each child diagnosed with autism receives the specific type of evidence-based behavioral health treatment best suited to him or her, as prescribed by his or her physician or developed by a psychologist.

(h) The Legislature intends that all forms of evidence-based behavioral health treatment be covered by health care service plans, pursuant to Section 1374.73 of the Health and Safety Code, and health insurance policies, pursuant to Section 10144.51 of the Insurance Code.

(i) The Legislature intends that health care service plan provider networks include qualified professionals practicing all forms of evidence-based behavioral health treatment other than just applied behavioral analysis.

SEC. 2. Section 1374.73 of the Health and Safety Code is amended to read:

(a)

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

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

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

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

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

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

(1) "Behavioral health treatment" means professional services and treatment programs, including applied behavior analysis and evidence-based behavior intervention programs, that develop or restore, to the maximum extent practicable, the functioning of an individual with pervasive developmental disorder or autism and that meet all of the following criteria:

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

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

(i) A qualified autism service provider.

(ii) A qualified autism service professional supervised and employed by the qualified autism service provider.

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

(C) The treatment plan has measurable goals over a specific timeline that is developed and approved by the qualified autism service provider for the specific patient being treated. The treatment plan shall be reviewed no less than once every six months by the qualified autism service provider and modified

whenever appropriate, and shall be consistent with Section 4686.2 of the Welfare and Institutions Code pursuant to which the qualified autism service provider does all of the following:

(i) Describes the patient's behavioral health impairments or developmental challenges that are to be treated.

(ii) Designs an intervention plan that includes the service type, number of hours, and parent participation needed to achieve the plan's goal and objectives, and the frequency at which the patient's progress is evaluated and reported.

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

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

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

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

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

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

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

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

(A) Provides behavioral health treatment.

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

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

(D) Is a behavioral service provider approved who meets one of the following criteria:

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

(ii) Possesses a bachelor of arts or science degree and has either of the following:

(I)Twelve semester units from an accredited institute of higher learning in either applied behavioral analysis or clinical coursework in behavioral health and one year of experience in designing or implementing behavioral health treatment.

(II) two years of experience in designing or implementing behavioral health treatment.

(III)The person is a registered psychological assistant or registered psychologist pursuant to Chapter 6.6 (commencing with Section 2900) of Division 2 of the Business and Professions Code.

(IV)The person is an associate clinical social worker registered with the Board of Behavioral Sciences pursuant to Section 4996.18 of the Business and Professions Code.

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

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

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

(B) Provides treatment and implements services pursuant to a treatment plan developed and approved

by the qualified autism service provider.

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

(i) Possesses a high school diploma or equivalent.

(ii) Has six months experience working with persons with a developmental disability.

(iii) Has 30 hours of training in the specific form of evidence-based behavioral health treatment administered by a qualified autism provider or qualified autism service professional.

(iv) Has successfully passed a background check conducted by a state-approved agency.

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

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

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

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

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

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

(e) Nothing in this section shall be construed to limit the obligation to provide services under Section 1374.72. (f) As provided in Section 1374.72 and in paragraph (1) of subdivision (a), in the provision of benefits required by this section, a health care service plan may utilize case management, network providers, utilization review techniques, prior authorization, copayments, or other cost sharing.

(g) This section shall remain in effect only until January 1, 2017, and as of that date is repealed, unless a later enacted statute, that is enacted before January 1, 2017, deletes or extends that date.

SEC. 3. Section 10144.51 of the Insurance Code is amended to read:

(a) (1) Every health insurance policy provide coverage for behavioral health treatment for pervasive developmental disorder or autism no later than July 1, 2012. The coverage shall be provided in the same manner and shall be subject to the same requirements as provided in Section 1374.72.

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

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

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

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

(1) "Behavioral health treatment" means professional services and treatment programs, including applied behavior analysis and evidence-based behavior intervention programs, that develop or restore, to the maximum extent practicable, the functioning of an individual with pervasive developmental disorder or autism and that meet all of the following criteria:

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

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

(i) A qualified autism service provider.

(ii) A qualified autism service professional supervised and employed by the qualified autism service provider.

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

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

(i) Describes the patient's behavioral health impairments or developmental challenges that are to be treated.

(ii) Designs an intervention plan that includes the service type, number of hours, and parent participation needed to achieve the plan's goal and objectives, and the frequency at which the patient's progress is evaluated and reported.

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

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

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

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

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

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

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

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

(A) Provides behavioral health treatment.

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

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

(D) Is a behavioral service provider approved who meets one of the following criteria:

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

(ii) Possesses a bachelor of arts or science degree and has either of the following:

(I)Twelve semester units from an accredited institute of higher learning in either applied behavioral analysis or clinical coursework in behavioral health and one year of experience in designing or implementing behavioral health treatment.

