

**STATE OF CALIFORNIA
DEPARTMENT OF INSURANCE
45 Fremont Street, 21st Floor
San Francisco, California 94105**

**NOTICE OF PROPOSED EMERGENCY ACTION PURSUANT TO GOVERNMENT
CODE SECTION 11346.1 AND INSURANCE CODE SECTION 12921.7**

TEXT OF REGULATION

Add to Subchapter 3 of Chapter 5 of Title 10 of the California Code of Regulations new

Article 15.2: Mental Health Parity

Adopt: Section 2562.1. Scope of Article.

(a) This article shall apply only to coverage for services or treatments rendered for pervasive developmental disorder or autism under a policy of health insurance as defined in Insurance Code section 106.

(b) This article shall not apply to a policy described in Subdivision (g) of Insurance Code section 10144.5.

NOTE: Authority cited: Sections 10144.5, 12921 and 12926, Insurance Code; *CalFarm Ins. Co. v. Deukmejian*, 48 Cal.3d 805 (1989); *20th Century Ins. Co. v. Garamendi*, 8 Cal. 4th 216 (1994). Reference: Section 10144.5, Insurance Code; *Harlick v. Blue Shield of California*, 686 F.3d 699 (2012).

Adopt: Section 2562.2. Medical Necessity; Case Management and Utilization Review.

(a) Nothing in this article shall be construed to mandate coverage of services that are not medically necessary.

(b) Nothing in this article shall be construed to preclude an insurer from utilizing the following in accordance with the provisions of this article and Insurance Code sections 10144.5 and 10144.51:

- (1) Case management;
- (2) Managed care;
- (3) Network providers;
- (4) Utilization review techniques;
- (5) Prior authorization;
- (6) Copayments; or
- (7) Other cost sharing.

NOTE: Authority cited: Sections 10144.5, 12921 and 12926, Insurance Code; *CalFarm Ins. Co. v. Deukmejian*, 48 Cal.3d 805 (1989); *20th Century Ins. Co. v. Garamendi*, 8 Cal. 4th 216 (1994). Reference: Section 10144.5, Insurance Code; *Harlick v. Blue Shield of California*, 686 F.3d 699 (2012).

Adopt: Section 2562.3. Prohibited Limits on Coverage.

For purposes of Insurance Code section 10144.5:

(a) If treatment or services are:

(1) Medically necessary;

(2) Rendered to an individual diagnosed with a health condition indicated in Subdivision (a) of Insurance Code section 10144.5; and

(3) Rendered for the purpose of treating that condition:

(b) Then an insurer shall not impose:

(1) An annual visit limit; or

(2) An annual dollar limit when the same limit is not equally applicable to all benefits under the policy.

NOTE: Authority cited: Sections 10144.5, 12921 and 12926, Insurance Code; *CalFarm Ins. Co. v. Deukmejian*, 48 Cal.3d 805 (1989); *20th Century Ins. Co. v. Garamendi*, 8 Cal. 4th 216 (1994). Reference: Section 10144.5, Insurance Code; *Harlick v. Blue Shield of California*, 686 F.3d 699 (2012).

Adopt: Section 2562.4. Behavioral Health Treatment for Pervasive Developmental Disorder or Autism.

(a) Scope of Section. In addition to the limitations on scope set forth in Section 2562.1 of this article, the scope of this Section 2562.4 shall be further limited by the following sentence: This section does not apply to a policy or plan described in Subdivision (d) of Insurance Code section 10144.51.

(b) Definition. As used in this section, the term “behavioral health treatment” has the meaning set forth in Paragraph (c)(1) of Insurance Code section 10144.51.

(c) In cases where behavioral health treatment is medically necessary, an insurer shall not deny or unreasonably delay coverage:

(1) Based on an asserted need for cognitive or intelligence quotient (IQ) testing;

(2) On the grounds that behavioral health treatment is experimental, investigational, or educational; or

(3) On the grounds that behavioral health treatment is not being, will not be, or was not, provided or supervised by a licensed person, entity or group when the provider or supervisor in question is certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies.

NOTE: Authority cited: Sections 790.10, 10144.5, 10144.51, 12921 and 12926, Insurance Code; *CalFarm Ins. Co. v. Deukmejian*, 48 Cal.3d 805 (1989); *20th Century Ins. Co. v. Garamendi*, 8 Cal. 4th 216 (1994). Reference: Sections 790.03, 10144.5(a) and (c), 10144.51, Insurance Code.

**FINDING OF EMERGENCY/DESCRIPTION OF THE JUSTIFICATION FOR
ADOPTION OF THE REGULATION AS AN EMERGENCY REGULATION**

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OPPORTUNITY FOR INTERESTED PARTIES TO SUBMIT COMMENTS TO THE OFFICE OF ADMINISTRATIVE LAW

Paragraph (a)(2) of Government Code section 11346.1 requires that, at least five working days prior to submission of the proposed emergency action to the Office of Administrative Law, the adopting agency provide a notice of the proposed emergency action to every person who has filed a request for notice of regulatory action with the agency. After submission of the proposed emergency to the Office of Administrative Law, the Office of Administrative Law shall allow interested persons five calendar days to submit comments on the proposed emergency regulations as set forth in Government Code section 11349.6.

EXPRESS FINDING OF EMERGENCY

The Insurance Commissioner has determined that an emergency exists. This regulation is being adopted on an emergency basis for the immediate preservation of the public health and safety, and general welfare, within the meaning of Government Code Section 11346.1.

Emergency regulations are necessary: (1) because of widespread confusion among insurers and policyholders regarding the coverage requirements for medically necessary mental health services for autism, including behavioral health treatment such as Applied Behavior Analysis (ABA) therapy under California’s mental health parity law; and (2) to ensure that children

receive early treatment that will enable them to succeed in school and society, at insurer expense, saving the taxpayers approximately \$138.8 million to \$197.8 million over the next year and nearly \$2 billion in costs over eighteen years that should properly be borne by insurers.

Therefore, the Department of Insurance proposes this emergency regulation to clarify insurer obligations and ensure uniform and timely application of the Insurance Code provision requiring coverage of medically necessary mental health services, including ABA, for policyholders with autism under the mental health parity law.

EXECUTIVE SUMMARY

An Emergency Regulation is crucially necessary to elucidate to insurers their obligations under California mental health parity law requiring treatment of children with autism. Autism is a neurobiological disorder and developmental disability that severely limits a child's ability to interact with others, seriously hinders verbal and nonverbal communication and social interaction, and is characterized by repetitive problematic behaviors such as self-mutilation, aggression and tantrums. Unless the Emergency Regulation is adopted, California taxpayers will incur approximately \$138.8 million to \$197.8 million in costs in special education and Regional Center services for children with autism before a permanent regulation can be promulgated. Additionally, approximately 8,500 such privately-insured California children between the ages of 3 and 5 and about 42,000 children who are between the ages of 3 and 21¹ will be deprived of the benefits of early intensive behavioral treatment; and may be relegated to a lifetime of disability; deprived of the ability to communicate and achieve academically; denied the life skills needed for independent living; and consigned to a bleak future and ultimate institutionalization.

The escalating prevalence of autism among California children has resulted in a public health crisis. Insurer denials and delays of mandated treatment are exacerbating this crisis, causing substantial harm to the public health and welfare and making enormous and unsustainable demands on scarce governmental finances and services, such as special education and adult habilitative treatment. California health insurers are paying for only 9-13% of autism treatment, leaving taxpayer funded school districts and Regional Centers to bear burdens that they can ill afford in these difficult economic times. Among the medically necessary services for autism that insurers are resisting providing is behavioral therapy, including ABA. This therapy is transformative, enabling 47% of treated children to be mainstreamed by first grade and increasing IQ and success in regular school classrooms for fully 90% of treated children. Other medically necessary services, on which insurers are imposing inappropriate visit limits, are speech therapy that enables children to communicate with their families, schoolmates, and teachers and occupational therapy that enables them to perform tasks essential to self-care such as dressing and eating. Providing behavioral, speech, and occupational therapy to children with autism allows them to succeed in school, participate productively in family and community

¹ See Easter Seals Disability Servs., 2012 State Autism Profiles California (2012), available at http://www.easterseals.com/site/DocServer/2012_Autism_California.pdf?docID=155122 (citing State of California's Report in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education). The 42,000 estimated figure of total lives affected by CDI regulation promulgation takes the total number of California ASD children (reported in 2010-11) and multiplies that figure by the number of privately California ASD children (63.9% are privately insured).

activities, obtain gainful employment, and avoid institutionalization as adults, thereby lessening demands on public resources and services over their lifetimes.

California's Mental Health Parity Act, which the proposed Emergency Regulation interprets, was passed in 1999 to remedy a history of inadequate insurance coverage for mental illnesses, which deprived insureds of the benefits of policies on which they had paid premiums. The genesis for its passage was legislative recognition that autism and the other listed severe mental conditions are seriously disabling and that inadequate coverage for their treatment causes significant social harm. The Legislature found that the failure to provide adequate coverage for mental illnesses in private health insurance policies resulted in significantly increased expenditures for state and local governments and sought to mitigate the harm to the public health and welfare by mandating coverage of medically necessary treatment, thereby shifting the cost to insurers.

The scientific community agrees that the deficits in basic skills usually present in infants and toddlers with autism, the pervasiveness of these deficits, and the very early onset of symptoms require comprehensive interventions that begin as soon as the disorders are recognized. Many studies demonstrate that early intervention is the optimal treatment approach, leading to such significant improvement that children are able to function successfully in their homes, school classrooms, and communities without specialized services and may no longer be autistic.

Insurers are out of compliance with both the law and public policy despite the existence of the Parity Act, the passage of Senate Bill (SB) 946 that reconfirms the mandate for behavioral health treatment for autism and expands the definition of qualified autism service providers, and the scientific literature describing the importance of early intensive intervention. Enforcement actions by the Departments of Insurance (CDI) and Managed Health Care (DMHC) have not prevented insurers and health plans from continuing to improperly deny and delay treatment. CDI's Consumer Services division has received 71 complaints, reflecting cumulative delays of 12,864 days, or 35.2 years, in obtaining medically necessary treatment. A market conduct examination of another insurer identified 1,539 instances of improper claims payment practices involving behavioral and speech therapy for autism. In addition, approximately 1,600 individuals are transitioning from Regional Centers to insurers for behavioral health treatment for autism and experiencing delays and denials for seven months after the effective date of SB 946. In January 2013, the State Council of Development Disabilities (SCDD) reported that three and one-half months may pass before children going from Regional Center services to private ABA treatment providers begin receiving services. Insurer failures to comply with California statutes and promptly provide medically necessary behavioral, speech and occupational therapy cause severe consequences to children with autism, including immediate regression, stifled improvement, severe impairment, and permanent developmental damage.

Insurer conduct also generates dire results for governmental entities. The lifetime incremental societal cost for an individual with autism is \$3.2 million. Those costs, many of which should be borne by health insurers, include impacts on public education and special education programs in California's public school system. Services under the Lanterman Act included \$638 million for services for 16,367 children with autism between the ages of 3 and 6 in 2010. Additionally, nearly 40,000 California children with autism between the ages of 3 and 22 now receive special education services at approximate average annual per capita costs ranging from \$25,000 to \$90,000 and totaling \$1 to 3.6 billion annually.

Enormous and burdensome costs also flow to the State when Regional Centers provide therapies that insurance companies have refused to cover. The Department of Developmental Services (DDS) reported that autism is the fastest growing developmental disability in California and estimated that Regional Centers and developmental centers will be serving as many as 70,000 people with autism by June 2012. That Department further estimated that the General Fund would realize cost savings of \$80 million from enactment of SB 946 based on the assumption that insured individuals would no longer be receiving autism treatments from Regional Centers. That transition has not yet transpired, jeopardizing anticipated cost savings to the state and causing delay and damage to the approximately 1,600 insured children and families who have been Regional Center clients.

Finally, without early intensive treatment for autism, California will be facing an estimated 19,000 autistic adults who need DDS-funded adult habilitative services and employment support by 2018. The further costs for those services are estimated to be at least \$190 million because each individual will require at least \$10,000 for care, education and support services each and every year of their adult lives.

Therefore, in order to ensure that insurers provide medically necessary treatment for children with autism and avoid continued devastating financial consequences to state coffers, CDI must clarify insurers' obligations to provide such services to this vulnerable population, subject only to financial conditions applicable equally to all benefits under the policy, and do so as expeditiously as possible.

DESCRIPTION OF SPECIFIC FACTS THAT CONSTITUTE THE EMERGENCY/ DESCRIPTION OF THE PROBLEM

A. An Emergency Regulation Is Needed to Clarify That Insurers Must Provide All Medically Necessary Treatment Under the Mental Health Parity Act

1. Autism Has Reached Epidemic Proportions But Insurer Denials and Delays of Treatment Are Harming the Public Health, Welfare and Finances

A 2007 report by the Legislative Blue Ribbon Commission on Autism characterized the dramatic and sustained rise in Autism Spectrum Disorders (ASD) as a "Public Health Crisis" in California.² The Centers for Disease Control and Prevention (CDC) estimated the prevalence of ASD as 1 in 88 children in 2012—a 23 percent increase in two years.³ The CDC also noted that the incidence of ASD for boys is 1 in 54; while for girls, it is 1 in 242.⁴ To put these numbers into context, ASDs are more common than childhood cancer, juvenile diabetes and pediatric

² Cal. Legislative Blue Ribbon Comm'n on Autism, *The California Legislative Blue Ribbon Commission on Autism Report: An Opportunity to Achieve Real Change for Californians with Autism Spectrum Disorders* (2007), available at <http://senweb03.senate.ca.gov/autism/documents/whatsnew/Commission's%20Report%20to%20the%20Governor%20&%20Legislature.pdf>.

³ Autism and Developmental Disabilities Monitoring Network, *Community Report From the Autism and Developmental Disability Monitoring (ADDM) Network: Prevalence of Autism Spectrum Disorders (ASDs) Among Multiple Areas of the United States in 2008* (2012), available at <http://www.cdc.gov/ncbddd/autism/documents/ADDM-2012-Community-Report.pdf>.

⁴ *Id.*

AIDS combined.⁵ California leads the nation in the number of individuals with ASD, at least 72,000, but health insurers are paying for only 9-13% of autism treatment.⁶ That means taxpayer funded school districts and Regional Centers must shoulder the bulk of the burden, at 42% and 23% respectively, while parents who can afford to private pay carry 23% of the cost.⁷

Managing this crisis requires prompt and effective regulatory action to mitigate further serious harm to the public health and welfare. Transformative treatment is available which allows almost half of treated children with ASD to be mainstreamed by first grade.⁸ The decisions in CDI's and DMHC's Independent Medical Reviews (IMR) consistently find behavioral health treatment, such as ABA, as well as speech and occupational therapies to be medically necessary. The scientific literature relied on by these independent medical reviewers demonstrates that treatment is efficacious, well-documented through decades of research, and consistent with the recommendations from the Office of the Surgeon General, the National Institute of Mental Health, and other national governmental agencies, scientific institutions and professional organizations.

Yet insurers have engaged in a history of denying these medically necessary treatments for unsupportable reasons. For years they denied ABA therapy as experimental and investigational despite findings by the clinician reviewers that ABA therapy is neither experimental nor investigational and leads to significant improvements in IQ, communication and language skills, and adaptive behaviors, as well as to reduction in self-injurious and other aberrant behaviors. The reviewers further note that providing ABA to children with autism enables them to learn in school, succeed at work, and participate productively in family and community activities.

Senate Bill (SB) 946, signed into law by Governor Brown in October, 2011, added Section 10144.51 to the Insurance Code. But even after the passage of SB 946 reconfirmed the mandate for behavioral health treatment for autism, insurers are imposing barriers to coverage as described in section B.2 below. In addition, because insurers are now indisputably required to provide behavioral health treatment for autism, approximately 1,600 families will no longer be eligible for treatment at the Regional Centers, which are attempting to transition those families to insurers' contracted providers and encountering difficulties, barriers and delays.⁹

⁵ Ctrs. for Disease Control and Prevention, Pediatric HIV Surveillance (2012), *available at* http://www.cdc.gov/hiv/topics/surveillance/resources/slides/pediatric/slides/2010_Pediatric_HIV.pdf (stating pediatric AIDS occurs at a rate of less than 20 out of 100,000); *National Survey of Children's Health*, Data Res. Ctr. for Child and Adolescent Health (2012), <http://www.childhealthdata.org> (showing childhood diabetes occurs at a rate of 400 per 100,000 based on the Child and Adolescent Health Measurement Initiative); *United States Cancer Statistics (USCS): 1999–2009 Cancer Incidence and Mortality Data*, Ctrs. for Disease Control and Prevention, <http://www.cdc.gov/uscs> (last visited Feb. 18, 2013) (illustrating that childhood cancer occurs at a rate of 15.5 per 100,000).

