

Chapter 5

Children with Special Needs

I. CONDITION INDICATORS

Children with special needs vary widely by disability and circumstance. They include children damaged prenatally, those with physical handicaps, and those with a mental illness, learning disability, or severe emotional problems. On a national basis, 8.1% of persons from 5–20 years of age have a disability as defined by the Bureau of the Census. The California census percentage for this population is 7.5% and amounts to 609,000 children.¹ Children in school are surveyed in greater detail and under somewhat broader criteria (see discussion of the 1975 Individuals with Disabilities Education Act (IDEA) statute below). Those children from 6–17 years of age with disabilities related to learning are diagnosed under specific categories, with the five most prevalent kinds indicated by Figure 5-A below. The overall IDEA disability rate for school age children is 9.18% for the state and includes the following types: Autism—0.2%, Serious Emotional Disturbance (SED)—0.4%, Mental Retardation—0.5%, Speech or Language Impairments—2%, Specific Learning Disabilities (such as dyslexia, ADD, ADHD)—5.3%.² An additional small but important group of 0.33% have health impairments, chiefly hearing and orthopedic limitations, and 0.05% have a vision impairment (not eyeglass correctable).

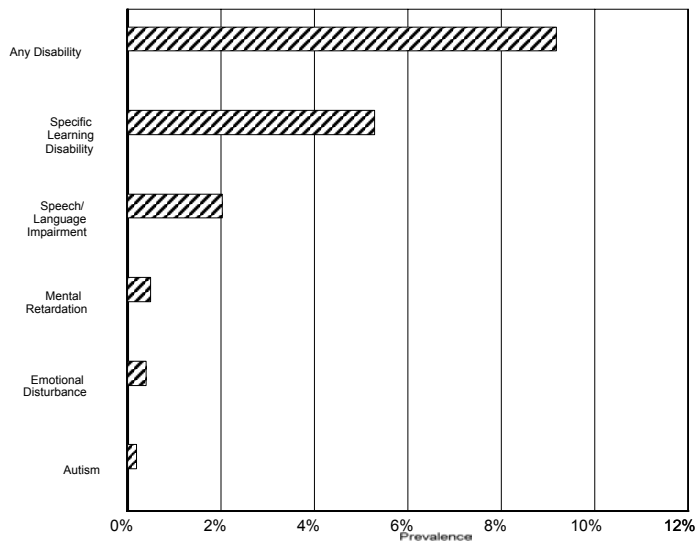


FIGURE 5-A. 2002 Prevalence of IDEA Screened Disabilities for California Children Ages 6–17³

These disability numbers for California are generally understated, consistent with the widely held thesis that the state does not comply with the screening mandate of IDEA. The national figure for covered disabilities screened via IDEA is 11.56%, 26% higher than the number identified in California.⁴ The incidence of disability is more than four times higher among incarcerated youth, with almost half of them suffering one of the four listed problems, and with 20% diagnosed as SED (see discussion of special education for incarcerated youth in Chapter 9).

A. California Child Disability Major Groupings

The figures in Figure 5-A indicate that 632,200 California children from 3–18 years of age suffer from a disability. These numbers exclude children under the age of three and, as noted above, include only those children diagnosed and receiving aid. A more accurate count, assuming the national percentage of school children receiving IDEA services and a proportionate share of the 0–3 years of age population, is 923,000.⁵ The “Learning Disabilities” category remains the largest and has grown from 4.2% of children to 5.3% within the past five years. The number of children with Attention Deficit Disorder (ADD) and diagnosed as seriously emotionally disturbed (SED) has increased over the past decade, but are also under-represented in the IDEA served population in the state. The national “emotional disturbance” and “autism” IDEA census rate is 0.94%, three times the California rate.

The “mental retardation” percentage diagnosed and served by the state of 0.49% is less than half the national percentage of 1.1%. No genetic or environmental factor explains a significant California difference in mental retardation incidence. The undercount suggests a less effective screen in the state or a much narrower definition sufficient to qualify for IDEA assistance.

The autism incidence listed for California at 0.2% is similar to the national number, but this category is increasing at a rate substantially beyond any other category (see discussion below).

1. Attention Deficit/Hyperactivity Disorder

Attention Deficit/Hyperactivity Disorder (ADHD) is a broadly defined neurobiological disorder. It entails developmentally inappropriate behavior: poor attention span, hyperactivity, impulsivity. Symptoms appear before age 7, last at least 6 months, and are chronic in nature. Some experts have estimated incidence currently at 5% of the school-aged population, with boys three times more likely than girls to have the disorder.⁶ Some research indicates that ADHD may be genetically transmitted and results in a chemical imbalance or deficiency in certain neurotransmitters. The disorder's imprecision is exacerbated by the common incidence of its symptoms among normal children; the issue is one of degree. In addition, some critics are concerned about its imprecision and about ritalin and other drug administration as a reflexive result.

Experienced teachers and health professionals believe that a growing number of children exhibit these symptoms at the far end of the spectrum—and the symptoms do not readily dissipate as a “stage.” The incidence increase is traced by some to more common and serious alcohol and drug use by pregnant women over the past two decades. The high incidence of cocaine use during the 1980s and 1990s caused highly publicized concern, with predictions of an epidemic of ADHD or otherwise permanently impaired children in large numbers (“crack babies”—children born with severe ADHD symptoms). Recent studies indicate that cocaine use by pregnant women is associated with somewhat lower birth weights, and one long-term study found substantial impacts on depression/anxiety, aggressive behavior, thought problems, insensitivity, and distractibility.⁷ Although the fear of a “lost generation” has proved exaggerated, there are real and measurable detriments. Abuse of methamphetamines and the two lawful contaminants—tobacco and alcohol—trigger perhaps the most ADHD concern.

In 2000, the American Academy of Pediatrics listed some guidelines to regulate the diagnosis of ADHD, amidst rising fear that many normal but active children were being mis-diagnosed and then subjected to ritalin or other drug regimens unnecessarily—perhaps to their detriment. These diagnostic guidelines have been followed by treatment guidelines in 2001. The more recent studies suggest a wide

range of incidence, ranging from 4%–12% of school-age children, with boys being so diagnosed at five times the rate of girls.⁸

2. Autism and Pervasive Developmental Disorder: Autism, Rett's, CDDD, Asperger's, and PDDNOS

“Pervasive Developmental Disorder” is a term evolving from the 1980s to describe a class of disorders involving impairments in social interaction, communication skills, and repetition of a limited number of activities. The Diagnostic and Statistical Manual of Mental Disorders was revised in 1994 to list five specific disorders under this rubric: autistic disorder, Rett's disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and “Pervasive Developmental Disorder Not Otherwise Specified” (PDDNOS). Each of these categories involves the significant loss of previously acquired skills (before age 10) in at least two of the following areas: language, social skills, bowel/bladder control, play, motor skills, plus abnormalities in two of the following: social interaction, communication, restricted, repetitive behavior. Causes are traced to neurological, genetic, or environmental problems—but precise contributors remain elusive. In general, children with this problem are impaired in symbolic or abstract thought and sequential logic. The process of learning—which involves comprehension of spoken words, inventiveness, applying rules, and using acquired information—is difficult for them.

A number of therapies are currently possible: facilitated communication, auditory integration therapy (AIT), sensory integration therapy, vitamin therapy, dietary intervention, anti-yeast therapy, and the Lovaas method. The last, although involving labor intensive intervention (4–6 hours per day of one-on-one training), has shown some success—with one source reporting substantial progress in about 50% of treated children.⁹

National sources place incidence at 5–15 per 10,000 births, with boys four times more likely to be afflicted than girls.¹⁰ Prior national estimates of incidence may be artificially low. However, a screening of the Eureka Union School District (a sample with no idiosyncratic indicators) found 22 autistic children among the 2,930 children surveyed. This rate would project to 0.8%—over ten times the previously presumed rate, and seven times the rate so diagnosed under the IDEA program in California.¹¹

A survey by the state's Department of Developmental Services (DDS) released on April 16, 1999 revealed a 273% increase in the number of reported autism cases over an eleven-year period—from 2,778 in 1987 to 10,360 in 1998. Other disorders, such as cerebral palsy and epilepsy, had been increasing consistent with population growth. At the end of 2002, DDS estimated that 20,377 of its clients have autism; over 82% of those autistic clients are between the ages of 0–21.¹²

Some experts consider the growth to be alarming. While some experts have cautioned that some of the increase may reflect better diagnosis, the scale and longevity of the increases infer that incidence increase is real, and that causative factors warrant high priority study. Importantly, a study released in October 2002 indicated that the marked 273% increase noted above represented actual case increases without distortion from new definitions or heightened screening.¹³ Moreover, no change in vigilance or sensitivity can account for the remarkable 31% increase during 2001, with a record number of 3,577 new children suffering from severe autism.

Thus far nationally, very little public money is funding autism research. As discussed above, the precise cause of autism or its growth over the last decade is in dispute, with explanations including environmental contaminants, large vaccination groupings that overly burden a child's system, infectious agents, genetics, and allergic etiologies.¹⁴ Republican Congressman Dan Burton of Indiana has taken a special interest in the subject, and cites as one possible cause the use of the preservative thimerosal, long used in childhood vaccines. Others contend that the large number of new vaccinations and dosage or groupings in their administration may be a factor. Burton has introduced the National Vaccine Injury Compensation Program Improvement Act of 2003 to extend the statute of limitations for vaccine defect claims and increase funds available to those injured. This vaccine recovery fund was created federally as an alternative to mass toxic tort cases, relieving the industry and agencies of liability under the product protection safeguards generally applicable in civil court.

3. Mental Health Disorders (including Severe Emotional Disability)

The Census Bureau places the Severe Emotional Disability (SED) rate at 4.8% of all school-age children.¹⁵ A broader definition of mental health disorder yields incidence estimates in the 12–20% range. At the 12% level, approximately 1.2 million children in California could be included among those appropriate for treatment.¹⁶ The 1992 California Mental Health Survey of the Department of Mental Health indicates serious problems in 5–7% of the child population, a range of 500,000–700,000 children. Currently, 76,000 children are served in state mental health programs,¹⁷ administered at the county level under realignment (as discussed below). As noted above, the IDEA count of SED children was up from 0.27% in 1999 to 0.4% in 2002. However, California's reported rate is still just one-third of the national IDEA count of 1.13%. The disparity in numbers between IDEA inclusion and other measures may reflect a state policy that SED is not a learning disability but a mental health problem not addressable by special education.

Persons under the age of 25 accounted for 14% of all suicides in 1999.¹⁸ A 1993 study by the Centers for Disease Control (CDC) of 16,000 high school students found that one in twelve said he/she had attempted suicide in the previous year.¹⁹ Youth suicides increased substantially between 1965–1993, but have been declining since, and are expected to reach previous levels.²⁰ Nevertheless, the accomplished suicides of from 170 to 240 children per year—which has continued over the past twenty years—is of continuing concern. It does not include the much larger number of attempted suicides. The number of accomplished suicides in the U.S. remains relatively high compared to incidence in other nations, and remains the third leading cause of death for children from 15–19 years of age (see Chapter 4).²¹

4. Mental Retardation

Mental retardation refers to significant subaverage intellectual functioning, usually involving scores of 70 or below on intelligence tests. It is not a disease or illness in the traditional sense, although a large percentage have chromosome abnormalities. More effort is required to educate, and there is often a ceiling on likely progression. However, contrary to public perception, the mentally retarded are not necessarily locked into a dependent lifestyle, but can learn and develop, and in most cases achieve contributive self-sufficiency if investment in them occurs. One study suggests that 3 out of every 100 people in the country have mental retardation.²² In 2002, over 613,000 students nationally aged 6–21 were classified as having some level of mental retardation, needing special education in school.²³

5. Reading and Learning Disabilities: Dyslexia, Vision, Hearing

There are a series of specific disabilities which pose particular obstacles to learning, including vision and hearing disability, dyslexia, and language (communication) disorders. Child advocates argue that these children warrant special vigilance to screen and treat because the correction or amelioration of the disability can allow learning to reach a child with otherwise normal capacity. Hence, overcoming a vision, hearing, or language disability can actualize considerable potential.

Nationally, more than one million students are in special education programs with identified communication impairments. Note that some among this group may suffer from retardation, autism, or other problems. Experts estimate that about 10% of the population suffers from communication disorders (speech, language, and hearing).²⁴

Hearing loss is a substantial subset within this category. During the 1999–2000 school year, 71,671 students from 6–21 (1.3% of students with disabilities) received hearing impairment-related services nationally.²⁵ However, the category includes only children with a hearing impairment diagnosis (and no other disability). Experts believe that the percentage is substantially higher—with four different types of hearing loss problems.

Visual impairments run across a spectrum from low vision to legally blind. Substantial visual impairment occurs among children at a rate of 12.2 per 1,000. The legally blind category rate is .06 per

1,000.²⁶ Children with visual impairment at any level generally benefit enormously from early intervention technology—from optical aids to special tapes and computer equipment can be used if appropriate skills are learned.

Recent evidence suggests that some learning disabilities may be diagnosed based on simple reading deficiency, sometimes due to poor teaching, lack of home support, vision or other problems, or foreign language barriers. According to one source, “[a]lmost 345,000 students are diagnosed with a learning disability, usually not until third or fourth grade. But, far fewer would have been referred to special education if in kindergarten and first grade they had received proper reading instruction from informed teachers....”²⁷

6. Traumatic Brain Injury

Traumatic brain injury (TBI) is distinguishable from other categories of special need. Rather than disease or genetic problem, its cause is injury from accident or attack. TBI is the leading cause of death and disability in children and adolescents nationally. The most frequent causes are related to automobile collisions and child abuse (from “shaken baby syndrome” to direct blows to the head). Nationally, more than one million children suffer head injuries annually (sufficiently serious to be diagnosed and treated), 165,000 require hospitalization,²⁸ and more than 30,000 have lifelong disabilities.²⁹

7. Other Problems

Several additional diseases raise serious special need issues for children, although less common than those listed above. They include cerebral palsy (each year, 8,000 infants and nearly 1,500 preschool-age children are diagnosed with cerebral palsy);³⁰ Down Syndrome (4,000 babies born each year nationally);³¹ epilepsy (62,500 new cases each year among children and adolescents);³² and spina bifida (one in every 1,000 births nationally).³³

B. Causes

The causes of disability involve a mix of heredity and environment. Some children may be genetically predetermined or disposed to some disabilities. Others may be subjected to environmental harm. Three additional causes are also closely correlated with serious, lifetime disability for large numbers of California’s children: undernutrition, prenatal alcohol and drug use, and lead contamination.

1. Undernutrition

A leading environmental cause of child disability is undernutrition. Although difficult to identify with precision, the impact is clearly momentous—and strongly correlating with child poverty. Longstanding research has established a strong connection between nutrition and optimum brain development. One source has concluded that even moderate but chronic undernutrition correlates with lower scores in cognitive function tests, and found “substantial relations between nutrition and mental development.”³⁴ A decades long longitudinal study of diet and mental development from 1968 into the 1990s has found that nutrition is highly correlated with cognitive competence, especially between ages 3–7. There is a remarkable relationship between nutrition and language test performance.³⁵

Some harm is permanent—particularly where malnutrition occurs during the first five years of brain development. Recent research shows that even low levels of malnutrition for various nutrients harm children in a variety of ways; some—but not all—are irreversible. These developmental, growth, health, and educational effects are all preventable—and some can be wholly or partly reversed—if children are properly fed.³⁶

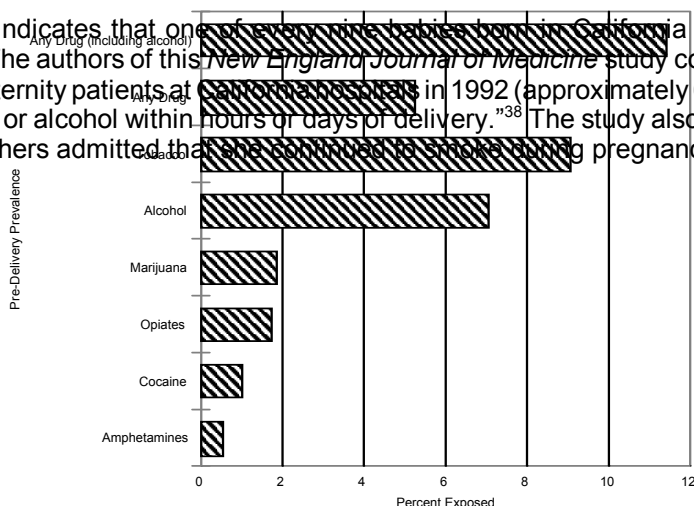
Apart from the absence of nutrients, some experts believe that some children are predisposed to common disabilities—but that predisposition can be countered with nutrient supplements not now offered—particularly for the more than one million California children suffering from ADD/ADHD, and dyslexia—both correlating with certain fatty acid deficiencies.³⁷

Overall, nutritional shortfall deepens as poverty declines to one-half of the poverty line. As Chapter 2 discusses, the basic safety net for children is at a record low. As welfare reform sanctions are implemented on a large scale during the current 2003–04 year and beyond, substantial numbers—estimated at from 260,000–360,000 children—will suffer cuts to these levels associated with serious nutritional shortfall. In addition to these numbers is a larger group receiving no safety net support, but who have left TANF and instead of employment now face stark poverty without safeguard for their children. See Chapter 3 discussion of (a) the inadequacy of food stamp levels for developing children, (b) the remarkable fall-off in food stamp participation and the partial but inadequate offset from WIC and school lunch programs, and (c) current evidence of severe nutritional shortfall for some populations, including immigrant children, those living in the impoverished East side of Los Angeles, and those in the state’s Central Valley—one of the most productive agricultural regions of the world.

