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CALIFORNIA
HEALTH BENEFITS REVIEW PROGRAM

Analysis of Senate Bill 749
Health Care Coverage:
Diagnosis of Autism

A Report to the 2005-2006 California Legislature
April 16, 2005

CHBRP 05-08



Established in 2002 to implement the provisions of Assembly Bill 1996 (*California Health and Safety Code*, Section 127660, et seq.), the California Health Benefits Review Program (CHBRP) responds to requests from the State Legislature to provide independent analysis of the medical, financial, and public health impacts of proposed health insurance benefit mandates. The statute defines a health insurance benefit mandate as a requirement that a health insurer and/or managed care health plan (1) permit covered individuals to receive health care treatment or services from a particular type of health care provider; (2) offer or provide coverage for the screening, diagnosis, or treatment of a particular disease or condition; or (3) offer or provide coverage of a particular type of health care treatment or service, or of medical equipment, medical supplies, or drugs used in connection with a health care treatment or service.

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

A Report to the 2005-2006 California State Legislature

Analysis of Senate Bill 749
Health Care Coverage: Diagnosis of Autism

April 16, 2005

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PREFACE

This report provides an analysis of the medical, financial, and public health impacts of Senate Bill 749, a bill to mandate that health care service plans and insurers cover the diagnosis of pervasive developmental disorders (PDD) or autism that follows current best practice standards developed by the Department of Developmental Services (DDS). In response to a request from the California Senate Banking, Finance, and Insurance Committee on February 15, 2005, the California Health Benefits Review Program (CHBRP) undertook this analysis pursuant to the provisions of Assembly Bill 1996 (2002) as chaptered in Section 127600, et seq., of the California Health and Safety Code.

Theodore Ganiats, MD, Lisette Giepmans, PhD, Catherine Brouillard, MA, and Sara Fernandez, BA, of the University of California, San Diego (UCSD), prepared the medical effectiveness analysis. Penny Coppernoll-Blach, MLS of UCSD conducted the literature search. Pauline A. Filipek, MD, University of California, Irvine, provided technical assistance with the literature review and expertise for the medical effectiveness analysis. Helen Halpin, PhD, Sara McMenamin, PhD, Nicole Bellows, MHSA, all of the University of California, Berkeley, prepared the public health impact analysis. Gerald Kominski, PhD, Miriam Laugesen, PhD, and Nadereh Pourat, PhD, all of the University of California, Los Angeles, prepared the analysis of the cost impact. Robert Cosway, FSA, MAAA, Chris Girod, FSA, MAAA, of Milliman, provided actuarial analysis. Michael E Gluck, PhD, Sachin Kumar, BA, and Robert O'Reilly, BS, of CHBRP staff prepared the background section and integrated the individual sections into a single report. Other contributors include Susan Philip, MPP, and Cynthia Robinson, MPP, of CHBRP staff, and Sarah Ordody, who provided editing services. In addition, a subcommittee of CHBRP's National Advisory Council (see final pages of this report) reviewed the analysis for its accuracy, completeness, clarity, and responsiveness to the Legislature's request.

Jay Ripps, FSA, MAAA of Milliman recused himself from contributing to this and all other CHBRP analyses beginning March 1, 2005. His recusal is valid through his duration as acting chief actuary at Blue Shield of California.

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

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EXECUTIVE SUMMARY

California Health Benefits Review Program Analysis of Senate Bill 749

The California Legislature has asked the California Health Benefits Review Program to conduct an evidence-based assessment of the medical, financial, and public health impacts of Senate Bill (SB) 749.

SB 749 would amend existing law[1] to require health care service plans licensed by Knox-Keene[2] and health insurance policies regulated under the California Insurance Code to cover the diagnosis of pervasive developmental disorders (PDD), or autism, according to the best practice standards developed by the California Department of Developmental Services (DDS). These guidelines were developed pursuant to a previously enacted law (AB 430, 2001). SB 749 would also require the Department of Managed Health Care and the Department of Insurance to develop regulations specifying responsibility for reimbursement when a health plan or insurer contracts with another entity to manage its mental health benefits.

Diagnosis according to the DDS best practice guidelines include services and professionals not usually reimbursed by health plans or insurers (e.g., language/communication evaluations, and certain mental health care evaluations and professionals). Hence, CHBRP's analysis of the impact of SB 749 focuses on how ensuring reimbursement for all elements of diagnosis as laid out in the best practice guidelines would affect medical, cost, utilization, and public health outcomes.

I. Medical Effectiveness

- SB 749 would mandate coverage for a *specific process for diagnosing autism*, as opposed to mandating coverage for a benefit or treatment intervention. There are no data evaluating the effectiveness of that process. Elements of the process have been studied, but the degree to which these elements interact to improve (or decrease) diagnostic accuracy is not known. In addition, the degree to which the current health care system has the capacity to fully implement the mandated process is not known.

- Because there is no data evaluating the diagnostic process mandated by SB 749, this analysis relies on available published literature as well as expert opinion. These suggest that the bill would increase the accuracy of diagnosis, decrease the time between first referral and diagnosis, lower the average age at diagnosis, and improve overall parental satisfaction with the diagnostic process.

[1] Section 1374.72 of the Health and Safety Code and Section 10144.5 of the Insurance Code, relating to health coverage.
[2] Health maintenance organizations in California are licensed under the Knox-Keene Health Care Services Plan Act, which is part of the California Health and Safety Code.

- To the extent that treatment can improve outcomes when optimally practiced, this bill would lead to improved health outcomes for individuals with autism, especially when patients are diagnosed at an earlier age. However, this conclusion relies on expert opinion and is based on very limited literature.

II. Utilization, Cost, and Coverage Impacts

- 20,368,000 individuals are currently enrolled in health plans or insurance policies that would be affected by this proposed mandate, including 6,706,000 children aged 0-18 years.

- CHBRP's survey of health plans confirms that 100% of these individuals currently have some coverage for autism diagnostic services. However, as noted in the survey responses, current coverage may not necessarily include all of the services mentioned in the California Department of Developmental Services (DDS)'s best practices protocol.

- Increased awareness of coverage for autism diagnosis could result in a 10% increase in children tested annually for autism.

- Increased use of the services included in the DDS best practice guidelines would
    - increase the average unit cost of diagnosis (excluding physician services) from $1,871 to $2,318.
    - reduce the proportion of false negative diagnoses of autism by 10% among those tested, due to improved accuracy of the "best practices" protocol mandated by the bill.

- Total annual expenditures for the diagnosis of autism would increase by $1,357,000, or 0.0023%, as a result of the mandate.

- Over the longer term, expenditures by California's schools and other public agencies for treatment and other services provided to children with autism would increase as a result of the additional, more accurate, and earlier diagnoses associated with SB 749. These additional treatment costs are excluded from this analysis because they are generally not borne by health insurers, but by school districts and other public agencies. In addition, there would be decreased expenditures for treatment and other services provided to children with autism later in school as a result of successes in early treatment. Our key assumptions and findings are summarized in Table 1.

Table 1. Summary of Coverage, Utilization, and Cost Effects of SB 749

Total insured population = 20,368,000	**Premandate**	**Postmandate**	**Increase/ Decrease**	**% Change After Mandate**
Coverage				
Percentage of insured individuals with coverage for mandated benefit	100%	100%	-	-
Number of insured individuals in California with coverage for the benefit	20,368,000	20,368,000	-	-
Number of insured individuals aged 0-18 years in California with coverage for the benefit	6,706,000	6,706,000	-	-
Number of insured individuals aged 0-18 years in California without coverage for the benefit	0	0	-	-
Total Unit Cost				
Diagnostic testing for autism	$1,871	$2,318	$447	23.9%
Utilization				
Percentage of total members aged 0-18 years tested for autism per year	0.0253%	0.0278%	0.0025%	10.0
Percentage of total members aged 0-18 years tested for autism with a confirmed diagnosis per year	0.0205%	0.0230%	0.0026%	12.6
Proportion of cases tested for autism with a negative diagnosis of autism	19%	17%	-1.9%	-10.0
Expenditures				
Premium expenditures by private employers for group insurance	$35,360,055,000	$35,360,652,000	$597,000	0.0017%
Premium expenditures by individuals with group insurance, CalPERS, or Healthy Families	$10,261,105,000	$10,261,288,000	$183,000	0.0018%
Premium expenditures for individually purchased insurance	$3,818,726,000	$3,818,821,000	$95,000	0.0025%
CalPERS employer expenditures	$2,212,881,000	$2,212,915,000	$34,000	0.0015%
Medi-Cal state expenditures	$3,939,663,000	$3,939,964,000	$301,000	0.0076%
Healthy Families state expenditures	$347,858,000	$347,937,000	$79,000	0.0227%
Expenditures for non-covered services	$4,074,893,000	$4,074,961,000	$68,000	0.0017%
Total annual expenditures	$60,015,181,000	$60,016,538,000	$1,357,000	0.0023%

Source: California Health Benefits Review Program, 2005

Notes:

The population includes individuals and dependents in California who have private insurance (group and individual), or are enrolled in public plans subject to the Health and Safety Code, including Cal-PERS, Medi-Cal, or Healthy Families.