⁶ Autism Soc'y of Cal., *Autism in California 2012 Survey* (2012), *available at* https://autismsocietyca.org/uploads/ASC_Survey_April_2012.pdf. Autism Society of California, *Autism in California 2012 Survey* (April, 2012), https://autismsocietyca.org/uploads/ASC_Survey_April_2012.pdf.

⁷ *Id.*

⁸ Horner et al., *Problem Behavior Interventions for Young Children with Autism: A Research Synthesis*, 32 *J. Autism and Developmental Disorders* 423, 431 (2002); John J. McEachin et al., *Long-term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment*, 97 *Am. J. on Mental Retardation* 359, 359-72 (1993).

⁹ Letter from Karen Fessel, Dr PH, Autism Health Ins. Project, to Patricia Sturdevant, Deputy Comm'r, Cal. Dep't of Ins. (Oct. 24, 2012) (on file with CDI and attached as Addendum G).

A 2012 Survey by the Autism Society of California (“Survey”) reveals the extent of health insurer denials of coverage. The Survey not only determined that health insurers are funding the smallest share of the cost of autism treatments at only 9-13%, but have the highest rates of denials for the four most common therapies. It found that health insurers denied 36% of claims for ABA, speech, occupational and physical therapy and funded 64%, while Regional Centers denied 18% and funded 82%, and school districts denied 12% and funded 88% of claims.¹⁰

In late summer 2012, CDI challenged improper denials by two major insurers who are imposing visit limits on speech and occupational therapy for children with autism. Shortly thereafter, on August 21, 2012, the Association of California Life & Health Insurance Companies (ACLHIC) sent CDI a Request for Rulemaking and sought cessation of mental health parity enforcement.

This pattern of insurer delays and denials of medically necessary care to ASD children causes serious harm to the public health and safety and the general welfare. Delays and denials of treatment relegate California’s ASD children to a lifetime of disability and engender enormous societal costs for their special education in California schools, lost productivity of family members, and increased costs for adult habilitative treatment, as described in Section C below.

2. The Regulation is Urgently Needed to Implement the Mental Health Parity Act and Achieve the Legislative Purpose to Avoid Significant Social Harm

California passed the Mental Health Parity Act (MHPA) in 1999 to remedy a history of inadequate insurance coverage for mental illnesses.¹¹ Wholesale denials and delays of treatment to insureds had deprived them and members of their families of the benefits of policies for which they had paid premiums. As a consequence, the cost and burden of providing treatment for these severe mental conditions was improperly shifted to governmental entities and taxpayers.

The genesis for passage of the MHPA was legislative recognition that autism and the other nine listed severe mental conditions are seriously disabling and that inadequate coverage for their treatment results in significant social harm. The Legislature specifically found that insurers’ failure to cover adequate treatment shifts the burden to state and local governments by forcing policyholders to seek treatment from local Regional Centers and other public agencies.¹² In the historical and statutory notes of the legislation, the drafters stated that inadequate treatment “causes relapses and untold suffering as well as homelessness . . . and other significant social problems experienced by individuals with mental illness and their families.” They concluded:

¹⁰ Autism Soc’y of Cal., *supra* note 6, at 20.

¹¹ Cal. Assem. Comm. on Health, Committee Analysis of A.B. 88: Mental Health Parity Act, Reg. Sess. (Mar. 9, 1999), *available at* http://www.leginfo.ca.gov/pub/99-00/bill/asm/ab_0051-0100/ab_88_cfa_19990309_113734_asm_comm.html (“The author argues that this bill will prohibit discrimination against people with biologically-based mental illnesses, dispel artificial and scientifically unsound distinctions between mental and physical illnesses, and require equitable mental health coverage among all health plans and insurers to prevent adverse risk selection by health plans and insurers. The author stresses that mental illness is treatable in a cost-effective manner and that the failure of the health care system to provide adequate treatment for persons with mental illness has been costly not only to mentally ill individuals and their families, but to society as a whole and particularly to state and local governments.”).

¹² Cal. Assem. Comm. on Appropriations, Committee Analysis of A.B. 88: Mental Health Parity Act, Reg. Sess. (Mar. 24, 1999), *available at* http://www.leginfo.ca.gov/pub/99-00/bill/asm/ab_0051-0100/ab_88_cfa_19990324_184728_asm_comm.html.

“The failure to provide adequate coverage for mental illnesses in private health insurance policies has resulted in significant increased expenditures for state and local governments.”¹³

The legislative history cites studies of the financial impact of the 1998 Federal Mental Health Parity Act, including an April 1998 United States Department of Health and Human Services report stating that full parity for mental health and substance abuse in managed care plans would increase premiums less than 1%.¹⁴ Modeling state law after the 1998 federal law, the California Legislature fully intended the California law to shift significant costs to private insurers.

The MHPA requires all health plans and insurers within the scope of the Act to provide coverage for the diagnosis and medically necessary treatment of the enumerated severe mental illnesses, including autism, subject to the stated condition. It is codified in California Insurance Code (CIC) Section 10144.5, and Health and Safety Code Section 1374.72, in virtually identical terms. The Insurance Code specifies that “every policy of disability insurance that covers hospital, medical or surgical expenses in this state . . . shall provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses of a person of any age, and of serious emotional disturbance of a child” Autism is included in the list of conditions for which medically necessary treatment is mandated, subject to financial terms and conditions that are applied equally to all benefits under the policy.

The legislative history of the MHPA strongly supports the proposed Emergency Regulation. The Legislature intended to change insurers’ practices and lessen social harm by requiring coverage for the adequate treatment of autism and other severe mental health conditions. The MHPA was the State’s attempt to mitigate and manage the public mental health crisis. But private insurers are undermining this ameliorating public policy by continuing to impose barriers to treatment.

As is stated more fully in Part B.2., insurers have engaged in a practice of denying and delaying medically necessary treatment for autism, which shifts those costs to the state. Unfortunately, California’s faltering economy has required implementing a series of devastating cuts to an already strained budget, leaving many ASD individuals and their families with fewer publicly-funded treatment options. This fact underscores the importance of private insurer compliance with state mental health parity law. Therefore, in order to ensure that insurers properly and timely provide medically necessary treatment for children with ASD, CDI must clarify insurers’ obligations to provide medically necessary mental health services to this vulnerable population.

¹³ A.B. 88 Mental Health Parity Act § 1(b)(2)-(3), 1999 Leg., Reg. Sess. (Cal. 1999) (stating that “limitations in coverage for mental illness in private insurance policies have resulted in inadequate treatment for persons with these illnesses”).

¹⁴ Cal. Assem. Comm. on Appropriations, Committee Analysis of A.B. 88: Mental Health Parity Act, Reg. Sess. (Mar. 24, 1999), *available at* http://www.leginfo.ca.gov/pub/99-00/bill/asm/ab_0051-0100/ab_88_cfa_19990324_184728_asm_comm.html (“The [National Advisory Mental Health] [C]ouncil concluded that in states where managed care is prevalent, such as in California, full mental health parity would result in premium increases of less than one percent.”).

B. Children with Autism Are Suffering Imminent, Serious and Irreparable Harm Because of Insurers' Failure to Provide Crucially Needed Treatment

1. Treatment, and Especially Early Treatment, Is Transformative and May Prevent Permanently Impaired Development and a Lifetime of Disability

Behavioral health, speech, and occupational therapies have been recognized in the scientific literature as appropriate treatments for ameliorating the core deficits of autism, which include severe, pervasive impairment in social interaction, verbal and nonverbal communication, and repetitive behaviors. Therefore, the MHPA requires insurers to provide coverage for these therapies to treat autism whenever they are medically necessary, subject only to the financial terms and conditions that apply equally to all benefits under the policy.

Children with autism may be moderately to severely impaired and may exhibit the following problem behaviors: aerophagy/swallowing, aggression, bruxism/teeth grinding, coprophagy/feces eating, dawdling, destruction, depression, disruption/tantrum, drooling, elective mutism, elopement (running), feces smearing, fears, food refusal, food theft, genital stimulation, hallucinating, hyperactive behavior, hyperventilation, inappropriate vocalizations, insomnia, noncompliance, obesity, obsessive compulsive disorder, pica, public disrobing, rapid eating, rectal digging, rumination, seizure behavior, self-injurious behavior, stereotypy, tongue protrusion, and vomiting.¹⁵

The scientific literature further recognizes that early intervention is critically important to enable these children to function in their families, schools and society. The seminal Lovaas study found that 47% of children who received early intensive behavioral intervention therapy could be mainstreamed into regular classrooms by first grade. Those children also significantly outperformed those in the two control groups. Although all three groups were similar at intake, by age 7, the mean IQ of the ABA treatment group was 83 compared to 52 and 58 in the two control groups, respectively. Most significantly, 9 of the 19 ABA treated children received passing grades without special assistance in classes for typically developing children, compared to only 1 of 40 in the two control groups.¹⁶

In a follow-up study by Lovaas and colleagues, when the children averaged 12 years old, the intensively ABA-treated children maintained their gains over the control group. They also functioned more satisfactorily on adaptive behavior and personality measures. Of the nine experimental subjects who had achieved the best outcomes at age 7, 8 were indistinguishable from average children on tests of intelligence and adaptive behavior. Thus, behavioral treatment produces long-lasting and significant gains for many young children with autism.¹⁷

ABA was found effective in another study comparing the results of intensive ABA treatment with eclectic special education services for a year. The 13 children who received ABA made significantly larger gains than the comparison group — 17 points in IQ, 13 points in language comprehension, 23 points in expressive language, and 11 points in adaptive behavior. The

¹⁵ Horner, *supra* note 8, at 431.

¹⁶ O. Ivar Lovaas, *Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children*, 55 *J. of Consulting and Clinical Psychology* 3, 3-9 (1987).

¹⁷ McEachin, *supra* note 8, at 359-72.

comparison group increased only 4 points in IQ, decreased by one point in language comprehension and by 2 points in expressive language, and were unchanged on adaptive behavior. ABA-treated children also achieved average standardized test scores more often than the control group.¹⁸

A 2005 survey of the autism treatment literature emphasized the significance of early diagnosis and treatment, citing many studies finding that children with ASDs who receive services prior to 48 months of age make greater improvements than those who enter programs after that age. In one study, 22% of the children had IQ changes from mental retardation to average. The author also found that behavioral approaches resulted in good outcomes for teaching language content, including single word vocabulary, describing objects and pictures, responding to questions, and increasing the intelligibility of speech. The author concluded that the evidence from a variety of programs and studies suggests that early intervention leads to better outcomes.¹⁹

As that survey indicates, the importance of early treatment is generally accepted within the scientific community. A National Institutes of Health meeting in 2006, attended by scientists who focus on investigating treatment of ASDs, revealed a consensus that early intervention is the most effective for significantly altering outcomes. Participants noted that the deficits in very basic skills that are usually present in infants and toddlers with ASD, the pervasiveness of these deficits, and the very early onset of symptoms require interventions that are as comprehensive as the disorders are pervasive, and that begin as early as the disorders are recognized.²⁰

A 2010 study of toddlers with ASD as young as 12 months involved behavioral intervention programs supervised by an experienced lead therapist in consultation with speech-language pathologists and occupational therapists. These researchers found significantly increased IQ scores after one year of treatment and significantly improved cognitive ability, receptive and expressive language skills, and adaptive behavior after two years of treatment, compared to children in the control group receiving community based services. Moreover, there were significant differences in the number of children in the behavioral intervention group whose diagnoses improved after two years of treatment, from autistic disorder to pervasive developmental disorder. Of greatest significance, only 56% of the children who received behavioral intervention were still diagnosed as autistic after two years of treatment, while 71% of the children receiving community based services retained their ASD diagnosis.²¹

The Lovaas Institute's Eric Larsson and Scott Cross provided CDI with a summary of the scientific literature regarding the evidentiary basis for ABA treatment. Those studies found that the benefits of ABA include improved developmental functioning, decreased maladaptive behaviors, and decreased symptom severity. The research also found that the substantial benefits of behavioral programs include increases in IQ, and cognitive and language ability, and that

¹⁸ Svein Eikeseth et al., *Intensive Behavioral Treatment at School for 4- to 7-Year Old Children with Autism: A 1-Year Comparison Controlled Study*, 20 *Behavior Modification* 49, 63-64 (2002) (citing results that are particularly significant in showing the value of ABA treatment because the ABA treated group did not differ from the comparison group at the beginning of the trial, yet they made larger gains).

¹⁹ Christina M. Corsello, *Early Intervention in Autism*, 18 *Infants and Young Children* 74, 75, 80-81 (2005).

²⁰ Catherine Lord et al., *Challenges in Evaluating Psychosocial Interventions for Autism Spectrum Disorders*, 35 *J. of Autism and Developmental Disorders* 695, 695-708 (2005).

²¹ Geraldine Dawson et al., *Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model*, 125 *Pediatrics* 17, 21-23 (2010).

recovery from autism is possible in a significant minority of cases. These studies demonstrate that early intervention treatment is the optimal treatment approach, leading to improvement in overall functioning to the point children are able to function successfully in their homes, school classrooms, and communities without specialized services and may no longer be autistic.²²

2. Insurers Are Denying and Delaying Transformative Treatment to Children with Autism, Resulting in Serious Harm

Despite these compelling studies on the importance of early intensive intervention, insurers and health plans have engaged for more than a decade in a pattern of denying and delaying ABA and speech and occupational therapy for children with autism. Indeed, insurers' current medical policies continue to contain rationales for denying coverage for ABA therapy as unproven and not established in the published medical literature for treating ASDs. One such policy's conclusion is contradicted by the clinical evidence and findings from the same studies described in the insurer's medical policy. That policy further cites the American Academy of Pediatrics Clinical Guidelines for the Management of Autism, which also contradict the insurer's conclusion, stating, "[C]hildren who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ (intelligence quotient), language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups."²³

Insurers and health plans have continued their pattern of denial and delay of medically necessary treatment for autism regardless of the state regulatory body involved. The DMHC reported in the documents supporting its request for an emergency regulation interpreting the MHPA in light of SB 946 that historically health plans denied claims for ABA for children with autism on the grounds that the services were either experimental/investigational or not medically necessary. DMHC also stated that its external independent medical reviewers generally overturned the health plan decisions and required that treatment be covered. DMHC further noted:

However, a few years ago health plans began denying coverage for those services altogether, arguing they have no legal obligation to cover ABA because the services are: (1) not health care services and health plans are only obligated under the Knox-Keene Act to cover health care services; (2) excluded under the terms and conditions of the health plan contract; or (3) educational services.²⁴

The DMHC also related that it took enforcement actions against Anthem Blue Cross and Blue Shield of California "for their systemic denial of ABA authorizations for individuals with autism, in violation of Section 1374.72, the mental health parity statute," and entered into settlement agreements to provide coverage for medically necessary ABA. CDI similarly has required insurers under its jurisdiction to provide ABA treatment when medically necessary for autism. CDI ordered Anthem to provide ABA in November 2009, took enforcement action against Blue

²² Larsson & Cross, Analysis of the Evidence Base for ABA and EIBI for Autism (2012) (unpublished manuscript submitted to the Department of Insurance) (included as Addendum M).

²³ See UnitedHealthcare Medical Policy, Intensive Behavioral Therapy for Autism Spectrum Disorders, pp. 1-8, 11 (Oct. 1, 2012) (on file with CDI and attached) (highlighting conclusion at page 1 and evidence at pages 2 to 8 and 11).

²⁴ Cal. Code of Regs., tit. 28, § 1300.74.73 (2012) (California Department of Managed Health Care emergency regulations regarding Pervasive Developmental Disorder and Autism Coverage, 3).

Shield in July 2011 and negotiated settlements with Blue Shield, Cigna, Health Net, and United Health Group early in 2012 requiring coverage of ABA therapy. The CDI agreements expired on July 1, 2012, when SB 946 became effective, and those with DMHC were superseded by the enactment of SB 946.

Both CDI and DMHC construe the MHPA to require that insurers and health plans provide all medically necessary treatment for autism, subject only to the stated statutory condition. However, both departments have seen denials and delays of treatment by insurers and health plans, which have consistently resisted providing such services despite enactment of the MHPA in 1999 and SB 946, effective July 1, 2012.

CDI's experience with insurers under its jurisdiction parallels that of DMHC. Insurers, like health plans, have denied ABA as experimental and investigational; or, more recently, on the grounds that ABA therapy is not medical service, because it is instead educational, or is not being provided or supervised by a licensed individual. Moreover, CDI has found that improper claims handling practices are rampant. CDI's recently completed market conduct examination of Aetna Life Insurance Company's claims handling practices for ABA and speech therapy for individuals with ASD for the period from June 1, 2010 through March 21, 2011 disclosed a total of 1,539 alleged claims handling violations of the California Insurance Code involving failures to pay for medically necessary ABA and speech therapy for autism. *See* Addendum O.