(II) two years of experience in designing or implementing behavioral health treatment.

(III)The person is a registered psychological assistant or registered psychologist pursuant to Chapter 6.6 (commencing with Section 2900) of Division 2 of the Business and Professions Code.

(IV)The person is an associate clinical social worker registered with the Board of Behavioral Sciences pursuant to Section 4996.18 of the Business and Professions Code.

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

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

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

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

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

(i) Possesses a high school diploma or equivalent.

(ii) Has six months experience working with persons with a developmental disability.

(iii) Has 30 hours of training in the specific form of evidence-based behavioral health treatment administered by a gualified autism provider or gualified autism service professional.

(iv) Has successfully passed a background check conducted by a state-approved agency.

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

# **APPENDIX B LITERATURE REVIEW METHODS**

Appendix B describes methods used in the medical effectiveness literature review for AB 796, a bill that would expand the definition of a QAS professional and QAS paraprofessional to include persons who have a specified combination of educational and experience requirements. AB 796 would not make any modifications to the definition of a QAS provider, who is responsible for the design and supervision of the behavioral health treatment that is delivered by the QAS professional or paraprofessional.

The medical effectiveness review focuses on the effectiveness of IBIT. In particular, the review focuses the characteristics of personnel providing IBIT and whether the effectiveness of intensive behavioral treatments varies by the types of personnel providing the treatment.

Studies of IBIT for PDD/A were identified through searches of 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. The following Web sites were also 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. Because a CHBRP medical effectiveness review had previously conducted through literature searches on this topic in 2014 for AB 2041, the search was limited to studies published from 2014 to present. Of the 278 articles found in the literature review, 18 were reviewed for potential inclusion in this report on AB 796, and 9 studies were included in the medical effectiveness review for this report. The medical effectiveness review also presents findings from the studies that were previously included in the CHBRP AB 2041 report.

#### **Evidence Grading System**

In making a "call" for each outcome measure, the medical effectiveness lead and the content expert consider the number of studies as well the strength of the evidence. Further information about the criteria CHBRP uses to evaluate evidence of medical effectiveness can be found in CHBRP's *Medical Effectiveness Analysis Research Approach.*<sup>38</sup> To grade the evidence for each outcome measured, the team uses a grading system that has the following categories:

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

<sup>&</sup>lt;sup>38</sup> Available at: www.chbrp.org/analysis\_methodology/docs/medeffect\_methods\_detail.pdf.

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

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

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

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

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

#### **Search Terms**

The search terms used to locate studies relevant to AB 796 were as follows:

#### Major MeSH terms used to search PubMed

 Pervasive Developmental Disorder

Autistic Disorder

- Sexism
- Costs and Cost Analysis

Healthcare Disparities

- Asperger Syndrome
- Exp Behavior Therapy
- Mortality
- Morbidity

- Cost of Illness
- Cost-Benefit Analysis
- Outcome Assessment (Health Care)

Keywords used to search PubMed, Cochrane Library, EconLit, Web of Science, and relevant websites

- Autism
- Autistic
- ASD

- Asperger
- Autism Spectrum
   Disorders
- Applied Behavior Analysis
- Applied Behavioral Analysis

- ABA
- Behavioral Therapies
- Costs
- Disparities or Disparity
- Economic

- Inequality
- Manpower
- Morbidity
- Mortality
- Outcome Assessment

- Outcomes
- Personnel
- Paraprofessionals
- Quality of Life
- Racial Disparities

# APPENDIX C COST IMPACT ANALYSIS: DATA SOURCES, CAVEATS, AND ASSUMPTIONS

This appendix describes data sources, estimation methodology, as well as general and mandate-specific caveats and assumptions used in conducting the cost impact analysis. For additional information on the cost model and underlying methodology, please refer to the CHBRP website at: <a href="https://www.chbrp.org/analysis\_methodology/cost\_impact\_analysis.php">www.chbrp.org/analysis\_methodology/cost\_impact\_analysis.php</a>.

The cost analysis in this report was prepared by the members of the cost team, which consists of CHBRP task force members and contributors from the University of California, Los Angeles, and the University of California, Davis, as well as the contracted actuarial firm, Milliman, Inc.<sup>39</sup>

#### **Data Sources**

This subsection discusses the variety of data sources CHBRP uses. Key sources and data items are listed below, in Table 3. Data for 2016 Projections.