All population figures include enrollees aged 0-64 years, except the Medi-Cal population, which includes dually eligible Medicare/Medi-Cal recipients of all ages enrolled in managed care plans.

Employees and their dependents that receive coverage from self-insured firms are excluded because these plans are not subject to mandates.

III. Public Health Impacts

- As of December 2002, the total number of all persons with autism served by regional centers in California was 20,377 and the estimated prevalence rate for children (aged 0-19 years) was 15.5 per 10,000. In addition, as of December 2002 the estimated prevalence for the birth year 1997 was 31.2 per 10,000, which represents an increase of 774% from the prevalence rate of 4 per 10,000 in the 1970 birth cohort.

- Although it is likely that this mandate would improve autism diagnosis through 1) a more accurate diagnosis of children with autism, 2) a shorter time between diagnosis and referral for treatment, and 3) a younger age at diagnosis, our ability to quantify the impact of the mandate on the public's health may be limited by the availability of effective treatment programs, which may not achieve the same impact as those observed in the research studies.

- There is evidence of gender and racial/ethnic differences in the prevalence of autism in California with highest prevalence rates among males and Blacks. In addition, there is evidence of a disparity in treatment in that Blacks are diagnosed and treated for autism later compared to Whites. To the extent that this mandate results in earlier diagnosis and treatment for autism, it could have the potential to reduce this disparity.

- Although there is evidence indicating that persons diagnosed with autism have a shorter life expectancy than those without autism, there is no evidence that this mandate would have an impact on the prevalence of autism or its associated mortality rate. Therefore, we are not able to assess the impact that SB 749 on premature death.

- There is evidence indicating that autism leads to economic loss due to the reduced productivity of people with the disease and their caregivers. To the extent that this mandate would result in earlier diagnosis, effective treatment, and improve functioning for people with autism, it is possible that the mandate could improve the productivity of people with autism and their caregivers. However, it is not possible to provide an estimate.

INTRODUCTION

Senate Bill (SB) 749 would require a health care service plan or a disability insurer to cover the diagnosis of pervasive developmental disorders (PDD) or autism that follows the current best practice standards developed by the California Department of Developmental Services (DDS). In addition, SB 749 would require the Department of Managed Health Care (DMHC) and the California Department of Insurance (CDI) to enact regulations that would specify how a health plan or a disability insurer and a separate mental health plan would determine reimbursement of diagnostic services. Although this analysis focuses on diagnostic outcomes, it examines the limited evidence available concerning the relationship between diagnosis and ultimate health outcomes.

Autism is a relatively uncommon but potentially devastating disorder that begins in childhood. According to "Autism Spectrum Disorders: Changes in the California Caseload, An Update: 1999 through 2002," the state has experienced an increase in the number of children diagnosed with autism. From December 1998 to December 2002, the population of persons diagnosed with autism in California's Developmental Services System had nearly doubled (a 97% increase). During the last 10 years, autism diagnoses have risen in the rest of the country as well as internationally.

As required in 2001 by Assembly Bill 430 (AB 430 Sections 25 and 26, and Welfare and Institutions Code, Section 4643.3 [a and b]), the DDS developed *Autism Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment* as an evidence-based, standard diagnosis process for use in developmental and regional centers that specialize in diagnosing autism and related conditions.[3] Use of the term "autistic spectrum disorder" or "ASD" in these Guidelines is limited to three of the conditions specified under pervasive developmental disorder in the DSM-IV, (1) autistic disorder, (2) Asperger's disorder, and (3) PDD-not otherwise specified." (DDS, 2002). Throughout this report we refer to these diagnoses collectively as "autism."

The DDS guidelines provide one assessment protocol for children from birth through age five and another for children age six and older. As reviewed later in this analysis, age of diagnosis is predictive of a child's ultimate prognosis. At the same time, autism has historically been more difficult to diagnose in younger children than in older ones. The DDS guidelines incorporate recent research findings indicating that certain behavioral and other indicators have improved the accuracy of autism diagnosis in children younger than 3 years (Gillberg, 1990; Lord, 1995; Stone and Hogan, 1993; Stone et al., 1994).

Current law also requires a health care service plan or a health insurer to provide coverage for the diagnosis and medically necessary treatment of serious emotional disturbances in a child. In addition, California's current mental health parity statute identifies autism among nine mental health diagnoses for which health plans and insurers must provide benefits on par with benefits for medical conditions (AB 88, 1999). Because current law is silent on the specific diagnostic services (or providers) for which health plans and insurers must reimburse, private insurers may

[3] DDS provides services through state-operated developmental centers and contracts with 21 nonprofit agencies called "regional centers."

not necessarily cover all elements of the DDS best practice guidelines (e.g., language/communication evaluations, and certain mental health care evaluations and professionals). Hence, CHBRP's analysis of the impact of SB 749 focuses on how ensuring reimbursement for all elements of diagnosis as laid out in the best practice guidelines would affect medical, cost, utilization, and public health outcomes.

SB 749 would apply to health care service plans licensed by Knox-Keene and to health insurance policies regulated under the California Insurance Code. Currently, no other states have laws similar to SB 749 in mandating coverage for the diagnosis of autism according to a specific protocol or process.

I. MEDICAL EFFECTIVENESS

Autistic disorder and pervasive developmental disorder-not otherwise specified (PDD-NOS), along with Asperger's Disorder, are three of the five diagnoses that make up "autistic spectrum disorder" (ASD). Together, these diagnoses refer to a pattern of behaviors involving three central features—impairments in socialization, atypical verbal and nonverbal communication, and restricted patterns of interest and stereotyped actions. The features can vary widely in symptom expression, degree of impairment, and onset. The Diagnostic and Statistical Manual, 4th Edition, revised (DSM-IV-TR) is the current classification standard to establish the diagnosis of autism.

The detection of developmental and behavioral problems in young children can be difficult due to the variety of disorders and their manifestations at different ages. This is particularly apparent in young children with autism; their communicative and social difficulties are often poorly understood and are therefore frequently attributed to normal variations in typical development. However, advances have been made in identifying behavioral indicators as well as atypical development in children younger than two years who are later diagnosed with autism. Furthermore, it has been demonstrated that autism can be reliably diagnosed by an experienced clinician in children between the ages of 24 and 30 months (Gillberg et al., 1990; Lord, 1995; Stone & Hogan, 1993; Stone et al., 1994). It is generally acknowledged that early diagnosis has many advantages, including earlier delivery of appropriate medical care to the child, earlier educational planning and treatment, provision for family supports and education, and reduction of family stress and anguish. Several studies show that intensive early intervention in optimal educational settings results in improved outcomes in most young children with autism. A direct comparison between children with autism younger and older than 60 months at the start of the intervention showed significantly better results for the younger children (Fenske et al., 1985).

Diagnosis

According to *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment*, developed by the DDS and the basis for what services would be mandated for reimbursement under SB 749, best practice for a diagnostic evaluation of autism includes the following elements:

- The primary care provider holds a central role in screening and coordination of health care.
- The complexity of the diagnostic evaluation makes an interdisciplinary team the preferred vehicle for achieving appropriate diagnosis and recommendations for intervention.
- The variability and evolution of symptoms over time require regular, periodic reevaluation to confirm the diagnosis and plan treatment.
- A comprehensive diagnostic evaluation for autism includes specific activities and examination of multiple domains of function to differentiate autism from other conditions and to provide a complete profile of the individual.