At least four other major California health insurers are failing to provide medically necessary ABA treatment by ignoring governing laws. For example, one insurer offers an individual and family plan that requires enrollees to meet a calendar year copayment responsibility before the plan pays anything for ABA therapy for the remainder of the calendar year. But the insurer further interprets the plan's language to mean that claims for office visits to a mental health services provider for severe mental illness or serious emotional disturbances of a child, or outpatient ABA therapy visits in the insured's home, where ABA therapy is most often provided, do not count toward the insured's copayment responsibility.²⁵ Thus, the only way an insured child with autism may obtain coverage under this policy is for the child or the family to satisfy the plan's calendar year copayment responsibility by incurring \$4,900 for the child, or \$9,800 for the family for treatment for physical conditions, which the plan allows to count toward the copayment responsibility. Although behavioral health treatment is ostensibly covered by the plan, because copayments for mental health treatment do not count towards the plan's copayment guidelines, such benefits are illusory.

Additionally, other policies contain contradictory and ambiguous provisions regarding coverage for autism, placing 12 and 20 visit limits on speech and occupational therapy for Mental or Nervous Disorders, but elsewhere stating that Mental or Nervous Disorders do not include Severe Mental Illnesses or Extreme Emotional Disturbances of a Child. Even though Severe Mental Illnesses and Extreme Emotional Disturbances of a Child are described as a different benefit and that benefit has no limitations on the number of covered visits, insurers are invoking inapplicable visit limits and improperly denying medically necessary treatment to insured children with autism.

²⁵ *See* Blue Shield of Cal. Life & Health Ins. Co., Vita Shield Plus 2900 Generic Rx Policy, p. 3; Letter from Blue Shield of Cal. Life & Health Ins. Co. (Oct. 31, 2012) (on file with CDI and attached as Addendum P) (denying a claim for benefits for ABA).

Other policies place annual visit limits on any combination of speech therapy, occupational therapy and physical therapy, which are narrowly defined and unrelated to autism treatment. Nevertheless, despite inapplicable narrow exclusions, insurers are denying medically necessary treatment. They further are defending patient appeals by stating unilaterally and without any citation of authority that speech therapy and occupational therapy for autism are not mental health benefits but instead are medical/surgical benefits so the MHPA is inapplicable.

CDI initiated enforcement action challenging the propriety of such visit limits. However, the Department's draft Orders to Show Cause sent to two major insurers asserting their limits on speech and occupational therapy for children with autism were unenforceable were challenged in a Request for Rulemaking from ACLHIC, a trade association. ACLHIC asserted that the *Harlick* opinion is applicable only to interpretation of the MHPA by the DMHC because the holding is based in part on a regulation promulgated by that agency, "and CDI does not have a parallel regulation to the DMHC's in place."²⁶

a. A History of Delay and Denial Harming Children and Families: Insurers Resist and Obstruct California's Statutory Laws and Public Policies

Statistics from the CDI Consumer Services Division and reports from autism advocates unfortunately demonstrate that children with autism are frequently still being denied treatment. The Division has received at least 71 complaints since January 2011 involving delays and denials of behavioral, speech and occupation therapies. Transition from Regional Centers to insurer-covered services is difficult because some insurers continue to insist on supervision by a licensed provider despite the plain authorization in SB 946 of supervision by certified behavioral analysts.²⁷ About 1,600 individual and families are in transition and experiencing difficulties and delays in obtaining treatment, as described in Part B.2.b below.

Several consumer complaints further show that one major insurer is requiring IQ testing before approving behavioral therapy for children with autism. That insurer is systematically denying ABA to children with cognitive delays even though their cognitive ability is not measurable and behavioral therapy is proven to benefit both IQ and cognitive ability. These denials are occurring even when the child's medical history documents and demonstrates progress on these measures with treatment. This insurer is also refusing to re-authorize cases without such wholly

²⁶ See Letter from Anne Eowan, Vice President of Gov't Affairs, Assoc. of Cal. Life & Health Ins. Cos., to Dave Jones, Cal. Ins. Comm'r, Cal. Dep't of Ins. (Aug. 21, 2012) (on file with CDI and attached as Addendum Q) (requesting rulemaking).

²⁷ Cal. Ins. Code § 10144.51 (West 2012) (authorizes that behavioral health treatment be "provided under a treatment plan prescribed by a qualified autism service provider and is administered by one of the following: (i) A qualified autism service provider; (ii) A qualified autism service professional supervised and employed by the qualified autism service provider; (iii) A qualified autism service paraprofessional supervised and employed by a qualified autism service provider. 'Qualified autism service provider' means either of the following: (A) A person, entity, or group that is certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies, and who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the person, entity, or group that is nationally certified").

unnecessary cognitive testing, and providing only phantom lists of providers to do that testing, thereby imposing further barriers to plainly mandated treatment.²⁸

At least 12 of those complaints regarding behavioral therapy remain unresolved and are causing significant delays, averaging 11.2 months, in the provision of crucially important treatment for which early intervention is the key to success. For a child of two or three at diagnosis, a delay of nearly a year may significantly narrow the window of opportunity and diminish the child's ability to benefit from treatment. New complaints from parents, autism advocates, and treatment providers are increasing, as individuals seek to transition from Regional Centers and are faced with barriers to behavioral health treatment imposed by their insurance companies.

Moreover, SB 946 concerned only behavioral therapy, and after its enactment, insurers are continuing to impose limits on the speech therapy that can enable children to communicate with their families, schoolmates, and teachers, and occupational therapies that enable them to perform tasks essential to self-care, such as eating, dressing and toileting. As described in Part B.2 above, insurers are failing to provide medically necessary therapies by improperly invoking inapplicable policy limits, causing delays, and often total denials, if parents are not aware of their rights to appeal with the insurer and request IMR from their regulator.

b. ASD Individuals Being Required to Transition from Regional Centers to Insurers by SB 946 Are Experiencing Delays and Denials of Treatment

Seven months after passage of Senate Bill 946, insurers continue to deny and delay services previously supplied by California's 21 Regional Centers to children with autism who have insurance coverage. Despite the July effective date, Regional Centers are still in the process of transitioning about 1,600 individuals and families, many of whom are experiencing substantial barriers and lengthy delays in obtaining medically necessary treatment.

DDS serves individuals with autism through the Regional Center system. DDS estimated for the 2012 May Revision budget proposals that implementation of Senate Bill 946 would result in \$79.8 million in savings for the Regional Centers since they would not have to provide behavioral health treatment services to individuals with insurance coverage for ABA. *See* Addendum R. Assuming that the annual cost of treatment averages \$50,000, the number of individuals who will be transitioning to private insurer coverage is 1,596 or about 1,600.

Those ASD children and their families are facing delays and denials of treatment, as is further evidenced by the letter from Dr. Karen Fessel of Autism Health Insurance Project, which is included as Addendum G. Delays result from a number of kinds of insurer conduct, such as requesting excessive numbers of evaluations, IQ tests, psychological batteries, individual education plans, treatment plans for services that are not being requested, and even the initial autism diagnosis report, which may be years old, of little relevance, and unavailable. Insurers are also disagreeing with the autism diagnoses even where the children have classic autism with numerous evaluations from physicians affirming that diagnosis. Insurers are basing denials on assertions that the child's cognitive ability is too low for him or her to be able to learn, the child

²⁸ These complaints were brought to CDI's attention by Kristin Jacobson and Sally Brammell of Autism Deserves Equal Coverage in a series of e-mail and telephonic communications in July through November, 2012.

is too old to be able to benefit from treatment, or the child no longer needs treatment, all despite treatment recommendations from the child’s physician.

In January 2013, Area Boards of the Statewide Council on Developmental Disabilities (SCDD) noted they “have been hearing from families in their catchment areas of difficulties accessing services through their private insurance. Area Boards 9 and 13 queried their communities on the difficulties ASD families” continue to have with SB 946 implementation.²⁹ For example, families across the state are having very different experiences with co-pays and deductibles as Regional Centers have different approaches to who will pay the co-pay and have instituted variable caps on co-pays.³⁰ Families are also reporting that their health insurance plan has failed to contract with an adequate network of providers in their geographic area to meet the timelines provided in SB 946.³¹ Families experience significant delays for assessment and approval by the plan (4-6 weeks) and the beginning of service provision (1-2 weeks following the first delay). A total of three and one-half months may transpire before the child begins to receive services.³²

Families further report that health insurance plans will not contract with their current ABA provider, even if the provider has a long-standing relationship with the family and/or community. ASD families are forced to either opt for the provider offered by the plan or go “out of network” for the current provider.³³ Concurrently, providers report that plans are using rates that are not “usual/reasonable and customary” for their given area.³⁴ The result is that providers will either pass the difference between actual rate and reimbursement rate on to the family or the provider will simply decline to serve the family because they cannot afford to see the patient at such a low rate.³⁵ Seven months after SB 946’s effective date, insurers are still delaying and denying treatment, necessitating the promulgation of this Emergency Regulation.

c. Complaints to CDI Are Only the Tip of the Iceberg: There Is Significant Under-Reporting of Self-Reported Unmet Needs Under the MHPA

While denials of medically necessary treatment for children with autism are generally overturned by the regulator, for those individuals with the knowledge and fortitude to seek IMR, the delays in providing treatment significantly harm children. Furthermore, since families are often unaware that they may complain to regulators, many may not challenge denials. Therefore, although the reports to regulators understate the numbers of affected individuals, they are illustrative, as are reports from advocates such as Dr. Fessel, in showing treatment delays, which cause harm to insureds even if they do challenge insurer denials and delays and ultimately prevail.

Health plans, providers and consumer advocates all recognize that consumers lack understanding of the extent of their entitlement to mental health benefits under the parity law.³⁶ Accordingly,

²⁹ Issue Alert, Statewide Council on Developmental Disabilities, Senate Bill 946 Council Meeting Notice/Agenda (Jan. 16, 2013) available at <http://www.scdd.ca.gov/res/docs/pdf/Council%20Meetings/Package/Council%20Packet%201.4.13.pdf>.

³⁰ *Id.* at 17.

³¹ *Id.* at 18.

³² *Id.*

³³ *Id.*

³⁴ *Id.*

³⁵ *Id.*

³⁶ Margo L. Rosenbach et al., *Implementation of Mental Health Parity Lessons from California*, 60 *Psychiatric Servs.* 1589, 1589-93 (2009).

the promulgation of this emergency regulation is necessary to provide clarity to insurers and the autism community and safeguard the health and welfare of this vulnerable population.³⁷

3. Denied Treatment Can Result in Severe Impairment, Reliance on a Lifetime of Special Education and Social Services, and Institutionalization

Severe consequences flow from failing to provide early intervention behavioral treatment. Delays in such treatment can result in immediate regression, stifled improvement, severe impairment, and permanent developmental damage that may not be regained through later treatment.³⁸ Children with autism generally find change extremely difficult and can suffer harm even from temporary disruptions or delays in obtaining medically necessary ABA treatment. Providers usually recommend ABA therapy for 40 hours a week for 2 years. If children do not receive those services for that period of time as toddlers, they are not only unlikely to be able to be mainstreamed by first grade, but will continue to exhibit chronic and severe symptoms of autistic disorder. This will result in lifelong disability for a greater number of children, who will require extensive and expensive public services throughout their lifetimes.³⁹

a. Speech Therapy Is Both Important and Valuable

There are also serious negative consequences from delayed or denied speech therapy. If children do not communicate through speech, the standard method in our society, families will experience more difficulty in managing challenging behavior and increased parental stress. The cumulative effect of delayed and denied speech therapy for ASD is a generation of children who cannot communicate with their parents, health professionals and other members of society. Basic language skills can make a tremendous difference in children's ability to control their environment because language is an adaptive alternative to highly disruptive forms of communication such as tantrums, aggression towards others, or self-injurious behavior.⁴⁰ Since there is a strong relationship between language skills and other academic and social domains, comprehensive speech therapy programs are likely to significantly impact long-term outcomes, such as academic achievement, the extent of special education services required, school dropout rates, and vocational placements.⁴¹

More than 20 years of peer-reviewed research shows “substantial evidence” that interventions exist to teach communication skills to children with autism. Even though most studies reviewed were conducted with a few subjects, investigators demonstrated clearly and repeatedly that treatment was associated with improved communicative performance. The positive effects of treatment include comprehension, production, and social use of language form (phonology,

³⁷ Ruopeng An et al., *Self-Reported Unmet Need for Mental Health Care After California's Parity Legislation*, 61 *Psychiatric Servs.* 861 (2010).

³⁸ See Beverly A. Pringle et al., *Diagnostic History and Treatment of School-Aged Children with Autism Spectrum Disorder and Special Health Care Needs*, NCHS Data Brief No. 97 (Nat'l Ctr. for Health Statistics ed., 2012); see also Dawson, *supra* note 21, at 21-23 (analyzing the study that suggests that the Early Start Denver Model can be effective for improving outcomes of young children with autism).

³⁹ See Scott Cross et al., *The Adverse Effects and Societal Costs of Denying, Delaying, or Inadequately Providing EIBI for Children with Autism* (2012).

⁴⁰ Howard Goldstein, *Communication Intervention for Children with Autism: A Review of Treatment Efficacy*, 32 *J. of Autism and Developmental Disorders* 373, 373-394 (2002).

⁴¹ *Id.*

syntax, and morphology), content (semantics), and use (pragmatics).⁴² Success is seen through traditional psychosocial treatment strategies, such as a social communication intervention that targets parents. It aims to educate and train parents in adapted communication tailored to their child's individual competencies and can complement other behavioral therapy approaches. Parental communication with children is improved by replacing controlling and intrusive responses with responses intended to facilitate the child's active communication exchanges and signaling pragmatic intentions. The effects of treatment were increases in reciprocal social interaction, engagement, rapport, responses, and spontaneous initiation of social interaction.⁴³

Newer, creative strategies have been effective as well. Auditory-Motor Mapping Training (AMMT) promotes speech production directly by training the association between sounds and articulatory actions using intonation and bimanual motor activities. AMMT capitalizes on the inherent musical strengths of children with autism, offering activities that they intrinsically enjoy. It engages and potentially stimulates a network of brain regions that may be dysfunctional in autism. This proof of concept study showed that intervention was valuable; in fact, "all participants made significant improvements not only in their production of the trained set of items, but also in their production of the untrained set. This indicates that the children successfully learned how to vocalize and produce speech sounds when provided with a model, whether or not the words were specifically practiced during the training sessions."⁴⁴

b. Occupational Therapy Provides Important and Valuable Training

Occupational Therapy (OT) allows individuals with ASD to function and participate in key areas of their lives to the fullest extent possible. ASD individuals are often limited in their ability to participate in play or leisure activities, to involve themselves in interactions socially, and to undertake normal activities of daily life, such as eating, drinking, bathing, and taking a walk to the corner store. The goal of OT is to allow ASD individuals to be involved and engaged in normal societal activities. The ASD individual often is unwilling to accept touch, has difficulty with attention and organization, and in some cases, exhibits rigid and stereotypical eating behaviors. Without comprehensive OT, the ASD individual could continue to function in a withdrawn, disorganized and distracted fashion. The untreated individual would be unable to fully perform routine self-care and grooming such as bathing and brushing teeth and could be unable to consume a healthy and varied diet.⁴⁵

Research indicates that ASD children who receive intensive, early occupational therapy are more likely to improve and maintain that improvement over the long term. This is due to the decreasing neural plasticity of the brain as it ages, which reduces the ability to learn new

⁴² *Id.*

⁴³ C. Aldred et al., *A New Social Communication Intervention for Children with Autism: Pilot Randomized Controlled Treatment Study Suggesting Effectiveness*, 45 *J. of Child Psychology and Psychiatry* 1420, 1420-30 (2004).

⁴⁴ Catherine Y. Wan et al., *Auditory-Motor Mapping Training as an Intervention Facilitate Speech Output in Non-Verbal Children with Autism: A Proof of Concept Study*, 6 *PLOS ONE* (2011) available at <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0025505>.

⁴⁵ Claire Broderick et al., "Can I Join the Club?": *A Social Integration Scheme for Adolescents with Asperger Syndrome*, 6 *Autism* 427, 427-31 (2002); see also Patricia Howlin & Pamela Yates, *The Potential Effectiveness of Social Skills Group for Adults with Autism*, 3 *Autism* 299, 299-307 (1999); S. Ozonoff & J. Miller, *Teaching Theory of Mind: A New Approach to Social Skills Training for Individuals with Autism*, 25 *J. of Autism and Developmental Disorders* 415, 415-33 (1995).

behaviors and skills. OT encompasses an integrative approach to address a wide variety of behavioral and functional difficulties that ASD individuals typically encounter. To address difficulty in social skills, interventions which include peer modeling and cueing by individuals with higher skills are undertaken. The trademarked “Social Stories”⁴⁶ are used to decrease disruptive behavior and promote more appropriate behavior. Play therapy and the trademarked “Floortime” therapy address the sensory development issues and sensitivity that ASD children often exhibit, as well as encouraging engagement in activity. OT is also used to address and improve mealtime behaviors.⁴⁷

c. Severe Financial Consequences Result from Treatment Delays

When insurers deny or delay coverage for autism, even when the coverage denials are challenged and overturned, families with children with autism must pay for the ABA, speech and occupational therapy out-of-pocket during the appeals process in order to obtain treatment. This requires them to incur costs, sometimes thousands of dollars a month, and then wait many more months to obtain reimbursement from their insurer. Regardless of families’ means or the other demands on families’ finances, they must find the funds for critically needed therapies or consign their children to failure to reach their potential functioning and perhaps to a lifetime of disability and ultimate institutionalization.

d. Delays and Denials of Treatment by Insurers Are Shifting Substantial Costs to the Government and Seriously Harming the Public Health, Safety, and General Welfare

Public entities are incurring enormous societal costs that should be borne by private health insurers for early intervention services and treatments for the skyrocketing numbers of children with autism. Autism is a very expensive disorder costing California huge sums for direct and indirect medical and nonmedical costs to care for ASD individuals over their lifetimes.⁴⁸ The lifetime incremental societal cost for an individual with autism is \$3.2 million. Lost productivity and adult care are the largest components of the lifetime per capita cost.⁴⁹ These tremendous costs of autism are adversely affecting California’s public education system, special education programs, and other agencies, which expend significant portions of their limited funds on providing access to care and treatment for ASD individuals.