2. Child Abuse: Fetal Drug Injury and Fetal Alcohol Syndrome

Parental abuse and neglect is a cause of child disability across a range of injuries as Chapter 8 below outlines in detail. However, one particular type of abuse has a close connection with future disability appropriate for emphasis: the contamination of the fetus by pregnant women through alcohol ingestion or drug use—either of which can devastate and permanently injure a child. Child advocates argue that the issue is not one of abortion rights; the children involved will be born. They contend that children lack the organization and presence in the media to counter politically correct notions about a woman’s body—notions steeped in the assumption that a child which will be born remains the possession of the birth mother not until viability (per *Roe v. Wade*) but until birth. And until the birth is completed, the mother is entitled to do what she will with this appendage to her body—regardless of the lifetime consequences to a human being who will be born. Hence, the criminal justice system is not applied and the child welfare (dependency court) system operates only *post hoc*, eschewing any preventive measures as an objectionable challenge to adult reproductive rights.

A 1993 study indicates that one of every nine babies born in California in 1992 was exposed to alcohol or drugs. The authors of this *New England Journal of Medicine* study concluded: “[W]e estimate that 11.35% of maternity patients at California hospitals in 1992 (approximately 67,000 women) had used a licit or illicit drug or alcohol within hours or days of delivery.”³⁸ The study also found that an additional one in eleven mothers admitted that she continued to smoke during pregnancy.³⁹



Source: 329:12 NEW ENG J. MED (9/16/93) at 850.

Figure 5-B. 1992 California Pre-Delivery Drug Prevalence

The results of the California perinatal substance abuse study came from urinalysis tests done on women in labor at 202 randomly-selected California hospitals.⁴⁰ According to one author of the study, the results were “conservative.”⁴¹ None of the toxicology tests could detect drug use prior to the last month before delivery, and most only measured exposure within the last several days or hours.⁴² Figure

5-B presents the results of the study, showing exposure levels by type of drug. Not every exposure results in child disability. Many infants exposed to detectable levels of alcohol, drugs, or tobacco through maternal use will not suffer irreparable harm. Nevertheless, there is a strong correlation between such use and later complications—many involving lifelong disability. The chemicals here of greatest concern—alcohol, tobacco-borne substances, opiates, and amphetamines—are not blocked by the placenta, and may infuse the small body-weight fetus at effective concentrations many times the level felt by the mother.

Damage will depend on substance used, duration of use, degree of use, and developmental period of the fetus, among other factors. However, such direct infusion of harmful chemicals poses a serious risk to the child—one distinguishable from the advisable weight, diet, or exercise regimen of a mother.

The recent results in California are lower than a 1992 national study which did not rely on use within the several days or weeks before birth. The larger study relied on self-reporting—also likely to understate use of dangerous substances. The National Institute on Drug Abuse gathered self-reported information from a national sample of women who delivered babies. Of the four million women who gave birth, 5.5% used illicit drugs while they were pregnant, close to the California results.⁴³ However, the self-reporting of alcohol or cigarette use involves less stigma (and only recent use would be detected by the California survey). Alarmingly, 18.8% of pregnant women admit to exposing their fetuses to alcohol, and the most recent self-report of smoking during pregnancy is 12.3%.

A recent report from the National Household Survey on Drug Abuse estimated that in 1999 the rate of drug use among pregnant women was 3.4% for illicit drugs; 17.6% for tobacco; and 13.8% for alcohol.⁴⁴

A different survey obtained similar results, finding 3.7% of pregnant women aged 15 to 44 years self-reporting use of illicit drugs in the month prior to interview. Particularly alarming is the 15% rate among pregnant women aged 15 to 17, actually slightly *higher* than the rate for nonpregnant women of the same age (14.1%). In 2001, the rates of current illicit drug use were similar for white (4.0%), African American (3.7%), and Hispanic (3.3%) pregnant women.⁴⁵

Figure 5-C, based on data from the Centers for Disease Control, presents an indicator of the trend in perinatal alcohol abuse harm. The CDC found that the rate of American babies born with health problems caused by diagnosed fetal alcohol syndrome (FAS) rose almost sixfold from 1979 through 1993.⁴⁶ Babies born with FAS suffer central nervous system dysfunction, including delayed motor development, mild to profound mental retardation, and learning disabilities.⁴⁷ FAS also causes problems that affect speech, language, swallowing, and hearing development.⁴⁸

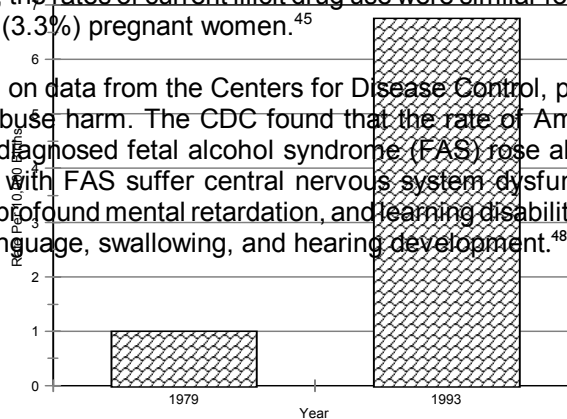


FIGURE 5-C. U.S. Trend in Alcohol-Injured Infants per 10,000 Births

The effects of FAS are well documented. In one large study in the state of Washington, FAS

correlated with an average IQ of 79; other problems revealed by the study included the following:⁴⁹

- ◆ Nearly all FAS children had reading and spelling levels below their IQs;
- ◆ Only 10% lived independently after emancipation (reaching adult years);
- ◆ 60% were suspended, expelled, or dropped out of school prior to high school graduation;
- ◆ 50% had been confined or were confined in mental hospitals, rehab facilities, or prisons;
- ◆ 30% had drug or alcohol problems; and
- ◆ Of those studied who had given birth to a child themselves, 57% no longer had the child in their custody, 40% drank during their own pregnancies, and 17% had children diagnosed with FAS, with another 13% suspected as FAS injured.

3. Lead Contamination/Environmental Injury

There are several environmental contaminants disproportionately dangerous to children. However, one is a particular concern: lead contamination. It is estimated that 560,000 children live in 2.5 million pre-1950 housing units in California that are likely to have serious lead hazards for children. A 1989 screening in a high-risk Alameda County community found that 67% of the children had lead blood levels above the 10 micrograms per deciliter level set by the Centers for Disease Control—and many of these are at levels where IQ diminution or other observable health effects begin.⁵⁰

Although blood lead levels in children have decreased over 88% since the late 1970s, elevated levels remain more common among low-income children, urban children, and those living in older housing.⁵¹ Substantial lead based paint remains in fragile condition in older buildings, lead remains environmentally common due to decades of leaded gasoline, and most ominously, there are signs of excessive lead in some drinking water supplies. The most recent large-scale study of lead exposure in California involved a state Department of Health Services (DHS) survey of drinking water, paint, and soil at elementary schools and child care centers from 1994 to 1998. As discussed in Chapter 4, the survey found that 37% of public elementary schools have deteriorating lead-containing paint significant enough to pose a hazard, 18% have lead levels in drinking water above the federal action level of 15 parts per billion (ppb), and 6% have soil lead levels above the federal action level of 400 ppb.⁵² The danger here is exacerbated by the nature of lead ingestion in children: They are very disproportionately harmed *vis-a-vis* adults. Serious brain damage—including IQ diminution and ability to read and write—correlate in the research to low exposure levels (well short of visible lead poisoning symptoms). Most important, intake of lead poses a cumulative danger—each exposure adds to an overall tolerance budget which must not be exceeded. The DHS survey indicates multiple sources of exposure for the long periods many children are in public schools, possibly adding to home exposure. (See more detailed discussion of research on incidence and effects in Chapter 4.)

The health evidence is summarized by one expert: “Recent studies of children with low but elevated blood-lead levels strongly link lead with decreased intelligence and impaired neurobehavioral development.”⁵³ Another leading 1995 study concludes that “even low levels of lead in blood (10 ug/dL) can drop the IQ of young children measurably—and to below normal ranges.”⁵⁴ The 10 ug/dL level is one-eighth the “lead poisoned” line of 80 ug/dL where diagnosis from observable symptoms most often occurs. The leading study concludes that the result of current “low level” exposure “could be a tripling of the number of youngsters who need specialized educational services.”⁵⁵ Research published in 2003 and discussed in Chapter 4 indicates that substantial IQ deficiency (7 points) occurs not at the 10ug/dL level previously assumed to be safe, but at half that level.

Figure 5-D presents the research findings published in the *Journal of the American Medical Association* on February 7, 1996. The data indicate a high, statistically significant, and consistent correlation between bone lead levels and delinquent and dysfunctional behaviors in young boys.⁵⁶ The figure presents the scores of teachers using a “Child Behavior Checklist.” The study neutralized other variables, adjusting for mother’s IQ, mother’s highest grade achieved, mother’s age at birth, both parents present in the home, child’s age, child caregiver job code, number of siblings, race, and health status. The control and sampled groups were also tested as to IQs, reaction time, and memory. Attesting to the complexity of some types of disability, the latter measures were roughly comparable between the two

groups. However, disability can involve brain and nervous system features not traditionally measured, and increase aggressive, anti-social, and dysfunctional traits. The “Child Behavior Checklist” findings of the study were confirmed by self-report indicators of antisocial behavior at age 7, and of delinquency at age 11.⁵⁷ Such “personality alteration” is also one of the alleged outcomes of heavy cocaine contamination of babies *in utero*, and may be as significant in terms of child opportunity loss and social cost as is the traditional retardation, loss, or physical disability.

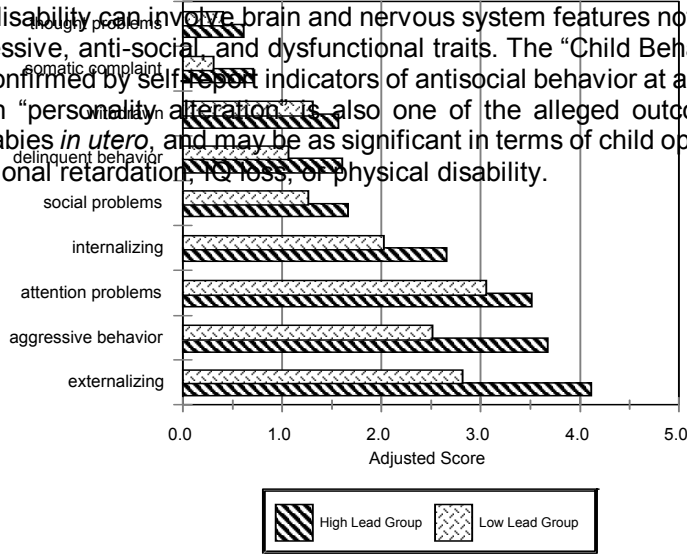


FIGURE 5-D. Bone Lead Concentration and Behavior Correlations

C. Detection and Response: Special Education Qualification

Figure 5-E tracks the growth in the number of special education students in California public schools. The growth is not simply a reflection of population growth; the percentage of special education enrollees was 8.8% in 1987–88; 10.4% in 1994–95; and 10.75% in 2000–01.⁵⁸ The Figure 5-E total includes all those in special education from 0–22 years of age—a figure somewhat larger than the Figure 5-A discussion above and including community college enrollees. The 650,719 special education students enrolled in California K–14 public schools and in preschool during the 2000–01 school year are categorized by the state somewhat differently than the federal disability categories discussed above.

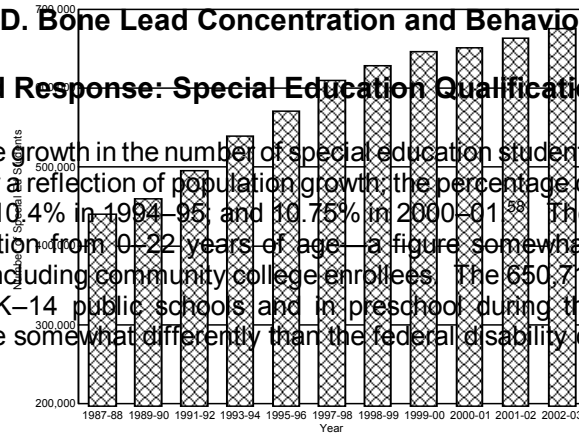


FIGURE 5-E. Number of California Public School Children Enrolled in Special Education, 1987–2002

The California Department of Education’s categorization of its special education population from 0–21 as of 2002–03 is as follows:

- ◆ specific learning disability—344,571;
- ◆ speech or language impairment—172,417;
- ◆ mental retardation—43,302;
- ◆ emotional disturbance—26,144;
- ◆ other health impairment—28,161;
- ◆ orthopedic impairment—15,131;
- ◆ autism—21,066;⁵⁹
- ◆ multiple disabilities—6,670;
- ◆ hard of hearing—6,934;
- ◆ visual impairment—4,624;
- ◆ deaf—4,540;
- ◆ traumatic brain injury—1,565; and
- ◆ deaf/blindness—207.⁶⁰

California has been phasing in a required high school examination that must be passed to graduate. As discussed in Chapter 7, full implementation may be delayed by several more years. However, students are now taking the examination to gauge their progress and the likely flunk rate. Those who do not pass will not obtain a high school diploma. The results of the most recent examination announced in September 2002 indicated a passage rate of under 10% among the disabled (IDEA assisted) population.⁶¹ A total of 26,393 disabled students flunked the examination, representing over 90% of special needs kids tested. During 2001, 88% of disabled exit exam test-takers flunked.

Similarly, special education students did not fare well on the 2003 California Standards Test, given to students in the 4th and 8th grades: 20% of special education students in 4th grade were proficient or above on the math portion, and 15% were proficient or above on the English portion, while 6% of special education students in 8th grade were proficient or above on the math portion, and 5% of special education students were proficient or above on the English portion.

D. Mental Health Care in the Juvenile Justice System

In 2003, the National Council on Crime and Delinquency (NCCD) conducted a study of California’s county probation departments and mental health departments in order to determine how those departments identify, assess, and provide care to youth in the delinquency system who have mental health issues.⁶² The study’s findings regarding the prevalence of mental illness among youth in the delinquency system are presented in Table 5-A(1) below.

	Youth in Detention	Youth in Placement	Youth Under Field Supervision
Percentage of youth who have a mental health issue serious enough to require treatment or services	42%	59%	33%
Percentage of youth who have been prescribed psychotropic medication	23%	32%	18%
Percentage of youth who have an actual diagnosis of a major mental health issues	29%	44%	18%
Percentage of youth who have some other indication or severe mental illness	24%	28%	16%

Source: National Council on Crime and Delinquency (September 2003)

**TABLE 5-A(1). Percentage of Youth with Mental Health Problems
in the California Juvenile Justice System**

According to NCCD, in-depth psychological assessments are performed on approximately 14% of youth in an average month (9% in small counties, 12% in medium counties, and 24% in large counties).⁶³ Over one-third of counties reported to NCCD that non-mental health professional staff who work directly with youth receive little, if any, additional training in mental health issues beyond what is provided by the Board of Corrections-mandated training—“which only minimally addresses mental health issues.”⁶⁴ Almost two-thirds of probation departments and most mental health directors reported not having enough staff for handling the number and severity of mental health issues their systems see.⁶⁵

II. MAJOR PROGRAMS AND BUDGETS

California has a large number of children with special needs who are served by a variety of federally-funded programs. The programs are administered through several different federal, state, and local agencies, including the Social Security Administration (SSA), the Department of Developmental Services (DDS), the Department of Social Services (DSS), county departments of social services, separate mental health programs, the California Youth Authority (CYA), and special education programs administered by the Department of Education and local school districts.

Several programs included in the state budget focus on children with special needs: special education, regional centers, developmental centers, SSI/SSP spending for children, “system of care” spending for mental health services, AB 3632 spending for assessment and treatment of children with mental health problems which interfere with their learning, the Early Mental Health Initiative (EMHI), and the State Council on Developmental Disabilities. The largest amount (over \$2 billion) is spent on special education. Particularly after the realignment of county funds in the area of mental health, other programs at the county level serve some children with special needs.

Certain special needs programs in California are heavily reliant on federal funding. Since education is primarily a state responsibility, federal funds for education in this category have amounted to 10% of total spending, but increased in 1997 with federal legislation (see IDEA discussion below). For the other three major programs (regional centers, developmental centers, and SSI/SSP benefits), federal spending provides 30–80% of the dollars available to children. The “system of care” grants to counties, while a relatively small budget item, also rely heavily on federal funding.

A. Implications of the Personal Responsibility and Work Opportunity Reconciliation Act

1. Temporary Assistance to Needy Families (TANF) and the Disabled Family Assistance Program

California’s enforcement of the Personal Responsibility and Work Opportunity Reconciliation Act (PRA) changes the way California’s Department of Social Services (DSS) treats families with a disabled parent or child. The Disabled Family Assistance Program (DFAP) is one of the alternative categories for TANF applicants.⁶⁶ It is intended by CDSS to “assist families with disabilities when the barrier to employment is the disability of a child or the adult.”⁶⁷ The special needs of disabled children often prevent full participation in the labor market by adult caregivers. Disabled adults may be unable to meet the basic needs of their children.

All individuals qualifying under DFAP are expected to participate in the labor force to the extent that they are able.⁶⁸ The new five-year time limit (sixty total cumulative months of aid) on receipt of benefits will apply, except those for whom work is physically “not possible” may qualify for exemption within the

PRA's 20% "hardship" exception.⁶⁹ (See Chapter 2 for a discussion of the problems with TANF's work requirements.)