#### Table 3. Data for 2016 Projections

Data Source	Items
California Department of Health Care Services (DHCS) administrative data for the Medi-Cal program, data available as of end of December 2014	Distribution of enrollees by managed care or FFS distribution by age: 0–17; 18–64; 65+ Medi-Cal Managed Care premiums
California Department of Managed Health Care (DMHC) data from the interactive website "Health Plan Financial Summary Report," August–October, 2014	Distribution of DMHC-regulated plans by market segment*
California Department of Insurance (CDI) Statistical Analysis Division data; data as of December 31, 2013	Distribution of CDI-regulated policies by market segment
California Health Benefits Review Program (CHBRP) Annual Enrollment and Premium Survey of California's largest (by enrollment) health care service plans and health insurers; data as of September 30, 2014; responders' data represent approximately 97.3% of persons not associated with CalPERS or Medi- Cal with health insurance subject to state mandates — 98.0% of full-service (nonspecialty) DMHC-regulated plan enrollees and 97.0% of full-service (nonspecialty) CDI- regulated policy enrollees.	<ul> <li>Enrollment by:</li> <li>Size of firm (2–50 as small group and 51+ as large group)</li> <li>DMHC vs. CDI regulated</li> <li>Grandfathered vs. nongrandfathered</li> <li>Premiums for individual policies by:</li> <li>DMHC vs. CDI regulated</li> <li>Grandfathered vs. nongrandfathered</li> </ul>

<sup>&</sup>lt;sup>39</sup> CHBRP's authorizing legislation requires that CHBRP use a certified actuary or "other person with relevant knowledge and expertise" to determine financial impact (<u>www.chbrp.org/docs/authorizing\_statute.pdf</u>).

Data Source	Items
California Employer Health Benefits Survey, 2014 (conducted by NORC and funded by CHCF)	<ul> <li>Enrollment by HMO/POS, PPO/indemnity self- insured, fully insured,</li> <li>Premiums (not self-insured) by:</li> <li>Size of firm (3–25 as small group and 25+ as large group)</li> <li>Family vs. single</li> <li>HMO/POS vs. PPO/indemnity vs. HDHP employer vs. employer premium share</li> </ul>
California Health Interview Survey (CHIS) 2012/2013/T7 ("T7" representing the first 6 months of 2014)	Uninsured, age: 65+ Medi-Cal (non-Medicare), age: 65+ Other public, age: 65+ Employer-sponsored insurance, age: 65+
California Public Employees' Retirement System (CalPERS) data, enrollment as of October 1, 2014	CalPERS HMO and PPO enrollment • Age: 0–17; 18–64; 65+ HMO premiums
California Simulation of Insurance Markets (CalSIM) Version 1.9.1 (projections for 2016)	Uninsured, age: 0–17; 18–64 Medi-Cal (non-Medicare) (a), age: 0–17; 18–64 Other public (b), age: 0–64 Individual market, age: 0–17; 18–64 Small group, age: 0–17; 18–64 Large group, age: 0–17; 18–64
Centers for Medicare and Medicaid (CMS) administrative data for the Medicare program, annually (if available) as of end of September	HMO vs. FFS distribution for those 65+ (noninstitutionalized)
Milliman estimate	Medical trend influencing annual premium increases

*Notes:* \*CHBRP assumes DMHC-regulated PPO group enrollees and POS enrollees are in the large-group segment. *Key:* CDI = California Department of Insurance; CHCF = California HealthCare Foundation; CHIS = California Health Interview Survey; CMS = Centers for Medicare & Medicaid Services; DHCS = Department of Health Care Services; DMHC = Department of Managed Health Care; FFS=fee-for-service; HMO = health maintenance organization; NORC = National Opinion Research Center; POS = point of service; PPO = preferred provider organization.

Further discussion of external and internal data follows.

#### Internal data

- CHBRP's Annual Enrollment and Premium Survey collects data from the seven largest providers
  of health insurance in California (including Aetna, Anthem Blue Cross of California, Blue Shield of
  California, CIGNA, Health Net, Kaiser Foundation Health Plan, and United Healthcare/PacifiCare)
  to obtain estimates of enrollment not associated with CalPERS or Medi-Cal by purchaser (i.e.,
  large and small group and individual), state regulator (DMHC or CDI), grandfathered and
  nongrandfathered status, and average premiums. CalSIM and market trends were applied to
  project 2016 health insurance enrollment in DMHC-regulated plans and CDI-regulated policies.
- CHBRP's other surveys of the largest plans/insurers collect information on benefit coverage relevant to proposed benefit mandates CHBRP has been asked to analyze. In each report, CHBRP indicates the proportion of enrollees — statewide and by market segment — represented

by responses to CHBRP's bill-specific coverage surveys. The proportions are derived from data provided by CDI and DMHC.