The MHPA was very clear in specifying how the State would address the rising costs of mental health treatments and services. The bill author’s statement “stresses that mental illness is treatable in a cost-effective manner and that the failure of the health care system to provide adequate treatment for persons with mental illness has been costly not only to mentally ill individuals and their families, but to society as a whole and particularly to state and local

⁴⁶ C. Hilton, *Social Skill for Children with an Autism Spectrum Disorder*, *Autism: A Comprehensive Occupational Therapy Approach* 333-64 (R. Watling & Miller-Kuhanek eds., 3d ed. 2010).

⁴⁷ William G. Sharp et al., *Pediatric Feeding Disorders: A Quantitative Synthesis of Treatment Outcomes*, 13 *Clinical Child and Fam. Psychology Rev.* 348, 348-65 (2010).

⁴⁸ Michael L. Ganz, *The Costs of Autism*, in *Understanding Autism: From Basic Neuroscience to Treatment* (S.O. Moldin & J.L.R. Rubenstein eds., 2006).

⁴⁹ Michael L. Ganz, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, 161 *Archives of Pediatric Med.* 343, 343-49 (2007).

governments.”⁵⁰ The Legislature plainly intended the MHPA to shift costs of treatments and services for severe mental disorders to insurers and away from state and local governments and California families,⁵¹ but achieving that result is being undermined by insurer noncompliance.

4. Providing Behavioral Intervention Therapies Between the Ages of 3 and 22 Imposes Immense Costs of Special Education on California’s Public School Districts, Which Are Experiencing Statewide Budget Cuts

Costs for ASD therapies and treatments shift to California’s public school system when children reach the age of 3. Special education, a critical part of California’s public education system, ensures that school districts meet the individual needs of disabled students. According to Governor Brown’s 2012-13 Budget Summary, apportionments for special education will be cut by \$171.2 million statewide.⁵² The statewide average of special education spending per pupil is about \$14,000 per special education student — a major expenditure for school districts.⁵³ Delay and denial of ASD early intervention services by insurers impose increased burdens on school districts since 77% of students with ASD are enrolled in special education.⁵⁴

Additionally, in 2009, just 17% of ASD families reported speech therapy, and 13% reported occupational therapy, was available in school districts.⁵⁵ As of April 2012, those numbers substantially increased at the expense of school district budgets.⁵⁶ Now, 69% of ASD families report speech therapy, and 56% report occupational therapy support from school districts.⁵⁷ The delay and denial of early intervention services by private insurers impairs the fiscal health of California’s public school districts, as described more fully below.

a. The ASD Service Net Prior to Special Education: The Early Start Program and the Lanterman Developmental Disabilities Services Act

Children under the age of 3 may receive early intervention services through the Early Start program implemented by DDS in collaboration with other state and local agencies.⁵⁸ Under Part C of the federal Individuals with Disabilities Act (IDEA), Early Start serves California children who have, or are at risk of, a delayed developmental disability.⁵⁹ Services provided include screening and assessment, speech, occupational and physical therapies, and family counseling

⁵⁰ Cal. Assem. Comm. on Health, Committee Analysis of A.B. 88: Mental Health Parity Act, Reg. Sess. (Mar. 9, 1999), available at http://www.leginfo.ca.gov/pub/99-00/bill/asm/ab_0051-0100/ab_88_cfa_19990309_113734_asm_comm.html,

⁵¹ *Id.* (citing to studies conducted to assess the financial impact of the 1998 Federal Mental Health Parity Act, including an April 1998 U.S. Department of Health and Human Services report finding that full parity for mental health and substance abuse in managed care plans would increase premiums less than 1%).

⁵² Office of the Governor Edmund G. Brown, Governor’s Budget Summary 2012-13: K Thru 12 Education (2012), available at <http://www.ebudget.ca.gov/pdf/budgetsummary/kthru12education.pdf>.

⁵³ Stephen Lipscomb, *Special Education Financing in California: A Decade After Reform*, Pub. Policy Inst. of Cal. (2009), available at http://www.ppic.org/content/pubs/report/R_809SLR.pdf.

⁵⁴ Autism Soc’y of Cal., *supra* note 6.

⁵⁵ *Id.*

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ Cal. Legislative Blue Ribbon Comm’n on Autism, *supra* note 2.

⁵⁹ Cal. Dep’t. of Developmental Servs., California Early Start: Facts at a Glance (2011), available at https://dds.ca.gov/EarlyStart/docs/EarlyStart_InformationPacket.pdf.

and training.⁶⁰ Services are provided with state and federal funds and at no cost to families. More than 40,000 California children are served annually, and that number is increasing rapidly.⁶¹

Passage of the Lanterman Act in 1977 provided parents better opportunities and resources to raise their mentally disabled children at home. The Act ended the long-standing practice of warehousing developmental disabled people in state hospitals and provided state-funded services tailored to individual needs. Funding comes from DDS to service providers through 21 Regional Centers and nonprofit agencies. Services are free for life, regardless of a family's means. Last year, the program cost about \$4 billion, including \$638 million for services to ASD individuals. In 2010, the system served 16,367 ASD children between the critical ages of 3 and 6, spending an average of \$9,751 per child,⁶² which ranged from \$1,991 at the South Los Angeles Regional Center to \$18,356 at the Orange County Regional Center.⁶³

b. Costs of State Education Services to Public School Districts Are Rapidly Increasing: Special Education and the IDEA

California's public education system is responsible for the education of children with ASD beginning at age 3. Local education agencies (LEAs), primarily school districts, educate many high-functioning ASD children through regular education programs. The agencies also provide specialized educational interventions and related services to many children with ASD so they can benefit from a free and appropriate public education (FAPE). Nearly 40,000 California children with ASD between the ages of 3 and 22 now receive special education services from LEAs.⁶⁴

Part B of the IDEA requires states to provide specialized instruction and related services to children with disabilities, including autism, in the least restrictive environment.⁶⁵ Services are without cost to parents through a combination of federal, state, and local funds. LEAs must evaluate a child's disability and needs for educational programming, develop an individualized education program (IEP) to meet the child's needs, and provide services according to the IEP. The IEP defines the appropriate type and amount of services based on a child's needs and is developed by a team, including parents, clinicians, district personnel, teachers and other experts. Children are educated in mainstream classrooms full- or part-time, in specialized classrooms within the regular school, or in a specialized public or nonpublic school for special needs children.⁶⁶ Placement in a public school or program is financed by LEAs. As a result, the annual costs to educate a California student with autism can range from \$25,000 to \$90,000.⁶⁷

⁶⁰ *Id.*

⁶¹ Cal. Legislative Blue Ribbon Comm'n on Autism, *supra* note 2.

⁶² Alan Zarembo, *Discovering Autism: Warrior Parents Fare Best in Securing Autism Services*, L.A. Times (Dec. 13, 2011), <http://www.latimes.com/news/local/autism/la-me-autism-day-two-html,0,3900437.htmlstory>.

⁶³ *Id.*

⁶⁴ Cal. Legislative Blue Ribbon Comm'n on Autism, *supra* note 2.

⁶⁵ *Id.*

⁶⁶ Autism Soc'y of Am., *Building Our Future: Educating Students on the Autism Spectrum* (2006), *available at* <http://support.autism-society.org/site/DocServer/buildingourfuture06.pdf?docID=4201>.

⁶⁷ Randall White, *The Legal Rights of Children with Autism: An Expert Interview with Jill G. Escher, BA, MA, JD*, Medscape News Today (July 29, 2005), <http://www.medscape.com/viewarticle/508088>.

c. A Broken System: Special Education Financing and Spending at the School District Level

Public schools are required by federal law to provide a free, appropriate education to all special needs students once they reach the age of 3.⁶⁸ The law also requires that school districts work with parents to design IEPs that specify the learning goals for every child who receives special education services. If a district cannot provide the services required in the IEP, the district must pay for a private program. The cost of meeting FAPE needs of an ASD student with private agency services ranges from \$30,000 to \$100,000 annually.

Parents of ASD students frequently request school districts to provide 40 hours or more of ABA therapy a week as part of an appropriate education under FAPE. These requests often create disagreements between districts and parents, who have begun to utilize the legal process to obtain ABA services, raising the legal and administrative costs associated with ASD. The dispute may go to mediation and a due process hearing conducted by state appointed hearing officers with attorneys for the districts and parents. Hearings can take months and incur substantial legal fees. For example, in 2003-04, Las Virgenes School District spent almost \$900,000 in legal fees, primarily related to a case litigated in Superior Court.⁶⁹ This is a growing trend facing school districts, which can ill-afford such increased costs because of budget cuts.

Each year, school districts must show that they are using federal special education grants to supplement, rather than to supplant, state and local funds.⁷⁰ Under AB 602 (1997), California distributes most special education funds based on the average daily attendance of each Special Education Local Plan Area's (SELPA) entire student population since 1998-99.⁷¹ Disability numbers or special education expenditures for a particular school district do not factor into the funding equation because California's funding process is a capitation or census-based model. The model, in theory, increases equity and transparency in the funding process district by district. However, school districts which classify more children as disabled incur additional costs but receive no additional funding. As a result, the funding process incentivizes the identification of fewer disabilities, particularly ASD, and provides less costly services.⁷²

All census models assume that disabilities are spread evenly across the population. California justified AB 602's goal of equalizing funding per student based on the premise that "handicapping conditions of similar severity" occur with "roughly equal frequency."⁷³ AB 602 thus distributes funds to SELPAs as a way to reduce fears that the equal frequency assumption of funding may not hold for smaller populations like school districts.⁷⁴ The result of systemic

⁶⁸ Dr. Marie Bristol Powers, *Autism: The Impact on Public Education*, Nat'l Inst. of Child Health and Hum. Dev. (2005), http://www.fremont.k12.ca.us/cms/lib04/CA01000848/Centricity/Domain/85/Autism_Impact.pdf.

⁶⁹ *Id.*

⁷⁰ Lipscomb, *supra* note 53, at 14. California developed a Maintenance of Effort (MOE) worksheet for school districts to demonstrate their compliance. School districts also show Special Education Local Plan Area (SELPA), a group of nearby school districts that cooperatively provide services, spent more on special education from local or combined state and local funds in a year (either in total or per pupil) than in the previous year. The California Department of Education (CDE) allocates federal, state and local funds to 120 regional SELPAs.

⁷¹ *Id.*

⁷² *Id.*

⁷³ *Id.*

⁷⁴ *Id.* This was a recommendation from a 1995 report published by the Legislative Analyst's Office, the Department of Education, and the Department of Finance.

funding disparities is that they are directly associated with the treatment outcomes, severity of disability, and income of ASD students.

Both the prevalence of disabilities and the amount of special education funds affect school spending on disabled children. Districts are required to use federal IDEA funding for disabled children to help pay for "excess costs" of educating them.⁷⁵ Excess costs occur when needs are not identified correctly or when districts are not providing services efficiently. Special education and regular education share spending on children with disabilities. In California, state and federal aid for special education share the same purpose of helping defray additional spending on children with disabilities. Federal and local special education funds are deducted from state aid when calculating SELPA allocations; thus, federal spending is a safety net for excess costs and the depletion of local support costs. Therefore, the system incentivizes efficiency and a low margin of error that may not be realistic. School districts are forced to navigate a difficult budgetary process with built-in high personnel costs, potentially low local support funding and a higher-than-average severity level of special education students.⁷⁶ Total spending on children with disabilities was \$12 billion or about \$17,633 per disabled student in the state.⁷⁷ These costs continue to show an upward trajectory.⁷⁸

Educators and California school districts face not only a rapidly growing incidence of autism, but a new mandate requiring that special education students with disabilities pass the high school exit examination to graduate. These factors heighten the problems that school districts and educators confront in narrowing the achievement gap between disabled and non-disabled students. If current trends persist, special education will become an even larger portion of school district budgets. School districts annually face excess costs in the support of their special education students, and as result special education funding for school districts continues to grow faster than any other school expenditure.⁷⁹ This is simply unsustainable. School districts suffer, education suffers, and ASD students receive lower quality services and treatment.

5. After the Age of 22: The Mounting Crisis Facing Public Access to ASD Treatments and Services at California's Regional Centers for ASD Adults Further Harms the Public Health and Welfare

California's system of funding community-based services for developmentally disabled people through Regional Centers has generated increased criticism because of the growth in its budget, which is generally greater than that of other state-funded health and human services programs.⁸⁰ One of the primary causes of the Regional Centers' costliness is the increase in consumers with autism. According to the Association of Regional Center Agencies (ARCA), that number has increased by an average of 12.7 % per year from December 2002 to December 2007.⁸¹ In

⁷⁵ See Cal. Educ. Code § 56841(a) (West 2012); Lipscomb, *supra* note 53, at 14. School districts incur excess costs when they spend more educating disabled children than they spend on average on all children. Costs are defined as the minimum expenditure for the services a student needs.

⁷⁶ Lipscomb, *supra* note 53, at 19-20.

⁷⁷ *Id.* at 20.

⁷⁸ *Id.*

⁷⁹ *Id.* at 21.

⁸⁰ Ass'n of Reg'l Ctr. Agencies, Information Brief: Unique Factors Impacting Regional Centers' Budget Growth (2009) [hereinafter ARCA], available at http://arcanet.org/pdfs/ARCA_POS_information_brief.pdf.

⁸¹ *Id.*

December 2002, 12.4 % of the consumers served by Regional Centers had an autism diagnosis; by December 2007, the percentage had grown to 19.1 %.⁸² Since 1987, there has been a twelve-fold increase in the number of individuals with autism served by Regional Centers. Additionally, as reported by DDS for the period from 1990 to 2000, “[T]he number of persons with autism being served by regional centers rose 26 times faster than that of the general California population.”⁸³ Average annual point-of-service expenditures for consumers with autism are higher than the average expenditures for other consumers.⁸⁴ The average Regional Center expenditure per consumer with autism is at least 53.7% higher than the expenditure per consumer without autism, depending on the age group.⁸⁵ The expenditure per consumer with autism in the age group from 3 to 21 years old is \$10,878. This cost significantly increases with the age of the consumer. The annual expenditure is \$33,007 for consumers with autism 22 to 41 years old; it peaks at \$42,034 for those 62 years old or older.⁸⁶

The DDS notes that “[a]utism continues to be the fastest growing developmental disability in California” and “[b]ased on current projections, regional centers and developmental centers will be serving as many as 70,000 people with ASD by June 2012.”⁸⁷ The median age of this population of consumers continues to decrease, and as a result, California is experiencing both a need for longer durations of service and a state law that mandates that services be provided for life for anyone who is eligible.⁸⁸ The public health crisis identified in the 2006 report by the Legislative Blue Ribbon Commission on Autism when ASD was affecting one in every 150 children⁸⁹ has subsequently intensified.

a. AB 1472 Further Mandates Shifting of Costs from Regional Centers to Private Insurers, and Reduces Regional Center Budgets

Effective June 27, 2012, AB 1472, a Budget Committee bill, passed the Legislature and was signed by the Governor. As part of automatic budget cuts due to less than anticipated revenue projections, the Department of Finance announced in December 2011 that DDS’s 2011-12 budget would be reduced by \$100 million.⁹⁰ The proposed budget for 2012-13 includes the full year impact of the \$200 million revenue trigger reduction for DDS.⁹¹ The new law requires Regional Centers to streamline delivery efficiency and strategically review the care given to developmentally disabled individuals. The law further requires them to reduce payments for services and support by 1.25% more from July 1, 2012 to June 30, 2013.⁹²

⁸² *Id.*

⁸³ Andrew T. Cavagnaro, Ph.D., Autism Spectrum Disorders – Changes in the California Caseload – An Update: June 1997 – June 2007, Cal. Dep’t of Developmental Servs. (2009), *available at* <http://www.feat.org/Portals/0/PublicDocuments/AutisticSpectrumDisordersReport2007.pdf>.

⁸⁴ ARCA, *supra* note 80.

⁸⁵ *Id.*

⁸⁶ *Id.*

⁸⁷ Cavagnaro, *supra* note 83, at 9.