2. SSI Redefinition of Qualifying Child Disability/Cut-offs of Legal Immigrants

The Supplementary Security Income (SSI) Program provides cash grants to aged, blind, or disabled persons, including children. The program is administered by the federal Social Security Administration. California supplements the federal SSI payment with the State Supplementary Payment (SSP). Approximately 33% of SSI/SSP recipients receive help under the "aged" category, but children make up a share of the remaining 67% in the disabled and blind recipient categories. The PRA changes the criteria for qualification for children for "disabled" assistance. It also cut off or denied SSI to the vast majority of lawful immigrants otherwise qualified for it, until amended last year to allow immigrants here as of August 22, 1996 to continue to receive benefits—or to newly qualify. However, most of those arriving after that date, regardless of need, are barred for five years (see Chapter 2). Both of these changes are discussed in detail as a part of the SSI/SSP budget account below.

B. Department of Education: Special Education

1. The Account

The scope and complexity of the state's education budget is presented in detail in Chapter 7; however, children who qualify for special education are children with special needs. Under federal law, all children are guaranteed a free and appropriate education.⁷⁰ Students may be enrolled in special education due to a great variety of disabilities, among them mental retardation; hearing, speech, or language difficulties; orthopedic impairments; autism; or visual impairments. The California Advisory Commission on Special Education is charged with monitoring the system and recommending improvements.⁷¹

Although spending for special education is substantial and has increased since the statute's enactment in 1975, the average amount spent nationally is \$688 per child per year, about 12% of average education costs. This 12% additional cost is about one-fourth the expected and promised federal commitment to these children, as discussed below.⁷²

The 2000–01 budget added \$60.8 million from federal funds to school districts for more consistent decisions between them as to services to be provided—a continuing serious problem. Districts that refuse help may save monies by denying services and drive some students into districts where assistance is offered. Hence, the equalization effort works from two funds: \$33.2 million taken from districts that spend below the state average in per pupil special education, and \$27.6 million sent to districts with a disproportionate share of disabled students. Other additions included \$7 million to expand the "workability I" program training disabled youth for employment, and \$3.9 million for two "state special schools" teaching deaf and/or blind students.

Within the 2001–02 budget, then-Governor Davis increased or created programs directed at specific needs. Specifically, \$50 million was allocated for a new "Primary Education Intervention Program," directed at reading education and behavioral modification of problem children aged 5–9. The purpose is to reach those who indicate serious reading problems earlier, when amelioration may be more cost effective. The 2001–02 budget also included increases for special education based on caseload and cost of living adjustments (both required given its status as a federal entitlement). As described above, caseload levels were rising faster than K–12 enrollment.

The 2002–03 budget included four other major new funding additions:

(1) \$125 million in general fund monies to fully pay for the costs of children placed in licensed children's institutions and attending non-public schools (such as group homes);

(2) \$87 million (including \$29.8 million from the general fund) for State Special Schools, much of it

for the Schools for the Deaf and Blind in Riverside and Fremont;

(3) \$39.8 million in federal IDEA funds for its Preschool Grant Program;

(4) \$10.8 million to districts with higher than average population of students with rare disabilities (as part of equity equalization).

Another \$25 million was added for 2002–03 (as is required through 2010–11) to Special Education Local Plan Areas (SELPA) as a result of the settlement of litigation based on the state’s under-funding of school districts for special education. California was obligated to pay districts \$125 million over the 2000–01 and 2001–02 fiscal years for prior underpayments. Given the state’s failure to cover up costs, districts denied services rather than sacrifice their other spending obligations. Those underpayments had stimulated district avoidance of costs not unlike the problems faced by consumers in managed care systems. Accordingly, eleven plaintiff districts in two companion cases negotiated an overall increase for statewide application, including \$25 million per year until 2010⁷³ (see discussion of litigation below).

The federal abandonment of IDEA has been a source of continuing bitterness for state and local educators. In 1975, the federal government pledged to pay 40% of special education costs, but currently pays less than 20%, placing the burden substantially on the states. Congressional efforts to “fully fund” special education (have the federal government pay the full share it promised to pay) have encountered Republican opposition and are unlikely to be approved. However, in March 2002, the state was notified that it would receive \$135 million to reimburse school districts for money they have been compelled to pay based on federal special education mandates above and beyond federal contribution. Unfortunately, rather than transmit these funds through to districts for special education, it was applied entirely to general fund reduction.

	Budget Year							Estimated	Proposed	Percent Change	
	1989-90	1997-98	1998-99	1999-2000	2000-01	2001-02	2002-03			2003-04	2004-05
General Fund	\$1,354,594	\$1,870,172	\$2,125,891	\$2,256,695	\$2,442,641	\$2,732,658	\$2,711,073	\$2,686,728	\$2,674,600	98.3%	-0.5%
Federal Trust Fund	\$176,298	\$329,040	\$398,801	\$453,198	\$522,141	\$664,818	\$798,369	\$950,750	\$1,025,095	439.3%	7.8%
Total	\$1,530,892	\$2,199,212	\$2,524,692	\$2,709,893	\$2,964,782	\$3,397,476	\$3,509,442	\$3,637,478	\$3,699,695	137.6%	1.7%
Adjusted Total	\$2,809,085	\$2,695,745	\$2,982,549	\$3,099,314	\$3,258,712	\$3,608,924	\$3,604,815	\$3,637,478	\$3,598,595	29.5%	-1.1%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets. Adjusted to K–12 enrollment and deflator (2003–04=1.00). Adjustments by Children’s Advocacy Institute.

TABLE 5-A. Special Education

As Table 5-A indicates, the January 2004 budget proposal included a \$74.5 million increase in federal funds for special education in 2004–05. The new federal special education funds are treated as an “offset” to state funding and not as an augmentation that would increase special education base funding level by that amount; this offset complies with state law that requires federal funds to be used to offset state funds in any year where total funding for special education funding is higher than the prior year.⁷⁴

Although general fund spending is proposed for a 0.5% cut overall, the Proposition 98 contribution to this account is proposed to increase by \$70 million, to fund a 1.84% special education cost of living allowance. Total spending as proposed in January 2004, when adjusted for inflation and population changes, will decrease by 1.1%.

2004 May Revise. In his 2004 May Revise, Governor Schwarzenegger provided a general fund increase of \$44 million for special education, and an additional \$63.7 million in federal funding over amounts proposed in the January 2004 Governor’s Budget. The general fund increase is caused by the reduction in property taxes due to the local government revenue swap; according to the Governor, these increases allow for full funding of growth at 0.95 percent, COLA at 2.41%, and maintains the state funding commitment at the 2003–04 level, consistent with federal requirements.⁷⁵

In addition, \$31 million in federal funds is allocated to schools as a permanent increase to the base

funding level for the special education program to assist in continuing the provision of federally-required mental health-related services. Further, the May Revise provides \$38.4 million to partially fund a revised formula for allocating funding for pupils with exceptional needs placed in non-public, non-sectarian schools (NPS) who reside in licensed children's institutions.

2. Federal "IDEA" 1997 Amendments

The federal government's policy guiding its funding contribution to special education has been guided by the 1975 Individuals with Disabilities Education Act (IDEA). On June 4, 1997, the President signed substantial amendments to the statute.⁷⁶ The new statute recognizes that the strict federal standards to education-disabled children lacked (as Table 5-A indicates) accompanying federal fiscal commitment. The new measure adds federal funds and, when that addition surpasses \$4.9 billion, changes the distribution formula for that additional money to schools. Instead of basing funds for schools based on their respective numbers of "identified" disabled children, distribution would be based on broader population and poverty characteristics. That limit was reached by fiscal 2000–01.

The major funding occurs through Part B of IDEA, covering school-aged children. The \$3.1 billion nationally appropriated in fiscal year 1997 grew to \$9 billion in state grants for fiscal year 2004. While President Bush's proposed fiscal year 2005 budget adds \$1 billion to IDEA's grants-to-states program, it freezes most of the preschool, personnel preparation, and research initiatives in special education at 2004 levels; the \$12.2 billion request for special education would increase the federal contribution to 20% per-pupil cost, halfway to meeting full funding of IDEA.⁷⁷

Part C of IDEA concerns special education programs for infants and toddlers up to three years of age (grants for preschool children and infants/families is not included in the federal numbers above).

The 1997 amendments to IDEA also made some changes in substantive requirements accompanying federal funding. Chief among them are the following:

- Parents are to participate in all eligibility and placement decisions, and have access to records concerning their child;
- If the child is in regular school, a regular teacher must be on the Individual Education Plan (IEP) team formulating what services will be provided;
- School districts must "ensure" that parents participate in placement decisions;
- Disabled students must be allowed to participate in districtwide assessments, or the district must explain its reasons for excluding them;
- IEPs must outline how a disability affects a student's performance in the general education curriculum, include goals and short-term objectives (rather than the often common formulaic generalizations), and identify the support needed to participate in general education;
- Attorneys' fees for an IEP meeting are eliminated, unless court- or administratively-ordered;
- Attorneys' fees for mediation prior to the filing of a due process action are prohibited;
- Awarded fees will be reduced if the attorney fails to provide the district with information included in the notice provisions of IDEA; and
- Parents are required to notify school districts of their concerns in detail before filing a due process action in order to receive later attorney fees.

The final four changes constitute a considerable impediment to effective application of special education. Only a small percentage of the parents of disabled children can afford legal representation to help them secure appropriate services. Experience over the past two decades has established clearly the need for attorney representation. Similar to the pattern of insurance firms in claims pay-outs, California school districts commonly ignore special education requests until legal representation appears. Such representation has become the condition precedent to the provision of services for a substantial percentage of the eligible population. A growing number of legal practitioners now specialize in securing special education benefits. They get paid under current arrangement only if they prevail. Hence, their own self-interest guides their professional evaluation of a case. One unlikely to prevail or secure an administrative law judge or superior court order for services as sought will not attract legal

representation. The changes made in the 1997 federal changes preclude compensation in the often critical early proceedings where the presence of counsel may often resolve matters short of litigation. And they reduce incentives to pursue cases, including meritorious cases, based on ancillary procedural failings of counsel or of parents—fee deductions are not applied to counsel for school districts.

As of May 2004, IDEA is currently facing its Congressional reauthorization. Among other things, the IDEA bill currently under consideration in the Senate would push the highly-qualified deadline for all special educators to the end of the 2006–07 school year, thus allowing less qualified persons to be in charge of special education amelioration for children until that time.

3. California’s Special Education Reform Act of 1997

The budget of 1997–98 included “funding reform” (supported by both former Governor Wilson and the LAO).⁷⁸ The stated purpose of the 1997–98 change was to alter the complex formulae of distribution of special education funds to 116 territorial “Special Education Local Plan Areas” (SELPA), and is intended to rationalize fund distribution. That is, using the state’s 1,000 school districts or counties is hampered by the wide population and need disparities—which the SELPAs can equalize by (in some cases) having a SELPA made up of two or three small counties, or several could function in the largest counties. However, the Governor and LAO argue that the SELPA system is overly complex and provides inappropriate fiscal incentives.⁷⁹ The system changes allocations more consistent with “population.”⁸⁰ Prior allocations commonly resulted in widely divergent special education qualification and spending patterns between districts; the impact of the changes on this problem remains unclear. The litigation brought by 11 districts and the settlement obtained in October 2000 redresses some of the prior imbalance, but with a disproportionate reward to the 11 districts who were parties (out of 1,010 districts statewide). The budget does include limited funds for redress of imbalances based on population and on concentration of special education students (see discussion above).

4. Special Education Facility Investment

A 1998 statute created a new program to assist in school facility funding. Grants from \$2,300 to \$7,300 for new classrooms are available. The State Allocation Board allows the ceiling to increase to \$15,000 for special education classrooms (which often need separate equipment). In January 2000, the Legislative Analyst released a report on special education facilities funding. Her study concluded that local authorities should determine facility needs; that the \$2,300–\$7,300 range is adequate for most special education, except for the “special day class” enrollees (30.5% of special education students) who require special facilities. Further, the local classification of these special day enrollees as “severe or non-severe” does not reflect their facility needs. (Hence, setting grant levels based on such categories from Sacramento is not advisable.) The Analyst recommends a uniform facility grant for all pupils, accounting for special day class enrollments. This general formula then allows local districts to decide in streamlined fashion what facilities are needed. She recommends a separate facility grant for county offices of education, which has a separate population of severely disabled (which consistently warrants the State Allocation Board’s higher grant ceiling). Under the Analyst’s recommendation, new construction grants for pupils in the county’s programs (as opposed to the more varied school district offerings) would be \$10,480 for grades K–6, \$11,084 for grades 7–8, and \$14,510 for grades 9–12. The assumed classroom size is 9 pupils (the statewide average for severely disabled pupils).⁸¹

5. State Special Education Refunds to School Districts

Under Proposition 4, enacted by the electorate in 1979, the state must provide funding wherever it imposes “local mandates.” The rationale for the measure is buttressed by serious restrictions on local tax revenue resources. Local jurisdictions are confined to marginal sales tax and property taxes capped at 1% of assessed valuation, itself limited to a 2% per annum increase. Most bond and other financing requires a 2/3 local vote for approval, including school financing. Accordingly, the law provides that the state—with its enhanced revenue generating authority—must provide funding wherever it acts to require a local jurisdiction to spend public funds.

Starting in 1980, the county superintendent (of the local Office of Education) sought reimbursement from the State Board of Control for local special education services, mandated by the state in the late 1970s. The Board of Control, with authority to initially decide local mandate recompense from the state, determined that the state money was owed. However, the Deukmejian administration appealed to the courts during the 1980s, as other county offices and school districts filed their requests for recompense. In 1992, an appeals court determined that the state owed payments for services mandated, but only those which exceeded underlying mandates under federal law, remanding the matter to the Board of Control for determination of proper amount. The Board, since named the Commission on State Mandates, identified eight programs involving \$1.9 billion in state funds for eight special education state mandates locally funded and which were above and beyond federal mandates. However, the state Department of Finance contends that the state has paid for those programs in the form of general fund contributions for special education to local agencies beyond the \$1.9 billion in amount, even though none of the functions was specifically identified as a separate line item (or mentioned).

Faced with a political quandary, the Commission voted 5–1 on October 28, 1999 to ask the former Governor to personally intervene to “negotiate” a compromise. After initial travail, a settlement was reached on October 26, 2000. Under the terms of the settlement, the state will pay a total of \$520 million in retroactive funding, and guarantee an increase in future special education funding of \$100 million annually, beginning in 2001–02 (see inclusion in proposed budget as discussed above). Of the retroactive costs, \$270 million was paid during the 2000–01 fiscal year, and will be followed by \$25 million per year in fiscal 2001–02 through 2010–11, as discussed above.

6. Special Education Legislation

Related to the state mandate dispute, the Governor vetoed all six major special education bills passed by the Legislature in 1999 to improve education for disabled students. Almost all of the Governor's veto messages cited the possible state liability for reimbursable expenses where services are provided beyond federal mandates. Two of the measures were enacted by unanimous vote of the Legislature. The signal sent by the Governor was received by the Legislature, terminating plans to enact further legislative improvements for the special education system. The bills would have ended common abuses and unjustified assistance denials by local districts.⁸²

The Legislature has enacted little legislation addressing special education or special needs investment since 1999, and is not expected to enact any measure involving new general fund expenditure in 2004.

7. Special Education Inadequacy: An Alternative Funding Concept

In April 1999, the U.S. Department of Education issued a report highly critical of California's special education performance, including lax oversight by state officials. Findings of the study were harsh, including common failure to provide educational programs required by federal law, lack of staff training, inadequate funding, and failure running from adequate screening to the provision of required Individual Education Plans (IEPs), to facilities and services.⁸³

Child advocates contend that special education financing preordains it to failure. Special education funding may be effectively supplanted for other purposes, or often requires the sacrifice of services to non-disabled students who compete within each school's budget. Further, districts which provide first rate educational opportunity will tend to attract more parents with special education students, providing an incentive to provide lesser services than neighboring districts for financial advantage.

Services are skewed in favor of children with aggressive parent advocates, or those who can afford counsel. This has further disadvantaged the disabled children of impoverished parents *vis-a-vis* their middle class and wealthier counterparts. In essence, special education reflects the same disincentive to provide services as does the managed care systems, by providing a budget determined by formula, and allowing recipients to redirect (to any purpose) amounts not expended for the designated purpose.

However, a budgetary policy analogous to fee-for-service will produce abuses in the opposite

direction: payment based on services offered will yield an excess of services, including highly marginal activities. This problem is especially true where parents want what is best for their child, and will push for expenditures without any realistic ceiling, imposing serious costs on other deserving students, including the optimum development of gifted children from whom society also benefits greatly.

A spending mechanism replicating successful market-based incentives would work in the reverse from capitated managed care, but could avoid the blank check of fee for service. In such a system, districts and county offices of education would be paid a sum for every special education student served at a rate which is compensatory for their average costs (so districts would have no incentive to avoid screening). Districts could then receive bonus payments above those levels based on child improvement indices, to be measured independently (from the districts). The more you succeed, the more you receive, with levels above previous costs achievable. Such sums may then be expended for lawful, public purposes as local discretion determines, including employee bonuses. Such a system gives local agencies and professionals some of the same incentives which effectively drive successful market performance.

