

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, about one in every eight children aged 6–14 has some type of disability; 6.8% of children in that age range have difficulty doing regular schoolwork, 5.2% have a learning disability; 1.5% have a developmental disability (including mental retardation, autism, or cerebral palsy), and 3.7% have some other developmental condition for which they had received therapy or diagnostic services.¹

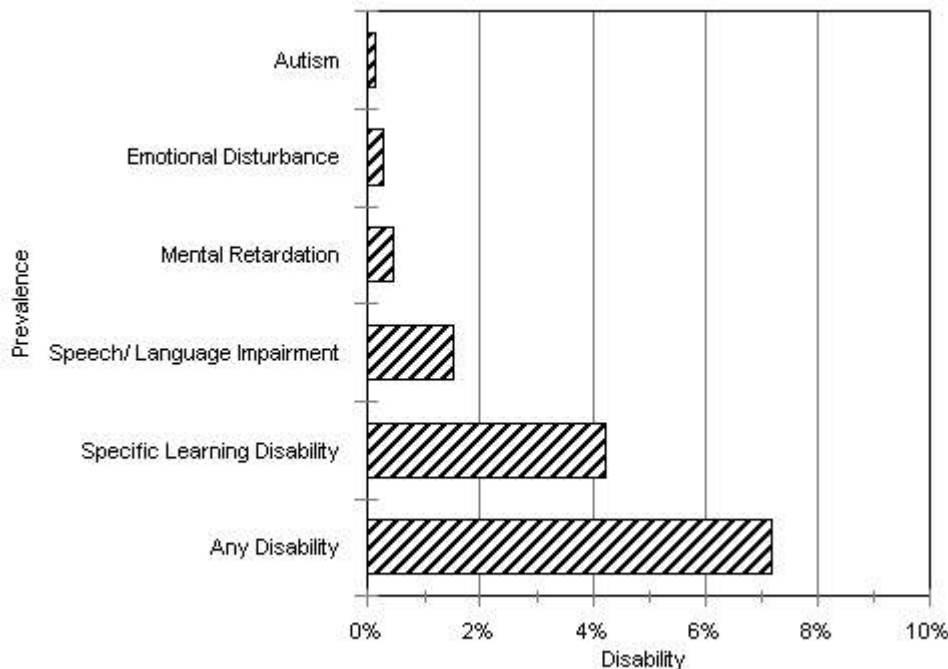


FIGURE 5-A. Prevalence of Acknowledged Disabilities Among School-Age Children²

A. California Child Disability Major Groupings

Over seven hundred thousand children in California suffer from some type of disability. Figure 5-A shows the incidence of basic disability by type among diagnosed school-age children. These figures may understate levels because they reflect those children acknowledged as disabled and receiving assistance. Learning disabilities continue to be the most prevalent problem, affecting about 4.2% of the state's children. The number of children with Attention Deficit Disorder (ADD) and diagnosed as seriously emotionally disturbed (SED) has increased over the past decade, but are under-represented in the IDEA served population in the state. The national IDEA "emotional disturbance" IDEA census rate is 0.72%, three times the California rate. 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).

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 research indicates that ADHD may be genetically transmitted and results in 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 particularly in ritalin and other drug administration as a reflexive result. However, experienced teachers and health professionals believe that a growing number of children exhibit these symptoms at the far end of the spectrum and they 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. 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.³

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"—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.⁴ 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, or 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% to 12% of school age children, with boys being so diagnosed at five times the rate of girls.⁵

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 interactive, 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).⁶

National sources place incidence at 5 to 15 per 10,000 births, with boys four times more likely to be afflicted than girls.⁷ 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.⁸

A survey by the state's Department of Developmental Services released on April 16, 1999 counted 11,995 autistic children enrolled in the Department's 21 regional programs in 1998, and representing a 210% increase compared to the 3,864 enrolled in 1987. Other disorders, such as cerebral palsy and epilepsy, had been increasing consistent with population growth. Another survey of autism diagnoses in California counted 5,281 in 1994, increasing steadily each year by more than 10% per annum to the 2001 level of 14,777.⁹ The most recent estimate of 2002–03 demand for services is 22,906, a 16% increase from the current year.¹⁰

Some experts call the growth national in scope and alarming. While some 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. Thus far nationally, very little public money is funding such research. The precise cause of autism or its growth over the last decade is in dispute, with explanations including environmental contaminants, child large vaccination groupings that overly burden a child's system, infectious agents, genetics, and allergic etiologies.¹¹

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.¹² A broader definition of mental health disorder yields incidence estimates in the 12–20% range. At the 12% level, just over one million children in California could be included among those appropriate for treatment.¹³ 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 460,000–644,000 children. Currently, 76,000 children are served in state mental health programs,¹⁴ administered at the county level under realignment (as discussed below). As noted above, the IDEA count of SED children is a low 0.27%, 1/3 the national IDEA count of 0.72%. The disparity in numbers between IDEA inclusion and other measures partly reflects the view of SED as not a learning disability but a mental health problem not addressable by special education—but more the territory of counselors or non-school professionals.