⁸⁸ ARCA, *supra* note 80.

⁸⁹ Cal. Legislative Blue Ribbon Comm’n on Autism, *supra* note 2.

⁹⁰ A.B. 1472, 2012 Leg., Reg. Sess. (Cal. 2012) (concerning health care facilities, mentally retarded and developmentally disabled persons, and rehabilitation).

⁹¹ *Id.*

⁹² *Id.* A payment reduction of three percent was initiated in 2009. It was increased to 4.25 percent on July 1, 2012 and is scheduled to sunset June 30, 2012. This bill would instead extend the reduction for one additional year, but at a lower amount. This provision is anticipated to result in savings of \$30.7 million to the General Fund.

Anticipating the devastating effects of these budget cuts on Regional Center health care delivery, the law protects individuals and families who seek to transition to insurance coverage for treatment. “This bill would provide that the use of private health insurance or a health care service plan to pay for early intervention services may not result in the loss of specified benefits for the covered individual or family, may not negatively affect the availability of health coverage for the covered individual or family, and may not be the basis for increasing health insurance or health care service plan premiums for the covered individual or family, as specified.”⁹³ Furthermore, the use of private health insurance or a health care service plan to pay for early intervention services cannot:

- Negatively affect the availability of health coverage for the infant or toddler with a disability, the parent, or the child's family members who are covered under that health insurance policy or health care service plan contract, or result in a discontinuance of coverage for these individuals, or
- Be the basis for increasing the premium of the infant or toddler with a disability, the parent, or the child's family members covered under that health insurance policy or health care service plan contract.⁹⁴

The law’s purpose is to decrease “reliance on developmental centers, residential facilities for which Medicaid funding is not available, and out-of-state placements.”⁹⁵ Thus, the effective gutting of California’s Regional Centers for budgetary reasons heightens the emergency for numerous ASD individuals who need early intervention treatment, the families who care for them, and the public. Reduced funding for Regional Centers creates an enormous void in public access to vital early intervention services, and the California Legislature has clearly indicated both in MHPA and AB 1472 that costs for early intervention for ASD individuals must shift to private insurers. Without this shift, ASD individuals, California families and ultimately taxpayers will continue to bear an excessive burden for early intervention service costs. The State can no longer adequately provide services to a growing ASD population; the proposed regulation is needed to ensure that private insurers comply with the MHPA’s requirements and promptly provide treatment to California’s autistic children.

6. The Consequences of Delayed and Denied Behavioral Intervention: The Cost Impact of Adult Habilitative Services and Employment Support Imposes Further Intolerable Burdens on State Finances

The level of care of people with autism is closely tied to cognitive delay.⁹⁶ Individuals with autism who have more severe cognitive delays tend to reside in licensed community residential facilities, Intermediate Care Facilities (ICFs), and developmental centers. Sixty percent of people with autism and severe or profound mental retardation live in community care, developmental centers, or ICFs. Those with lesser cognitive delays are more likely to reside in the home of a parent/guardian or independent or supported living settings. Fully 95.8% of people with autism and either mild or no mental retardation live at home or in independent living.⁹⁷ As ASD

⁹³ *Id.*

⁹⁴ *Id.*

⁹⁵ *Id.*

⁹⁶ Cavagnaro, *supra* note 83, at 9.

⁹⁷ *Id.*

individuals are forced to move outside of a parental home setting, costs to society dramatically increase. Adults aged 20 and over tend to reside in a variety of settings: home (49.5%), community care (27%), independent/supported living (11.8%), developmental centers (5.5%), intensive care facilities (4.8%), skilled nursing facilities (0.4%) or other (0.9%).⁹⁸ The costs for treatment and services are dramatically higher in settings outside the home.

Additionally, while 81.7% of all autism cases in the DDS system involve children under 18, that ratio is about to change. There are now 6,300 adult Californians receiving autism services through DDS. However, over the next four years, more than 4,000 teenagers will join their ranks. By 2018, the total number of adults with autism will more than triple to 19,000 people — each requiring tens of thousands of dollars in care, education and support services every year.⁹⁹ Thus, the need for promulgation of the proposed regulation requiring health insurers to share costs rather than deny and delay treatment is of the utmost urgency and concern.

7. Insurers' Failure to Cover Treatment Foists Constant and Crippling Costs onto California's Families

Autism is often a devastating diagnosis for families to struggle with and manage. In addition to understanding the diagnosis and coping with the child's aberrant behavior, the limitations in funding for necessary behavioral interventions add even more stress for these families. Out-of-pocket expenditures for diagnosis and treatment, as well as costs for the value of lost employment, income and leisure time, increased stress, disruptions in family life and reduced time with other family members impose immense burdens on families of children with autism.

California families find themselves in a very difficult position. A free and appropriate education for every child with a disability is guaranteed under IDEA. However, FAPE is not ideal and parents generally do not believe it is best for their child.¹⁰⁰ Schools typically offer some form of speech and occupation therapy but cannot afford to pay the high cost of ABA therapy for each child with ASD. Private insurers' noncompliance with the MHPA forces California families to wait a year or more to participate in state- or community-funded therapy programs, depriving them of the benefits of early intervention.¹⁰¹ Families must then navigate the complex system of public programs to obtain some level of care and treatment to assist with the huge direct medical costs throughout the early life of an ASD child.

a. Out-of-Pocket Expenditures: Direct ASD Medical Costs to Families

The annual cost of intensive behavioral therapies and behavior support services is estimated to be \$41,295 for a child aged 3 to 6, and \$4,140 to \$5,914 per child, depending on level of disability, for ages 6 to 19.¹⁰² Population-weighted annual average per capita direct medical costs for individuals with autism in 2003 was \$29,091 for lower levels of disability and \$29,569 for higher

⁹⁸ *Id.*

⁹⁹ *Id.*

¹⁰⁰ Dana Lee Baker & Deanna L. Sharpe, *Financial Issues Associated with Having a Child with Autism*, 28 J. of Fam. Econ. Issues 247, 247-64 (2007).

¹⁰¹ *Id.*

¹⁰² *Id.*

levels of disability.¹⁰³ These estimates account for dental, prescription medication, physician, outpatient and clinical services, complementary and alternative therapies, behavioral therapies, hospital and emergency department services, allied health, equipment, supplies and home health and medically-related travel expenses.¹⁰⁴

b. Family Financial Planning Issues

Planning the financial future of a family with an ASD child is a complex process. Seeking ways to privately pay for treatment for a child with autism, California families have taken out home equity loans, charged credit cards to their limits, or declared bankruptcy after exhausting their financial resources. These actions have long-term financial consequences for families and for society. Depending on the intensity of the disorder and capabilities of the ASD child, families have to arrange financially for care that may extend beyond the life of the parent-caregivers. California families must pay constant attention to lifestyle, legal, financial and governmental benefit issues in order to remain solvent.¹⁰⁵

c. Productivity Losses of Parents of People with ASD

Parents suffer productivity losses due to caring for their children with ASD, which do not necessarily diminish as children grow to adulthood.¹⁰⁶ Children with lower levels of disability have fathers who are unemployed 10% of the time and mothers who are unemployed 55% of the time.¹⁰⁷ These numbers increase to 20% for fathers and 60% for mothers of children with higher levels of disability.¹⁰⁸ Parents' annual lifetime lost productivity is \$39,681 to \$129,785 on average depending on the level of disability of the child. Of the total medical and nonmedical costs over a lifetime of ASD individuals, 59% can be accounted for by the indirect costs of lost productivity of the individual with ASD and his or her parents.¹⁰⁹

d. Family Cost of Adult ASD Care

Starting at age 23, adults receive services through day programs, tailored to the level of dependence.¹¹⁰ In 2003, estimates of families' annual costs for adult care is roughly \$44,536 per person with lower levels of disability and \$52,025 per person with higher levels of disability for ages 23 through the end of life.¹¹¹ In the aggregate, medical and nonmedical costs to families are enormous and impact not only parents but society as a whole.

¹⁰³ *Id.*

¹⁰⁴ *Id.*

¹⁰⁵ Dana L. Baker & Deanna L. Sharpe, *The Financial Side of Autism: Private and Public Costs*, in A Comprehensive Book on Autism Spectrum Disorders 275, 275-96 (Dr. Mohammad-Reza Mohammadi ed., 2011), available at http://cdn.intechopen.com/pdfs/20045/InTech-The_financial_side_of_autism_private_and_public_costs.pdf (emphasizing the private and public costs of autism).

¹⁰⁶ Steven O. Moldin, *Understanding Autism from Basic Neuroscience to Treatment* 486 (CRC Press ed., 1st ed. 2006).

¹⁰⁷ *Id.*

¹⁰⁸ *Id.*

¹⁰⁹ *Id.*

¹¹⁰ *Id.*

¹¹¹ *Id.*

8. A Crisis of Conscience: Regional, Racial and Class Disparities Exist in Autism Service and Treatment Spending in California

Public spending on autistic children varies significantly by ethnic group and socio-economic status.¹¹² For autistic children aged 3 to 6, which is a critical period for treatment, DDS last year spent on average \$11,723 per child on whites, \$11,063 on Asians, \$7,634 on Latinos and \$6,593 on blacks.¹¹³ Data from public schools indicate that whites are more likely to receive basic services, such as occupational therapy, to help with coordination and motor skills.¹¹⁴ The divide is even starker when it comes to the most coveted service — a behavioral aide from a private company to accompany a child throughout each school day at a cost that often reaches \$60,000 a year.¹¹⁵ In the state's largest school district, Los Angeles Unified, white elementary school students on the Westside have such aides at more than 10 times the rate of Latinos on the Eastside.¹¹⁶

What accounts for the disparity is not necessarily prejudice, but the utilization of parents' voices and resources to garner the services ASD children need. In the developmental system and the schools, the process for determining what services a disabled child receives is based on negotiation by parents. Consequently, parents are fighting with school districts for limited finances and resources; without parents who are highly educated and trained as advocates, children face disparities and lack of services. Denial and delay of treatment by private insurers exacerbate the disparities in the public financing system for ASD services. Without private insurers sharing the costs of ASD, this system harms ASD individuals and their families.

C. The Emergency Was Not Known In Sufficient Time to Address Through a Non-Emergency Regulation

While the Department has been aware of the situation described in this finding of emergency for a period that would likely have been sufficient to promulgate permanent regulations, CDI refrained from doing so. Historically, CDI interpreted the directive in the Mental Health Parity Act as so clear there was only one tenable interpretation and expressed that view as amicus in *Harlick v. Blue Shield of California*, 686 F.3d 699 (2012) in a brief filed in November 2011. After the issuance of the revised *Harlick* decision in June 2012, which included a dissenting opinion that was subsequently adopted in a Superior Court decision in *Rea v. Blue Shield* issued that same month, CDI refrained from promulgating a regulation because CDI reasonably expected that the problem of insurers' denying legally mandated medically necessary care to patients diagnosed with ASD would be effectively addressed through legislation.

Indeed, SB 946, which reconfirmed the mandate for provision of behavioral health treatment for children with autism, was signed into law in October 2011, took effect on July 1, 2012, and was expected to end delays and denials of this transformative treatment for insured children with autism. However, the pattern that has subsequently emerged from complaints to CDI's Consumer Service Division, reports from providers and autism advocates, and information from the State

¹¹² Zaremba, *supra* note 62.

¹¹³ Cavagnaro, *supra* note 83, at 15-18.

¹¹⁴ Zaremba, *supra* note 62.

¹¹⁵ *Id.*

¹¹⁶ *Id.*

Council on Developmental Disabilities demonstrates that insurers are, in fact, continuing to impose barriers to treatment and continuing to deny and delay treatment.

Given the clear scientific literature demonstrating that behavioral health treatment, as well as speech and occupational therapies, are life changing for children with autism and are more effective when they are provided as soon as the child is diagnosed, this public health emergency cannot now be addressed effectively through the standard regulatory process. Proceeding by the standard process would mean that toddlers who have been recently diagnosed would have to wait a year or more to begin receiving behavioral health therapy, missing the window of opportunity to enable them to receive the maximum benefit from treatment, including possible recovery from autism. Still other children would experience the interruptions and delays in treatment, which CDI currently is receiving complaints about, causing regression and lasting damage.

AUTHORITY AND REFERENCE

The proposed regulations will implement, interpret and make specific the provisions of Insurance Code sections 10144.5 and 10144.51, with reference also to *Harlick v. Blue Shield of California*, 686 F.3d 699 (2012). Insurance Code sections 10144.5, 10144.51, 12921 and 12926 provide authority for this rulemaking, as do the following decisions of the California Supreme Court: *CalFarm Ins. Co. v. Deukmejian*, 48 Cal.3d 805 (1989), and *20th Century Ins. Co. v. Garamendi*, 8 Cal.4th 216 (1994).

COMPARABLE FEDERAL LAW

There is no existing federal statute or regulation that is comparable to the proposed regulations.

INFORMATIVE DIGEST/POLICY STATEMENT OVERVIEW

A. Autism Is A Seriously Disabling Developmental Disorder

Autism is a neurobiological disorder that affects a child's development by severely limiting his or her ability to interact with others.¹¹⁷ It is a developmental disability that significantly hinders verbal and nonverbal communication and social interaction and is generally evident before age 3.¹¹⁸ Autism is part of a larger class of pervasive developmental disorders (PDD) or ASD, which are synonymous terms referring to a continuum of related cognitive and neurobehavioral disorders. These disorders are characterized by severe and pervasive impairment in reciprocal social interaction and communication skills and stereotyped behavior, interests, and activities.

¹¹⁷ *McHenry v. PacificSource Health Plans*, No. CV-08-562-ST, slip op. 1230 (D. Or., Jan. 5, 2010) (citing Dep't of Def., Report and Plan on Services to Military Dependent Children with Autism 5 (2007) for definitions and 34 C.F.R. §300.8(c)(1)(i) (2012), which defines autism as a "developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance").

¹¹⁸ *See id.*

The conditions are present from birth or early in development and are typically diagnosed in early childhood.¹¹⁹

A Report on Mental Health by the United States Surgeon General recognizes autism as a severe, chronic developmental disorder, which results in significant lifelong disability.¹²⁰ That Report notes that because autism is severe, chronic and disabling, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained behavior therapy early in life can increase the ASD child's ability to acquire language and to learn. The American Psychological Association similarly characterizes autism as the most severe developmental disability. Appearing within the first 3 years of life, autism involves impairments in social interaction, such as being aware of other people's feelings, and verbal and nonverbal communication.¹²¹

B. The Proposed Regulation Will Ensure that Autism Is Treated by Effective, Established Therapies

The benefits anticipated from this proposed regulation are the timely provision and coverage of medically necessary treatments that can ameliorate the core deficits of autism, saving the State enormous sums and enhancing the health and wellbeing of children with autism and their families. Behavioral health treatment is particularly useful in improving the condition of individuals with ASDs. ABA therapy, a type of behavioral health treatment, is defined as “the design, implementation, and evaluation of systemic instructional and environmental modifications to promote positive social behaviors and reduce or ameliorate behaviors which interfere with learning and social interaction.”¹²² The remarkable success of behavioral therapy in substantially increasing IQ scores and improving cognitive ability, receptive and expressive language skills, and adaptive behavior, and enabling some children to achieve recovery from autism is described in Part B.1 above. The proposed regulation will enable many more children to receive and benefit from this life-changing therapy.

Research demonstrates that early intervention is vital to effective treatment of autism, indicating that treatment should begin immediately upon preliminary diagnosis.¹²³ The National Institute for Mental Health recognizes that ABA is widely accepted as an effective treatment for individuals with autism. Effective programs will teach early communication and social interaction skills. In children younger than 3 years, appropriate interventions usually take place in the home or a child care center. These interventions target specific deficits in learning,

¹¹⁹ Pauline A. Filipek, *Intervention for Autism Spectrum Disorders*, 3 *NeuroRx* 207, 207-08 (2006).

¹²⁰ Office of the Surgeon Gen., Ctr. for Mental Health Servs., Nat'l Inst. for Mental Health Servs., *Mental Health: A Report of the Surgeon General 137* (1999) (“Children with autism and other pervasive developmental disorders often suffer from disordered cognition or thinking and have difficulty understanding and using language, understanding the feelings of others, or, more generally, understanding the world around them. Such disorders are often associated with severe learning difficulties and impaired intelligence. The disorders in this category include the pervasive developmental disorders, autism, Asperger's disorder, and Rett's disorder (DSM-IV).”).

¹²¹ *Autism*, Am. Psychological Ass'n, <http://www.apa.org/topics/autism/index.aspx> (last visited Feb. 20, 2013) (“Autism is the most severe developmental disability. Appearing within the first three years of life, autism involves impairments in social interaction — such as being aware of other people's feelings — and verbal and nonverbal communication.”).

¹²² Cal. Gov't Code § 95021(d)(1) (West 2012).

¹²³ See *supra* note 111, at 137-142 and accompanying text.

language, imitation, attention, motivation, compliance, and initiation of interaction, and include behavioral, speech and occupational therapy.