These elements address two components of the diagnostic process where improvement is needed and likely to be achieved: a better organization of the process with coordination between the professionals involved, and a more elaborate diagnostic evaluation. Early diagnosis allows for early treatment, and early treatment is associated with improved outcomes. To detect and diagnose autism as early as possible, the guidelines advocate routine screening for autism at ages 18 and 24 months and a timely referral by primary care providers to an interdisciplinary team for a comprehensive diagnostic evaluation.

The comprehensive diagnostic evaluation described by the DDS best practice guidelines differentiates between children aged 0-5 years and those 6 years and older. The evaluation for the youngest children includes the following six components: Review of relevant background information, parent/caregiver interview, comprehensive medical evaluation, direct observation, cognitive assessment, and measures of adaptive functioning. The evaluation for the children aged 6 and older starts with these 6 components and adds: child interview; mental health assessment/psychiatric functioning; communication assessment; evaluation of social competence and functioning; restrictive behaviors, interests, and activities; and family functioning. The guidelines indicate recommended and optional tests. Given the wide variance in symptoms of autism, the optimal combination of tests has to be defined on an individual basis.

Outcomes

The DDS best practice guidelines aim to improve the accuracy of the diagnosis of autism, as early in life as possible. Outcomes of interest regarding the *diagnostic evaluation* are therefore:

- Number of correctly diagnosed and misdiagnosed children with autism
- Time between first referral and diagnosis
- Age at which diagnosis is made
- Parental distress/satisfaction regarding the diagnostic process

The medical effectiveness of a more efficient diagnostic evaluation is largely dependent on the timely start of an effective intervention. Since the treatment of autism is not included in the

mandate, a complete evaluation of treatment effectiveness is not performed. Instead, we focus on the few major studies to help inform the assessment of the public health and utilization/cost impacts of the mandate, with a special emphasis on the first year after diagnosis.

Outcomes of interest are:

- Functioning of the child (language, social and cognitive skills)
- Health care utilization

There are no published studies that provide information about the effect of implementing the DDS best practice guidelines, *per se*, on the outcome of the diagnostic process. Baseline data about the current practice with regards to the outcome measures are not readily available for several reasons, which are discussed in the next paragraph. Expert opinion was therefore obtained about the impact of the guidelines on the number of children identified as needing a diagnostic evaluation and the number of children being diagnosed with autism.

In current practice, autism is often not the diagnostic code given to the child because reimbursement for these diagnostic codes is low. As a result, all data regarding the children currently diagnosed with autism will be incomplete. Estimating the impact of the guidelines on abovementioned outcomes, including cost outcomes, is therefore a difficult task. A literature search for the time period between first referral and diagnosis, age of the child at diagnosis, and parental distress/satisfaction gave only anecdotal information, which is discussed later.

Data regarding the medical effectiveness of behavioral interventions for children with autism is derived from a recent evaluation by the Committee on Educational Interventions for Children with Autism, commissioned by the National Research Council (Educating Children with Autism, 2001). The results of this evaluation serve as a basis for the data described later in the section Indirect Outcomes. A description of the evaluation process and additional literature search can be found in Appendix A: Literature Review Methods.

Diagnostic outcomes

As noted earlier, the mandate would increase the number of diagnostic evaluations that take place each year. The capacity of the current system to complete the evaluations on all patients deemed appropriate is something that is not possible to ascertain. However, even without an optimal system, several key outcomes would result.

Number of correctly diagnosed and misdiagnosed children with autism

Because of the complexity of the diagnostic process, the variety in professionals involved, the assumed current lack of coordination of the diagnostic process, and the underreporting of autism, it is not possible to describe based on data the ‘current practice’ with regard to the diagnostic process of autism. Estimations of how the guidelines would change current practice were obtained by expert opinion. With the support of anecdotal reports, expert opinion suggests that the guidelines would not likely result in a more thorough screening of infants, but that more children would be referred for diagnostic testing, and those referred would receive a more thorough evaluation. This process would result in more children being diagnosed with autism, a result of fewer children being misdiagnosed with other conditions.

Time between referral and diagnosis and Average age at diagnosis
An improvement of diagnostic tools and an increasing awareness of autism have contributed to a decrease in the age at which children are diagnosed. The average age at which the diagnosis is made is 3-4 years in the US (Filipek et al., 1999), while first symptoms are often recognized much earlier (Filipek et al. 2000). A survey of 1,300 families in the UK revealed a delay of 3.8 years from the time the parents of a child with autism first sought professional help to the time a final diagnosis was made (Howlin and Moore, 1997). The average age at which the final diagnosis was made was 6 years in the total survey, but had decreased to 3.7 years for the children younger than 10 years.

It has been shown that autism can be reliably diagnosed by an experienced clinician in children between the ages of 24 and 30 months (Gillberg et al., 1990; Lord, 1995; Stone & Hogan, 1993; Stone et al., 1994). The DDS best practice guidelines are aimed at making a diagnosis as early as possible, so theoretically the average age at diagnosis could be lowered from the current 3-4 years to 2.5-3 years of age.

Parent satisfaction
Adherence of health care professionals to the best practice guidelines, which also recommend greater parental involvement during the diagnostic process and treatment planning, is expected to greatly reduce parental stress and to improve satisfaction. Studies of diagnostic procedures for children with a range of developmental disorders consistently indicate that the earlier the age at which diagnosis is made, the greater the degree of parental satisfaction (Piper and Howlin, 1992). Satisfaction with the diagnostic process was far higher among parents whose children were diagnosed with autism in the preschool years. Moreover, the degree of satisfaction was related to the length of time parents had waited before receiving a final diagnosis (Howlin and Moore 1997).

Indirect outcomes

The bill addresses health plan and insurer reimbursement of the diagnostic process (i.e., not treatment), so the direct impacts of the bill would be its effects on the accuracy and costs of diagnosis, the number of children receiving the service, and the number of children diagnosed with autism, and the age at diagnosis. However, we can expect “indirect” outcomes, or those outcomes that result from the improved diagnosis of autism. An improved diagnostic process has a positive impact on the health of the diagnosed individual only when an effective intervention is available. Education or behavioral intervention is currently the primary form of treatment in autism. Pharmacological treatment and other non-behavioral interventions are not evaluated here.

A wide variety of interventions have been shown to improve functioning of individuals with autism. The National Research Council’s Committee on Educational Interventions for Children with Autism recently evaluated the large body of research on educational interventions for children with autism up to an age of 8 years (National Research Council, 2001). These studies involved either a limited, or more focused, evaluation or a more comprehensive treatment program. For example, an intervention may focus on one of the problem domains associated with autism, such as language development or social interaction. Effect of the intervention is often reported as pre-post changes in scores on domain-specific assessment instruments, and also as

changes in IQ. As an outcome measure for long-term effects, school placement is also sometimes reported (regular class, class for aphasic children, class for developmentally delayed children).

The level of evidence supporting effectiveness of these domain-focused interventions is limited. Very few randomized studies have been done, and direct comparisons between interventions are completely lacking. The generally poor description of study subjects and the use of different outcomes make an estimation of overall effect size very difficult. The report of the Committee on Educational Interventions for Children with Autism evaluates the evidence for interventions in each of the following domains: development of communication (Goldstein, 2002), social development (McConnell, 2002), sensory and motor development (Baranek, 2002), and problem behaviors (Horner et al., 2002). The Committee on Educational Interventions for Children with Autism concludes that for all available domains' interventions, promising results are shown, but that more sound research is needed to substantiate the effects and to identify the most effective interventions.

A limited number of comprehensive treatment programs have been developed that aim at improving functioning of individuals on all problem domains. The programs outcome measures can be grouped into five categories: cognitive or intellectual status, developmental and achievement status and/or progress, post-intervention placement, reclassification of diagnosis, and autism symptom reduction (Wolery and Garfinkle, 2002).