C. Department of Developmental Services (DDS)

The Department of Developmental Services (DDS) is the major state agency providing direct services to developmentally disabled children, particularly those requiring substantial out-of-home care. DDS serves approximately 190,000 Californians, of whom about 105,000 are children and youth between the ages of 0–21. Demographically, 59.4% of DDS clients are male; 43.1% are white, 30.1% are Hispanic, 10.3% are African-American, 6.9% are Asian, Filipino, or Pacific Islander, 0.4% are Native American, and the remainder are unknown.⁸⁴

A developmental disability is defined by statute as a substantial disability which originates before the age of 18 and which can be expected to continue indefinitely, including mental retardation, cerebral palsy, epilepsy, and autism.⁸⁵ DDS administers two major programs to this population: the Community Services Program, made up of 21 private nonprofit Regional Centers under contract to DDS to provide local services, and the DDS Developmental Center Program, which provides services in five state developmental centers. These hospital-like facilities can provide 24-hour care for severe cases.

Within DDS are thirteen local Area Boards which engage in local planning and which review services for the developmentally disabled. Each of the five developmental centers also has an Advisory Board.

Only 2% of those served are subject to intensive Developmental Center services. Most of those served remain in their local communities, with 69% (including most children) living at home, 15% in community care facilities locally, 8.7% in partially supported “Independent Living” settings, and 4.8% in “skilled nursing or intermediate care” facilities.⁸⁶

DDS’ departmental budget is funded by reimbursements, the state general fund, and federal funds. Reimbursements generally come from redirected federal dollars, either from the Medi-Cal program (federal Medicaid) or from disability payments from the Social Security system. Total DDS spending adjusted to overall population and inflation has increased by 78% from 1989 to the current year (see Table 5-B). A higher increase in the special needs population (almost double the overall child population growth) flattens that increase substantially in terms of spending per person actually served. DDS recently completed a four-year plan to more aggressively and effectively treat clients. That plan involved the addition over four years of 1,700 new positions at a cost of \$106.5 million per annum, and which explains most of the general fund increase since 1997-98, as indicated in Table 5-B.

	Budget Year							Estimated	Proposed	Percent Change	
	1989-90	1997-98	1998-99	1999-2000	2000-01	2001-02	2002-03			2003-04	2004-05
General Fund	\$543,591	\$537,509	\$706,380	\$910,746	\$1,127,094	\$1,717,747	\$1,874,193	\$2,054,876	\$2,169,085	278.0%	5.6%
Federal Trust Fund	\$6,871	\$44,172	\$44,336	\$46,864	\$50,058	\$47,191	\$49,333	\$52,200	\$53,341	659.7%	2.2%
Reimbursements (Medi-Cal)	\$535,558	\$1,072,396	\$1,158,657	\$1,248,125	\$1,380,356	\$995,596	\$1,047,479	\$1,188,056	\$1,203,388	121.8%	1.3%
Other	\$8,310	\$2,425	\$2,954	\$4,470	\$4,975	\$5,928	\$3,739	\$3,652	\$4,017	-56.1%	10.0%
Total	\$1,094,330	\$1,656,502	\$1,912,327	\$2,210,205	\$2,562,483	\$2,766,462	\$2,974,744	\$3,298,784	\$3,429,831	201.4%	4.0%

California Children's Budget 2004–05

Adjusted Total	\$1,850,442	\$2,026,841	\$2,271,600	\$2,551,555	\$2,840,740	\$2,955,772	\$3,073,720	\$3,298,784	\$3,319,260	78.3%	0.6%
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Dollar amounts are in \$1,000s. Sources: Governor's Budgets.
Adjusted to California population and deflator (2003–04=1.00). Adjustments by Children's Advocacy Institute.

TABLE 5-B. Department of Developmental Services

2004 May Revise. Table 5-B reflects the proposed funding for DDS as contained in the Governor's January 2004 budget. The Governor's May Revise increases total DDS funding to \$3.5 billion (\$2.2 billion general fund), an increase of \$ 68.0 million above the January 2004 proposal. Specifically, the May Revise includes general funding increase of \$46.4 million over the January 2004 proposal.

1. DDS Regional Centers

In 1965, legislation created two pilot project Regional Centers in Los Angeles and San Francisco to assist mentally retarded people (and their families) in obtaining services in their communities. This effort was part of a movement away from institutional care, and was designed to benefit both the client and the state budget. The initial pilot projects expanded into the existing 21 Regional Centers, usually serving population based on county boundaries. By statute, the state may not operate a Regional Center; instead, private nonprofit community agencies contract with the state and operate the Regional Centers.

Individuals served by Regional Centers may live at home or in family care homes, small and large group homes, or licensed residential facilities. The services include case management, assessments, counseling, development of an "Individual Program Plan," genetic counseling, and client rights advocacy. Much of the funding for the cost of care comes from SSI (see discussion below). Because of the way this account is reported, it is not possible to single out services to children from those to the entire regional center client population.

The Regional Centers themselves may purchase certain services for clients when no other public or private money is available. Services funded on the basis of need include respite care, dental work, adult training activity, and out-of-home placement (with parental reimbursement for minors).

a. Personal Responsibility and Work Opportunity Reconciliation Act (PRA)

Title IX of the PRA reduces the Social Services Block Grant (Title XX) funds to states by 15% and holds the amount constant for federal fiscal years 1996 through 2002.⁸⁷ California uses Social Services Block Grant funds to support DDS' regional centers.⁸⁸

b. Regional Centers Account

The Regional Center line items account for over two-thirds of DDS' total departmental budget. As Table 5-C indicates, this account as adjusted has increased markedly since 1989–90. The federal reimbursement amounts have grown through the Medi-Cal contribution from the early 1990s. The state's general fund contributions have kept pace, consistent with state match requirements.

This account received meaningful additional state investment from general fund sources during the former Davis Administration. Real growth has occurred in these regional community center operations of DDS, as public officials attempt aggressive early intervention to avoid more costly institutionalization.⁸⁹

Regional Center population has increased from 157,475 in 1999 to almost 200,000 currently.⁹⁰ Much of the increase shown in Table 5-C has been to accommodate that growth and inflation; also, an increasing percentage of new consumers are diagnosed with autism, a disability requiring a greater number of expensive services.⁹¹ The average cost per client (including support from all fund sources) has increased steadily between 1998–99 and 2003–04, from about \$9,500 to \$13,400; the Governor's proposed budget would bring the estimated cost per client in 2004–05 to about \$13,600.⁹²

	Budget Year								Estimated	Proposed	Percent Change	
	1989-90	1997-98	1998-99	1999-00	2000-01	2001-02	2002-03	2003-04			2004-05	'89-'03
General Fund	\$501,392	\$498,809	\$659,835	\$799,307	\$949,782	\$1,359,429	\$1,521,719	\$1,681,561	\$1,792,043	235.4%	6.6%	

Dev. Disab. Prog. Dev. Fund	\$3,759	\$2,123	\$2,353	\$3,846	\$2,934	\$2,047	\$2,051	\$1,431	\$1,496	-61.9%	4.5%
Federal Trust Fund	\$5,804	\$43,427	\$43,578	\$46,176	\$49,487	\$46,627	\$48,736	\$51,375	\$52,528	785.2%	2.2%
Reimbursements (Medi-Cal)	\$30,413	\$642,770	\$709,060	\$788,300	\$902,076	\$717,026	\$742,544	\$836,325	\$881,494	2649.9%	5.4%
Dev. Disab. Services Account	\$0	\$30	\$30	\$30	\$1,000	\$2,900	\$0	\$0	\$300	na	na
Total	\$541,368	\$1,187,159	\$1,414,856	\$1,637,659	\$1,905,279	\$2,128,029	\$2,315,050	\$2,570,692	\$2,727,861	374.9%	6.1%
Adjusted Total	\$919,873	\$1,396,146	\$1,617,624	\$1,827,271	\$2,054,166	\$264,864	\$2,387,372	\$2,570,692	\$2,639,116	179.5%	2.7%

Dollar amounts are in \$1,000s. Sources: Governor's Budgets. Adjusted to California age 0-19 population and deflator (2003-04=1.00). Adjustments by Children's Advocacy Institute.

TABLE 5-C. Community Services, Regional Centers

The Governor's 2004-05 budget proposes \$2.7 billion to support the regional centers; this includes \$103.7 million to support the Habilitation Services Program, which transferred to DDS from the Department of Rehabilitation as of July 1, 2004. Unlike many other social service programs, the Governor is not proposing to impose a cap on caseload or eliminate services. The Governor's proposed budget also reversed an earlier proposal to end certain community services, such as respite care. State savings would be achieved in 2004-05 through such steps as establishing copayments to families of certain children receiving services and standardizing statewide the services that are provided in the community. The Schwarzenegger Administration is also proposing to pursue the development of additional cost-saving measures for implementation in 2005-06, including an expansion of copayments, statewide standardization of the rates paid for the major services purchased by regional centers, and implementation of a proposed waiver program to cap individual allowances for client services while giving them increased client control over their services.

2004 May Revise. The Governor's 2004 May Revise provided additional detail on the \$100 million general fund savings for proposed cost containment measures in the Regional Centers purchase-of-services budget. The 2004-05 savings are associated with the following: statewide purchase-of-services standards (\$11.9 million); Family Cost Participation Program (\$570,000); ongoing impact of temporary cost containment measures implemented in 2003-04 (\$67.5 million); decreased rate of program growth (\$11.3 million); and an offset from increased federal funds (\$8.7 million).⁹³

Regarding the Family Cost Participation Program, Welfare & Institutions Code section 4620.2 required DDS to develop a system of enrollment fees, copayments, or both, to be assessed against the parents of children between the ages of 3-17 who live in the parent's home, receive regional center purchased services, and are not Medi-Cal eligible. On April 1, 2004, DDS delivered its report and recommendations to the Legislature; among other things, DDS concluded that a system involving copayments and/or enrollment fees would result in an increase in the state workforce and administrative costs; require access to Franchise Tax Board records; and require DDS to collect fees from families. Accordingly, DDS determined that this alternative is not feasible.⁹⁴

Instead, DDS proposed the implementation of a Family Cost Participation Assessment Program (FCPAP) without an enrollment fee. The FCPAP would eventually be administered by each regional center, which would determine a family's ability to pay. The regional center would then pay its portion of the authorized services, and the family would purchase the remaining authorized services directly from the providers; no revenue would be collected by the regional centers.⁹⁵ Under DDS' proposal, a family of four with \$73,600 in annual income would have pay an average per capita annual cost sharing assessment of \$313; a family of four with \$165,600 in annual income would pay \$888; and a family of four with more than \$239,200 in annual income would pay \$1,179.⁹⁶

At this writing, the Legislature has not yet acted on DDS' recommendations.

2. DDS Developmental Centers

The other major DDS account funds developmental centers, which provide 24-hour care and supervision to approximately 3,500 individuals statewide. All the facilities provide residential and day programs as well as health care and assistance with daily activities, training, education, and

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employment; more than 7,800 permanent and temporary staff serve the current population at all seven facilities.⁹⁷

The state's developmental centers have experienced a rapid downsizing as a result of the *Coffelt* settlement agreement, which precipitated the integration of developmental center clients back into their communities.⁹⁸ The centers have gone from an average population of 6,000 clients to 4,457 by the end of fiscal year 1995–96, to 3,844 last year (2000–01) to 3,500 currently. The *Coffelt* settlement required the devolution of at least 2,000 patients within five years of its 1994 issuance—the state met that goal within three years. These reductions have led to the closures of the Stockton Development Center, Camarillo State Hospital and Development Center, and more recently Napa State Hospital—to the consternation of many mental health advocates. The DDS clients now at Napa were transferred to Porterville and Lanterman in March 2000. Hence, the state is now down to five developmental centers (Agnews, Fairview, Lanterman, Porterville, and Sonoma) and two smaller facilities (Sierra Vista, a 54-bed facility located in Yuba City, and Canyon Springs, a 63-bed facility located in Cathedral City, both of which provide services to individuals with severe behavioral challenges).

In his proposed budget for 2004–05, Governor Schwarzenegger is continuing with the development of a closure plan for Agnews Developmental Center. Current law requires the Administration to provide the Legislature with a detailed closure plan by April 1 preceding the year of closure (*i.e.*, April 1, 2004 plan due for a June 30, 2005 closure date). However, on April 1, 2004, DDS submitted a recommendation to the Legislature to postpone the closure until July 2006, in order to allow for the development of the community capacity necessary to ensure the health and safety of Agnews' current residents. The Governor's 2004 May Revise incorporated this one-year delay.

While the integration of patients ("clients") into local and decentralized facilities has clear advantages, it is a pattern often abused in California. The "realignment" of mental health funding to counties has been the final step in the dismantling of once extensive treatment for the deeply troubled. Realignment into jurisdictions lacking resources and the ability to provide funding has led to difficult local decisions, in fora where mental health clients are not highly influential. The price of mental health realignment grows when the person needing help is a parent with a child affected by the illness. The proliferation of mentally ill persons into local communities has contributed somewhat to a growing homeless, begging, street population in California's cities, with children increasingly involved.

Currently, 3,490 residents reside in the state Developmental Center system; the Governor estimates the population to decrease by 123 residents in 2004–05, for a total population of 3,367. According to recent DDS data, the average annual cost per person residing at a developmental center is about \$180,000; however, due to differences between the centers (such as resident medical and behavioral needs, overall resident population size, staffing requirements, fixed facility costs and related factors), the annual cost per resident varies considerably, ranging from \$225,574 annually at Canyon Springs to \$147,590 at Fairview.

The Governor's budget proposes \$701 million from all funds (\$377 million from the general fund) for support of the developmental centers in 2004–05. The 1% increase in general fund expenditures is mainly due to increases for employer retirement contributions and additional funding for employee compensation. However, total funding from all sources is proposed to decline by 3.6%, primarily due to reductions in staffing due to the estimated population decline.

	Budget Year								Estimated	Proposed	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01	2001-02	2002-03			2003-04	'89-'03
General Fund	\$42,199	\$40,412	\$38,351	\$46,133	\$111,103	\$177,030	\$357,990	\$352,470	\$373,311	\$377,038	784.6%	1.0%
Federal Trust Fund	\$1,067	\$735	\$745	\$758	\$688	\$571	\$564	\$597	\$825	\$813	-22.7%	-1.5%
Reimbursements (Medi-Cal)	\$505,155	\$494,134	\$429,626	\$449,597	\$459,825	\$478,280	\$278,570	\$304,935	\$351,731	\$321,894	-30.4%	-8.5%
Other	\$4,541	\$315	\$272	\$571	\$594	\$1,041	\$981	\$1,688	\$2,221	\$2,221	-51.1%	0.0%
Total	\$552,962	\$535,596	\$468,994	\$497,059	\$572,210	\$656,922	\$638,105	\$659,690	\$728,088	\$701,966	31.7%	-3.6%
Adjusted Total	\$935,023	\$672,084	\$573,846	\$590,443	\$660,584	\$728,256	\$681,771	\$681,639	\$728,088	\$679,336	-22.1%	-6.7%

Dollar amounts are in \$1,000s. Sources: Governor's Budgets.

Adjusted to California population and deflator (2003–04=1.00). Adjustments by Children's Advocacy Institute.

TABLE 5-D. Developmental Centers

2004 May Revise. Table 5-D reflects the 2004–05 funding as proposed in the Governor’s January 2004 budget. The 2004 May Revise included a net increase of \$26.2 million (\$19.4 million general fund) for Developmental Centers as a result of the following changes: anticipated decrease in developmental center caseload resulting in \$1.2 million general fund savings; an increase of \$11 million related to the timely closure of Agnews Developmental Center by July 2006, which requires preparation activities in 2004–05; \$7.3 million for increased employee compensation; an increase of \$1.8 million general fund for newly-bid and awarded janitorial contracts; delayed implementation of the Administration’s proposal to contract out food services in the Developmental Centers results in an increase of \$910,000 general fund; the annual adjustment in Medi-Cal base funding results in a reduction of \$476,000 general fund and an equivalent increase in reimbursements; funding for the Life Services Alternative Project is increased by \$750,000 in reimbursements from the Regional Centers budget to help transition consumers from Agnews Developmental Center into community settings.⁹⁹

As Table 5-D indicates, the Development Center account as a whole includes significant reimbursements from federal Medicaid and SSI payments. The state general fund contribution was fairly consistently in the \$38–\$46 million range from 1989 to 1998. However, general fund increases have been committed since 1999; this major spending increase reflects the four-year plan discussed above to change services from passive warehousing to active treatment. The new funds are required due to the aging plant housing existing patients. As former Governor Davis noted in a prior Budget Summary, “[t]he five existing Developmental Centers were designed and constructed from the late 1800s to 1964...with the last renovation in 1982.”¹⁰⁰

3. 1997 Legislation: An Office of Client Rights Advocacy

Those confined to DDS facilities are not all volunteers, particularly children served by the Centers. Given the fact of confinement for some, a check on error and abuse is of particular importance. A series of state cases and statutes have given child patients in mental institutions limited but important due process rights.¹⁰¹ Prior to 1998 that representation was provided by in-house staff of the Regional Centers, with conflict of interest implications. SB 391 (Solis) (Chapter 294, Statutes of 1997) mandated the provision of these services by contract to an independent entity. That contract was awarded to the respected attorneys of Protection & Advocacy Inc. The supervision of the contract was then left to a separate office (Office of Clients’ Rights Advocacy (OCRA)), in operation since 1999. As of the current year, 11 of the 21 Regional Centers allow counsel from OCRA to work on-site, obviously important in serving this population—where personal presence and observation of the client is important.

4. 1998 “Self-Determination” Legislation

The most significant change in the DDS account over the past decade was spawned by SB 1038 (Thompson) (Chapter 1043, Statutes of 1998), implementing a “self determination” model. Instead of dictating care from the top down, this model allows disabled persons (with help from case managers) to “shop” among alternative services available to put together a customized package responsive to their individual and self-determined needs. Supporters cite three advantages to this concept: (1) “buy-in” from the disabled consumer is implicit, and is likely to facilitate success (as opposed to a dictated regime); (2) the consumer himself or herself is the best judge of what works; (3) the system effectuates the same kind of natural selection improvement of a marketplace, as those who attract consumers will survive and grow, and those who are rejected will atrophy.