The Department has examined several factors in its analysis of the benefits anticipated from this regulation, considering the long-term impact of treatment disruption and/or delay. The literature clearly establishes the efficacy of behavioral health treatment and the outcomes for children who undergo treatment provide benchmarks for measuring future medical and non-medical costs and savings. One such study by Chasson, et al. shows the substantial benefits resulting from treatment and provides strong support for the need for prompt enactment of the proposed regulation. That study concluded that upon receiving appropriate treatment, 47% of children with autism recover “typical” function, 40% make “significant” improvement, and just 13% make little progress.¹²⁴ See Figure 1 below.

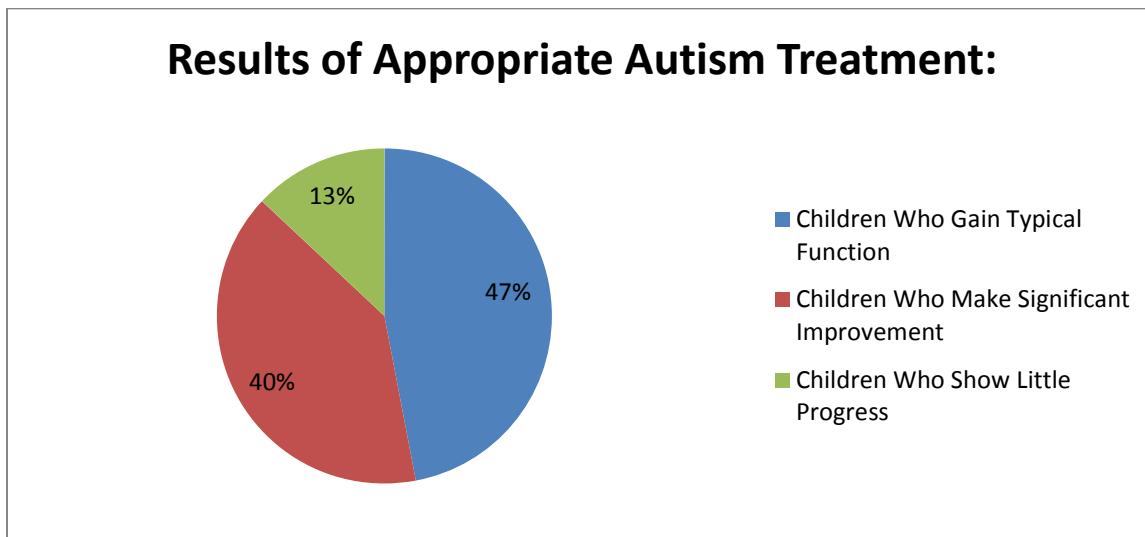


Figure 1: Chasson, et al.: Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism.

Another study titled “The Lifetime Distribution of the Incremental Societal Costs of Autism”¹²⁵ calculates the lifetime societal costs associated with autism, including medical and non-medical costs, as well as lost productivity of both the diagnosed and his or her caretakers (parents). This study measured the lifetime per capita incremental societal cost of autism at \$3.2 million, where lost productivity and adult care are the largest components. These costs are discounted in 2003 dollars.

In a 2009, Jon Hockenyos of Resources for Hope produced a Benefit-Cost analysis based on these two studies, among others, that show the difference in lifetime societal cost between Chasson’s categories¹²⁶. The results are significant and are included in Figure 2 below.

¹²⁴ Gregory S. Chasson et al., *Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism*, 16 J. of Child and Fam. Studies 401, 401-13 (2007).

¹²⁵ Michael L. Ganz, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, 161 Archives of Pediatric and Adolescent Med. 343, 343-49 (2007).

¹²⁶ Jon Hockenyos, *Benefit-Cost Analysis of Appropriate Intervention To Treat Autism (2009)*, available at <http://www.dads.state.tx.us/autism/publications/USAutismCost-BenefitAnalysisNovember2009.pdf>.

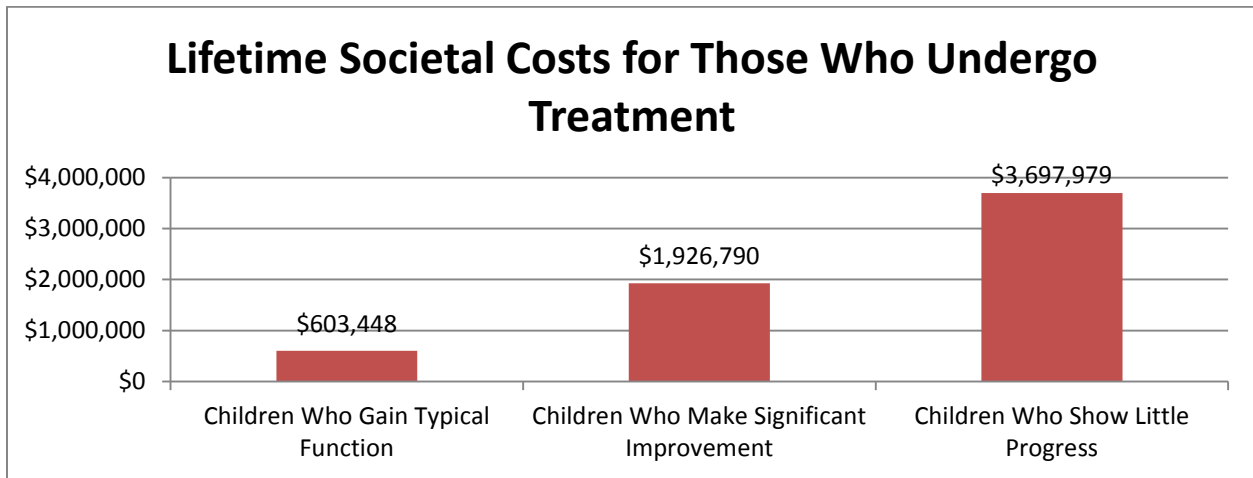


Figure 2: Categorized lifetime costs

These analyses demonstrate that minimizing treatment disruption results in better outcomes for children which, in turn, results in significant lifetime societal cost savings. Children who are treated immediately upon diagnosis stand the best chance of falling into Chasson’s “Typical Function” category. Widespread early intervention with these proven therapies, as a result of the proposed regulation, will enable more ASD children to learn in school and succeed in family and community life.

While an exact cost based on the length of treatment delay is unavailable, it is clear that a significant treatment disruption or delay has unacceptable financial consequences for the State of California. This is, of course, in addition to the moral and ethical challenges raised by delaying and disrupting treatment with full knowledge of the lifetime consequences associated with that decision for children, families, and society. It is for these reasons that the Department believes that it is in the best interests of California’s government and the health and welfare of its citizens to minimize treatment delay and disruption by promulgating this emergency regulation.

C. The Proposed Regulation Will Curtail or Eliminate Pervasive and Harmful Insurer Delays and Denials of Treatment

Disputes over whether certain types of treatments are medically necessary or a covered health care service often delay necessary treatment for children with autism. CDI has tracked cases involving delays and denials of behavioral health treatment, as well as speech and occupational therapy, for children with this serious disorder since 2009. During that time, CDI has sent 23 cases related to denials of behavioral health and other autism treatment to external clinicians for IMR. Of those, 19 denials were overturned by the reviewers, finding in favor of the insured child receiving treatment. Another 19 IMR cases are currently open involving denials of behavioral, speech and occupational therapy.

Individual delays in obtaining treatment for 40 closed cases average 5.8 months, nearly half a year; delays currently average 10.33 months, or almost a year, for those cases which are still open. Another 12 of those complaints are either awaiting submission of additional information or are in process. The cumulative total delays on open and closed cases combined total 12,864 days, or 35.2 years. These lengthy delays all involve treatment that experts agree is most effective

when provided in early childhood. The benefits anticipated from the proposed regulation include significantly lessening or eliminating these delays and denials of treatment and substantially improving treatment efficacy and outcomes.

D. The Proposed Regulation Will Benefit Children with Autism As Well As State Entities and Taxpayers

California leads the nation with 72,000 individuals with a form of ASD.¹²⁷ As the numbers of individuals with ASD increase, more burdens and financial demands are placed on the State's budget. Early behavioral intervention treatment not only protects children with autism, but reduces demands on limited public resources and thereby lessens the burden on taxpayer-provided healthcare networks and other support services.

At present, those burdens are enormous, as is explained in B.3.d above because of the immense need for treatment and services. Between 22% and 41% of individuals with ASD need assistance with basic life skills. The 2012 Autism Society of California survey showed that 41% of individuals with ASD need assistance with dressing, 37% need assistance with toileting and 22% need assistance with feeding. Families also reported communication is an area of struggle for many individuals with ASD: 49% cannot indicate when they are sick; 29% cannot request items they need; and 26% cannot request items they want.¹²⁸

Moreover, those needs are increasingly unmet because of declining access to Regional Center services. The percentage of families accessing services through the DDS has decreased since 2009. In 2009, 77% of California families said they were Regional Center clients, while only 70% were in 2012.¹²⁹ Navigating the Regional Center service system provides yet another obstacle for parents and children to overcome: 81% of parents rated it moderate to very hard to navigate while 51% gave the medical health insurance system that rating.¹³⁰

Insurer failures and refusals to provide therapy have exacerbated the public health crisis facing California, worsening the current emergency. Despite the 1999 passage of the MHPA, expressing the California Legislature's purpose to shift ASD therapy costs away from state and local governments to private insurers, health insurers still pay the smallest percentage of overall ASD therapy costs. Parents report that school districts are currently funding 48% of ABA, speech, occupation and physical therapies. Regional Centers pay 22% of the bill — yet another significant cost to the State. Parents pay roughly 17% out-of-pocket for ASD therapies. Finally, health insurance companies, despite the MHPA, are still only paying 9-13%.¹³¹

The need for services for autism continues throughout the affected individuals' lives. The percentage of adults with ASD who are employed or attending day programs has decreased from 29% in 2009, to 20% in 2012. The number of employed ASD adults was 42% in 2009 and dropped to 25% in 2012. This means that there is a sharp increase in the number of ASD adults with no employment or day program. The percentage of ASD adults accessing Adult Services has decreased; only 65% of ASD adults reported being a current Regional Center client,

¹²⁷ Autism Soc'y of Cal., *supra* note 6, at 10.

¹²⁸ *Id.*

¹²⁹ *Id.*

¹³⁰ *Id.* at 4.

¹³¹ *Id.* at 5.

compared to 90% of individuals under age 18.

When treatment and services are not effectively and timely provided, still further costs accrue from involvement of ASD individuals with yet other governmental entities. California's Justice System is now encountering adults and youths with ASD: 14% of families had interactions with police, including school police; 5% reported severe behavior and interactions with Child Protective Services, neighbors, or school personnel; 3% said the person with ASD had been entered into a behavioral unit or confined under Section 5150; 3% received a warning from Law Enforcement; 1% were arrested; and 1% spent time in jail or a juvenile detention center.¹³²

This crisis is imposing staggering costs on many of California's governmental entities and on its taxpayers. Through a pattern of failing to provide mandated services, insurers have shifted the costs of ASD therapies and services to California's public education system and school districts. Insurer failures to provide services have had devastating fiscal impacts on limited governmental and taxpayer resources, requiring the promulgation of this emergency regulation to rectify.

E. The Proposed Regulation Is Consistent With Existing Laws and Regulations

The MHPA requires in CIC 10144.5 that every policy that covers hospital, medical, or surgical expenses shall provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses of a person of any age and severe emotional disturbances of a child. It includes autism in the enumerated mental conditions to which it applies, contains a list of required categories of benefits, and specifies financial terms and conditions that must be applied equally to all benefits under the policy.

DMHC promulgated Title 28 California Code of Regulations Section 1300.74.72 in 2003, interpreting the MHPA, which is also codified in Health & Safety Code Section 1374.72. That regulation construes the MHPA as a mandate for all medically necessary treatment required for the diagnosis and treatment of the enumerated conditions. It provides in subsection (a):

The mental health services required for the diagnosis, and treatment of conditions set forth in Health and Safety Code section 1374.72 shall include, when medically necessary, all health care services required under the Act including, but not limited to, basic health care services within the meaning of Health and Safety Code sections 1345(b) and 1367(i), and section 1300.67 of Title 28. These basic health care services shall, at a minimum, include crisis intervention and stabilization, psychiatric, inpatient hospital services, including voluntary psychiatric inpatient services, and services from licensed mental health providers including but not limited to, psychiatrists and psychologists.

Subsection (h) of that regulation further underscores that medical necessity is the test of whether services must be covered and provided. It specifies that “[n]othing in this section shall be construed to mandate coverage of services that are not medically necessary or preclude a plan from performing utilization review in accordance with the Act.”

CDI has construed the virtually identical statute in CIC 10144.5 to require all medically necessary treatment be covered for insureds with the listed severe mental conditions, subject only

¹³² *Id.* at 4.

to the stated condition. Believing that the statutory directive was so clear there was only one tenable interpretation, CDI communicated its interpretation to the Senate Select Committee on Autism in preparation for testifying before that body at a hearing on July 13, 2011. CDI also expressed that view as amicus in *Harlick v. Blue Shield of California*, Case No. 10-15595, in a brief filed in November 2011, when only limited and consistent case law existed.

CDI's interpretation of the MHPA was based on the statutory language, legislative history and a California appellate case holding that the language of the MHPA makes clear that parity is a mandate. *Yeager v. Blue Cross of California*, 175 Cal. App. 4th 1098 (2009). At issue in *Yeager* was the interpretation of a provision of the California Health and Safety Code that provides a checklist of benefits that are legally required to be offered by a plan and includes coverage for fertility treatment. In *Yeager*, the plaintiff's insurance carrier offered infertility coverage that plaintiff challenged as inadequate, alleging that the applicable Health and Safety Code section was a mandate on insurance carriers to offer full coverage for fertility treatment.

Yeager, construing the statutory language and reviewing the legislative intent, held that the statute's wording only required insurers to offer fertility coverage for purchase and not to actually provide full coverage for treating infertility. The court reasoned that if the legislature had wanted to create a mandate for insurers to provide coverage for fertility treatment, they knew how to do so and would have enacted a statute similar to the MHPA. The court described the MHPA as a mandate to provide coverage, not merely to require that coverage be available.

The Ninth Circuit Court of Appeal recently reconsidered and reissued its decision in *Harlick v. Blue Shield*, 686 F.3d 699 (9th Cir. 2012) on June 12, 2012. The plaintiff sought residential treatment under her ERISA plan for anorexia, one of the severe mental illnesses enumerated in the MHPA. Her plan covered treatment for mental illnesses, including inpatient services, but excluded coverage for residential care. The Ninth Circuit found that the plan did not provide coverage for residential care for anorexia but that the MHPA mandated it, reasoning:

Some medically necessary treatments for severe mental illness have no analogue in treatments for physical illnesses. For example, it makes no sense in a case such as *Harlick's* to pay for time in a Skilled Nursing Facility — which cannot effectively treat her anorexia nervosa — but not to pay for time in a residential treatment facility that specializes in treating eating disorders.

The court concluded that the MHPA requires that a plan within the scope of the act must pay for all medically necessary residential treatment for anorexia, whether or not such benefits are covered for physical illnesses. The court further concluded that the only limitation on coverage for mental illness permitted under the MHPA is that insurers may impose financial “terms and conditions” on mental illness coverage, which are limited to “monetary conditions, such as copayments and deductibles.” The court accordingly required the plan to provide coverage for *Harlick's* residential treatment for anorexia.

In reaching its conclusion about the scope of the MHPA, the court cited and relied on the DMHC's implementing regulation. That regulation construed the MHPA, as CDI does in the proposed emergency regulation, to require that all medically necessary treatment for parity diagnoses be covered, subject to the stated statutory condition.

CDI has taken a series of enforcement actions consistent with its interpretation of the MHPA. It ordered Anthem to provide behavioral health treatment, and Anthem agreed to do so in November, 2009.¹³³ Additionally, CDI initiated an enforcement action against Blue Shield in July, 2011, which was resolved on January 26, 2012 by that insurer agreeing to provide all medically necessary behavioral health therapy to its insureds. That settlement was followed in early 2012 by a series of settlement agreements involving Cigna, Health Net, and United HealthGroup similarly agreeing to provide all medically necessary behavioral health treatments to insureds with autism.¹³⁴ Those agreements, by their terms, expired on June 30 or July 1, 2012 when SB 946 took effect.

SB 946, which became CIC section 10144.51, makes it indisputable that behavioral health treatment must be covered whenever it is medically necessary therapy for autism, subject only to financial terms and conditions applicable to all benefits under the policy. The bill was needed because health plans and insurers had consistently failed to provide and cover medically necessary behavioral health treatment. As the DMHC explained in the documents supporting its 2012 emergency rulemaking, plans and insurers resisted providing such treatment arguing first that it was experimental and investigational, so was not covered. More recently, health plans and insurers have contended that behavioral therapy is educational in nature, rather than medical treatment, so is not covered. Finally, even though California has no license for behavioral therapists, health plans and insurers assert that if the treatment is or could be provided by an unlicensed individual, the treatment is not “medical” so will not be covered.