The Committee on Educational Interventions for Children with Autism evaluated the effectiveness of 10 comprehensive treatment programs, reported in 13 publications (National Research Council, 2001; Kasari, 2002). The programs presented positive and similar findings in: IQ scores, language, autistic symptoms, future school placements, and several measures of social behavior. Although possible changes in diagnosis are implied ("recovery" from autism), these have not been systematically documented or supported with independent observations or reports. Considered as a group, these outcome studies suggest a positive change in the language, social, or cognitive outcomes of children with ASD who received intensive intervention beginning at young ages. However, most studies had methodological limitations and almost no information is available about other interventions and therapies in which the children participated, precluding the attribution of the progress to specific interventions.

Only three studies have comparison group data, of which one study randomly assigned the children to conditions. These studies all report on the effect of the Early Intervention Project (EIP) developed by Lovaas et al. (1981) and applied in the University of California, Los Angeles (UCLA) Young Autism Project. The behavioral intervention is delivered in a one-to-one discrete-trial format, which is implemented by parents and trained therapists who work in a child's home. Age at entry is 30 to 46 months and intervention takes 20-40 hours per week. The first year of intervention is aimed at teaching children to respond to basic requests, to imitate, to begin to play with toys, and to interact with their families. During the second year, the focus on teaching language continues. The third year focuses on teaching emotions, preacademic skills, observational learning, and adjustment to school settings. When children are ready for a class environment, assistance is provided for participation in regular preschool or kindergarten setting.

The first publications about the results of the project report favorable results (Lovaas 1987, McEachin et al., 1993). Subjects either received intensive intervention of 40 hours per week (experimental group, n=19), minimal treatment of less than 10 hours per week (control group 1, n=19), or were not treated within the program but received interventions through community systems (control group 2, n=21). Outcome variables were obtained after first grade (ages 6-7 years) and in early adolescence (ages 12-13 years). At the first follow-up, mean IQ of the experimental group was 83, while for the two control groups mean IQ was 52 and 57, respectively. In the experimental group, 8 of 19 children (47%) were functioning well in typical first-grade classrooms, without any special supports, whereas only 1 out of 40 children (2%) in the control groups had reached this goal. These differences between the experimental group and the control groups remained until the second follow-up measurement.

Although the Young Autism Project has generated the most rigorously controlled early intervention research published to date, there is considerable controversy due to various methodological and interpretational limitations (Gresham and MacMillan, 1998). The investigators assigned children to intensive or minimal treatment on the basis of therapist availability, rather than a less arbitrary procedure. At intake, different children received different intelligence tests, as selected by the examiner. This practice may have lowered the reliability of the intake IQ data.

Several evaluations have been conducted replicating the Young Autism Project, with generally positive but mixed results. Sheinkopf and Siegel (1998) report similar gains in IQ scores (30 points compared to pre-treatment and to control group) in a retrospective study on 22 subjects. Birnbrauer and Leach (1993) report less clear results. In the experimental group, 4 out of 9 children were considered to have made high improvement, versus 1 out of 5 in the control group. In a randomized trial, Smith et al. (2000) report a significant effect of intensive intervention over parent training in 28 children with autism or PPD-NOS. The intensive treatment group gained 16 points in IQ scores versus 0 points in the control group, and had a significant advantage in visual-spatial skills, but not in language development or adaptive behavior. The intensively treated group had significantly less restrictive school placements than did the parent training group (4 children in regular education, and 11 in regular education with support versus 3 children in regular education with support).

Effect of insurance coverage on outcomes

Insurance coverage is not expected to affect the recommended *screening* of infants of 18 or 24 months old during routine well-child visits. However, knowing that the diagnostic evaluation is reimbursed might lead to more referrals by the pediatrician or primary care provider for further diagnostic testing. The insurance coverage is likely to increase the amount of diagnostic testing per individual, presumably leading to an earlier and more accurate diagnosis, and associated less parental distress and higher satisfaction.

In addition to changing the current practice, insurance coverage is also likely to have an administrative impact on the number of children diagnosed with autism. In those cases where the physician currently makes the diagnosis of autism, but avoids the diagnostic codes for autism for reimbursement reasons, the mandate would result in an administrative correct diagnosis for the child.

II. UTILIZATION, COST, AND COVERAGE IMPACTS

SB 749 would affect those enrolled in plans subject to the Health and Safety Code, and those with private health insurance polices subject to the Insurance Code in California. This includes 20,368,000 Californians, including 6,706,000 children aged 0-18 years.

According to CHBRP's survey of health plans, all members currently have coverage for the diagnosis and treatment of autism. However, SB 749 would mandate the use of DDS best practice standards when diagnosing autism. These standards are expected to increase both the unit cost of diagnostic testing and the proportion of cases tested that are identified with autism. In addition, CHBRP estimates that the mandate would increase awareness of coverage for diagnostic testing and therefore is likely to increase the percentage of children tested by approximately 10%.

Present Baseline Cost and Coverage

Current coverage of the mandated benefit (3(i))

An estimated 20,368,000 Californians currently have coverage for the mandated benefit, including:

- 3,200,000 Medi-Cal recipients in HMOs
- 494,000 Healthy Family recipients in HMOs
- 795,000 CalPERS members in HMOs
- 1,952,000 persons with individually purchased coverage
- 13,927,000 persons with employment-based coverage

CHBRP surveyed the seven largest insurers in California regarding their coverage of testing for autism. At the time of writing, only two insurers had responded. Both respondents indicate that they covered diagnostic services for autism and PDD. However, one of the two respondents confirmed that they did not necessarily provide coverage for all services in the DDS best practice guidelines such as those that might be considered educational evaluation. One other carrier stated that autism testing payment is limited to 8 hours. CHBRP was unable to ascertain the extent to which insurers restrict access to autism testing services as defined by the DDS best practice guidelines. CHBRP estimates all 6,706,000 children aged 0-18 years have coverage for the mandated benefit, however, current coverage might not extend to include all of the diagnostic services indicated by the best practice guidelines. Children with current coverage include:

- 1,548,000 Medi-Cal recipients in HMOs
- 463,000 Healthy Family recipients in HMOs
- 210,000 CalPERS members in HMOs
- 467,000 children with individually purchased coverage
- 4,020,000 children with employment-based coverage

Current utilization levels and costs of the mandated benefit (Section 3(h))

The current average cost of diagnostic testing for autism and PDD is estimated to be $1,871. This value is shown in Table 2, and is based on expert opinion as to which services are used for autism testing, and the percentage of tested children that receive each service. The unit cost for each service was estimated based on average fee contracted with health plans in California.

The current average time paid for by health plans for providers to conduct tests is assumed to be eight hours. This includes the physician's time as well as time for other practitioners that conduct behavioral and other types of tests. This assumption is based on limited California claims data available to evaluate the current level of reimbursed testing, the current time limit set by one insurer, and anecdotal evidence.

CHBRP estimates that about 0.0253% of insured children aged 0-18 years are tested for autism per year, and that about 80% of those tested (0.0205%) have a positive diagnosis. These estimates are based on national claims data that shows 0.112% of commercially insured children aged 0-18 years are treated annually for autism and that 18.27% of those treated have received diagnostic testing for autism in the current year. (0.112*.1827=0.0205%).

Our assumption that 80% of those tested have a positive diagnosis is a rough estimate, due to lack of data. To estimate the sensitivity of this assumption, we also looked at results assuming 60 or 100% of those tested have a positive diagnosis. If 100% of those tested have a positive diagnosis, the PMPM and percentage impacts shown in this report would decrease by about 20%. If 60% of those tested have a positive diagnosis, the PMPM and percentage impacts shown in this report would increase by about 33%.

The extent to which costs resulting from lack of coverage are shifted to other payers, including both public and private entities. (Section 3(f))

CHBRP estimates no shift in costs among different payers as a result of current coverage because all insured Californians have coverage for some autism diagnostic services. However, any significant delays in receiving authorization for those services may currently encourage parents to seek testing through public agencies.

Public demand for coverage (Section 3(j))

CalPERS, which provides health insurance and other benefits to state and some local government employees, is the largest purchaser of private health insurance in California. Its decisions about the inclusion or exclusion of particular services among the health insurance benefits it provides is one measure of public demand for those services. Beyond current statutory requirements concerning coverage and parity of autism services, CalPERS's self-insured PPO plan identifies autism as a severe mental illness for which they cover psychological testing for the assessment and diagnosis of autism as well other inpatient and outpatient mental health services, speech therapy, and rehabilitative care. The plan requires preauthorization for autism services and reviews utilization.