#### External sources

- California Department of Health Care Services (DHCS) data are used to estimate enrollment in Medi-Cal Managed Care (beneficiaries enrolled in Two-Plan Model, Geographic Managed Care, and County Operated Health System plans), which may be subject to state benefit mandates, as well as enrollment in Medi-Cal Fee For Service (FFS), which is not. The data are available at: <u>www.dhcs.ca.gov/dataandstats/statistics/Pages/Monthly\_Trend\_Report.aspx.</u> Medi-Cal enrollment is projected to 2016 based on CalSIM's estimate of the continuing impact of the Medi-Cal expansion implemented in 2014.
- California Employer Health Benefits Survey data are used to make a number of estimates, including: premiums for employment-based enrollment in DMHC-regulated health care service plans (primarily health maintenance organizations [HMOs] and point of service [POS] plans) and premiums for employment-based enrollment in CDI-regulated health insurance policies regulated by the (primarily preferred provider organizations [PPOs]). Premiums for fee-for-service (FFS) policies are no longer available due to scarcity of these policies in California. 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. More information on the CHCF/NORC data is available at: www.chcf.org/publications/2014/01/employer-health-benefits.
- California Health Interview Survey (CHIS) data are used to estimate the number of Californians aged 65 and older, and the number of Californians dually eligible for both Medi-Cal and Medicare coverage. CHIS data are also used to determine the number of Californians with incomes below 400% of the federal poverty level. CHIS is a continuous survey that provides detailed information on demographics, health insurance coverage, health status, and access to care. More information on CHIS is available at: www.chis.ucla.edu.
- California Public Employees Retirement System (CalPERS) data are used to estimate premiums and enrollment in DMHC-regulated plans, which may be subject to state benefit mandates, as well as enrollment in CalPERS' self-insured plans, which is not. CalPERS does not currently offer enrollment in CDI-regulated policies. Data are provided for DMHC-regulated plans enrolling non-Medicare beneficiaries. In addition, CHBRP obtains information on current scope of benefits from evidence of coverage (EOC) documents publicly available at: <u>www.calpers.ca.gov</u>. CHBRP assumes CalPERS's enrollment in 2016 will not be affected by continuing shifts in the health insurance market as a result of the ACA.
- California Simulation of Insurance Markets (CalSIM) estimates are used to project health insurance status of Californians aged 64 and under. CalSIM is a microsimulation model that projects the effects of the Affordable Care Act on firms and individuals. More information on CalSIM is available at: <u>http://healthpolicy.ucla.edu/programs/health-</u> economics/projects/CalSIM/Pages/default.aspx.
- 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. Most of the data sources underlying the HCGs are claims databases from commercial health insurance plans. The data are supplied by health insurance companies, HMOs, self-funded employers, and private data vendors. The data are mostly from loosely managed health care plans, generally those characterized as PPO plans. More information on the Milliman HCGs is available at:

http://us.milliman.com/Solutions/Products/Resources/Health-Cost-Guidelines/Health-Cost-Guidelines---Commercial/.

- The MarketScan databases, which reflect the health care claims experience of employees and dependents covered by the health benefit programs of large employers. These claims data are collected from insurance companies, Blue Cross Blue Shield plans, and third party administrators. These data represent the medical experience of insured employees and their dependents for active employees, early retirees, individuals with COBRA continuation coverage, and Medicareeligible retirees with employer-provided Medicare Supplemental plans. No Medicaid or Workers Compensation data are included.
- Ingenix MDR Charge Payment System, which includes information about professional fees paid for health care services, based upon claims from commercial insurance companies, HMOs, and self-insured health plans.

#### **Projecting 2016**

This subsection discusses adjustments made to CHBRP's Cost and Coverage Model to project 2016, the period when mandates proposed in 2015 would, if enacted, generally take effect. It is important to emphasize that CHBRP's analysis of specific mandate bills typically addresses the *incremental* effects of a mandate — specifically, how the proposed mandate would impact benefit coverage, utilization, costs, and public health, *holding all other factors constant*. CHBRP's estimates of these incremental effects are presented in the *Benefit Coverage, Utilization, and Cost Impacts* section (page 20) of this report.

#### Baseline premium rate development methodology

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

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

For each market segment, CHBRP first obtained an estimate of the insurance premium PMPM by taking the 2014 reported premium from the abovementioned data sources and trending that value to 2016. CHBRP uses trend rates published in the Milliman HCGs to estimate the health care costs for each market segment in 2016.