CIC section 10144.51 expands the definition of qualified autism service provider and mandates that private health plans and insurance companies provide behavioral health treatment for autism spectrum disorders no later than July 1, 2012. It further requires that every health insurer must maintain an adequate network that includes qualified autism service providers, who are defined to include individuals certified by a national entity such as the Behavior Analyst Certification Board, as well as those licensed in California.

However, in July, 2012, a Los Angeles Superior Court Judge sustained a demurrer to a complaint under the MHPA in *Rea v. Blue Shield of California* declining to follow *Harlick* and holding that the MHPA requires only equality of benefits between mental and physical conditions and is not a mandate of all medically necessary treatment, subject only to equivalent financial terms and conditions. Although the decision is unpublished, therefore not citable as authority, and is also on appeal, its existence makes it more difficult for CDI to assert that the MHPA may be interpreted in only one way. Hence, the proposed regulation is necessary.

CDI’s proposed regulation is consistent with the regulation DMHC promulgated in 2003. Both

¹³³ Letter from Michael J. Daponte, Legal Counsel, Anthem Blue Cross Life and Health Ins., to Patricia Sturdevant, Deputy Comm’r, Cal. Dep’t of Ins. (Jan. 23, 2012) (on file with CDI and attached in Addendum 19) (regarding Anthem’s provision of Applied Behavioral Analysis therapy for Autism); Letter from Michael J. Daponte, Legal Counsel, Anthem Blue Cross Life and Health Ins., to Patricia Sturdevant, Deputy Comm’r, Cal. Dep’t of Ins. (Feb. 15, 2012) (on file with CDI and attached in Addendum 19) (stating that Anthem has been offering ABA services as in-network benefits to its insureds).

¹³⁴ See *CDI Action to Secure Insurance Coverage for Autism: Litigation*, Cal. Dep’t of Ins., <http://www.insurance.ca.gov/0100-consumers/0070-health-issues/0025-autism/index.cfm#Litigation> (last visited Feb. 20, 2013).

regulations require that medically necessary treatment be provided and covered for severe mental illnesses and serious emotional disturbances of a child. That interpretation by a sister administrative agency of a parallel statute, which it is charged with implementing, must be given great weight. As the California Supreme Court has concluded, “The Department’s interpretation of the Act has presumptive value due to its expertise of related and regulatory issues.” *Yamaha v. State Board of Equalization*, 19 Cal. 4th 1, 11 (1998). Moreover, California appellate courts have repeatedly followed that rule, holding that “[c]onsistent administrative construction of a statute over many years, particularly when it originated with those charged with putting the statutory machinery into effect, is entitled to great weight and will not be overturned unless clearly erroneous.” *Sara M. v. Superior Court*, 36 Cal. 4th 998, 1012 (2005). See also *Tidewater Marine Western, Inc. v. Bradshaw*, 14 Cal. 4th 557, 568 (1996).

CDI’s proposed regulation is also consistent with the interpretation of the MHPA in the Ninth Circuit Court of Appeal’s decision in *Harlick v. Blue Shield*. The consistent interpretation of the MHPA to require that all medically necessary treatment be covered under the MHPA by the Departments of Managed Health Care and Insurance, in accord with the persuasive reasoning of the federal appellate court, is entitled to deference.

Other California statutes are also relevant to the proposed regulation and its essential role in fulfilling California policy. Enacted in September 1993, Senate Bill 1085, the California Early Intervention Services Act, established a mandate for Regional Centers and local education agencies to provide comprehensive services to infants and toddlers with, or at risk of, developmental delays. The requirements for this program are set forth in Part C of the IDEA, to which the state legislation conforms. Meeting the requirements of this program has been costly, while federal funding increases have been negligible. Expenditures for Fiscal Year 2009-2010 totaled about \$400 million (\$350 million from the State General Fund and \$50 Million from federal funds).¹³⁵ This represents a 19-fold increase in Regional Center costs for the program since its inception.¹³⁶ Furthermore, the 2012-13 Regional Center budget anticipates an increase of roughly \$126 million, which is insufficient to meet the need.¹³⁷ Nevertheless, the state has fulfilled the mandate, honoring its commitment to providing services to these individuals.

Prior to the passage of the MHPA in 1999, the California Legislature adopted a comprehensive public policy of early intervention for children with autism. It found that “[t]here is a need to provide appropriate early intervention services individually designed for infants and toddlers from birth to two years of age, inclusive, who have disabilities or are at risk of having disabilities, to enhance their development and to minimize the potential for developmental delays.”¹³⁸ Although not mandating insurance coverage for early intervention autism treatment and services, the State demonstrated its commitment to promoting early intervention as an:

[I]nvestment of resources, in that these services reduce the ultimate costs to our society, by minimizing the need for special education and related services in later school years and by minimizing the likelihood of institutionalization. These services also maximize the ability of families to better provide for the special

¹³⁵ ARCA, *supra* note 80, at 7.

¹³⁶ *Id.*

¹³⁷ Cal. Dep’t of Developmental Servs., Governor’s Budget: Regional Center Local Assistance Estimate for Fiscal Years 2011-12 and 2012-13, at B-4 (2011).

¹³⁸ Cal. Gov’t Code § 95001 (West 2012).

needs of their children. Early intervention services for infants and toddlers with disabilities maximize the potential of the individuals to be effective in the context of daily life and activities, including the potential to live independently, and exercise the full rights of citizenship. The earlier intervention is started, the greater is the ultimate cost-effectiveness and the higher is the educational attainment and quality of life achieved by children with disabilities.¹³⁹

The law created a public network of options and resources for individuals with autism and their families. DDS, the Departments of Education, Health Care Services, Social Services, and Alcohol and Drug Programs coordinate services to infants and toddlers and their families. These agencies provide a family-centered, comprehensive, multidisciplinary, interagency, community-based, early intervention system for infants and toddlers with disabilities.¹⁴⁰ The law was designed to commit California's existing program resources to "reduce the number of children with disabling conditions that hinder normal development and to strengthen the family's ability to provide a supportive home environment."¹⁴¹ Direct services for eligible infants and toddlers and their families are provided through the existing Regional Center system.¹⁴² These centers were empowered to focus on early intervention treatments and provide meaningful access to low and middle-income families who could not afford to pay for them.

The MHPA and Early Intervention Services Act created multiple points of access for California families of all financial means to receive vital early intervention health care services. These statutes embody public policies favoring early intervention and requiring private insurers to provide coverage for those treatments. CDI's propose emergency regulation interpreting the MHPA is entirely harmonious with these salutary public policies and with statutory law and related regulations.

SPECIFIC PURPOSE OF THE REGULATION/DESCRIPTION OF THE NECESSITY FOR THE REGULATION

The primary objective of the proposed emergency regulation is to bring an end to the continuing pattern of improper insurer delay and denial of medically necessary treatment for individuals with autism. Further, the emergency regulation seeks to ensure that private insurers comply with the MHPA and fulfill their obligation to provide all medically necessary treatments and services to California's children with autism, subject to financial terms and conditions applicable to all benefits under the policy. Another objective of the proposed emergency is to interpret SB 946 (2011, Steinberg). The regulation will accomplish these objectives by interpreting and making more specific the MHPA and providing guidance to industry, stakeholders and consumers about the scope of the MHPA's provisions as they relate to autism treatment, to which the scope of the article is limited, as set forth in section 2562.1

Section 2562.1

¹³⁹ *Id.*

¹⁴⁰ *Id.*

¹⁴¹ Cal. Sen. Comm. on Health & Human Servs., Committee Analysis of S.B. 1085, Reg. Sess. (Apr. 28, 1993), available at http://www.leginfo.ca.gov/pub/93-94/bill/sen/sb_1051-1100/sb_1085_cfa_930428_102111_sen_comm.

¹⁴² *Id.* Services are provided under the Lanterman Developmental Disabilities Services Act and the existing local education agency and Part C of the federal Individuals with Disabilities Education Act via Government Code § 95004.

This section limits the ambit of the regulations to the scope of the underlying statute (Insurance Code section 10144.5) and ensures that the proposed action may properly be adopted on an emergency basis. For this reason the products excluded by Subdivision (g) of Insurance Code section 10144.5 are also excluded by Subdivision (b) of Section 2562.1 of the proposed regulations. Further, though the MHPA by its terms applies to the broad category of “disability insurance, it was necessary in Subdivision (b) of Section 2562.1 of the proposed regulations to restrict the scope of the subject regulations to the slightly narrower category of “health insurance” as that term is defined in Insurance Code section 106. (Insurance Code section 10144.5, subd. (a).) This is true because the disability insurance products that are excluded from the definition of health insurance by Insurance Code section 106 are of such a limited and specialized nature that they cannot reasonably be expected to provide the kind of general coverage for health care which would trigger the requirement of parity for coverage for the parity diagnoses indicated in Subdivisions (d) and (e) of Insurance Code section 106.

While the MHPA applies to several different diagnoses, the rulemaking emergency that is demonstrated in this document is limited to pervasive developmental disorder or autism. According, it is reasonably necessary in Subdivision (a) of proposed Section 2562.1 to limit the scope of the regulations to pervasive developmental disorder or autism, to comply with the requirement of Paragraph (b)(2) of Government Code section 11346.1 that emergency regulations must “address only the demonstrated emergency.”

Section 2562.2

Section 2562.2 will benefit insurers and enhance the fairness and consistency of decision making by clarifying that medical necessity is the test of whether services must be covered; if treatment or services are not medically necessary, neither this section nor the underlying statutes require that the treatment or services be covered. Accordingly it is reasonably necessary to state this fact in Subdivision (a). Otherwise, it is conceivable that the regulations could be construed to require coverage when the treatment or services in question are not medically necessary.

Subdivision (b) of proposed Section 2562.2 specifies that nothing in the regulation shall be construed to preclude an insurer from utilizing case management, utilization review, and similar techniques in accordance with Insurance Code sections 10144.5 and 10144.51. This language is reasonably necessary because, in the provision of the benefits required by Insurance Code sections 10144.5 and 10144.51, insurers are permitted by the express terms of those statutes to engage in the activities and techniques listed in Paragraphs (b)(1) through (b)(7) of proposed Section 2562.2. (Ins. Code section 10144.5, subd. (f)(3); Ins. Code section 10144.51, subd. (f).)

Section 2562.3

The Department of Insurance has received a petition for rulemaking, dated August 21, 2012, requesting that we interpret the MHPA. (Addendum Q.) In interpreting the MHPA, the Department has maintained consistency with the construction of that statute set forth in *Harlick v. Blue Shield of California* (2011) 686 F.3d 699. While *Harlick* interpreted Health and Safety Code section 1374.72, and not the Insurance Code, that section is substantially identical to Insurance Code section 10144.5; both sections are part of the MHPA and were added by the same bill: AB 88 (1999, Thomson). The only difference between the two statutes is that the Health and Safety Code section applies to health care service plans or contracts, whereas the Insurance Code section refers to policies of disability insurance; while the names of the products

differ, the substantive rules set forth in the act are identical and are expressed in identical language. It is necessary that the Department's interpretation be consistent with the construction set forth in *Harlick*, because the Department is bound to follow the "rule of statutory construction that identical language appearing in separate statutory provisions should receive the same interpretation when the statutes cover the same or analogous subject matter. (*People v. Cornett* (2012) 53 Cal. 4th 1261, 1269, fn. 6 (citing *Kibler v. Northern Inyo County Local Hospital Dist.* (2006) 39 Cal.4th 192, 201; *Walker v. Superior Court* (1988) 47 Cal.3d 112, 132).)

In *Harlick*, Blue Shield denied coverage for medically necessary treatment or services for a patient diagnosed with anorexia nervosa, a condition that, like pervasive development disorder or autism, is specified in Subdivision (d) of Insurance Code section 10144.5 and of Health and Safety Code section 1374.72 (both sections are referred to collectively hereinafter as "the Parity Act"). The court ruled:

If additional demonstration of the incorrectness of Blue Shield's argument is necessary, we point to subsection (b)(4) of the Parity Act. Subsection (b)(4) provides that plans within the scope of the Act must cover "[p]rescription drugs, if the plan contract includes cover-age for prescription drugs." The Parity Act thus specifies that a plan need not cover prescription drugs for severe mental illnesses, even if they are medically necessary, unless the plan covers such drugs for physical illnesses. The Parity Act's specific carve-out from the coverage mandate for medically necessary prescription drugs indicates that all other benefits for severe mental illnesses must be provided whenever they are medically necessary, whether or not such benefits are covered for physical illnesses.

(686 F.3d at 715-16.) Nonetheless, there is a statutory exception to the rule that insurers must provide all medically necessary benefits to patients diagnosed with a condition set forth in Subdivision (d) of the Parity Act (each such condition, together with the conditions indicated in Subdivision (e) of the Parity Act, is referred to hereinafter as a "parity diagnosis"). Subdivision (c) of the Parity Act lists three examples of terms and conditions that are to be applied equally to all benefits under the policy (or plan): maximum lifetime benefits, copayments, and individual and family deductibles. This list is a nonexclusive list, introduced by the words "shall include, but not be limited to, the following." However, since each example is a financial term or condition, we follow the rule of statutory construction known as *ejusdem generis* to interpret Subdivision (c) as limiting to financial terms and conditions the restrictions on the benefits that the Parity Act requires insurers to provide to individuals diagnosed with a parity diagnosis. Again, the California Supreme Court teaches that this:

principle of statutory construction explains that, when a particular class of things modifies general words, those general words are construed as applying only to things of the same nature or class as those enumerated. (*Sally v. Pacific Gas & Electric Co.* (1972) 23 Cal.App.3d 806, 819 [100 Cal. Rptr. 501].) This canon of statutory construction, which in the law is known as *ejusdem generis*, "applies whether specific words follow general words in a statute or vice versa. In either event, the general term or category is "restricted to those things that are similar to those which are enumerated specifically." [Citation omitted.]" (*International Federation of Professional & Technical Engineers, Local 21, AFL-CIO v. Superior Court* (2007) 42 Cal.4th 319, 342. (*People v. Arias* (2008) 45 Cal. 4th 169, 180.)

The *Harlick* court also acknowledges this exception to the rule set forth in the Parity Act that insurers must cover all medically necessary treatment of parity diagnoses:

Thus, plans need not provide more generous financial terms for coverage for severe mental illnesses than they provide for coverage of physical illnesses. For instance, if a plan has a twenty dollar deductible for each office visit to treat a physical illness, it may also have a twenty dollar deductible for each office visit to treat a severe mental illness.

(686 F.3d at 711.) Accordingly, financial terms or conditions that are “applied equally to all benefits under the disability insurance policy” may be applied to treatment or services rendered to an individual with a parity diagnosis.

Consistent with *Harlick*, Paragraph (b)(1) of proposed Section 2562.3 interprets the MHPA by specifically prohibiting annual visit limits, which are not financial terms or conditions and so do not fit within the stated exception. Similarly, paragraph (b)(2) prohibits annual dollar limits that are not equally applicable to all benefits under the policy; though an annual dollar limit is indeed a financial term or condition, an annual dollar limit that does not apply equally to all benefits under the policy does not fit within the exception set forth in Subdivision (c) of the Parity Act, because by the express terms of that subdivision, the exception applies only to terms and conditions that are applied equally to all benefits under the policy. Of course, the MHPA prohibits not just these two limitations with respect to an individual with pervasive developmental disorder or autism but a wider range of practices with respect to all the parity diagnoses. However, it is necessary to explicitly state in Subdivision (b) of proposed Section 2562.3 that annual visit limits and annual dollar limits not applicable to all benefits under the policy are prohibited with respect to pervasive developmental disorder or autism, because the Department has become aware that insurers are engaging in these two practices on a widespread basis with respect to that diagnosis, resulting in the serious harm to health, individuals, families and general welfare that is demonstrated in this document.

The protections provided by the MHPA apply only to medically necessary treatment of parity diagnoses. For this reason, it is necessary to state in Paragraphs (a)(1) and (a)(2) of proposed Section 2562.3 these conditions to the rule stated in Subdivision (b) of that section. However, it is also necessary to state in Paragraph (a)(3) of proposed Section 2562.3 the condition that the treatment or services in question must be rendered for the purpose of treating the parity diagnosis. This is true because the protections afforded by the MHPA apply not to all medical treatment or services rendered to an individual who has been diagnosed with a parity diagnosis but only to the diagnosis and treatment of the particular condition indicated in Subdivision (d) or (e) of the Parity Act with which the individual has been diagnosed. The MHPA does not speak whether other treatment or services rendered to such an individual must be covered.

Section 2562.4

It is reasonably necessary in Subdivision (a) of proposed Section 2562.4 to provide an additional limitation on the scope of this section, in order to avoid a consistency problem that would result if the scope of the proposed regulation exceeded that of the underlying statute, namely Insurance Code section 10144.51. For a similar reason it is reasonably necessary in Subdivision (b) of proposed Section 2562.4 to state that behavioral health treatment (BHT) has the same definition in the proposed regulation as in the underlying statute.