Impacts of Mandated Coverage

How will changes in coverage related to the mandate affect the benefit of the newly covered service and the per-unit cost? (Section 3(a))

As mentioned, SB 749 requires the use of best practice guidelines created by the DDS for the diagnosis of autism. CHBRP estimates that the unit cost of diagnostic testing would increase by 23.9%, from $1,871 to $2,318. (See Table 1 for a summary of cost impacts based on the details presented in this section and Tables 2, 3, and 4.) The increase in the per-unit cost of diagnostic testing is based on 1) the likely changes in the volume of individual services (as defined by CPT or procedural codes) and 2) the likely changes in the intensity of those individual services provided.

Volume

Based on expert input, a subset of testing procedures would be provided at greater frequency as a result of the mandate (Table 2). However, not all diagnostic procedures would be provided at greater frequency because not all procedures would be considered medically appropriate for each child. Table 2 illustrates this. Hence the utilization of some services post mandate would still be less than 100%.

Intensity

The number of testing hours, including any physician charges, is assumed to increase from 8 to 13 hours. This was based on consistent information from two expert sources as to the typical hours required to perform the evaluation under the DDS best practice guidelines. These hours include time needed for medical evaluation, direct patient contact, and a case conference.

CHBRP also estimates that SB 749 would improve the average benefit of diagnostic testing because diagnoses are expected to be more accurate when conducted according to the best practice guidelines. Based on expert input, this improved accuracy would result in the proportion of children tested for autism who are ruled not to have autism to decline from 19% to 17%—a 10% reduction in the rate of false negative diagnoses.

How will utilization change as a result of the mandate? (Section 3(b))

Although all insured children currently have coverage for some autism diagnostic testing, there appears to be a public perception that existing coverage for autism testing is limited. Due to increased awareness associated with the SB 749, more parents may pursue autism testing for their children. Therefore CHBRP estimates that increased awareness would increase the percentage of children tested for autism by approximately 10% annually.

To what extent does the mandate affect administrative and other expenses? (Section 3(c))

CHBRP assumes the administrative costs are a fixed percentage of healthcare costs, which varies by group size and insurance type. These costs are included in the baseline and premium estimates. To the extent that SB 749 requires payers to credential providers with professional skills not previously reimbursed, health plans and insurers may face some one-time

administrative costs associated with establishing credentialing processes or possibly contracting with an outside entity to take on this task. CHBRP does not anticipate any other impact on administrative expenses, above and beyond the usual administrative expenses when expressed as a percentage of premiums.

Impact of the mandate on total health care costs (Section 3(d))

As summarized in Table 1, SB 749 would increase total health care expenditures from $60,015,181,000 to $60,016,538,000, for the 20,368,000 individuals affected by this mandate; an increase of $1,357,000, which equals 0.0023% of total expenditures for this insured population.

For each major category of payer, total annual expenditures would increase by the following amounts and percentages:

- Private employers: $597,000 (0.0017%)
- Private employees: $183,000 (0.0018%)
- Individually purchased insurance: $95,000 (0.0025%)
- CalPERS: $34,000 (0.0015%)
- Medi-Cal: $301,000 (0.0076%)
- Healthy Families: $79,000 (0.0227%)

Medi-Cal and Healthy Families would experience slightly greater percentage increases in total expenditures because children aged 0-18 years make up a greater proportion of their insured population relative to other insurers.

Long-term expenditures are difficult to predict, and are beyond the scope of this analysis. However, earlier diagnosis of autism may produce both cost-increasing and cost-saving effects. Earlier diagnosis should lead to earlier use of effective interventions, thus reducing some of the long-term costs of treatment. Expenditures by California's schools and other public agencies for treatment and other services provided to children with autism would likely increase as a result of the additional, more accurate and earlier diagnoses associated with SB 749. These treatment costs are excluded from this analysis, because they are generally not borne by health insurers, but by school and other public agencies.

Costs or savings for each category of insurer resulting from the benefit mandate (Section 3(e))

Because all insurers currently provide coverage for some autism diagnostic services, CHBRP estimates no shift in costs or savings related to diagnosis among payers because of the mandate.

As stated, California schools and other public agencies would likely face some cost-increasing and cost-savings effects as a result treatment and other services provided to children with confirmed autism diagnosis.

Impact on access and health service availability (Section 3(g)

CHBRP estimates that the proposed mandate will have no measurable effect on access to diagnostic services or the availability of diagnostic and treatment services for autism.

III. PUBLIC HEALTH IMPACTS

Present Baseline Health Outcomes

As of December 2002, the total number of persons of all ages with autism[4] served by the California DDS regional centers was 20,377 (DDS, 2003). Of these cases, 16,108 were in children (aged 0-19 years), for a prevalence rate of 15.5 per 10,000 (DDS, 2003).[5] As of December 2002, the estimated prevalence was 31.2 per 10,000 for children born in 1997 (DDS, 2003). There has been an increase in the prevalence of autism of 774% from 4 per 10,000 in the 1970 birth cohort to 31.2 per 10,000 in the 1997 birth cohort (DDS, 2003). In 2002, 3,500 new cases of autism were served through the California DDS. Estimates of the prevalence of the two other PDDs applicable to this mandate (Asperger's Disorder and PDD-NOS) are not available from the DDS data files because they are not DDS-eligible conditions[6] (DDS,2003). One study of autism in Brick Township, NJ estimated the prevalence of autistic disorder in a cohort of 3-10 year olds to be 40 per 10,000 and the combined prevalence of PDD-NOS and Asperger disorder to be 27 per 10,000 for an overall prevalence of 67 per 10,000 (Bertrand et al., 2001).

According to DDS records of regional center visits, the majority of people with autism (70%) have their first regional center visit between the ages of 2 and 5 (Table 5). In addition, 9% of persons with autism have their first regional center visit before the age of 2 and 21% have their first regional center visit after the age of 5. This clustering of first intake visits between ages 2 and 5 for children with autism is much higher than for persons with other developmental disabilities seeking regional center services (23%) (DDS, 2003).

The distribution of the level of cognitive ability for persons diagnosed with autism has shifted over time. In 1987, only 19% of the autistic population was classified as having no mental retardation compared to 56% in 2002. In 2002, 16% of the autistic population had mild mental retardation, approximately 10% had moderate mental retardation, and approximately 11% had severe or profound mental retardation[7] (DDS, 2003).

[4] The numbers presented in this section represent diagnosis code 1 (DSM-IV autistic disorder) and code 2 (DSM-III infantile autism, residual state) and do not include Code 9 (diagnosis of suspected autism) or other PDDs. These numbers differ from the utilization data presented in the cost section because they include all persons served by the California DDS and are not limited to only those persons affected by the mandate.

[5] This rate was calculated by summing the number of autism cases in 2002 by age (0-19 years) as presented in Table 4 of the DDS report and dividing by the total population aged 0-19 years as estimated by the census bureau at www.census.gov/popest/states/asrh/tables/SC-EST2004-02/SC-EST2004-02-06.pdf.

[6] It is possible that persons with PDDs other than autistic disorder are served by the DDS system, but to be eligible for services it must be determined that they have an impairment that constitutes a substantial handicap. The diagnosis alone does not make them eligible for DDS services, therefore the persons enrolled in the DDS system with PDDs other than autistic disorder do not represent the entire population of persons in California with these conditions.

[7] An additional 7% had an unknown level of mental retardation.

Impact of the Proposed Mandate on Public Health

Impact on Community Health (Section 1A)

As presented in the medical effectiveness section (Section I), the direct impact of the mandate would likely be a more accurate diagnosis of children with autism, a shorter time between diagnosis and referral for treatment and a younger age at diagnosis. In addition, it is likely that these improvements in diagnosis would positively impact health outcomes with early intervention, including improvements in cognitive or intellectual status, developmental and achievement status and/or progress, post-intervention placement, reclassification of diagnosis, and autism symptom reduction. However, the potential effects are difficult to quantify because of a lack of data regarding the effect of routine autism treatment on health outcomes. The positive impact of this mandate on the public's health may be limited by the availability of effective treatment programs, which may not achieve the same impacts as those observed in research trials.