The large-group market segments for each regulator (CDI and DMHC) are split into grandfathered and nongrandfathered status. For the small-group and individual markets, further splits are made to indicate association with Covered California, the state's health insurance marketplace. Doing so allows CHBRP to separately calculate the impact of ACA and of specific mandates, both of which may apply differently among these subgroups. The premium rate data received from the CHCF/NORC California Employer Health Benefits survey did not split the premiums based on grandfathered or exchange status. However, CHBRP's Annual Enrollment and Premium (AEP) survey asked California's largest health care service plans and health insurers to provide their average premium rates separately for grandfathered and nongrandfathered plans. The ratios from the CHBRP survey data were then applied to the CHCH/NORC aggregate premium rates for large and small group, to estimate premium rates for grandfathered and

nongrandfathered plans that were consistent with the NORC results. For the individual market, the premium rates received from CHBRP's AEP survey were used directly.

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

- Health care costs paid by the health plan = insurance premiums PMPM × (1 profit/administration load);
- Gross claims costs PMPM = health care costs paid by the health plan ÷ percentage paid by health plan; and
- Member cost sharing PMPM = gross claims costs × (1 percentage paid by health plan).

In the above formulas, the quantity "profit/administration load" is the assumed percentage of a typical premium that is allocated to the health plan/insurer's administration and profit. These values vary by insurance category, and under the ACA, are limited by the minimum medical loss ratio requirement. CHBRP estimated these values based on actuarial expertise at Milliman, and their associated expertise in health care.

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

#### **General Caveats and Assumptions**

This subsection discusses the general caveats and assumptions relevant to all CHBRP reports. The projected costs are estimates of 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 the premium paid by the subscriber (or employee) and the employer will be unaffected by the mandate.
- For state-sponsored programs for the uninsured, the state share will continue to be equal to the absolute dollar amount of funds dedicated to the program.

 When cost savings are estimated, they reflect savings realized for 1 year. Potential long-term cost savings or impacts are estimated if existing data and literature sources are available and provide adequate detail for estimating long-term impacts. For more information on CHBRP's criteria for estimating long-term impacts, please see:

www.chbrp.org/analysis\_methodology/docs/longterm\_impacts08.pdf.

Several studies have examined the effect of private insurance premium increases on the number of uninsured (Chernew et al., 2005; Glied and Jack, 2003; Hadley, 2006). Chernew et al. (2005) estimate that a 10% increase in private premiums results in a 0.74 to 0.92 percentage point decrease in the number of insured, whereas Hadley (2006) and Glied and Jack (2003) estimate that a 10% increase in private premiums produces a 0.88 and a 0.84 percentage point decrease in the number of insured, respectively. Because each of these studies reported results for the large-group, small-group, and individual insurance markets combined, CHBRP employs the simplifying assumption that the elasticity is the same across different types of markets. For more information on CHBRP's criteria for estimating impacts on the uninsured, please see *Criteria and Methods for Estimating the Impact of Mandates on the Number of Individuals Who Become Uninsured in Response to Premium Increases*, available at:

There are other variables that may affect costs, but which CHBRP did not consider in the estimates 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 benefits: To help offset the premium increase resulting from a mandate, deductibles
  or copayments may be increased. Such changes would have a direct impact on the distribution of
  costs between health plans/insurers and enrollees, and may also result in utilization reductions
  (i.e., high levels of 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, persons or employer groups who had previously foregone health insurance may elect, postmandate, to enroll in a health plan or policy because they perceive that it is now to their economic benefit to do so.
- Medical management: Health plans/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/policy types that previously had the least effective medical management (i.e., PPO plans).
- Geographic and delivery systems variation: Variation exists in existing utilization and costs, and in the impact of the mandate, by geographic area and by delivery system models. Even within the health insurance plan/policy types CHBRP modeled (HMO, including HMO and POS plans, and non-HMO, including PPO and FFS policies), there are likely variations in utilization and costs. 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/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 impacts, CHBRP typically assumes that plans and policies subject to the mandate will be in compliance with the benefit coverage requirements of the bill. Therefore, the typical postmandate coverage rates for persons enrolled in health insurance plans/policies subject to the mandate are assumed to be 100%.

#### **Determining Public Demand for the Proposed Mandate**

This subsection discusses public demand for the benefits AB 796 would mandate. Considering the criteria specified by CHBRP's authorizing statute, CHBRP reviews public demand for benefits relevant to a proposed mandate in two ways. CHBRP:

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

On the basis of conversations with the largest collective bargaining agents in California, CHBRP concluded that unions currently do not generally include issues related to the definitions of QAS professionals and QAS paraprofessionals in their health insurance negotiations. In general, unions negotiate for broader contract provisions such as coverage for dependents, premiums, deductibles, and broad coinsurance levels.

Among publicly funded self-insured health insurance policies, the preferred provider organization (PPO) plans offered by CaIPERS currently have the largest number of enrollees. The CaIPERS PPOs currently provide benefit coverage similar to what is available through 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 to ask carriers who act as third-party administrators for (non-CalPERS) self-insured group health insurance programs whether the relevant benefit coverage differed from what is offered in group market plans or policies that would be subject to the mandate. The responses indicated that there were no substantive differences.