Subdivision (a) of Insurance Code section 10144.51 states that BHT for pervasive developmental disorder or autism shall be covered in the same manner and subject to the same requirements as provided by Insurance Code section 10144.5. As with coverage for other, unspecified kinds of treatment or services rendered for the purpose of treating a parity diagnosis, the MHPA, together with Insurance Code section 10144.51, requires that coverage for BHT of a patient diagnosed with pervasive developmental disorder or autism must be provided if it is medically necessary, subject only to financial terms and conditions that are equally applicable to all benefits under the policy.

Accordingly, there are many impermissible reasons that an insurer could cite for denying or unreasonably delaying coverage for BHT. However, it is reasonably necessary that Subdivision (c) of proposed Section 2562.4 should address the three such impermissible reasons that have come to the attention of the Department and are known to cause the harm demonstrated in this document.

Paragraph (c)(1) prohibits insurers from citing the need for an IQ test as a barrier to coverage. The condition that the patient must have a certain IQ is not a financial term or condition and is therefore prohibited, as explained above, by the Parity Act. Further, the only conceivable reason why coverage for BHT could rationally be withheld on the basis of IQ is that a low-IQ patient could not benefit from BHT. However, whether a particular treatment is indicated for any individual patient is a question of medical necessity and not a question of coverage. In any particular case, BHT is either medically necessary or it is not. In cases where BHT is medically necessary for an individual diagnosed with autism, the law is that it shall be covered, regardless of the patient's IQ. For this reason it is reasonably necessary that the proposed regulations preclude IQ testing as a barrier to coverage for BHT.

Similarly, it is necessary that Paragraph (c)(2) of proposed Section 2562.4 should prohibit insurers from denying or delaying coverage on the basis that BHT is experimental, investigational or educational, because these, again, are reasons why a particular medical treatment might not be efficacious or, in other words, might not be medically necessary. Either the particular BHT regime in question is medically necessary or it is not. In cases where it is medically necessary, the law is that the BHT shall be covered. At any rate, BHT in general is categorically *not* experimental, investigational or educational; otherwise the requirement that it be covered where medically necessary would not have been codified in statute.

Indeed, Paragraph (c)(1) of Insurance Code section 10144.51 provides a very extensive definition of BHT. Built into this definition are various specifications as to the qualifications and employment relationships of the personnel who can provide BHT. The statute authorizes "qualified autism service provider[s]" to administer BHT. (section 10144.51, subd. (c)(1)(b)(i).) The term "qualified autism service provider," in turn, is defined to be either a licensed person or a person, entity or group certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies. (section 10144.51, subd. (c)(3)(A).) Accordingly, licensure is expressly not required. For this reason it is necessary that the proposed regulations bar insurers from imposing the nonlicensure of the provider or supervisor of BHT as a barrier to coverage when the BHT is provided or supervised by a person, entity or group certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies.

The mandate stated in Insurance Code sections 10144.5 and 10144.51 is that policies “shall provide coverage.” Ins. Code section 10144.5, subd. (a); Ins. Code section 10144.51, subd. (a.) It is obvious that an indefinite delay in providing the required coverage would, in effect, amount to a prohibited denial of coverage. However, because early treatment is essential to success, the Department interprets the requirement to provide coverage to mean that insurers are required to provide coverage with a reasonable degree of promptness. For this reason, when an insurer unreasonably delays coverage, citing a legally invalid reason for the delay in making its coverage decision, it cannot accurately be said to have complied with the mandate. However, in certain cases, delays in making coverage decisions do not amount to a failure to provide required coverage. Because there is an infinite number of permutations of conceivable fact patterns, it is impossible to spell out a bright line rule that would definitively distinguish permissible delays from impermissible ones. Accordingly, it is reasonably necessary to impose a reasonableness standard in Subdivision (c) of proposed Section 2562.4; even when an insurer delays its coverage decision, citing as the basis for the delay a reason that is expressly identified as invalid in regulations that are binding upon the insurer, such a delay will not be interpreted as a violation of underlying statute unless the delay is unreasonable. Given the critical nature of the timing of medically necessary BHT for autism as explained in this document — and the serious harm that will result when treatment is not provided during critical periods in patients’ development — even the slightest delay in providing required coverage would appear to be unwarranted. However, in the absence of a bright line rule, a reasonableness standard is appropriate.

As discussed above, proposed Section 2562.4 interprets the MHPA by prohibiting additional limitations on coverage for medically necessary BHT on grounds which are inconsistent with Insurance Code section 10144.5 or recently enacted Insurance Code section 10144.51, or which have been consistently rejected in independent medical reviews (where questions of medical necessity are adjudicated) on the grounds that such treatment is neither experimental, investigational, nor educational; to the contrary, BHT is effective and efficacious for pervasive developmental disorder or autism, and is the standard of care.

The specific benefits anticipated from adoption of the regulation for children and families include the cessation of improper denials of medically necessary treatment for autism and the elimination of unreasonable delays in providing these treatments, which are more likely to be successful when they are begun early. Coverage of early intervention through behavioral, speech, and occupational therapy will enable children with autism to improve in intelligence quotient, cognitive ability, receptive and expressive language skills, and adaptive behavior; and will lessen maladaptive, tantrum or self-injurious behaviors. Other anticipated benefits from adoption of the proposed regulation include the expectation that children will receive improved diagnoses from autistic disorder to pervasive developmental disorder, and a significant minority of children will recover from autism, resulting in lessening their needs for governmental services throughout their lifetimes.

EVALUATION OF COMPATIBILITY WITH EXISTING STATE REGULATIONS

After a review of relevant existing state regulations, CDI has concluded that the proposed regulations are neither inconsistent nor incompatible with existing state regulations. In fact, these proposed regulations are very consistent and compatible with the thrust of the DMHC regulations interpreting the Mental Health Parity Act, which is codified in virtually identical

terms in the governing statutes. *See* Cal. Ins. Code §10144.5 (West 2012); Cal. Health & Safety Code §1374.72 (West 2012); Cal. Code of Regs., tit. 28, § 1300.74.72 (2012).

OTHER MATTERS PRESCRIBED BY STATUTE

The Department has complied with Insurance Code section 12921.7.

MANDATES ON LOCAL AGENCIES OR SCHOOL DISTRICTS

The proposed regulations do not impose any mandate on local agencies or school districts. There are no costs to local agencies or school districts for which Part 7 (commencing with Section 17500) of Division 4 of the Government Code would require reimbursement.

COST OR SAVINGS TO STATE AGENCIES, LOCAL AGENCIES OR SCHOOL DISTRICTS OR IN FEDERAL FUNDING

The Commissioner has determined that the proposed regulations will result in no cost to any local agency or school district that is required to be reimbursed under Part 7 (commencing with Section 17500) of Division 4 of the Government Code, no other nondiscretionary cost or savings imposed on local agencies, and no cost or savings in federal funding to the State.

To the contrary, the proposed regulation would confer a substantial financial benefit on both local agencies and school districts through shifting costs, which they are now bearing for special education and services to children with ASD, to private insurers. Substantial cost savings will also be realized by state agencies as their costs are also shifted to private insurers. Among other savings, DDS estimated in the May 2012 Revised Budget that there will be an anticipated savings to the General Fund of \$79.8 million resulting from the transition of treatment for children with autism from Regional Centers to private insurers.

The proposed regulation's potential for saving taxpayer expenditures by requiring early intervention services by insurers is enormously important, in light of the economic and financial implications of the ASD epidemic. The California Legislature intended the MHPA and its mandate on private insurers to be the investment necessary to address the needs of the growing population of ASD individuals. There is evidence from other states that providing early intervention services can produce a positive monetary return on such an investment in children's health. In 1998, ASD researchers compared the projected costs between children with autism in Pennsylvania who received early intervention and those who did not.¹⁴³ Their investigation was wide in scope, spanning the individual's lifetime and taking into account such factors as public services, regular education, and family support services. Their analysis revealed a savings ranging from \$656,000 to \$1,082,000 per child across the lifespan, depending on the

¹⁴³ John W. Jacobson et al., *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism: General Model and Single-State Case*, 13 *Behav. Interventions* 201, 201-02 (1998).

effectiveness of early intervention services.¹⁴⁴ A similar 2007 study of cost comparisons between early behavioral intervention services and special education revealed that the state of Texas could save a potential \$2 billion in actual costs associated with special education services over an 18-year period.¹⁴⁵

California school districts spent \$9.3 billion on special education in 2006–07, the most recent year for which data are available.¹⁴⁶ The \$9.3 billion includes all special education spending on behalf of children with disabilities from birth to 22 years old. This amounts to \$13,742 per child served.¹⁴⁷ Special education spending includes separate class instruction, which is the largest spending category, accounting for more than one third of total spending and including all salary, supply, and associated costs of providing instruction in separate classes.¹⁴⁸ Resource specialist instruction and other specialized instructional services are the next largest categories. Resource specialists are credentialed special education teachers who provide specific instructional services as identified on IEPs, typically to non-severely disabled students. Professionals who fulfill pupil services functions often carry out other specialized instructional services, such as speech therapy instruction. Altogether, instructional spending accounts for 66 percent of the total.¹⁴⁹ Early intervention services can substantially reduce the high costs of instructional services as well as pupil services, which include psychological services, speech pathology and audiology services and guidance and counseling services.

Similarly, the proposed emergency regulation could save California taxpayers approximately \$138.8 million to \$197.8 million over the next year and nearly \$2 billion in costs over eighteen years for special education and other services. Several studies have quantified costs and savings to governments associated with providing early intensive behavioral interventions (EIBI) or ABA programs for young children. In summary, the studies quantify the costs of EIBI, assume success rates based on efficacy studies, and then assume cost savings to education and other government financed programs associated with these treatments. Virginia’s independent Joint

¹⁴⁴ *Id.* The Pennsylvania Legislature passed Act 62 of 2008 requiring health insurance companies to cover up to \$36,000 yearly for behavioral and other clinical services until the age of 21. The Pennsylvania Legislature concluded that insurance funding for behavioral programs leads to increased functioning and greater contributions to society.

¹⁴⁵ Gregory S. Chasson et al., *Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism*, 16 J. of Child & Fam. Studies 401, 410 (2007) (“Projected cost comparisons reveal that the state of Texas has the potential to save over \$2 billion in *actual* costs associated with special education services over an 18-year period. Moreover, this estimate of savings errs on the conservative side of calculation, since epidemiological data indicate an increase in autism prevalence worldwide. Furthermore, the United States Government Accountability Office (GAO; 2005) released a report that indicated that the average federal funds reserved for each child with autism in the United States is \$18,790 per year, which includes \$6,556 for regular education. Thus, regular education costs notwithstanding, an average of \$12,234 per year in federal funds are spent on each child with autism in special education across the country. We used an estimate of \$11,000 for each child per year in Texas state-budgeted funds, indicating that our estimate of saved governmental funds was conservative. The GAO (2005) report also provides support for our findings generalizing to other states. Although each state varies in the amount of state budgeted funds provided to children with autism, and the state of Texas covers most of the costs associated with this population, it is clear that a significant amount of federal funds would be saved in other states.”).

¹⁴⁶ Lipscomb, *supra* note 53, at 5.

¹⁴⁷ *Id.* at 21.

¹⁴⁸ *Id.* at 15-17.

¹⁴⁹ *Id.*

Legislative Audit and Review Commission (JLARC) issued a report in August 2009¹⁵⁰ which reviewed several studies related to the efficacy of EIBI, and resulting potential cost savings to state and local governments.. By applying the methodology of the Pennsylvania and Texas studies, cited above, to Virginia-related data, JLARC staff estimated that the Commonwealth could save approximately \$137,400 in special education costs per student with ASD if EIBI was consistently provided.¹⁵¹ In fact, the analysis indicates that states could realize savings as long as at least 42 percent of students with ASDs who received EIBI make moderate improvements, so require less intensive services and fewer supports, which is a substantially more conservative outcome than those reported in the research literature.¹⁵²

Applying this analysis to California-related data yields prodigious cost savings in California special education expenditures for children with ASD. The Lucile Packard Foundation reports that the number of California students diagnosed with ASD rose to 59,690 in 2010.¹⁵³ Of these roughly 60,000 California students with ASD, 12,895 are between the ages of 3 and 5.¹⁵⁴ A breakdown of insurance coverage for these children with ASD shows that 63.9% are privately insured, 28.2% are publicly insured and 7.9% are uninsured.¹⁵⁵ Thus, roughly 8,240 California children between the ages of 3 and 5 are privately insured and would be affected by the promulgation of this emergency regulation. Using the Pennsylvania, Texas and Virginia studies which quantified approximate special education costs savings per child with ASD over the span of a child's education (ages 3 to 22), total savings to California would range between \$137,400 and \$208,500 per child from age 3 to 22.¹⁵⁶ Accounting for inflation, the range for this estimate is \$143,647 to \$285,541. Thus, per year savings per child, given these estimation parameters, ranges from \$7,182.35 to \$14,277.05. Considering all privately insured California children between ages 3 and 5, potential special education costs savings range from \$59,182,564 (\$59 million) to \$117,642,892 (\$118 million) over a one-year period. Expanded to include the special education costs of a child from ages 3 to 22, the range of state special education savings would be between \$1.18 billion to \$2.35 billion.

The proposed Emergency Regulation requiring early intervention with behavioral health treatment and speech and language therapy will generate substantial cost savings to the State in a way that is fully consistent with applicable California law and public policy. Its promulgation will result in young children being better able to be mainstreamed into school and society, thereby lessening the burden on the taxpayer-provided healthcare network and other state-funded special education and support systems as the child matures.

¹⁵⁰ Joint Legislative Audit and Review Comm'n, Report of the Joint Legislative Audit and Review Commission to the Governor and the General Assembly of Virginia: Assessment of Services for Virginians with Autism Spectrum Disorders 15 (2009), available at <http://jlarc.virginia.gov/reports/Rpt388.pdf>.

¹⁵¹ *Id.*

¹⁵² *Id.*

¹⁵³ Lucile Packard Found. for Children's Health, Children with Special Health Care Needs: A Profile of Key Issues in California (2010), available at <http://www.lpfch.org/cshcn/fullreport.pdf>.

¹⁵⁴ Easter Seals Disability Servs., *supra* note 1.

¹⁵⁵ Lucile Packard Found. for Children's Health, *supra* note 153.

¹⁵⁶ Chasson, *supra* note 145, at 410.

STUDIES AND REPORTS

The Department is relying upon the following technical, theoretical, or empirical study, report, or similar document in support of its finding of emergency.

Document Name	Footnote	Addendum
Easter Seals Disability Services, 2012 State Autism Profiles California	1	A
Commission’s Report to the Governor and Legislature: An Opportunity to Achieve Real Change for Californians with Autism Spectrum Disorders	2	B
Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network	3	C
Autism in California 2012 Survey	6	D
Problem Behavior Interventions for Young Children with Autism: A Research Synthesis	8	E
Long-term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment	8	F
Karen Fessel, Dr PH, Autism Health Insurance Project, letter to CDI Deputy Commissioner Patricia Sturdevant, Oct. 24, 2012.	9	G
Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children	16	H
Intensive Behavioral Treatment at School for 4- to 7-Year Old Children with Autism: A 1-Year Comparison Controlled Study Behavior Modification	18	I
Early Intervention in Autism	19	J
Challenges in Evaluating Psychosocial interventions for Autism Spectrum Disorders	20	K
Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model	21	L
Analysis of the Evidence Base for ABA and EIBI for Autism	22	M
UnitedHealthcare Medical Policy, Intensive Behavioral Therapy for	23	N

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Autism Spectrum Disorders, effective October 1, 2012		
Market conduct examination of Aetna Life Insurance Company's claims handling practices for ABA and speech therapy for individuals with ASD for the period from June 1 through March 21, 2011	NA	O
Blue Shield of California Life & Health Insurance Company, Vita Shield Plus 2900 Generic Rx Policy	25	P
Letter Petition for Rulemaking from Vice President of Government Affairs Anne Eowan, Association of California Life & Health Insurance Companies, to Insurance Commissioner Dave Jones	26	Q
DEPARTMENT OF DEVELOPMENTAL SERVICES PROPOSALS TO ACHIEVE \$200 MILLION GENERAL FUND SAVINGS, MAY 2012	NA	R
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Auditory-Motor Mapping Training as an Intervention Facilitate Speech Output in Non-Verbal Children with Autism: A Proof of Concept Study	44	Z
"Can I Join the Club?" A Social Integration Scheme for Adolescents with Asperger Syndrome	45	1
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Autism Spectrum Disorders – Changes in the California Caseload – An Update: June 1997 – June 2007	83	14
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California Department of Developmental Services, November 2011 Regional Center Local Assistance Estimate for Fiscal Years 2011-12 and 2012-13 (Governor's Budget),	137	20

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Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism: General Model and Single-State Case	143	21
Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism	145	22
Report of the Joint Legislative Audit and Review Commission To The Governor and the General Assembly of Virginia—Assessment of Services For Virginians With Autism Spectrum Disorders	150	23
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