**BILL SUMMARY**

AB 2041 would modify and codify the definition of a behavior management assistant and a behavior management consultant to align with the existing behavioral treatment mandate for pervasive developmental disorder or autism (PDD/A), and would not represent an expansion of that mandate.

**Behavioral health treatment mandate**: An existing state benefit mandate in Health and Safety Code (H&SC) Section 1374.73 and Insurance Code (IC) Section 10144.51, referred to throughout as the “behavioral health treatment mandate,” requires health insurance benefit coverage for behavioral health treatment for PDD/A. State-regulated health insurance is subject to the existing behavioral health treatment mandate, and therefore would be subject to AB 2041. However, the existing mandate exempts Medi-Cal Managed Care Plans and the California Public Employees’ Retirement System (CalPERS). Therefore, the existing behavioral health treatment mandate, and thus AB 2041, would affect the health insurance of approximately 15.4 million enrollees (40% of all Californians) in 2015.

Existing code defines behavioral health treatments as “professional services and treatment programs, including applied behavior analysis and evidence-based behavior intervention programs, that develop or restore, to the maximum extent practicable, the functioning of an individual with pervasive developmental disorder or autism.” Behavioral health treatment can be provided by qualified autism service providers, qualified autism service professionals, and qualified autism service paraprofessionals. AB 2041 would modify the training required for qualified autism service professionals, as discussed below; AB 2041 would not make any modifications to qualified autism service providers or paraprofessionals.

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1 Health and Safety Code (H&SC) Section 1374.73(c)(1); Insurance Code (IC) Section 10144.51(c)(1).
CONTEXT FOR BILL CONSIDERATION: BACKGROUND ON AND PREVALENCE OF PERVERSIVE DEVELOPMENTAL DISORDER OR AUTISM IN CALIFORNIA

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

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

PDD/A is associated with other comorbidities, including intellectual disability. The Centers for Disease Control and Prevention’s (CDC) Autism and Developmental Disabilities Monitoring Network reports that 46% of their eligible network’s PDD/A population (children aged 8 years) scored in the average to above-average intelligence quotient (IQ > 85) range with the remaining 54% classified as intellectually disabled (IQ ≤ 70) or borderline status (IQ 71–85) (Baio, 2014). In California, the Department of Developmental Services (DDS) reported that 23% of its clients with PDD/A had some form of intellectual disability (mild, moderate, severe, or profound), of which 4.3% were severely or profoundly impaired.3

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, 2009). For example, the number of Californians with autism served by DDS increased 1,148% between 1987 and 2007 while the California

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2 HSC Section 1374.73(c)(4); IC Section 10144.51(c)(4); California Code of Regulations (CCR) Title 17, Section 54342.
3 AB 2041 would add a new section to the California Welfare and Institutions Code to define these providers; AB 2041 would add Section 468.32 to the California Welfare and Institutions Code.
4 California Code of Regulations, (Vol. 38), Title 28, Managed Health Care, Section 1300.74.72(c).
5 Personal communication, E. Gelber and P. Choate, DDS, February 2013.
population increased by 27% during the same time span.6

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

PDD/A is not a reportable condition nor are there registries established in the United States; therefore, the true prevalence of PDD/A is unknown. For CHBRP’s SB 126 report in 2013, CHBRP reviewed multiple sources to determine the best estimated PDD/A prevalence rate. Table 1 shows the estimated rates for California, which are close to national estimates. For the purposes of this analysis, it is assumed that the representation of the PDD/A population is similar between the insured and uninsured populations.

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

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

*Source: CHBRP: Analysis of Senate Bill 126*

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

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

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6 For more information about prevalence of PDD/A, see CHBRP’s report: *Analysis of Senate Bill 126: Health Care Coverage: Pervasive Developmental Disorder or Autism*. Available at: www.chbrp.org/completed_analyses/index.php.

7 The CDC’s March 20, 2013 report on the parent-reported prevalence of autism estimates 200/10,000 (1 in 50 children aged 6-17 yrs) in 2012 (Blumberg et al., 2013); the CDC’s March 28, 2014 report using 2010 ADMM Network data reports the prevalence of autism as 147/10,000 children (aged 8 years) (Baio, 2014).

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**Baseline Differences in Prevalence by Gender and Race/Ethnicity**

Multiple studies reported a higher PDD/A prevalence rate among males, in whom rates are three to seven times higher than in females (Blumberg et al., 2013; Baio, 2014; Newschaffer and Curran, 2003; Yeargin-Allsopp et al., 2003). California DDS reported a ratio of males to females with autism as 4.6:1, which corresponds with findings from other studies cited above. DDS also reported that the male-dominated prevalence crossed all races and geographic regions in California (DDS, 2009). Beyond prevalence of PDD/A in the population, there is some conflicting evidence of gender differences in PDD/A symptoms, but no evidence of gender differences in treatment patterns or health outcomes related to PDD/A.