Although the program is still in its early stages, both the concept and analogous precedents commend it. The major parallel is the Monadnock Project in New Hampshire funded in 1992 by the Robert Wood Johnson Foundation. Consumers controlled the planning process, and “bought” their own services; each was given 85% of previous average levels, and the remaining 15% was placed in a “risk pool” for allocation where individual programs failed. Initial external reviews of the program are positive, indicating greater efficacy, enhanced consumer control, and lower cost. Similar projects are underway in 29 other states (not including California).

SB 1038 allows the testing of a variety of submodels within the concept: flexible payments, non-traditional services, alternative case management (a guardian, relative, or other person rather than a regional center employee), individual budgeting, *et al.* The Office of Legislative Analyst has posed relevant questions to ask in evaluating its performance over the next several years.¹⁰²

Regrettably, the 2003–04 budget deleted this “System of Care” program in the Mental Health account, relegating it to counties as part of “realignment.” As discussed below with regard to the similarly realigned mental health services for the homeless, this transfer is equivalent to substantial termination given the extraordinary budget pressures in most counties.

D. Federal Supplemental Security Income/ State Supplementary Program (SSI/SSP)

As noted above, the Supplementary Security Income/State Supplementary Payment (SSI/SSP) Program provides cash grants to aged, blind, or disabled persons who meet the program's eligibility requirements. The program is administered by the federal Social Security Administration. California supplements the federal SSI payment with the state SSP payment. This cash assistance enables children to stay at home and helps their parents purchase needed equipment and services.

The disabled portion of the SSI/SSP caseload amounts to 68% of the total SSI/SSP population. Disabled recipients amounted to 671,796 in calendar 1998, 691,992 in calendar 1999, 712,164 in 2000, 750,040 in 2001, and 765,952 in 2002; currently, the disabled portion stands at 783,874. The blind portion (also including children) currently amounts to approximately 21,764 persons and has been relatively stable year to year. The remaining persons in the caseload of 1,153,306 for 2003–04 are in the aged category.

The overall SSI population ran well ahead of population growth from 1992 to 1995, at which time it began a steep retraction—about one year prior to the welfare reform year of 1996. Welfare reform cut additional numbers from benefits, including children. From 1999 to the current year caseload growth approximated population increase.¹⁰³ The proposed 2004–05 budget anticipates 1,177,670 total recipients, a small increase of 2% from the current year (see Table 5-E below).

Maximum SSI/SSP payments in calendar year 2004 for the aged and disabled in California are \$790 per month for an individual or \$1,399 for a couple. For a blind person the 2004 maximum was \$854 and \$1,619 for a blind couple. Of these totals, just over half come from the federal treasury (the SSI share). The federal portion generally increases from Congressionally-authorized COLA adjustments. While California has among the highest benefits under this program (its maximums are from \$100 to \$150 per month higher than other populous states due to the state contribution), the increase is largely consumed in the higher median rents applicable in California (see Chapter 2 data).

1. Impact of the Personal Responsibility and Work Opportunity Reconciliation Act (PRA) on Child Eligibility for SSI/SSP

New guidelines established by the PRA change the definition of disability. Under the old standards, children were eligible for SSI benefits if an impairment existed that prevented them from performing age-appropriate activities.¹⁰⁴ New guidelines eliminate references to the “comparable severity standard,” the “individual functional assessment,” and “maladaptive behavior.”¹⁰⁵ The new guidelines are in response to a 1990 Supreme Court decision which held that thousands of children had been illegally denied SSI benefits because their disorder was not on an arbitrary list of eligible disabilities.¹⁰⁶

New guidelines implemented by the Social Security Administration include a set of “medical listings.”¹⁰⁷ All children who qualified on the basis of comparable severity, the individual functional assessment, or maladaptive behavior must be reevaluated under the new guidelines established by the PRA.¹⁰⁸ The Social Security Administration had until February 22, 1998 to accomplish all of the redeterminations.¹⁰⁹ The new criteria applicable to children are more restrictive than the symptoms qualifying adults for coverage. Allegations of SSI claim abuse focus on the elderly. Some SSI critics contend that some adults were “coaching” children to elicit a disabled diagnosis. However, the U.S.

General Accounting Office independently investigated SSI child claimants to ascertain the prevalence of fabricated or coached child symptoms. In 1995, GAO released its report, concluding that the coaching and fabrication allegations regarding child claimants are not supported by the evidence.¹¹⁰ Children are not in the same position as are adults to spend discretionary grant monies for non-medical purposes; their regimen is more likely to involve SSI-financed therapy, special diets, or rehabilitation after a third-party diagnosis. Rather than direct denials or restrictions at the source of abuse, this PRA change tightens primarily aid to children. Many will now be denied assistance for problems that will support adult SSI claims.

Approximately 90,000 California children received SSI/SSP in 1998. According to the Department of Social Services, 14,756 cases were subject to reevaluation under the new standard. DSS reported that 12,176 of those cases have been reviewed, and 39.7% (4,837) resulted in benefit termination.¹¹¹

Although high, California's rate is actually below the national average. As of May 30, 1998, 245,349 children had been reevaluated out of the country's 998,280 child recipients of SSI. Of that number, only 147,933 (54%) were continued and 125,740 (46%) were terminated from SSI. In addition, 56.7% of the 61,402 adolescents turning age 18 were removed from SSI based on adult criteria even though many had been qualified previously under the very strict listings level criteria.¹¹²

The two largest categories of SSI/SSP withdrawal appear to be those who qualified based on non-medical referrals: "maladaptive behavior," as noted above, and children with respiratory problems. The former often involves seriously mentally retarded, ADD, or ADHD children who were born drug-addicted. While disability is clear and serious, there is no organ dysfunction, illness, or traditionally treatable medical condition involved. The condition does not meet the "list" oriented to common adult illness and injury which dominates qualification.

The second group suffering withdrawal of assistance, those with respiratory problems, confronts the same adult list. Under its terms, children must often show respiratory failure in a Forced Expiratory Volume Test in a doctor's office. Unfortunately, the often serious asthma disability of children can be episodic and may not be reflected in an office test while no asthma attack is occurring. Living with the suffocating feeling of not being able to breathe for many hours during an attack can be a serious and dangerous disability—requiring close monitoring and often expensive medicine.¹¹³

Adding to the concern over the withdrawal of SSI/SSP is the record of those cases reviewed by independent administrative law judges. As of 1998, 63% of the terminations nationally have been reversed.¹¹⁴ In contrast, about 11% of California state appellate decisions are reversed by the Supreme Court. The extraordinary reversal rate suggests a pattern of broad-brush denial, followed by reinstatement of those able to arrange for independent review. In addition to the issue of terminations, the same new strict criteria are used to deny new child claimants since the effective date of the PRA (August 22, 1996); here, the rejection rate nationally has risen to 56%. Final California-specific data are not yet available.

On November 16, 1997, Social Security Commissioner Kenneth Apfel promised an independent review of the termination and denial pattern.¹¹⁵ On December 18, 1997, he announced his intention to review the cases of 45,000 of the 135,000 children nationally who have had SSI benefits terminated.¹¹⁶ SSI children are automatically eligible for Medi-Cal. In some states, the Medi-Cal status of SSI-terminated children is ambiguous. Former Governor Davis proposed Medi-Cal pickup of those children terminated from SSI—an important back-up protection. However, Medi-Cal benefits are geared to temporary treatment, not longer-term rehabilitation or disability management.¹¹⁷

Fiscal Year	Number of SSI/SSP Recipients	% Change from Previous Year
1990-91	868,768	6.2% higher
1991-92	920,894	6% higher
1992-93	965,097	4.8% higher

1993-94	992,120	2.8% higher
1994-95	1,015,931	2.4% higher
1995-96	1,035,234	1.9% higher
1996-97	1,033,163	0.2% lower
1997-98	1,020,765	1.2% lower
1998-99	1,039,139	1.8% higher
1999-00	1,067,400	2.7% higher
2000-01	1,086,500	1.8% higher
2001–02	1,102,984	1.5% higher
2002–03	1,128,172	2.3% higher
2003–04	1,153,306	2.2% higher
2004-05	1,177,670	2.1% higher

Source: Governor’s Budgets

TABLE 5-E. California SSI/SSP Caseload Change from Prior Year

The tightening of these standards, and the SSI cut-offs to legal immigrants, follow the increase of SSI claims over the early 1990s when SSI/SSP caseload grew at two to three times the overall state population increase. Since benefit levels generally match inflation, total spending increases have been substantial. However, claims increases started to slow and flatten in 1995-96, before the 1997–98 implementation of the PRA, as presented below.

Table 5-E presents the trend as to all SSI/SSP recipients, including the 30% portion under the “aged” category and not included in the numbers discussed above as not pertaining to children. However, the basic trend is applicable to the disabled and blind groups as well—relatively minor changes and a stable population. The overall increase from 1990 matches overall population gain—indicating no increased rate of claims. Since 1993, claims have increased less than population. These data do not suggest a system gone wild. Although some troublesome false claims have been revealed, trends suggest that the anti-fraud and other tightening measures undertaken in the early 1990s had curbed new claim abuses by 1993. This approach directs denials and cut-offs at those abusing the system, rather than across a broad category of recipient not closely correlated with abusers.

2. Impact of the PRA on Legal Immigrant SSI/SSP Eligibility

The PRA, as enacted in 1996, cut off all food stamps and SSI assistance to most legal immigrants for the first five years after their arrival in the United States. Refugees, representing about 15% of California’s lawful immigrants, were excepted and were entitled to services for the first five years after their arrival. As Chapter 2 of the *California Children’s Budget 2001–02* discusses in detail, the group now most at risk are those arriving after August 22, 1996, including those arriving each month *in futuro*. Almost one-half of these arrivals settle in California. Many of these arrivals are categorically cut off from food stamps, SSI disability aid, TANF, and federally-funded Medi-Cal for the first five years after their arrival. Historically, about 14% of these families fall upon hard times to the point they fall below the poverty line and have received AFDC (TANF).

Those immigrants arriving prior to 1996 subject to cut-off in the PRA as originally drafted, won restoration of benefits in the Balanced Budget Amendment of 1997. The second group (those who arrive after August 22, 1996) remain barred from some benefits, with food stamps scheduled to be restored federally for the children of these arrivals after October 2003. Under conservative assumptions, this group includes 5,839 children each year who will have an otherwise qualified family member, or will themselves be denied federal SSI help under the PRA’s original terms—which remain in force.¹¹⁸

3. 1997 Budget Agreement, 1998 to Present State-Only (CAPI) Assistance, and Other Recent Changes to SSI Status

Although not critically affecting the elimination of many children from SSI coverage directly,

Congress in 1997 restored some SSI benefits for a number of immigrant groups¹¹⁹—moderating somewhat the effects of the PRA as to some legal immigrants (as opposed to children, whose required reevaluations and new claims under harsher criteria remain effectively unchanged).

Most of the restoration of SSI is directed at immigrants who arrived prior to August 22, 1996, many of whom were scheduled for benefit termination under the PRA. Ironically, this restoration substantially benefits (among others) the groups of elderly, middle-class claimants who were allegedly abusing the system and were cited in enacting the PRA. Under the 1997 Balanced Budget Act, legal immigrants who were receiving SSI/SSP benefits as of August 22, 1996 will continue to receive them. Accordingly, almost all of those who arrived in the United States before August 22, 1996 have their SSI/SSP eligibility restored.

However, as noted above, those legal immigrants who are not refugees/asylees arriving after August 22, 1996 remain categorically barred. Three important features about this group warrant concern. First, as described above, the cumulative number affected increases as arrivals enter year to year. Second, it includes large numbers of non-citizen children who are similarly barred from assistance. Unlike the immigrants already here who have U.S.-born children who are citizens based on their birth in the United States, most of the children brought here by new arrivals are not independently eligible, but assume the eligibility (or non-eligibility) status of their parents. Third, it is a group also categorically barred from federal food stamps/TANF safety net, and receives Medi-Cal only because of a stand-alone state program funded from state monies.

In 1998, the state established a Cash Assistance Program for Immigrants (CAPI) because of the federal denial of SSI to many non-citizens (those not already receiving grants as of September 30, 1998). The CAPI program provides state-only funds at \$10 less than the SSI grants. However, it covers two groups: (a) pre-1996 immigrants who were not enrolled prior to the 1998 date, a relatively small group, and (b) some of the post-1996 arrivals (where sponsors have died, are disabled or abusive). It originally was intended to cover all post-1996 arrivals, but that coverage sunsetted in 1999 and was regrettably not renewed. That more restrictive version missed many post 1996 arrivals, all of whom are also excluded federally (see discussion in Chapter 2 of the PRA generally). Eligibility for this limited CAPI benefit sunsetted on October 1, 2001. However, during 2001, the Legislature enacted Chapter 111, Statutes of 2001, to include documented persons (including children) arriving after 1996, subject to the deeming of sponsor income (most of those affected have no sponsor).

The Budget Act of 2003 provided \$94.1 million to fund CAPI, serving approximately 11,000 individuals. Governor Schwarzenegger has proposed to cap enrollment for CAPI in early 2004, for a savings of \$4.2 million. Under his proposal, counties would be required to screen for eligibility and maintain a waiting list. Beneficiaries will become eligible for services on a first-come, first-served basis. The budget does not provide any funding for increased administrative costs associated with administration of the proposed cap.

In January 2004, Governor Schwarzenegger proposed to eliminate the CAPI program and instead provide block grant funding to counties to support safety net programs for immigrants effective October 2004, for general fund savings of \$3.1 million.

2004 May Revise. In his 2004 May Revise, however, the Governor rescinded his proposal to combine funding for the California Food Assistance Program, CAPI, and CalWORKs benefits for recent documented immigrants in a block grant, thus allowing full benefits “to continue to be provided to this population without altering the administrative structure of these programs.”¹²⁰

4. Categorical Removal of Alcohol/Drug Addiction as Disability

The 1996 PRA categorically eliminates alcohol or drug addiction as the basis for an SSI disability claim—a provision not altered in 1997 legislation. Governor Wilson predicted a substantial \$28 million general fund savings in 1998 due to denials of alcohol/drug-based claims. Expert advice and common sense dictate that the state not provide any cash to an addict, but available alternatives include service vouchers and direct payment of rehabilitation and job training costs.

Child advocates argue that the loss of SSI/SSP funds will affect many who have a mix of problems—of which addiction is a symptom. Most important, alcohol and drug abuse correlate strongly with child abuse by parents. Child advocates contend that child welfare services money to pay for reunification services is limited, and waiting lists for drug or alcohol rehabilitation have grown to three to six months in many counties. Although harsh threshold qualification to assure likely treatment efficacy may be warranted, advocates argue that a categorical rejection may preclude fruitful rehabilitative investment and protection of children in some cases where well warranted.

5. SSI/SSP Account Levels

As illustrated in Table 5-F, the actual adjusted cost of SSI/SSP has been flat. Adjustments here are not to increases in persons disabled, but general population growth. Because disability incidence has risen faster than has population growth, and benefit levels include a required COLA (for the federal portion), the trend suggests more restrictive qualification since 1989. The Governor’s 2004–05 budget proposal did not pass through the SSI/SSP cost-of-living adjustment for general fund savings of \$62.5 million, and suspended the state SSI/SSP COLA for general fund savings of \$84.6 million; the combined proposals would amount to \$32 in lost income for individuals receiving SSI/SSP benefits.¹²¹

2004 May Revise. In the Governor’s 2004 May Revise, total general fund expenditures for the SSI/SSP program are \$3.2 billion in 2003–04 and \$3.4 billion in 2004–05, representing increases of \$11.9 million in the current year and \$25.3 million in the budget year, compared to the Governor’s Budget. Caseload for the SSI/SSP program is projected at 1,158,300 recipients in 2003–04, and 1,185,700 recipients in 2004–05. Significant general fund adjustments include increases of \$11.4 million general fund in 2003–04 and \$24.5 million general fund in 2004–05, due to higher-than-anticipated caseload growth and a higher average grant in the SSI/SSP program; the year-to-year caseload growth is projected at 2.4 percent.¹²²

	Budget Year							Estimated	Proposed	Percent Change	
	1989-90	1997-98	1998-99	1999-2000	2000-01	2001-02	2002-03			2003-04	2004-05
State (SSP) Total	\$2,215,736	\$2,026,301	\$2,243,056	\$2,501,786	\$2,555,829	\$2,794,125	\$3,005,490	\$3,144,739	\$3,346,995	41.9%	6.4%
SSI (direct fed.)	\$1,804,170	\$3,595,258	\$3,842,155	\$3,993,844	\$4,135,308	\$4,360,611	\$4,544,477	\$4,971,870	\$4,937,856	175.6%	-0.7%
Total Benefits	\$4,019,906	\$5,621,559	\$6,085,211	\$6,495,630	\$6,691,137	\$7,154,736	\$7,549,967	\$8,116,609	\$8,284,851	101.9%	2.1%
Adj. Total Benefits	\$7,241,015	\$7,371,844	\$7,686,717	\$7,827,721	\$7,594,366	\$7,727,276	\$7,824,204	\$8,116,609	\$7,947,568	12.1%	-2.1%

Dollar amounts are in \$1,000s except average benefits as noted. Sources: Governor’s Budgets. Adjusted to California population and CPI-U (2003–04=1.00). Adjustments by Children’s Advocacy Institute.