# APPENDIX D PUBLIC HEALTH CALCULATIONS

For this analysis, the California Health Benefits Review Program (CHBRP) calculated an estimated prevalence rate of pervasive developmental disorder or autism (PDD/A) for Californians, based on a study cited by the California Department of Developmental Services (DDS) in their 2007 report and adjustments to the report's 2007 data updated by DDS in 2015.<sup>40</sup> 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 796. The decision criteria used to choose the most appropriate rates are: California data preferred over national data (to reflect California population characteristics); studies using multiple ages, with access to age distribution, rather than a single age (to analyze the more intensive use and cost of services at younger ages when screening, diagnosis, and treatment begin); and robust sample size. All sources of data had strengths and limitations. Based on these criteria and CHBRP's analytic needs, the California DDS data are used in this report because of its presentation of California-specific data and distribution of ages diagnosed with PDD/A. Furthermore, requisite data are available from the literature to make necessary adjustments to the undercounts in the California data, considered a potential limitation to the data. CHBRP's estimated prevalence rates are based on the number of people receiving treatment from DDS at a point in time, rather than on survey data or a review of medical or school records. The appearance of declining prevalence of PDD/A in the older age groups is assumed to be a combination of fewer PDD/A persons seeking services through DDS as they age, and a true lower prevalence rate (due to longitudinal differences in diagnostic criteria or actual changes in incidence during the last two decades).

The sources reviewed by CHBRP estimated prevalence rates from 132/10,000 (Kogan et al., 2009) to 200/10,000 (CDC, 2012) with large variation in ages studied, and study methodology (including measurement years). An analysis of CHBRP's estimated prevalence rates shows that using the higher CHBRP estimate of 256/10,000 (aged 5 to 9 years) would yield about 58,323 California children aged 5 to 9 years diagnosed with PDD/A in 2014. The difference in prevalence estimates is due in part to the data's different baseline years (2008 vs. 2014). Clearly, prevalence rates have been increasing over time and a seven-year gap explains some of the difference. Additionally, CDC notes a 23% increase in prevalence between 2006 and 2008 (9.0/1,000 vs. 11.0/1,000) and CHBRP estimates a 71% increase between 2007 and 2014 (14.9/1,000 vs. 25.6/1,000) — an additional 5 years of data likely explains the larger increase in the CHBRP estimates. Furthermore, differences may be attributable to California's public diagnostic and support service system, which may be more comprehensive than many other states (King and Bearman, 2009), and may identify PDD/A more accurately. CHBRP's estimate may be closer to the true prevalence rate in 2014 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 DDS, which is the primary state agency that serves residents with developmental disabilities, including 75% to 80% of persons diagnosed with Autism Disorder (Croen et al., 2002). Updates to the 2007 report data by DDS show that, in 2014, DDS served 72,199 persons with PDD/A who met the service eligibility criteria (defined as those who are diagnosed by a qualified provider with full spectrum, suspected, or residual autism [56,309] and "Other PDD" [4,241]

<sup>&</sup>lt;sup>40</sup> Personal communication, P. Choate, DDS, March 2015

[DDS, 2013]). This administrative data appears to be the most comprehensive accounting of California cases of PDD/A.

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

#### Adjustments to DDS data

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

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

In Table 5, DDS reported that it served an estimated 75% to 80% of Autism Disorder diagnoses in California. To find the total persons diagnosed with Autism Disorder, the reported caseload is divided by the midpoint between 75% and 80% (67,641/0.775 = 87,279). DDS also provided the distribution of its Autism Disorder population by age group, which CHBRP used to estimate the California Autism Disorder prevalence rates by age using the following steps in Table 4:

1. "DDS reported number of people with Autism Disorder served by DDS": Multiply the percentage distribution reported by DDS (column B) by 67,641.

2. "Estimated number of people with Autism Disorder in California": Divide "DDS reported number of people with Autism Disorder served by DDS" by 0.775 (to adjust by age category).

3. "Estimated prevalence of Autism Disorder in California (per 10,000)": Divide "estimated number of people with Autism Disorder in California" by 2014 California population (CDPH, 2015) and multiply by 10,000.