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 a statistically significant greater prevalence among White children (15.8/1,000) than among Black children (12.3/1,000) and Hispanic children (10.8/1,000) (Baio, 2014), 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).

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**CHBRP KEY FINDINGS: PERVERSIVE DEVELOPMENTAL DISORDER OR AUTISM AND BEHAVIORAL HEALTH TREATMENT**

**Medical Effectiveness**

Many children with PDD/A are treated with behavioral health treatments.8 These treatments can be grouped into two major categories. Focused treatments target specific behaviors or skills, such as improving communication and reducing challenging behavior. Comprehensive treatment models are grounded in a central conceptual or theoretical framework of behavior.
change and target multiple domains of development. Focused treatments are typically of shorter duration and typically provided fewer hours per week than comprehensive treatments (Boyd et al., 2014).

Applied behavior analysis (ABA) is one of the most widely used comprehensive treatment models. This approach to behavior change draws upon the theories of B.F. Skinner and emphasizes using reinforcement to teach children with PDD/A basic social skills such as attention, compliance, and imitation (Howlin et al., 2009; Tchaconas and Adesman, 2013). Other comprehensive treatment models are based on developmental theories of behavior change, such as the Relationship Development Intervention and the Developmental, Individual-Differences, Relationship-based Model. The Early Start Denver Model is a comprehensive treatment model that combines ABA-based and developmental approaches (Tchaconas and Adesman, 2013).

CHBRP’s medical effectiveness reviews for previous bills on behavioral health treatments for PDD/A (SB 126 and SB TBD-1) focused on comprehensive behavioral health treatments based on ABA because SB 126 and SB TBD-1 specifically mentioned ABA. For its analysis of AB 2041, CHBRP expanded the literature review for SB 126 to include controlled studies of all types of comprehensive behavioral health treatments that have been published since CHBRP last reviewed this literature in 2013. The literature review for AB 2041 covered studies published from January 2013 to present. Seven additional studies were identified. Most new studies identified were observational studies with comparison groups. The number of randomized controlled trials (RCTs) conducted has increased in recent years. While observational studies with comparison groups make important contributions to the literature on behavioral health treatments for PDD/A, RCTs provide stronger evidence of the impact of these treatments. The sample sizes of most studies remain small, often less than 50 children. Small sample size limits the precision with which the effects of treatments can be estimated.

Characteristics of populations studied: Studies of behavioral health treatments enrolled children who ranged 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 comparisons: Most studies of comprehensive behavioral health treatments identified by CHBRP have assessed treatments based on ABA. Many of these treatments are provided to children for 1 to 2 years for more than 25 hours per week. Some studies compare more intensive to less intensive behavioral health treatments. Others compare intensive behavioral health treatments to treatment as usual which typically consists of an eclectic mix of interventions. In recent years, some studies have compared different treatments based on ABA (e.g., Mohammadzaheri et al., 2014). Recent studies have also investigated whether behavioral health treatments are effective for children with PDD/A who have severe impairments in communication and other areas of development (e.g., Goods et al., 2013). In addition, a growing number of studies have assessed the Early Start Denver Model (Dawson et al., 2010; Eapen et al., 2013) and other behavioral health treatments based on developmental theories of behavior change.

Characteristics of personnel providing treatments: The comprehensive behavioral health treatments assessed by the studies included in CHBRP’s review 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. 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. A recent systematic review concluded that behavioral health treatments based on ABA that were delivered by “non-specialized” personnel (e.g., nurse practitioner, teacher, teacher’s aide, parent) who were trained and supervised by persons with expertise in ABA improved intelligence quotient (IQ), language, daily living skills, and motor skills among lower functioning children with autism relative to usual care (Reichow et al, 2013).

Descriptions of the credentials of personnel providing behavioral health treatments were inconsistent across studies, making it difficult to determine which treatments utilized personnel similar to Behavioral Management Assistants and Behavioral Management Consultants as defined in AB 2041. No studies directly compared the provision of behavioral health treatments by different personnel. Thus, the optimal staffing for delivering these interventions is unknown. Some studies compared comprehensive behavioral health treatments provided by paid personnel to interventions provided by parents (e.g., Sallows and Graupner, 2005). A recent synthesis of the meta-analyses included in CHBRP’s medical effectiveness review for SB 126 found that comprehensive behavioral health treatments that included both paid therapists and parents as treatment providers were more effective than treatments that were provided solely by either paid therapists or parents (Strauss et al., 2013).