**TABLE 5-F. Supplemental Security Income/State Supplementary Program (SSI/SSP)
E. Mental Health**

In October 2001, California's Little Hoover Commission released a major report on the mental health of our children and the state's existing programs of prevention and treatment.¹²³ The report concluded that "more than 1 million children in California will experience an emotional or behavioral disorder this year, and more than 600,000 will not receive adequate treatment."¹²⁴ The Commission concluded that mental health response for children is fragmented and inadequate and that even those who "get in the door" may not receive help. The report estimated that more than 50,000 children in the foster care system may need mental health services but few receive them, and that some 50% to 90% of the children in the juvenile justice system—many victims of abuse themselves—need services not reliably provided. The report harshly condemned the state for a lack of vision, a failure to address prevention, and a lack of commitment to troubled children—who too often become incarcerated at \$40,000 per year in public expense. The recommendations of the Commission were many, and include:

(1) Require each county to establish a Child and Family Services Board to assess needs, organize resources, and fill gaps. The concept is similar to the Project Heartbeat experiment in San Diego—the creation of a supervening authority to coordinate the fragmented efforts at the local level for children needing mental health help;

(2) Establish an Office of Prevention within the Department of Mental Health (DMH);

(3) Direct DMH to develop a policy regarding private health insurance mental health coverage;

(4) Direct DMH to develop a Human Services Research Center to coordinate between DMH and the local Boards above and to serve as a research pipeline;

(5) Add substantial new funding for child mental health prevention and treatment, with outcome accountability and built-in incentives to improve;

(6) Redress the current shortage of mental health professionals (the annual turnover of mental health professionals exceeds 30%).¹²⁵

As discussed below, the budget for 2002–03 implemented none of the recommendations, nor were they included in the 2003–04 budget. In general, the budget has moved in the opposite direction in recent years. For example, the Medi-Cal provider reimbursement rate reductions include compensation for mental health professionals—rates that have suffered many years of reduction from inflation and will not act to redress the supply shortage of mental health professionals noted in (6) above. In general, services and their coordination are regressing and will regress more over 2004–05. In fact, Governor Schwarzenegger has proposed that in 2004–05, all children's mental health programs be eliminated, reduced, or restructured for purposes of cost-shifting to the counties.

1. Realignment and Spending for Mental Health

Mental health spending, substantially defunded during the early 1980s, was "realigned" to the counties by the Governor and Legislature in 1991 (see discussion in Chapter 1). Realignment promised a dedicated revenue source—a state fund consisting of \$0.005 of the state sales tax. However in 1991–92, as the California recession took hold, counties received only 94.7% of the prior year's spending, excluding inflation and population increase. Counties caught up in 1995, and are now receiving more than the original 1991 allocation—in raw numbers. But inflation and population increases have accomplished adjusted (real) spending reductions. A survey conducted by the California Mental Health Directors Association found that most counties had already made cuts as of 1992 as a result of the funding decline, with the degree of reductions unclear.¹²⁶ Since that finding, the problem of fragmented local cuts has been exacerbated by the state's removal from the counties of \$3 billion in local property tax funds during 1993 and years following (see Chapter 1).

Another survey by the California Mental Health Planning Council indicated where the cuts were being made locally. State hospital bed referrals by counties dropped precipitously, because counties were charged the expensive full cost of care by the state from scarce realigned funds.¹²⁷ The survey also found that, in most counties, mental health accounts have not been “raided” to please more politically powerful constituencies. However, transfers between accounts—allowed within limits—have understandably occurred where unanticipated growth in entitlement accounts occurs. Entitlement accounts must be funded for all who qualify, and have a *de jure* priority.

More important is the apparent long-range impact after the 1993 removal (or retrieval) from counties of a substantial share of local property tax revenues by the state. While mental health spending may not be affirmatively slashed, it is likely to be gradually constricted. This normally occurs by leaving actual spending levels unchanged, or with 2–3% increases, while inflation and population (or caseload) combined increase at 4–7% each year.

Finally, prospective TANF cut-downs, TANF time limit cut-offs, CalWORKs spending obligations beyond state funding provided, legal immigrant cut-offs of SSI, and food stamps reductions could all place a substantial burden on county general assistance accounts, which will likely compel reductions in other accounts—mental health spending in particular.

Meanwhile, realignment was accompanied by promises of careful study of consequences. In particular, “outcome measures” were to be developed and imposed, and local mental health agencies were to be held accountable; where successful therapies were demonstrated, they would be shared and expanded with other counties. However, as the California Mental Health Planning Council recently concluded, the state’s byzantine process for creating outcome standards for adult and children’s services has, after seven years, produced no generally accepted quality gauge of mental health outcomes for children.

2. Managed Care and Mental Health

Having shifted the fiscal burden of mental health financing to counties, the state is now engaged in transferring programmatic responsibility coextensive with Medi-Cal managed care implementation (see Chapter 4). The state Department of Mental Health has reported that over 95,000 children between the ages of 0–17 used public Medi-Cal funds for mental health services.¹²⁸ This 1993 figure combines Medi-Cal fee-for-service patients visiting mental health professionals and those treated by community mental health programs with Short-Doyle Medi-Cal funds. In general, preventive funding has predictably given way to triage treatment of the most visibly troubled and dangerous youth. An analysis of Medi-Cal fee-for-service mental health dollars spent in San Diego County revealed that 77% was spent on the hospitalization of children, as compared to .08% on outpatient services.¹²⁹ In such an environment, early intervention is not feasible, and meaningful prevention spending is precluded.

Under the current plan for Medi-Cal Managed Mental Health Care, all counties were required to have a single plan fully in place by July 1998. All previous funding from the state, including Medi-Cal allocations and Short-Doyle funds, were consolidated, with each county adding its realigned sales tax-based “Mental Health Subaccount.” Additional state general fund contribution and federal matching (Medicaid) dollars have been added.

As discussed in Chapter 4, Medi-Cal patients are being moved into a capitated “managed care” format. Under present plans, Medi-Cal mental health patients are to be absorbed into that system. Hence, a health care service plan will set a per-person up-front charge to be “covered” for mental health services. The average mental health expenditure per Medi-Cal beneficiary using services in fiscal 1999 was \$2,027.¹³⁰ Some counties are discussing contracts with private for-profit plans to provide services. As discussed in Chapter 4, the “gatekeeper” (the professional deciding who is treated for what and how) of such an enterprise has a strong incentive to deny services, particularly where expensive, because profits accrue from up-front collection followed by cost reductions.

Complicating matters further, managed care Medi-Cal is being provided in most counties by at least

two plans, and in some by as many as five (see Chapter 4). The original intent of mental health managed care was a single plan. As between two or more plans, who gets it? If it is to be shared, how will “cream skimming” be avoided—where plans attempt to avoid enrollment of those likely to require intensive treatment? Does this structure facilitate the “system of care” approach discussed below, where all providers subordinate their economic interests to the optimum treatment modality in a child’s best interests?

Some of these concerns came to a head on June 5, 1998, when four public interest groups filed a class action against DHS and Los Angeles County DHS for denial of mental health services to Medi-Cal children. *Emily Q. v. Belshe* contends that Early Periodic Screening, Diagnosis and Treatment (EPSDT) screening makes available “wraparound” services which work—especially in the mental health area—but that state and local officials do not inform parents of options and have not created a funding mechanism to pay for mentoring, tutoring, or other help, instead opting for non-treatment, or—at the other extreme—unnecessary confinement in a mental institution (see EPSDT mental health funding below).

Foster children are a particularly important population requiring substantial mental health services. Most have been neglected, beaten, or molested by the persons they depended the most upon and trusted. Whether they can overcome such a barrier, or are wounded and similarly treat their own children, may turn on effective mental health treatment. Almost 50% of these children use Medi-Cal assistance to finance their mental health care.¹³¹ And foster care children use a highly disproportionate 41% of Medi-Cal mental health dollars spent on children.¹³²

Underlying all of these concerns is the matter of Medi-Cal rates discussed in Chapter 4. Compensation rates for Medi-Cal providers were reduced 5% in 2003–04, and the Governor is proposing an additional 10% cut in 2004–05. In fact, pediatric mental health services are now paid less than half similar compensation for identical services under Medi-Care for seniors, and the supply of providers has diminished (see evidence and discussion in Chapter 4).

3. AB 377 “System of Care” Programs

The Children’s System of Care Program (CSOC)¹³³ (also known as “the Ventura model”) is a mental health program model administered on a county-wide level, designed in a collaborative fashion,¹³⁴ and targeted to seriously emotionally disturbed children under the age of 18 who are being served by more than one public agency.¹³⁵ Usually these children are either already in an out-of-home placement, or a mental health professional has determined that removal of the child from his or her home will happen without intervention. These out-of-home placements may be the result of behavioral problems which affect learning (e.g., the child has been placed in a residential treatment program as part of an educational plan), or the result of a court-ordered removal from the home due to a finding of delinquency or dependency.

Typically, there may be a Department of Mental Health, a separate Department of Developmental Services, SSI/SSP benefits from the federal jurisdiction, a Department of Social Services, juvenile courts and local probation departments spending federal and state child welfare and adoption assistance funds, newly available delinquency prevention funds and programs, and separate Department of Education, County Office of Education, and local school district special education and other programs—all treating the same youth population with mental health problems—who should do what?

	Budget Year								Estimated	Proposed	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01	2001-02	2002-03			2003-04	2004-05
General Fund	\$5,297	\$13,496	\$20,354	\$24,354	\$26,354	\$41,841	\$39,759	\$20,000	\$20,000	\$0	277.6%	-100.0%
Federal Trust Fund	\$5,806	\$12,511	\$12,511	\$12,511	\$0	\$0	\$0	\$0	\$0	\$0	-100.0%	Na
Total	\$11,103	\$26,007	\$32,865	\$36,865	\$26,354	\$41,841	\$39,759	\$20,000	\$20,000	\$0	80.1%	-100.0%
Adjusted Total	\$17,678	\$28,773	\$35,853	\$39,584	\$27,990	\$44,979	\$41,700	\$20,483	\$20,000	\$0	13.1%	-100.0%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets. Adjusted to California age 0–9 population and deflator (2003–04=1.00). Adjustments by Children’s Advocacy Institute.

TABLE 5-G. System of Care (Children’s Mental Health Services)

Each of the jurisdictions covered in this Chapter, and others, have their own eligibility criteria, purposes, funding levels, and capacity. How they fit together may not relate optimally to helping a child in need. Under the “system of care” model, a generalist social worker or an assigned “interdisciplinary team” is empowered to “shop” for a system of care between the programs available. Someone familiar with the strengths and weaknesses of each, and with the authority to surmount territories and put together a customized package of what will most likely work, may avoid common reliance on group home placement—with costs of four to five times other options, or similarly expensive and recidivist state hospitals or high-security confinement.

The Department of Mental Health (DMH) believes that such a “system of care” approach not only results in better care, but—if implemented in all counties—could save California \$171 million.¹³⁶ In its discussion of the advent of Medi-Cal managed care, DMH acknowledged the “system of care” approach as the philosophy that should infuse all children’s mental health services in coming years.¹³⁷

In 1993–94, the Legislature appropriated \$5.3 million to assist counties with pilot “system of care” projects. The account has been supplemented with federal money and a generous contribution from the Robert Wood Johnson Foundation. Its coverage had expanded from 26 counties to 43 in 1997–98.¹³⁸ As Table 5-G depicts, this account was essentially flat from 1989 to 1999. Then in the 2000–01 budget, the Governor proposed and the Legislature approved a \$15 million increase (see Table 5-G) with sufficient funds for at least skeletal implementation in all 58 counties. In May 2002, the Governor startled advocates by proposing its wholesale termination. The Legislature refused that proposal, but compromised by cutting its funding in half, to \$20 million. The 2003–04 budget maintained funding at \$20 million. Like his predecessor, Governor Schwarzenegger has proposed to eliminate this program for children with severe emotional disturbances for a proposed general fund savings of \$20 million.

The “system of care” beneficial approach makes relatively optimum treatment decisions child by child, but regrettably lacks a politically powerful constituency. Indeed, its format requires competition and implies accountability among service providers with voices in Sacramento—an outcome that is hardly a high legislative priority for most of them.

4. AB 3632 Assessment, Treatment, and Case Management of Special Education Students

Eligible special education students are provided mental health services through “AB 3632” interagency agreements mandated by the Legislature.¹³⁹ Under federal law, a child assessed as “seriously emotionally disturbed” (SED) is entitled to mental health services as necessary to receive appropriate public education.¹⁴⁰ While an individual school may provide some services on campus to a student who has not been assessed as AB 3632-eligible (e.g., services through the EMHI program described below, or some counseling time), all services to students who are AB 3632-eligible are to be coordinated under the direction of each county’s department of mental health. While not all of these children necessarily receive AB 3632 services, any child in that group could eventually qualify for them. It is estimated that AB 3632 services are provided to about 27,000 students each year for a total annual cost of \$120 million.¹⁴¹

The special education-eligible population has increased at approximately double the rate of overall enrollment since 1989. The SED population has increased annually an average of 5.9%,¹⁴² almost three times the overall school enrollment gain rate.

Until the current year, the state provided a portion of the funds for AB 3632 outpatient and day treatment services.¹⁴³ But counties have always been responsible for the majority of funding for evaluation and assessment of children who may be eligible for services. The California Mental Health Directors Association estimates that only 25% of the cost of AB 3632 evaluation and assessment of children was paid for by the state prior to the current year.¹⁴⁴ Due to recent fiscal constraints, the state has suspended state mandate claims for the past three years, including the current one. Though the Budget Act of 2003 appropriated \$69 million in federal IDEA funds to assist with AB 3632 services, counties are still underfunded going into the budget year. Governor Schwarzenegger’s proposed budget

does not identify any additional funding for these continuing services to special education students; accordingly, many counties are having to utilize their County Realignment Funds for this purpose.

The financial burden on counties and school districts to educate and treat this population has increased markedly, and is relevant to the realignment of mental health services to local jurisdictions (see data presented in Chapter 1). It is clear that the state is now violating federal guarantees to special education children requiring mental health services, particularly the AB 3632 children.

5. Early Mental Health Initiative (EMHI)

The Early Mental Health Initiative, one of the “prevention” initiatives which former Governor Wilson outlined upon taking office, was supposed to ensure that children get a good start in school, increase their self-esteem and likelihood of success, and minimize the need for more costly services as they grow older.¹⁴⁵ The Early Mental Health Initiative blends the Primary Intervention Program (PIP) into a more expansive EMHI. Services are targeted at students in grades K–3 who attend public schools and whose school performance is at risk as a result of emotional problems.

The program works through state grants to local school districts and county offices of education. Services provided pursuant to an EMHI grant are to be targeted at K–3 children who are having difficulty making the initial adjustment to school, not at students already experiencing serious difficulties or who have already been identified as failing in school. Schools may purchase the services of a para-professional to meet with students in unstructured sessions designed to develop a supportive relationship with a student. They may also purchase services that enhance parental involvement, referral to cooperating agencies, or teacher training.¹⁴⁶

To date, 434 programs serving 155,000 children have been funded. The program currently serves 45,000 children in 271 schools.¹⁴⁷ The size of the average grant has fallen from \$59,000 in 1992–93 to \$53,000. The budget for this program increased from \$1.3 million in 1989 to an adjusted \$16.3 million in 1997-98. It has since suffered adjusted cuts to \$10 million in the current year, and regrettably is proposed for a 50% reduction to \$5 million in 2004–05.

	Budget Year								Estimated 2003-04	Proposed 2004-05	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01	2001-02	2002-03			'89-'03	Proposed
General Fund	\$0	\$12,000	\$15,000	\$15,000	\$15,000	\$15,000	\$15,000	\$14,451	\$10,000	\$5,000	na	-50.0%
Other	\$1,337	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	-100.0%	na
Total	??	\$12,000	\$15,000	\$15,000	\$15,000	\$15,000	\$15,000	\$14,451	\$10,000	\$5,000	647.9%	-50.0%
Adjusted Total	\$2,129	\$13,276	\$16,364	\$16,106	\$15,931	\$16,125	\$15,732	\$14,554	\$10,000	\$4,873	369.8%	-51.3%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets.
Adjusted to California age 0–9 population and deflator (2003–04=1.00). Adjustments by Children’s Advocacy Institute.

TABLE 5-H. Early Mental Health Initiative (Primary Intervention Project)

6. EPSDT Mental Health Services

Another major mental health account with implications for children is the Early Periodic Screening, Diagnosis and Treatment (EPSDT) program for mental health services. Discussed in Chapter 4, the EPSDT concept is a federally generated (and 50% federal matching fund financed) effort to stimulate early detection and mitigation for a variety of public health dangers, including mental health.

Obviously, children can particularly benefit from such screening since it allows for early detection and possible mitigation or cure at an early age. The funds directed to this program increased dramatically in recent years, from \$25 million in 1995–96 to \$150 million in 1998–99 to \$440 million in 2001–02. This increase is the result of recent federal “entitlement” status for mental health EPSDT. It represents reimbursements from the state’s Medi-Cal program. It has been separated out from the generic EPSDT account within DHS and is examined as a part of the Department of Mental Health budget.

As of July 2003, 27,645 California special education children were receiving mental health services;

their providers are owed an outstanding \$95 million by the state (or counties).

As proposed by the Governor in January, the 2004–05 funding level incorporates several items related to the EPSDT program, such as recalculating the maximum rate paid for EPSDT services based on data from three years ago, to save \$40 million in general fund monies and up to \$90 million in federal funds. The budget also proposes a reduction of \$13 million by conducting audits of the EPSDT program. The proposed reduction is not justified by caseload changes and the reduced provider compensation will detrimentally impact children's ability to receive services they are promised by federal law.