#### To calculate the 2012 estimated prevalence rate of "other" PDDs in California:

DDS undercounts "other PDD" diagnoses because this population generally does not qualify for DDS services, although in 2014, DDS reported serving 4,558 Californians with "ASD other than Autism Disorder" (DDS, 2013). CHBRP adjusted the second half of the table for the "other PDDs" using prevalence rates from literature, 2014 DDS data, and 2014 state population estimates (the most recent year for data from the California Department of Public Health). Table 5 estimates the distribution of PDD/A subtypes using prevalence rates taken from Fombonne (2009b) in which Autism Disorder represents 32% of all PDD and "other" represents 68% of all PDD. To estimate the number of persons diagnosed with PDD subtypes, CHBRP divides (from Table 4) the "estimated number of people with Autism Disorder in California" (which has already been adjusted to account for DDS undercount by 23%) by 0.32, which equals the "Estimated total number of Californians with any PDD/A diagnosis"

(87,279/0.32=272,747). CHBRP subtracts 87,279 from 272,747 to determine the "Other" PDD population (185,468).

Using baseline data from Table 4 and Table 5, CHBRP applied the same logic used in the Autism Disorder calculations (steps 1–3) to calculate the age group–specific estimates for the "other" PDD columns.

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

#### *Review of other sources for prevalence rates*

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

#### California Health Interview Survey

The most recent CHIS to collect data on PDD/prevalence was administered in 2005 (CHIS, 2013). CHBRP considers this information out of date for the AB 796 analysis. A prior report by CHBRP for SB TBD-1 in 2011 (CHBRP, 2011) declined to use CHIS 2005 data due to a small number of cases, a narrower age interval than other studies, and limited questions discerning differences among types of PDDs.

#### National Survey of Children's Health127

CHBRP performed a data query of the 2009–2010 National Survey of Children' Health, which recorded that 1% of children aged 2 to 17 years are currently diagnosed with PDD/A (CAHMI, 2013). The second-most recent source for PDD/A prevalence comes from a 2007 National Survey on Child Health. Using these data, Kogan et al. (2009) published an estimated prevalence of 110/10,000 based on parent-reported diagnosis of "autism spectrum disorders" in children aged 3 to 17 years. The survey sample size was 78,037 parents, and the study included analysis of prevalence by age category, gender, race, education status, family income, and geographic region. This study reported the highest overall prevalence rate of the studies reviewed by CHBRP (and rates of 132/10,000 and 138/10,000 for children aged 6 to8 years and 9 to11 years, respectively). CHBRP considers this information out of date for the AB 796 analysis and prefers to use California-specific data when available as the California experience may differ from that of other locales.

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

The CDC's ADDM Network coordinated a multisite (14 ADDM sites) surveillance of prevalence, population characteristics, and public health impacts of ASDs and other developmental disabilities. The CDC derived the overall ASD prevalence rate of 113/10,000 from a retrospective review of medical and school records of 8-year-olds. The CDC reported that surveying 8-year-olds is optimal as the CDC has "demonstrated that this is the age of identified peak prevalence" (CDC, 2012). Study authors noted that, by age 8, children who were misdiagnosed will be categorized appropriately. Study results showed a wide variation in prevalence rates among sites, (48/10,000 to 212/10,000) and conformed to other study findings of almost five times as many males diagnosed with PDD/A as females. This study was not nationally representative of 8-year-olds and relied on a retrospective review of records (which may have

compromised the quantity and quality of data therein). However, the large sample size (more than 300,000, or 8%, of U.S. children aged 8 years), the standardized training of abstractors and clinician reviewers who confirmed cases according to standardized definitions, and the use of multiple sources of administrative data provided a sound methodology for estimating the prevalence of PDD/A. However, the lag in data collection (2008) and the absence of California involvement in the study and the wide variation in prevalence rates between the 14 participating sites support CHBRP's use of state-specific data when possible.

 Table 4. Calculations for Estimating California PDD/A Prevalence Rates Using Adjusted 2014 DDS Data