Medical Effectiveness Findings
The findings described below are from CHBRP’s report on SB 126 plus 7 studies that were published after CHBRP released its report on on SB 126 (CHBRP, 2013; Eapen et al., 2013; Goods et al., 2013; Mohammadzaheri et al., 2014; Peters-Scheffler et al., 2013; Reitzel et al., 2013; Schreibman and Stahmer 2014; Stock et al., 2015).
• The preponderance of evidence,\textsuperscript{10} which comes primarily from studies with moderately strong research designs, suggests that comprehensive behavioral health treatments are more effective than usual treatment\textsuperscript{11} in increasing intelligence quotient (IQ) and improving adaptive behaviors, such as communication, daily living, motor, and social skills.

• Behavioral health treatments that are more intensive and longer in duration have greater impact on IQ and adaptive behavior.

• Findings are ambiguous as to the effects that comprehensive behavioral health treatments 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.

Outcomes for individual children enrolled in studies of comprehensive behavioral health treatments vary widely. Findings from studies that have attempted to identify the characteristics of children who are most likely to benefit from these interventions suggest that children who are younger and who have higher IQs and greater adaptive behavior skills (e.g., communication, imitation, daily living skills, motor skills, social skills) at initiation of treatment derive greater benefit from treatment (CHBRP, 2013; Perry, Blacklock, and Geier, 2013. Virues-Ortega, Rodriguez, and Yu, 2013; Vivanti, et al., 2013).

**Benefit Coverage, Utilization and Cost**

• **Benefit Coverage:** AB 2041’s modification of the training descriptions for certain providers would not change the nature of the behavioral health treatment benefits for PDD/A mandated by law. Therefore, AB 2041 would have no impact on benefit coverage.

• **Access to providers:** AB 2041’s modification of the training description for Behavior Management Assistant or Behavior Management Consultant would align the training required for these providers with the existing mandate. Because the overall covered benefits or services would not change, CHBRP does not anticipate a change in access to providers who provide covered treatments.

• **Change in utilization:** Previous CHBRP reports (SB TBD-1 [2011], and SB 126, [2013])\textsuperscript{12} do not indicate that enrollees could not obtain treatments due to supplier bottlenecks. Therefore, CHBRP does not expect AB 2041 to change demand for these providers; thus, there would be no chance in utilization.

• **Cost:** Because CHBRP estimates that AB 2041 would not change benefit coverage or utilization, CHBRP concludes that AB 2041 would have no impact on total expenditures associated with the existing behavioral health treatment mandate.

**Public Health**

PDD/A is a chronic condition for which there is no known cure. Behavioral health treatments focus on ameliorating a variety of symptoms common to persons diagnosed with PDD/A. The measurable public health impacts most relevant to AB 2041 include changes in IQ, language skills, and adaptive behaviors; academic placement in mainstream classrooms; economic loss, including lost productivity of persons diagnosed with PDD/A and their family members; and financial burdens resulting from expenses for noncovered services or treatments.

**Estimated Public Health Outcomes:** Although the preponderance of evidence suggests comprehensive behavioral health treatments have greater effectiveness than usual treatment in improving adaptive behaviors and IQ, CHBRP concludes that passage of AB 2041 would produce no overall public health impact due to no change in coverage or utilization. This is because coverage for behavioral health treatments are currently required under the existing behavioral health treatment mandate. For the same reasons, CHBRP estimates AB 2041 also would have no impact on possible gender and racial/ethnic disparities in health outcomes, economic loss, or change the financial burden associated with the existing mandate.

**Long-term Impacts**

**Cost:** Because AB 2041 would not change benefit coverage, utilization, or total expenditures for enrollees with state-regulated health insurance beyond the existing behavioral health treatment mandate for PDD/A, CHBRP does not anticipate a long-term cost associated with AB 2041.

**Public health:** CHBRP estimates AB 2041 would have no measurable impact on long-term health outcomes.

**Essential Health Benefits and the Affordable Care Act**

The existing behavioral treatment mandate was enacted prior to December 31, 2011, thus it is already included in California’s definition of essential health benefits (EHBs). Only state benefit mandates enacted after December 31, 2011 that are “specific to the care, treatment, and services that a state requires issuers to offer to its enrollees” can exceed EHBs. AB 2041 does not modify the existing behavioral health treatment mandate in a manner that would exceed EHBs.

\textsuperscript{10} A definition of the term “preponderance of evidence” and other information about CHBRP’s medical effectiveness literature review methods can be found here: www.chbrp.org/analysis_methodology/medical_effectiveness_analysis.php.

\textsuperscript{11} As indicated above, usual treatment typically consists of an eclectic mix of interventions that are not based on a single theoretical framework of behavior change.

\textsuperscript{12} These reports are available on CHBRP’s website here: www.chbrp.org/completed_analyses/index.php.
REFERENCES