Impact on Community Health where Gender and Racial Disparities Exist (Section 1B)

There is a much higher rate of autism among males compared to females in California. As of December 2002, 82% of people in California with diagnosed autism were males (DDS, 2003). The literature confirms that there are substantially higher rates of autism disorders among males with prevalence rates of autism in males three to five times higher than in females (Newschaffer and Curran, 2003; Hartung and Widiger, 1998; Yeargin-Allsopp 2003. Another study on California birth cohorts from 1987 to 1994 found prevalence differences between males and females that were stable even as the overall rate of autism increased during the study period (Croen at al., 2002a).

Beyond prevalence, there is little information regarding gender differences in the symptoms, treatment patterns, and health outcomes of autism. One study found that females diagnosed with autism were more likely to have severe to profound mental retardation compared to males (Yeargin-Allsopp et al., 2003). Another article suggests possible differences in standardized mortality rates for patients with autism (as compared to the general population) and found that these rates were more than three times higher for females than males (Shavelle and Strauss, 1998).

The literature is mixed in regards to the distribution of autism by race and ethnicity. The majority of studies have shown no significant differences in autism prevalence by race (Bertrand et al., 2001; Dyches et al., 2004; Fombonne, 2003, Yeargin-Allsopp et al., 2003) while studies on autism in California have found higher rates among Blacks (Croen et al., 2002a; Croen et al., 2002b).

The distribution of persons with autism in California by race/ethnicity is presented in Table 6. For the 1987-1994 birth cohorts, Blacks had the highest rates of autism (16.4 per 10,000) followed by Asians (14.5 per 10,000), and Whites (12.5 per 10,000), while the lowest rate was among Hispanics (7.5 per 10,000) (Croen et al., 2002a).

It has been reported that White children are diagnosed and treated for autism sooner than Black children (Mandell et al., 2002). Other researchers have found that the diagnosis of children with

autism has a positive association with the amount of economic wealth in the school system (Palmer et al, 2005). Dyches et al. (2004) argue that further research is needed to understand the potential differences in autism among immigrant and multicultural groups.

There is evidence of gender and racial/ethnic differences in the prevalence of autism in California with highest prevalence rates among males and Blacks. In addition, there is evidence of treatment disparities in that Blacks are diagnosed and treated for autism later compared to Whites. To the extent that this mandate results in earlier diagnosis and treatment for autism, it could have the potential to reduce this disparity.

Reduction of Premature Death and the Economic Loss Associated with Disease (Section 1C)

It has been reported that persons with autism have an overall mortality rate more than double that of persons without autism in California (Shavelle et al., 2001; Shavelle and Strauss, 1998). Specifically, persons with autism are more likely to die from seizures, accidents such as suffocation and drowning, and respiratory disease (Shavelle et al., 2001). Although there is evidence that persons with autism have a higher mortality rate and reduced life expectancy compared to those without autism, there is no research examining the effect of early interventions on premature death. Therefore, it was not possible to assess the impact that SB 749 would have on premature death.

The economic loss associated with autism has been examined mainly in terms of lost productivity of care-givers of autistic children. Parents of autistic children report that their career or income are negatively affected by their child's condition (Jarbrink et al., 2003; Curran et al., 2001). These effects have not been explicitly quantified in the literature. To the extent that this mandate would result in early diagnosis of autism and improve functioning in autistic children as a result of effective treatments, it is possible that the economic loss faced by society by the lost productivity of caregivers for autistic persons would be reduced. In addition, the increased functioning of children with autism may provide economic benefits in terms of increased productivity. Therefore, it is concluded that SB 749 has the potential to decrease the economic loss associated with autism.

TABLES

Table 2. Total Unit Cost of Autism Testing Procedures Before and After the Mandate

	Before	After	Comment	CPT Code	Est. Ave. Contracted Fees
Lead screening	20%	20%	Little reason for change	83655	$15
Thyroid function	10%	10%	Little reason for change	84439	$13
Metabolic screening	20%	20%	Little reason for change	80048	$12
High-resolution karyotype	40%	60%	Now paid	88262	$422
Cytogenetic DNA Probe	40%	60%	Now paid	88271	$190
MECP 2	20%	20%	Rare; little change	83890	$11
EEG	40%	40%	Little reason for change	95816	$100
EEG (facility)	40%	40%	Little reason for change	95816	$117
Cranial MRI	40%	20%	Should decrease if best practice guidelines followed	70551	$592
MRI - Facility	40%	20%	Should decrease if best practice guidelines followed	70551	$436
Allergy testing	15%	15%	Little reason for change	95044	$307
Eye exam	70%	70%	Little reason for change	92004	$89
Hearing exam (BAER)	70%	80%	Now paid	92585	$202
Hearing exam (BAER) facility	70%	80%	Now paid	92585	$100
Testing (Hours Paid)	8	13			$100
Total Cost per Patient Tested	$1,871	$2,318			

Key: **FFS = fee for service; HMO = health maintenance organization; POS = point of service; PPO = preferred provider organization. CalPERS: = California Public Employees' Retirement System.**

Table 3. Baseline (Premandate) Per Member Per Month Premium and Expenditures, California, Calendar Year 2005

	Large Group				Small Group				Individual		Public				Total Annual Expenditures
	HMO	PPO	POS	FFS	HMO	PPO	POS	FFS	HMO	PPO	CalPERS HMO	Medi-Cal HMO Over 65	Medi-Cal HMO Other	Healthy Families HMO	Total (Members)
Population currently covered	7,400,000	3,220,000	457,000	19,000	1,498,000	875,000	454,000	4,000	887,000	1,065,000	795,000	354,000	2,846,000	494,000	20,368,000
Average premium paid by employer	$187.97	$283.90	$234.95	$240.59	$161.28	$234.40	$180.93	$181.88	$0.00	$0.00	$231.96	$235.05	$86.12	$58.68	$41,860,452,000
Average premium paid by employee	$50.45	$57.87	$51.96	$63.25	$83.36	$73.27	$94.91	$37.09	$214.23	$120.38	$44.18	$0.00	$0.00	$6.32	$14,079,828,000
Total premium	$238.42	$341.77	$286.90	$303.83	$244.64	$307.67	$275.84	$218.97	$214.23	$120.38	$276.14	$235.05	$86.12	$65.00	$55,940,289,000
Deductibles, copayments paid by members	$8.44	$46.18	$18.14	$67.04	$12.49	$45.71	$21.55	$51.02	$13.04	$28.09	$9.78	$0.00	$0.00	$1.77	$4,074,893,000
Benefits not covered	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0
Total Expenditures	$246.87	$387.95	$305.04	$370.87	$257.13	$353.38	$297.39	$269.98	$227.27	$148.47	$285.92	$235.05	$86.12	$66.77	$60,015,181,000

Source: California Health Benefits Review Program, 2005.
Note: The population includes individuals in California, younger than 65 years who have private insurance (group and individual), or are enrolled in public plans subject to the Health and Safety Code, including CalPERS, Medi-Cal, or Healthy Families. It also affects people who are over 65 who are enrolled in Medi-Cal managed care plans, excluding county-organized health systems. This figure excludes individuals who work for firms that self-insure.
Key: FFS = fee for service; HMO = health maintenance organization; POS = point of service; PPO = preferred provider organization. CalPERS: = California Public Employees' Retirement System.