2004 May Revise. In his 2004 May Revision, the Governor included a net decrease of \$21.5 million in reimbursements (\$12.8 million general fund within the DHS budget) for EPSDT. This change reflects several adjustments, including the following: (1) \$98.4 million (\$42.8 million general fund) in natural savings due to a decrease in the projected caseload; (2) restoration of \$60 million (\$40 million general fund) by rescinding both the Governor's Budget proposals to rebase maximum provider rates and the public provider exemption for obtaining federal reimbursement above the state rates (according to the Governor, before rebasing can occur, an alternative formula is needed to correct methodological problems and to prevent significant reductions in rates that could affect access to services); the restoration of \$25 million in federal funds for beneficiary services; \$12.6 million savings (general fund in DHS budget) by increasing the county share of costs from 10% to 20%, excluding small counties; restoration of \$4.5 million (\$2.6 million general fund) by updating the estimated savings associated with the Governor's Budget proposed EPSDT audits.¹⁴⁸

7. Homeless Mental Health Services

As discussed briefly in Chapter 2, the 2001–02 budget included \$55.6 million on an ongoing basis to provide mental health treatment to those with severe mental illness who are in danger of homelessness (Integrated Services for Homeless Adults Program). Although not a direct child-related program, the account reflects the increasing population of homeless persons, including larger numbers of families with children. Child advocates find increasing numbers of parents with mental health problems within the child welfare system, with many of them living substantially below the poverty line. The expenditure of monies in advance through this account could provide a savings to the reunification services account with the Department of Social Services which is activated when children are removed from their homes due to severe neglect or endangerment. More important, it could potentially detect and mitigate problems affecting parents, and hence children, before neglect becomes so severe it reaches mandated child abuse reporters *post hoc*. The Governor's proposed budget for 2004–05 seeks to continue the Integrated Services for Homeless Adults Program, with a general fund allocation of \$54.9 million.

8. Services for Children in Foster Care: *Katie A. v. Bonta*

Those children in foster care have a special claim to mental health services. Some children who are removed from their homes under child welfare statutes have suffered severe molestation and other abuses. They are entitled to mental health help under federal and state law. The cycle of abuse that is often perpetrated between multiple generations is best broken through such assistance.

In addition, the “reasonable services” mandate of federal law that applies to reunification may mandate such services for parents in order to allow return of children to families with appropriate reduction of danger (see detailed discussion in Chapter 8). A federal class action has been pending for several years in Los Angeles federal district court on behalf of children in the custody of the County's Department of Children and Family Services due to the failure to provide timely and appropriate mental health services. In 2003, the County agreed to expand “wraparound” services to ensure that mental health needs are identified and treated. Such services are normally provided for children—simply a program of treatment for a child without removing him or her from the home. The settlement to be effectuated after July 2003 calls for a panel of six experts—three to be selected by plaintiff's counsel—to make recommendations to the County and the Court as to how services can be provided to class members. The court will retain jurisdiction over the case to enforce the terms of the agreement. This particular case already produced the closure of the McLaren's Children Center, a facility where multiple abusive practices were alleged—ranging from onerous physical discipline to excessive drug administration.

Still pending are statewide claims against the state Department of Health Services and the Department of Social Services. Those claims include (1) the failure of Medi-Cal to provide required wrap-around services consistently or consistent with statutory requirement, (2) the failure of Medi-Cal to cover “therapeutic” or “treatment foster care” to include the parent where important to the child's progress, (3) lack of access by children to specialty mental health services. On June 18, 2003, the court

certified a statewide class of children who are in foster care or are at imminent risk of such placement, have a mental illness, and need individualized mental health services.

The litigation, pressed by the Western Center on Law and Poverty, the ACLU, Center for Law in the Public Interest, Protection and Advocacy, Bazelon Center, and Alliance for Children's Rights, creates a series of Hobson choices for local officials given the health shortfall in Los Angeles County and the state retraction of assistance and Medi-Cal cuts discussed above. It is clear that without the intervention of the federal court in a direct supervisory role the treatment promises in state and federal law would be breached *in extremis*. The litigation may provide some shift of funds for this high priority population, but will not generate resources without an order applicable to the state agencies still resisting the suit. The shortfall documented by these plaintiffs as to the acknowledged highest priority children subject to services suggests the larger lapse applicable to children in general, including the much larger number of children not subject to state dependency court jurisdiction, including those in delinquency settings, and the large number eligible for help through the IDEA special education goal of reducing barriers to school achievement for children in need.

9. The Proposed 2004 Mental Health Services Act

In May 2004, supporters of the proposed Mental Health Services Act succeeded in placing that measure on the November 2004 ballot. The measure would impose a surcharge of 1% on personal income over \$1 million, in order to fund new early intervention programs for mental illness; expansion of care for children who lack other health coverage; and financial incentives (such as stipends, loan forgiveness and scholarships) to encourage people to work in the mental health field. Specifically, the measure would provide funds to counties to expand services and develop innovative programs and integrated service plans for mentally ill children, adults, and seniors; require the state to develop mental health service programs including prevention, early intervention, education, and training programs; create a new commission to approve certain county programs and expenditures; and provide that current funding for mental health programs may not be reduced because of funding from the new tax.

The Legislative Analyst and the Director of Finance estimate that the initiative would generate new revenues of approximately \$250 million in 2004–05, \$680 million in 2005–06, \$700 million in 2006–07, and increasing amounts annually thereafter, with comparable increases in expenditures by the state and counties for the expansion of mental health programs. Supporters add that the measure would also save the state millions of dollars by keeping the mentally ill out of hospitals and prisons.

F. Childhood Lead Poisoning Prevention Project

As noted in the condition indicator discussion above, lead contamination correlates highly with child disability. The Childhood Lead Poisoning Prevention Project is administered by the Department of Health Services (DHS). It has been subject to an adverse court finding and order regarding inadequate DHS rules to screen children, and a second critical report from the State Auditor regarding mitigation and treatment performance of the children involved. The lead contamination problem is substantial, serious, and long term, and recent statutes and court decisions have strengthened the state's hand to address it. However, due to a lack of DHS leadership, needed additional authority, and a lack of resources committed, the state has failed to screen substantial numbers of clearly at-risk and injured children, and has treated only a handful of those known to have seriously elevated blood-lead levels (see Chapter 4 for detailed discussion and citations).

G. State Council on Developmental Disabilities

The State Council on Developmental Disabilities is an independent agency empowered by state and federal law to protect the rights of the disabled. The Council works with the state departments of Education, Developmental Services, and Rehabilitation, but is funded with a federal grant from the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. The Council evaluates the state's plans and programs. The Council's state budget account provides exclusively federal funds to the Area Boards. In addition, the budget item funds Protection and

Advocacy, Inc., a group of attorneys charged with the legal representation of qualified disabled clients.

The Council is funded exclusively with federal funds, except for \$25,000 from the state’s general fund allocated to it in 1991–92. As Table 5-I indicates, this lack of state general fund contribution has led to its adjustment to current and proposed years above inflation and population. The \$25,000 contribution from the state general fund stopped after 1992 and, as noted above, there is no state general fund commitment to the Council in the current or proposed fiscal year.

	Budget Year								Estimated 2003-04	Proposed 2004-05	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01	2001-02	2002-03			'89-'03	Proposed
Total (all fed. funds)	\$5,490	\$5,350	\$5,825	\$5,881	\$5,981	\$5,601	\$6,483	\$9,235	\$13,338	\$12,451	143.0%	-6.7%
Adjusted Total	\$7,529	\$5,973	\$6,438	\$6,391	\$6,423	\$5,880	\$6,692	\$9,383	\$13,338	\$12,231	77.2%	-6.3%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets.
Adjusted to deflator (2003–04=1.00). Adjustments by Children’s Advocacy Institute.

TABLE 5-I. Council on Developmental Disabilities

III. SUMMARY AND RECOMMENDATIONS

A. Consequences

Children with special needs are among our most vulnerable charges. Whether they need special instruction in school, special health care, or suffer from a mental debility, early intervention and investment can turn a lifelong expense into a lifelong asset. Recent changes have seen disinvestment in these children. Special education is under increasing pressure as rising need is colliding with fewer dollars. Under such circumstances, entitlement status becomes a ceremonial title—denials begin to increase, screening and outreach are stopped, and IEPs are delayed. Those whose parents can arrange for legal action become those given priority, and post 1996 federal changes now threaten to remove that critical inducement for compliance with legislative promises.

On the positive side, the Department of Developmental Services is receiving badly needed resources to increase positions and salaries for the seriously disabled, 40% of whom are children. However, the historical relegation of these accounts to counties through “realignment” has left the most powerless of children to fend in fragmented local settings where authorities are most limited in public funding options. These increases do not yet approach the prevention disinvestment of the last two decades, but the position and salary increases noted above signal some sensitivity to the plight of disabled children where supported by organized current funding recipients.

Other positive developments include funding for autism response, state coverage to those denied help federally (CAPI), and minor increases from federal monies for the Council on Developmental Disabilities.

Juxtaposed against these small commitments is a long list of cuts, including SSI coverage retraction and two state COLA cancellations, substantial Medi-Cal rate reductions on top of rates at the bottom of the nation for services to children, abolition of the important System-of-Care program, effective elimination (“realignment”) of the “3632” program for special education kids, substantial reductions in mental health for special education in general, and effective termination (“realignment”) of even the mental health for homeless children program. The overall picture is one of unprecedented withdrawal of assistance for the mental health of children.

B. California Children’s Budget Recommendations

A threshold problem in spending for special needs children is evident in the confusing mix of federal, state, and local agencies whose accounts are arrayed above. In addition, other special needs-related subaccounts are not included above, because they are part of other accounts described in other chapters, particularly in Chapter 4 (Health), Chapter 8 (Child Protection), and Chapter 9 (Juvenile Justice). They are uncoordinated, fragmented, and continue to proliferate in number and variety. No standard blueprint or “collaborative model” (in foundation-speak) will reconcile them. The first priority

in budget spending for special needs children is to devise an incentive structure to accomplish indirectly the coordination and child-first priority which cannot be ordered or cajoled into being through "multidisciplinary" review, committee meetings, or computer networks. Instead, our recommendation is a "bureaucracy bypass" variation of the "system of care" model described above, and includes the following general elements.

Recommendation #1. Mental health services for children who need them should be an entitlement under state law. Estimated cost: included in Medi-Cal/Healthy Families

The fact that some programs are entitlements, others are "capped entitlements," others are subject to annual appropriations, and still others are devolved into local agencies where funding is problematical leads to decisions about care apart from the medical merits. Such variation in legal status and budget resources is not directly related to treatment efficacy. They tend to misallocate decisions in favor of mandated categories.

California should establish by state law the entitlement status of children to mental health treatment where professionally diagnosed as necessary, or where so determined by a court. Such status should yield rights to an allocation of "vouchers" redeemable by the state and equally collectible by any public agency or private provider under public contract. All programs then stand on an even footing, making a decision on the medical merits more likely. Redemption should be a state responsibility, using federal funds where applicable.

Recommendation #2. A modified "system of care" approach should be mandated. Estimated cost: reorganization of current accounts

An assigned advocate or social worker generalist should receive vouchers and be permitted to "shop" among all of the available providers, order needed services (or recommend them to a court), and pay for treatment which a child needs to give him or her the best chance. The shopper will select what is most likely to help the child in his/her considered judgment—which may be informed by multidisciplinary review and collaboration, but which is not subordinate to a consensus demand. The shopper may seek boot camp, counseling, a mentor father, a group home, a foster family placement, special education, an operation, a mental hospital, speech therapy, respite child care, or whatever is most likely to work given the needs of the child. The shopper will be given a budget of vouchers based on the graded difficulty of his or her caseload. If a likely treatment will take her over budget, he or she may appeal (with justification) for augmentation. The "entitlement" established above is not for any and all services possible, but for those justifiable by the shopper as beneficial. A child will not have 20 caseworkers (one from each possible agency with jurisdiction)—there will be one, the shopper.

Such a "shopping" model creates a marketplace which replicates some of the desirable features of markets in general. To maintain caseload and survive, programs will have to sell the child's "shopper," and perform to his or her measured satisfaction. That shopper's only economic interest should be the child's successful treatment. Those programs—from whichever of the over 20 different public agencies now providing them—will expand as client referrals increase from success, or atrophy as voucher income falls and agencies are compelled to downsize. The "shoppers" should remain presumptively assigned to the same child if reentry occurs. And shoppers should receive bonuses based on successful outcomes of those assigned to them at three-, five-, and ten-year marks after treatment. Predictable opposition to varying pay based on performance should be overridden.

Recommendation #3. Vouchers should be fully available to the children of lawful immigrants, regardless of when they arrived. Estimated cost: \$10 million

There is little danger of immigration fraud so a child can collect vouchers for mental health treatment, special education, or disability rehabilitation, particularly when the decisions to spend are made by an outsider who does not benefit from the expenditure—except where it works.

Recommendation #4. Mental Health Services can operate in a managed care setting, if separated from other medical managed care plans and given separate identity and management, and if the guidelines for medical managed care recommended in Chapter 4 are similarly followed. *Estimated cost: part of Medi-Cal/Healthy Families*

The lodestar for the special needs recommendation is a simple and time-proven principle: Pay for it, and it will be done. To overcome the territoriality of twenty different programs, one must bypass them and make them compete for the overriding goal. Such an approach rationalizes care, and imposes the same kind of natural selection forces which have worked to produce our consumer product and service market. It does not encounter the abuses of thoughtless “privatization,” which often means turning over a non-competitive exclusive opportunity to a private provider—who then often combines the monopoly of the state with the avarice of the monopolist. It arranges the incentives where they serve the market goal, as determined by the surrogate shopper for the child.

Recommendation #5. The state should provide attorneys’ fees for prevailing special education claimants, free from the restrictions of 1997 federal changes, and from state sources. *Estimated cost: \$10 million statewide*

Contrary to current federal restrictions on class action and policy challenges by legal services attorneys, counsel who adjudicates a case for a large group, or whose precedent applies generally, should be rewarded for securing enforcement of the law in an efficient manner. Such a method is superior to a one-case-at-a-time struggle, and is the rationale for the American system of *stare decisis* precedents. The attorney fee system for special needs children should include the same multiplier opportunity applicable under the *Serrano* precedent, and under the same criteria.

Recommendation #6. The state should include a COLA for its SSP benefits. *Estimated Cost: \$12 million*

The SSI population is particularly vulnerable. In the case of children, parents must often provide constant treatment and care. It is to the advantage of all concerned that they not be institutionalized, nor subject to intensive medical interventions. The SSP addendum of California is laudable, but no longer covers the rent disparity between this state and those states not offering a state supplement. The persons receiving this assistance are among our most vulnerable citizens. Under the circumstances of disparate California rent and price inflation, a state COLA increase is warranted.

Chapter 5

ENDNOTES

1. U.S. Bureau of the Census – 2000, *Profile of Selected Social Characteristics United States and California*, respectively, Table DP-2, Department of Commerce, 2003.
2. *Id.*
3. The Institute for Development of Educational Activities, Inc., *2001–02 School Year National IDEA Census: Percentage of Children Ages 6–17 Served Under IDEA, By Disability* (Washington, D.C.; 2002) at Table AA13 (see http://www.ideadata.org/tables25th/ar_aa13.htm).
4. *Id.* at last row of tables.
5. *Id.*, at Table AA-1 listing numbers of IDEA children by state and age. At an 11.56% national rate rather than the 9.18% California IDEA inclusion figure, the 632,000 children from 3 to 18 becomes 796,000 and the proportionate share of those from 0 to 3 raises the total to 923,000.
6. National Information Center for Children and Youth with Disabilities, *Attention-Deficit/Hyperactivity Disorder* (September 2002) at 2 (available at www.nichcy.org).
7. IJ Cahsnoff, A. Anson, H. Stenson, R. Hatcher, J. DiCara, K. Iaukea, L.A. Randolph, *Prenatal Exposure to Cocain and Other Drugs: Outcome at Four to Six Years*, ANN. NY ACAD. SCI. (1998).
8. For discussion of new guidelines, see Jane Allen, *How Do You Know If It's Attention Deficit/Hyperactivity Disorder?* L.A. TIMES, May 8, 2000, B-3.
9. Luke Tsai, M.D., *Pervasive Developmental Disorders*, Briefing Paper FS20, National Information Center for Children and Youth with Disabilities (January 1998) at 12–13.
10. See National Information Center for Children and Youth with Disabilities, *Autism/PDD* (January 2004) at 1 (available at www.nichcy.org).
11. Thomas Maugh II, *State Study Finds Sharp Rise in Autism Rate*, L.A. TIMES, Apr. 16, 1998, at A-28; see Figure 1-A and cite for most recent IDEA census. The California 0.13% rate is similar to the national average for IDEA recipients at 0.12%.
12. Department of Developmental Services, *Client Characteristics at the End of December 2002* (Sacramento, CA; January 2003).
13. Robert Byrd, *et al.*, *Autism in California Children*, M.I.N.D. Institute, University of California at Davis, October, 2002, at 1-3.
14. *Id.*
15. U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Disabilities Affect One-Fifth of All Americans* (Washington, D.C.; Dec. 1997) at Table 5; see also National Information Center for Children and Youth with Disabilities, *Emotional Disturbance* (January 2001) at 1, noting that—nationally—463,172 children were provided services in public schools based on diagnosis of serious emotional disturbance in the 1998–99 school year (citing the U.S. Department of Education's 2000 annual report) (see www.nichcy.org).
16. In California, there are approximately 10 million Californians between the ages of 0–19. The National Conference of State Legislatures reports that an estimated 12% of children in the U.S. suffer from a mental illness serious enough to require mental health treatment. Twelve percent of the relevant population in California is approximately 1.2 million children. See Rebecca T. Craig, *What Legislators Need to Know About Children's Mental Health*, NAT'L CONF. OF STATE LEGIS. (1990) at 3.
17. California Department of Mental Health, *California Department of Mental Health* (October 1998) at 12.
18. Centers for Disease Control and Prevention, *Suicide in the United States* (Nov. 8, 2002), available at www.cdc.gov/ncipc/factsheets/suifacts.htm.
19. See Elizabeth Gleick, *Suicide's Shadow: A California High School Struggles with the Aftershocks from the Death of Three Students*, TIME, July 22, 1996, at 40.
20. See Mike Males, *Framing Youth*, Common Courage Press (1999) Chapter 7, Table 1; the figures appear to be correct, showing a 3.1 per 100,000 population aged 10–19 suicide rate in 1965, increasing to 5.4 in 1993 and declining to 4.5 in 1996. The author's thesis is supported by the 1997 figures: 179 suicides and a 3.8 suicide rate, the lowest rate since 1965. See Stephanie Ventura, Robert Anderson, Joyce Martin, Betty Smith, *Births and Deaths: Preliminary Data for 1997*, NAT'L VITAL STAT. REP., Vol. 47, No. 4; Center for Health Statistics, CDC (October 7, 1998).