Age Groups (years)	DDS Reported Age Group Distribution of Persons With Autism Disorder Served by DDS (a)	DDS Reported Number of People With Autism Disorder Served by DDS (a)	Estimated Number of People with Autism Disorder in California (b)	California Population (c)	Estimated Prevalence of Autism Disorder in California (per 10,000)	DDS Reported Age Group Distribution of Persons With "Other" PDD Served by DD	Estimated Number of People With "Other" PDD in California (c)	California Population (c)	Estimated Prevalence of "Other" PDD in California (per 10,000)	Estimated Prevalence of All PDD/A in California by Age Category (per 10,000)
0–4	10.7%	7,266	9,375	2,558,633	36.6	4.1%	7,570	2,558,633	29.6	66.2
5—9	29.2%	19,783	25,526	2,525,060	101.1	21.1%	39,152	2,525,060	155.1	256.1
10-14	22.6%	15,273	19,707	2,505,235	78.7	19.0%	35,205	2,505,235	140.5	219.2
15-19	15.3%	10,341	13,343	2,720,437	49.0	18.0%	33,373	2,720,437	122.7	171.7
20-24	10.3%	6,978	9,004	2,915,707	30.9	16.0%	29,710	2,915,707	101.9	132.8
25-29	4.3%	2,934	3,786	2,735,064	13.8	8.1%	14,977	2,735,064	54.8	68.6
30-34	2.1%	1,449	1,870	2,753,122	6.8	4.2%	7,814	2,753,122	28.4	35.2
35-39	1.3%	899	1,160	2,537,576	4.6	2.7%	4,965	2,537,576	19.6	24.1
40-44	1.0%	658	849	2,587,072	3.3	1.8%	3,256	2,587,072	12.6	15.9
45-49	1.0%	676	872	2,561,176	3.4	1.8%	3,337	2,561,176	13.0	16.4
50+	2.0%	1,384	1,786	12,052,524	1.5	3.3%	6,146	12,052,524	5.1	6.6
TOTAL	100.0%	67,641	87,279	38,451,606	22.7	100.0%	185,506	38,451,606	48.2	70.9

*Source:* California Health Benefits Review Program, 2015; DDS<sup>41</sup>.

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

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

(c) CHBRP uses the 2014 California population (California Department of Public Health: http://epicenter.cdph.ca.gov/ReportMenus/PopulationTable.aspx) as the denominator to correspond with the 2014 DDS to capture the prevalence rate (point in time) in 2014.

*Key:* DDS = California Department of Developmental Services.

<sup>&</sup>lt;sup>41</sup> Personal Communication, P. Choate, DDS, March 2015.

PDD and Its Subtypes	Epidemiology of PDD: Prevalence Rates (a)	Ре	rcentage and Number of PDD Subtypes (b)
Autism Disorder	20.6/10,000	32%	87,279
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		
"Other" PDDs (defined as total of PDD-NOS and Asperger's)	43.1/10,000	68%	185,468
Estimated total number of Californians with any PDD/A diagnosis (2007)	NA	100%	272,747

#### Table 5. Determining Distribution of PDD/A Subtypes in the California PDD/A Population

*Source:* California Health Benefits Review Program, 2015 (based on data from a report by DDS, 2009 and Fombonne, 2009b).

*Notes*: Table 5 explains the underlying calculations to estimating "other" PDD numbers (in Table 4) for the California population. The "other PDD" estimates are not available through DDS or other state agencies, thus the estimation by CHBRP.

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

(b) "Percentage and number of PDD subtypes" are derived from Fombonne prevalence rates and 2012 DDS data for Autism Disorder–only population. From Table 4, divide "estimated number of people with Autism Disorder in California" (which has already been adjusted to account for DDS undercount by 23%) by 0.32, which equals the "Estimated total number of Californians with any PDD/A diagnosis" (72,657/0.32=227,053). Subtract 72,657 from 227,053 to determine "other" PDD population (154,396).

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

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

#### Table 6. 2014 PDD/A Population Served by DDS — Data Used to Inform Table 4

Age	Autism	UCD Calculation	Other PDD	UCD Calculation
Statewide	67,641		4,558	
00-04	10.7%	7,266	4.1%	187
05-09	29.2%	19,783	21.1%	962
10-14	22.6%	15,273	19.0%	866
15-19	15.3%	10,341	18.0%	820
20-24	10.3%	6,978	16.0%	729
25-29	4.3%	2,934	8.1%	369

Age	Autism	UCD Calculation	Other PDD	UCD Calculation
30-34	2.1%	1,449	4.2%	191
35-39	1.3%	899	2.7%	123
40-44	1.0%	658	1.8%	82
45-49	1.0%	676	1.8%	82
50-99	2.0%	1,384	3.3%	150

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

*Note*: These data were used to inform columns B and G in Table 4. These data support calculations in Table 4 to estimate the prevalence of PDD/A in California by age category.

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

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A group of faculty, researchers, and staff complete the analysis that informs California Health Benefits Review Program (CHBRP) reports. The CHBRP **Faculty Task Force** comprises rotating senior faculty from University of California (UC) campuses. In addition to these representatives, there are other ongoing contributors to CHBRP from UC that conduct 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 manages all external communications, including those with the California Legislature. 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.

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 of its National Advisory Council. CHBRP assumes full responsibility for the report and the accuracy of its contents.

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The California Health Benefits Review Program is administered by the Division of UC Health at the University of California, Office of the President. The Division is led by John D. Stobo, MD, Senior Vice President.

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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. 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.

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.

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CHBRP assumes full responsibility for the report and the accuracy of its contents. All CHBRP bill analyses and other publications are available at www.chbrp.org.

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