Table 4. Postmandate Impacts on Per Member Per Month and Total Expenditures by Insurance Plan Type, California, calendar year 2005

	Large Group				Small Group				Individual		Public				Total Annual Expenditures
	HMO	PPO	POS	FFS	HMO	PPO	POS	FFS	HMO	PPO	CalPERS HMO	Medi-Cal HMO Over 65	Medi-Cal HMO Other	Healthy Families HMO	Total (Members)
Population currently covered	7,400,000	3,220,000	457,000	19,000	1,498,000	875,000	454,000	4,000	887,000	1,065,000	795,000	354,000	2,846,000	494,000	20,368,000
Average Portion of Premium Paid by Employer	$0.0039	$0.0035	$0.0036	$0.0030	$0.0027	$0.0030	$0.0028	$0.0030	$0.0000	$0.0000	$0.0036	$0.0000	$0.0088	$0.0133	$1,012,000
Average Portion of Premium Paid by Employee	$0.0010	$0.0007	$0.0008	$0.0008	$0.0014	$0.0009	$0.0015	$0.0006	$0.0047	$0.0035	$0.0007	$0.0000	$0.0000	$0.0014	$278,000
Total Premium	$0.0049	$0.0042	$0.0044	$0.0038	$0.0042	$0.0039	$0.0042	$0.0036	$0.0047	$0.0035	$0.0043	$0.0000	$0.0088	$0.0148	$1,290,000
Covered Benefits Paid by Member (Deductibles, copays, etc.)	$0.0002	$0.0006	$0.0003	$0.0008	$0.0002	$0.0006	$0.0003	$0.0008	$0.0003	$0.0008	$0.0002	$0.0000	$0.0000	$0.0004	$68,000
Benefits not covered	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	$0.0000	-
Total Expenditures	$0.0051	$0.0047	$0.0047	$0.0047	$0.0044	$0.0045	$0.0045	$0.0045	$0.0050	$0.0043	$0.0044	$0.0000	$0.0088	$0.0152	$1,358,000
Percentage Impact of Mandate															
Insured Premiums	0.002%	0.001%	0.002%	0.001%	0.002%	0.001%	0.002%	0.002%	0.002%	0.003%	0.002%	0.000%	0.010%	0.023%	0.002%
Total Expenditures	0.002%	0.001%	0.002%	0.001%	0.002%	0.001%	0.002%	0.002%	0.002%	0.003%	0.002%	0.000%	0.010%	0.023%	0.002%

Source: California Health Benefits Review Program, 2005.
Note: The population includes individuals in California, younger than 65 years who have private insurance (group and individual), or are enrolled in public plans subject to the Health and Safety Code, including CalPERS, Medi-Cal, or Healthy Families. It also affects people who are over 65 who are enrolled in Medi-Cal managed care plans, excluding county-organized health systems. This table excludes individuals who work for firms that self-insure. Total annual expenditures are not per member per month.
Key: FFS = fee for service; HMO = health maintenance organization; POS = point of service; PPO = preferred provider organization. CalPERS: California Public Employees' Retirement System.

Table 5: Comparison of Age at Time of First Regional Center Visit Between Persons with Autism (Codes 1 and 2) and Persons without Autism, California 2002.

Age at Intake	Persons with Autism	Persons with other Developmental Disabilities
0-1 Year	9%	28%
2-5 Years	70%	23%
5+ Years	21%	49%

Source: California Department of Developmental Services (DDS) (2003). Autistic spectrum disorders, changes in the California Caseload, an update: 1999 through 2002. Department of Developmental Services, California Health and Human Service Agency, Sacramento: CA.

Table 6: Distribution of persons with autism by race/ethnicity in California for birth cohorts 1987-1994.

Race/Ethnicity	Rate (Cases per 10,000 Births)
Black	16.4
Asian	14.5
Other	14.5
White	12.5
Hispanic	7.5
Total	11.0

Source: Croen et al., 2002a. The rate was calculated using the data presented in Table 1 (autism cases/live births).

APPENDIX A
Literature Review Methods

The report by the Committee on Educational Interventions for Children with Autism (National Research Council, 2001) and the separate reviews that were prepared in lieu of this report were used for the evaluation of the effectiveness of the proposed mandate on (indirect) health outcomes.
In addition to this report, PubMed and the Cochrane Library were searched for relevant RCT's, systematic reviews or meta-analyses that were published between 2000 and 2005 and concerned comprehensive behavioral treatment for children with ASD.

Search terms for PubMed were:
Pervasive development disorder (MeSH term with subheadings Asperger Syndrome, Autistic Disorder, Childhood Schizophrenia). The search was limited for children (0-18 years), publication date from 2000-2005, English language.
The search yielded 1 RCT about intensive early intervention (Smith at al., 2000), which was already included in the NRC report. No other relevant RCTs or systematic reviews were identified.

A search in the Cochrane Library for autism OR autistic OR pervasive yielded 11 Cochrane reviews, mostly on pharmacological treatments or domain-specific interventions. One review assessed the evidence for the effectiveness of parent-mediated early intervention for young children with ASD. No conclusions could be drawn on the basis of the two small studies that were found.

To "grade" the evidence for all outcome measures, the CHBRP effectiveness team uses a system[8] with the following categories:

1. Favorable (statistically significant effect): Findings are uniformly favorable, and many or all are statistically significant.
2. Pattern[9] toward favorable (but not statistically significant): Findings are generally favorable, but there may be none that are statistically significant.
3. Ambiguous/mixed evidence: Some findings are significantly favorable, and some findings with sufficient statistical power show no effect.
4. Pattern toward no effect/weak evidence: Studies generally find no effect, but this may be due to a lack of statistical power.
5. No effect: There is statistical evidence of no clinical effect in the literature with sufficient statistical power to make this assessment.
6. Unfavorable: No findings show a statistically significant benefit, and some show significant harms.
7. Insufficient evidence to make a "call": There are very few relevant findings, so that it is difficult to discern a pattern.

[8]The foregoing system was adapted from the system used by the U.S. Preventive Services Task Force, available at http://www.ahcpr.gov/clinic/3rduspstf/ratings.htm. The medical effectiveness team also considered guidelines from the Centers for Medicare & Medicaid Services,(available at http://www.cms.hhs.gov/mcac/8b1-i9.asp), and guidelines from the Blue Cross and Blue Shield Association (available at http://www.bcbs.com/tec/teccriteria.html).
[9] In this instance, the word "trend" may be used synonymously with "pattern."

APPENDIX B
Summary of Findings on Effectiveness of Best Practice Guidelines for Screening, Diagnosis and Assessment of Autistic Spectrum Disorders

Table B-1 provides a list of published studies informing the findings on the medical effectiveness of mandating that autism be diagnosed according to the DDS' best practice guidelines. In most contexts, medical effectiveness refers to measures of how well the intervention works when applied in the usual settings (not just tightly controlled clinical trials) to a population or populations similar to those that would be affected by the mandate in California. Standards for evaluating effectiveness of an *intervention* are not easily applicable to when evaluating effectiveness of a *diagnosis*. The first approach was to examine the literature for evidence supporting or (or not supporting) the assumption that applying the recommendations from the best practice guidelines would result in improved diagnostic accuracy. A secondary goal was to estimate how changes in diagnosis would impact outcomes over a one-year period. Full bibliographic information for citations is found in the list of references at the end of this report.

Table B-1. Summary of Publications on Effectiveness of Best Practice Guidelines for Screening, Diagnosis and Assessment of Autistic Spectrum Disorder

Citation	Type of study	Intervention vs. Comparison Group	Population Studied	Location
Howlin and Moore, 1997	Survey	1,295 parent members of autistic societies who were seeking a diagnosis for their child. No comparison group included	Parents of children with Autistic Spectrum Disorder	United Kingdom
National Research Council, 2001	Review	N.A.	N.A.	N.A.
Lovaas, 1987; McEachin et al., 1993	Matched group comparison	19 children receiving intensive intervention (40 hr/wk) for 2 or more years vs. 19 children receiving minimal treatment (<10 hr/wk) vs. 21 children receiving interventions though community systems	Children diagnosed with autism; mean chronological age 34 months, mean IQ 60	CA, Los Angeles area
Birnbrauer and Leach, 1993	Matched group comparison	9 children receiving 28.7 hr/wk intervention based on Lovaas's model for 2 years vs. 5 non-treated control children	Children diagnosed with autistic disorder, PDD or PDD-NOS; mean chronological age 39 months, mean IQ 60.	Australia
Sheinkopf and Siegel, 1998	Retrospective matched group comparison	11 children having received intervention for 20 hr/wk for 15 months based on Lovaas's model, matched with 11 control children otherwise treated	Children diagnosed with autistic disorder or PDD; mean chronological age 33 months, mean IQ 62.	CA, San Francisco Bay area

Citation	Type of study	Intervention vs. Comparison Group	Population Studied	Location
Smith and Groen., 2000	Randomized controlled trial	28 children were randomly assigned to intensive treatment in the UCLA program 30 hr/wk for 2 to 3 years, or to parent training	Children diagnosed with autistic disorder or PDD-NOS; mean chronological age 36 months, mean IQ 50.	CA, Los Angeles area

N.A. = Not Applicable
RCT = Randomized Controlled Trial

Table B-2 summarizes evidence of effectiveness by health outcome from the diagnostic process (Diagnostic Outcomes) and later intervention (Indirect Outcomes). Results of each study are shown as statistically significant (Sig), meaning that results are unlikely to have occurred just by chance, or not statistically significant (NS), meaning that results could have been obtained by chance more than one time in 20 even if there was no true difference. The direction of results is also categorized as being "favorable" (fav) or "not favorable" (not fav).