21. See Chapter 4 at Table 4-A-1 (2001 California Leading Causes of Child Death by Age Groups). At 148 deaths of youth from 16 to 20 years of age, only motor vehicle accidents and homicides (about 90% by firearms) exceed that total.
22. National Information Center for Children and Youth with Disabilities, *Mental Retardation* (January 2004) (see www.nichcy.org/pubs/factshe/fs8txt.htm).
23. *Id.*
24. National Information Center for Children and Youth with Disabilities, *Speech and Language Disorders* (Jan. 2003) at 1 (see www.nichcy.org).
25. National Information Center for Children and Youth with Disabilities, *Deafness and Hearing Loss* (Jan. 2003) at 1 (see www.nichcy.org).
26. National Information Center for Children and Youth with Disabilities, *Visual Impairments* (Jan. 2003) at 1 (see www.nichcy.org).
27. Patricia Winget, *Reading Initiative May Decrease Special Ed Referrals*, *The Special Edge*, Resources in Special Education, Vol. 12, No. 1 (Spring 1999) at 1.
28. National Information Center for Children and Youth with Disabilities, *Traumatic Brain Injury* (Feb. 1999) at 1 (see www.nichcy.org).
29. National Information Center for Children and Youth with Disabilities, *Traumatic Brain Injury* (Fact Sheet #18) (January 2004)_at 2 (see www.nichcy.org).
30. National Information Center for Children and Youth with Disabilities, *Cerebral Palsy* (January 2004) at 1 (see www.nichcy.org).
31. National Information Center for Children and Youth with Disabilities, *Down Syndrome* (January 2004) at 1 (see www.nichcy.org).
32. National Information Center for Children and Youth with Disabilities, *Epilepsy* (January 2004) at 1 (see www.nichcy.org).
33. National Information Center for Children and Youth with Disabilities, *Spina Bifida* (January 2004) at 1 (see www.nichcy.org).
34. A. B. Wilson, *Longitudinal Analysis of Diet, Physical Growth, Verbal Development and School Performance*, in Balderston, *et al.* (eds.) *MALNOURISHED CHILDREN OF THE RURAL POOR* (Auburn House, Boston) at 40.
35. See, e.g., H. E. Freeman, R. E. Klein, J. W. Townsend, and A. Lechtig, *Nutritional and Cognitive Development Among Rural Guatemalan Children*, *AM. J. PUB. HEALTH* (1980) at 1277–85.
36. Information about the effects of nutrition deficits on children’s development are summarized in Tufts University School of Nutrition Science and Policy, Center on Hunger, Poverty and Nutrition Policy, *The Link Between Nutrition and Cognitive Development in Children* (Medford, MA; 1995). See also J. Larry Brown and Ernesto Pollitt, *Malnutrition, Poverty and Intellectual Development*, *SCIENTIFIC AMERICAN*, Feb. 1996, at 38–43.
37. Note the research by Dr. Jacqueline Stordy contending that linoleic acid and alpha-linolenic acid—which come from diet, form key structures within the brain and that many children with ADHD and dyslexia apparently are unable to convert these dietary fatty acids into the longer chain of fatty acids then used for brain development. Supplements can assist that functions. In contrast, current strategy for dealing with ADHD is Ritalin, a form of speed, which was prescribed 7.7 million times six years ago, and 13.9 million times in 1998. Stanford University researchers believe that ADHD children have visible differences in their brain ganglia. See Thomas Maugh II, *Differences Found in Hyperactive Kids’ Brains*, *L.A. TIMES*, Nov. 24, 1998, A-3.
38. William A. Vega, Ph.D., Bohdan Kolody, Ph.D., Jimmy Hwang, Ph.D., and Amanda Noble, Ph.D., *Prevalence and Magnitude of Perinatal Substance Exposures in California*, 329:12 *NEW ENG. J. MED.* 850, at 853 (Sept. 16, 1993).
39. *Id.* at 852–54.
40. *Id.* at 851.
41. See Cheryl Clark, *11% of Pregnant Women in State Use Alcohol, Drugs*, *S.D. UNION-TRIB.*, Sept. 16, 1993, at A1 (quoting Bohdan Kolody, Ph.D.).
42. *Id.*

43. Robert Mathias, National Institute on Drug Abuse, *NIDA Survey Provides First National Data on Drug Use During Pregnancy*, NIDA NOTES (January/February 1995).
44. Barry M. Lester, Edward Z. Tronick, Linda LaAmerican Academy of Pediatrics, *The Maternal Lifestyle Study: Effects of Substance Exposure During Pregnancy on Neurodevelopmental Outcome I One-Month-Old Infants*, Pediatrics 2002 (American Academy of Pediatrics; December 2002).
45. Department of Health and Human Services, *Substance Abuse and Mental Health Services Administration, 2001 National Household Survey on Drug Abuse* (Rockville, MD; August 2002) at Figures 2.10 and 2.11.
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47. American Speech-Language-Hearing Association, *Fetal Alcohol Syndrome* (1996).
48. *Id.*
49. Online Clinic, *Fetal Alcohol Syndrome in Our Community 1999* (see www.online-clinic.com/community.html).
50. California Department of Health Services, *Childhood Lead Poisoning in California: Causes and Prevention* (Sacramento, CA; June 1989).
51. Centers for Disease Control and Prevention, CDC Fact Book 2000/2001 (Sept. 2000) at 15; Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report, *Blood Lead levels in Young Children—United States and Selected States, 1996–1999* (Dec. 22, 2000) (see www.cdc.gov/mmwr/preview/mmwrhtml/mm4950a3.htm).
52. California Department of Health Services, *Lead Hazards in California's Public Elementary Schools and Child Care Facilities* (Sacramento, CA; 1998).
53. See Lawrie Mott, Natural Resources Defense Council, *Our Children at Risk: The Five Worst Environmental Threats to Their Health* (New York, NY; 1997) at 12 (hereinafter "*Our Children at Risk*"), citing P. Mushak, et al., *Prenatal and Postnatal Effects of Low-Level Lead Exposure: Integrated Summary of a Report to the U.S. Congress on Childhood Lead Poisoning*, 50 ENV. RES. (1989) at 11–36; see also P. Baghurst, et al., *Exposure to Environmental Lead and Visual-Motor Integration at Age 7 Years: The Port Pirie Cohort Study*, 6:2 EPIDEMIOLOGY (March 1995) at 104–09 (hereinafter "*Exposure to Environmental Lead*").
54. *Exposure to Environmental Lead*, supra note 53, at 104–09.
55. See *Our Children at Risk*, supra note 53, at 13.
56. Herbert L. Needleman, M.D.; Julie A. Riess, Ph.D.; Michael J. Tobin, Ph.D.; Gretchen E. Biesecker; Joel B. Greenhouse, Ph.D., *Bone Lead Levels and Delinquent Behavior*, 275:5 JAMA 363 (Feb. 7, 1996). The study focused on 11-year-old boys.
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61. Detailed data is available on the CDE website; see also Nanette Asimov, *90% of Disabled Kids Flunk Exam*, SAN FRANCISCO CHRONICLE, September 27, 2002.
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63. *Id.*
64. *Id.*
65. *Id.*
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71. See *California Advisory Commission on Special Education, Annual Report 1997–98*, eds. Patricia Wiinget and Elissa Provance (1998).
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73. See Office of the Governor, *Governor's Budget Summary 2001–02* (Sacramento, CA; Jan. 2001) at 113 (hereinafter "*Governor's Budget Summary 2001–02*"). Note that two cases are involved, the so-called "Riverside" case, and the separate "Long Beach" case. The school districts receiving these funds include: Riverside, San Mateo-Foster City, Palo Alto, Oakland, the North Region Special Education Local Plan Area, Newport Mesa, Grant Union High School District, Contra Costa Special Education Local Plan Area, Castro Valley, and Long Beach.
74. Senate Budget and Fiscal Review Committee, *Overview of the 2004–05 Budget Bill* (Sacramento, CA; Feb. 2004) at 1-8.
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76. H.R. 5, Pub. L. No. 105-17, the IDEA Improvement Act of 1997.
77. *Bush Adds \$1 Billion to Part B, Level-Funds Part D*, *The Special Educator*, Vol. 19, No. 14 (LRP Publications, Feb. 24, 2004).
78. Legislative Analyst's Office, *Analysis of the 1997–98 Budget Bill* (Sacramento, CA; 1997) at E-104-06; see AB 602, Chapter 854, Statutes of 1997.
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81. Elizabeth Hill, Office of the Legislative Analyst, *Special Education Facilities Funding Report* (Sacramento, CA; Jan. 3, 2000) at 1, 13–14.
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83. Office of Special Education and Rehabilitative Services, *Assessment of California Special Education Performance*, U.S. Department of Education (Washington D.C.; May 1999).
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86. Department of Developmental Services, *DDS Demographics 2001* (Sacramento, CA; 2002).
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89. See discussion in Legislative Analyst's Office, *Analysis of the Budget Bill 1999–2000* (Sacramento, CA; Jan. 1999) at C-72.
90. Office of the Governor, *Governor's Budget Summary 2004–05* (Sacramento, CA; Jan. 2004) at 113.
91. *Id.*

92. *Id.* at C-171.
93. Office of the Governor, *May Revision 2004–05* (Sacramento, CA; May 2004) at 46.
94. Department of Developmental Services, *Report to the Legislature: Family Cost Participation Assessment Program* (Sacramento, CA; April 2004).
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97. Legislative Analyst's Office, *Analysis of the 2004–05 Budget Bill* (Sacramento, CA; Feb. 2004) at C-167.
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99. Office of the Governor, *May Revision 2004–05* (Sacramento, CA; May 2004) at 47.
100. Office of the Governor, *Governor's Budget Summary 2000–01* (Sacramento, CA; Jan. 2000) at 128.
101. *In Re Roger S.*, 19 Cal. 3d 921 (1977).
102. Office of the Legislative Analyst, *Analysis of the Budget Bill 1999–2000* (Sacramento, CA; Jan. 1999) at C-75-78.
103. Office of the Governor, *Governor's Budget Summary 2002–03* (Sacramento, CA; Jan. 2002) see esp. Figure HHS-24 at 198.
104. See *Fiscal Effect on California*, *supra* note 87, at 9.
105. See Judge David L. Bazelon Center for Mental Health Law, *New Rules for Children's SSI Program* (Washington, D.C.; Feb. 11, 1997) at 2 (hereinafter "*New Rules for Children's SSI*").
106. *Sullivan v. Zebley*, 493 U.S. 521 (1990).
107. See *New Rules for Children's SSI*, *supra* note 105, at 1–2.
108. *Id.* at 5.
109. *Id.*
110. See U.S. General Accounting Office, *Social Security: New Functional Assessments for Children Raise Eligibility Questions* (GAO/HEHS-95-66) (Washington, D.C.; March 1995) at 18; see also *Study: Kids on SSI Not Faking*, SACRAMENTO BEE, May 8, 1995, at A-9 (separate study by National Academy of Social Insurance contradicts claims that parents are coaching children to gain eligibility for SSI).
111. California Department of Social Services, *Supplemental Security Income/State Supplementary Payment (SSI/SSP): Questions and Answers* (Sacramento, CA; April 14, 1998) (see www.dss.cahwnet.gov/calworks/quesssi.html) at 3.
112. Prepared Statement of Robert E. Cooke, MD, Before the Senate Finance Committee/Social Security and Family Policy Subcommittee (July 7, 1998).
113. For a detailed discussion of the elimination of children with serious asthmatic conditions, see Chris Palamountain, National Center for Youth Law, *Children with Asthma Prove Vulnerable to SSI Cuts*, XIX:1 YOUTH LAW NEWS (San Francisco, CA; January–February 1998) at 1–8.
114. For an interesting discussion of the issue, see David Lash, *Cease Fire*, L.A. DAILY J., Jan. 22, 1998, at 6.
115. See Robert Pear, *Social Security to Help Children Regain Their Disability Benefits*, S.D. UNION-TRIB., Nov. 16, 1997, at A-1.
116. See Barbara Vobejda, *Review Ordered on Cutoff of Disability Aid to Children*, WASH. POST, Dec. 18, 1997, at A-1.
117. The concern of SSI critics that cash grants are subject to false claims and other abuses by and for adults does not apply to the direct funding of medically related services and support for children—*i.e.*, Medi-Cal.
118. See Chapter 2, Table 2-M.
119. Balanced Budget Act, Pub. L. No. 105-33.

120. Office of the Governor, *May Revision 2004–05* (Sacramento, CA; May 2004) at 57.
121. Senate Budget and Fiscal Review Committee, *Overview of the 2004–05 Budget Bill* (Sacramento, CA; Feb. 2004) at 3-3.
122. Office of the Governor, *May Revision 2004–05* (Sacramento, CA; May 2004) at 56.
123. California Little Hoover Commission, *Young Hearts and Minds: Making a Commitment to Children’s Mental Health* (Sacramento, CA; Oct. 2001) (hereinafter “*Young Hearts*”).
124. *Id.*, at i.
125. *Id.*, at i - xix.
126. California Mental Health Directors Association, *CMHDA Interim Report on Realignment* (June 11, 1992), *passim* (hereinafter “*CMHDA Interim Report*”).
127. California Mental Health Planning Council, *Effects of Realignment on the Delivery of Mental Health Services* (Jan. 1995) at 8.
128. California Department of Mental Health, *Medi-Cal Mental Health Managed Care* (Sacramento, CA; June 1, 1994) at Attachment H (hereinafter “*Medi-Cal Mental Health Managed Care*”). This figure includes some duplicate users.
129. Figures on file at the offices of the Children’s Advocacy Institute, 5998 Alcalá Park, San Diego, California; survey was conducted in 1992–93.
130. Medi-Cal Policy Institute, *Mental Health Services in Medi-Cal*, Medi-Cal Facts, Number 10 (April 2001) at 2.
131. *Medi-Cal Mental Health Managed Care*, *supra* note 128, at Attachment B.
132. Neal Halfon, M.D., M.P.H., Gale Berkowitz, D.P.H., Linnea Klee, Ph.D., *Mental Health Service Utilization by Children in Foster Care in California*, 89:6 PEDIATRICS 1238 (June 1992).
133. AB 377 (Wright) (Chapter 1361, Statutes of 1987) added Chapter 6.8 to Division 5 (commencing at section 5565.10) of the California Welfare and Institutions Code, entitled the Children’s Mental Health Services Act.
134. Different public systems—such as schools, Medi-Cal providers, dependency, or delinquency judicial and administrative entities, and private mental health providers—may come into contact with the same seriously emotionally disturbed child. Frequently, communication among agencies is poor. The “system of care” programs attempt to coordinate services to reduce out-of-home placement. See Daniel D. Jordan, Ph.D. and Mario Hernandez, Ph.D., *The Ventura Planning Model: A Proposal for Mental Health Reform*, 17:1 J. OF MENTAL HEALTH ADMIN. 26 (Spring 1990).
135. CAL. WELF. & INST. CODE § 5600.2(c).
136. California Department of Mental Health, Managed Care Implementation, *California Public Mental Health System Overview* (Sacramento, CA; Oct. 1993) at 9.
137. *Medi-Cal Managed Mental Health Care*, *supra* note 128, at 32–33.
138. See Office of the Governor, *Governor’s Budget Summary 1998–99* (Sacramento, CA; 1998) at 23.
139. CAL. GOV’T CODE § 7572.5.
140. 20 U.S.C. § 1412(b)(2) (Individuals With Disabilities Act); CAL. EDUC. CODE § 56500 *et seq.*
141. Senate Budget and Fiscal Review Committee, *Overview of the 2004–05 Budget Bill* (Sacramento, CA; Feb. 2004) at 3-39.
142. Office of the Legislative Advocate, *Overview of the Governor’s Budget 1995–96* (Sacramento, CA; Jan. 1995) at E-45.
143. Residential services are paid for with foster care moneys. These dollars are allocated through the county departments of social services with a state/county split. See Chapter 8’s data on TANF-FC.
144. *CMHDA Interim Report*, *supra* note 126, at 7.
145. California Department of Mental Health, *Early Mental Health Initiative* (Sacramento, CA; Jan. 1, 1993).
146. *Id.*
147. Office of the Governor, *Governor’s Budget Summary 1997–98* (Sacramento, CA; Jan. 1997) at 33, 116.

148. Office of the Governor, *May Revision 2004–05* (Sacramento, CA; May 2004) at 53.