Table B-2. Summary of Evidence of Effectiveness by outcome of Best Practice Guidelines for Screening, Diagnosis and Assessment of Autistic Spectrum Disorder

Diagnostic outcomes:

Number of correctly diagnosed and misdiagnosed children with autism—Insufficient Evidence

Data source	Results	Categorization of Results (Significance, Direction)
Expert opinion	Increase in number of correctly diagnosed children, decrease in number of misdiagnosed children	N.A.

Time between referral and diagnosis and Average age at diagnosis—Insufficient Evidence

Data source	Results	Categorization of Results (Significance, Direction)
Expert opinion	Decrease in time between referral and diagnosis, decrease in age at diagnosis	N.A.

Parent satisfaction—Favorable

Data source	Results	Categorization of Results (Significance, Direction)
Howlin and Moore, 1997	Higher parent satisfaction when diagnosis is made during preschool years, degree of satisfaction related to time between referral and final diagnosis	Sig, favorable

Indirect outcomes:

Data source	Results	Categorization of Results (Significance, Direction)
National Research Council, 2001	Domain specific interventions and comprehensive treatment programs yield positive results on a wide range of outcomes but the level of evidence is low	Mixed evidence
Lovaas, 1987; McEachin et al., 1993	First follow-up (6-7 years old): mean IQ experimental group 83, 2 control groups 52 and 57 8/19 in regular class without support vs. 0/19 and 1/21 in control groups Second follow-up (12-13 years old): mean IQ experimental group 85, control group 54 8/19 in regular class without support vs. 0/19 in control group No group difference on Vineland Personality scores	Sig, favorable
Birnbrauer and Leach, 1993	No group comparison of outcome data, no statistical analyses reported. At 24 months after intake, 4 out of 9 children were considered to have made high improvement in adaptive behavior, language skills and IQ score, vs. 1 out of 5 controls	not tested
Sheinkopf and Siegel, 1998	At 19 months after intake: mean IQ experimental group 90 vs. control group 62 ($p=0.01$) No difference in number of DSM-III-R symptoms Lower post-treatment severity rating ($p=0.014$)	Sig, favorable
Smith 2000	At age of 7-8 years: mean IQ experimental group 66 vs. control group 50 ($p<0.05$) Visual-spatial skills (Merrill-Palmer) 64 vs. 49 ($p<0.05$) No difference in Language (Reynell) and adaptive behavior (Vineland) School placement: 4/15 children in regular education, and 11/15 in regular education with support vs. 3/13 children in regular education with support	Sig. favorable

APPENDIX C
Cost Impact Analysis: General Caveats and Assumptions

This appendix describes general caveats and assumptions used in conducting the cost impact analysis. For additional information on the cost model and underlying methodology, please refer to the CHBRP Web site, http://www.chbrp.org/costimpact.html.

The cost analysis in this report was prepared by Milliman and University of California, Los Angeles, with the assistance of CHBRP staff. Per the provisions of AB 1996 (California Health and Safety Code, Section 127660, et seq.), the analysis includes input and data from an independent actuarial firm, Milliman. In preparing cost estimates, Milliman and UCLA relied on a variety of external data sources. The *Milliman Health Cost Guidelines* (HCG) were used to augment the specific data gathered for this mandate. The HCGs are updated annually and are widely used in the health insurance industry to estimate the impact of plan changes on health care costs. Although this data was reviewed for reasonableness, it was used without independent audit.

The expected costs in this report are not predictions of future costs. Instead, they are estimates of the costs that would result if a certain set of assumptions were exactly realized. Actual costs will differ from these estimates for a wide variety of reasons, including:

- Prevalence of mandated benefits before and after the mandate different from our assumptions
- Utilization of mandated services before and after the mandate different from our assumptions
- Random fluctuations in the utilization and cost of health care services

Additional assumptions that underlie the cost estimates presented here are:

- Cost impacts are only shown for people with insurance.
- The projections do not include people covered under self-insurance employer plans because those employee benefit plans are not subject to state-mandated minimum benefit requirements.
- Employers and employees will share proportionately (on a percentage basis) in premium rate increases resulting from the mandate. In other words, the distribution of premium paid by the subscriber (or employee) and the employer will be unaffected by the mandate.

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

- Population shifts by type of health insurance coverage. If a mandate increases health insurance costs, then some employer groups or individuals may elect to drop their coverage. Employers may also switch to self-funding to avoid having to comply with the mandate.
- Changes in benefit plans. To help offset the premium increase resulting from a mandate, members or insured may elect to increase their overall plan deductibles or copayments. Such changes would have a direct impact on the distribution of costs between the health plan and the insured person, and may also result in utilization reductions (i.e., high levels of patient cost sharing result in lower utilization of health care services). Milliman did not include the effects of such potential benefit changes in its analysis.

- Adverse Selection. Theoretically, individuals or employer groups who had previously foregone insurance may now elect to enroll in an insurance plan postmandate because they perceive that it is to their economic benefit to do so.
- Health plans may react to the mandate by tightening their medical management of the mandated benefit. This would tend to dampen our cost estimates. The dampening would be more pronounced on the plan types that previously had the least restrictive medical management (i.e., FFS and PPO plans).
- Variation in existing utilization and costs, and in the impact of the mandate, by geographic area and delivery system models: Even within the plan types we modeled (HMO, PPO, POS, and FFS), there are variations in utilization and costs within California. One source of difference is geographic. Utilization differs within California due to differences in the health status of the local commercial 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 health plans and providers.

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, the impact was estimated on a statewide level.

APPENDIX D
Information Submitted by Outside Parties for Consideration for CHBRP Analysis

In accordance with its policy to analyze evidence submitted by outside parties during the first two weeks of each 60-day review of a proposed benefit mandate, CHBRP received the following submissions:

No information was submitted to date.

CHBRP analyzes all evidence received during the initial public submission period according to its relevance to the proposed legislation and the program's usual methodological criteria. For more information about CHBRP's methods, to learn how to submit evidence relevant to an on-going mandate review, or to request email notification of new requests CHBRP receives from the California Legislature, please visit: http://www.chbrp.org.

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A group of faculty and staff undertakes most of the analysis that informs reports by the California Health Benefits Review Program (CHBRP). The CHBRP **Faculty Task Force** comprises rotating representatives from six University of California (UC) campuses and three private universities in California. In addition to these representatives, there are other ongoing contributors to CHBRP from UC. This larger group provides advice to the CHBRP staff on the overall administration of the program and conducts much of the analysis. The CHBRP **staff** coordinates the efforts of the Faculty Task Force, works with Task Force members in preparing parts of the analysis, and coordinates all external communications, including those with the California Legislature. The level of involvement of members of CHBRP's Faculty Task Force and staff varies on each report, with individual participants more closely involved in the preparation of some reports and less involved in others.

As required by CHBRP's authorizing legislation, UC contracts with a certified actuary, Milliman, to assist in assessing the financial impact of each benefit mandate bill. Milliman also helped with the initial development of CHBRP's methods for assessing that impact.

The **National Advisory Council** provides expert reviews of draft analyses and offers general guidance on the program to CHBRP staff and the Faculty Task Force. CHBRP is grateful for the valuable assistance and thoughtful critiques provided by the members of the National Advisory Council. However, the Council does not necessarily approve or disapprove of or endorse this report. CHBRP assumes full responsibility for the report and the accuracy of its contents.

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