Persons under the age of 25 accounted for 15% of all suicides in 1997.¹⁵ A 1993 study by the Centers for Disease Control (CDC) of 16,000 high school students found that one in twelve said he or she had attempted suicide in the previous year.¹⁶ Youth suicides increased substantially between 1965 to 1993, but have been declining since, and are expected to reach previous levels.¹⁷ 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. It 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.¹⁸

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 12 out of every 1,000 school children suffers from mental retardation.¹⁹ During the 1998–99 school year, 610,445 students aged 6 to 21 were classified as having mental retardation and were provided special educational and related by public schools.²⁰

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).²¹

Hearing loss is a substantial subset within this category, and during the 1998–99 school year, 70,813 students from 6 to 21 (1.3% of students with disabilities) received “hearing impairment” related services. 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.²²

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 1,000.²³ 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. “Almost 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....”²⁴

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,²⁵ and 30,000 have lifelong disabilities.²⁶

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);²⁷ Down Syndrome (4,000 babies born each year nationally);²⁸ epilepsy (62,500 new cases each year among children and adolescents);²⁹ and spina bifida (one in every 1,000 births nationally).³⁰

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. Chapter 4 discusses some of the state accounts relevant to prevention of genetically-based disability. The chapter also outlines the leading causes of serious injury from accidents, and the state EPIC account addressing it. As the discussion indicates, both of these causative factors receive virtually no state funding. The former is funded from private payments for services, the latter receives all of \$1.6 million in funding.

We discuss below three additional causes also closely correlating 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 growing as child poverty deepens with welfare reform benefit cut-offs.

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.”³¹ 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 and 7. There is a remarkable relationship between nutrition and language test performance.³²

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.³³

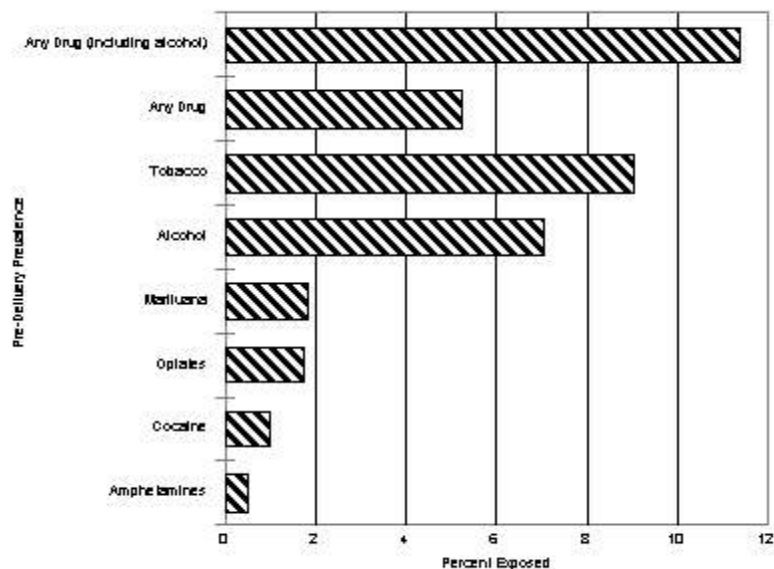
Apart from the absence of nutrients, some experts believe that some children are predisposed to common disabilities—but that predisposition can be countered with nutrient supplements not now offered—particularly for the more than one million California children suffering from ADD/ADHD, and dyslexia—both correlating with certain fatty acid deficiencies.³⁴

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 a large number of women with alcohol ingestion or drug use which can devastate and permanently injure their child. Child advocates argue that the issue is not one of abortion rights—that 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, 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.”³⁵ The study also found that an additional one in eleven mothers admitted that she continued to smoke during pregnancy.³⁶



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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.³⁷ According to one author of the study, the results were “conservative.”³⁸ 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.³⁹ 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.⁴⁰ However, the self-reporting of alcohol or cigarette use involves less stigma (and only recent use would be detected by the California survey). Alarming, 18.8% of pregnant women admit to exposing their fetuses to alcohol, and the most recent self-report of smoking during pregnancy is 13.6%.⁴¹

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 1993.⁴² Babies born with FAS suffer central nervous system dysfunction, including delayed motor development, mild to profound mental retardation, and learning disabilities.⁴³ FAS also causes problems that affect speech, language, swallowing, and hearing development.⁴⁴

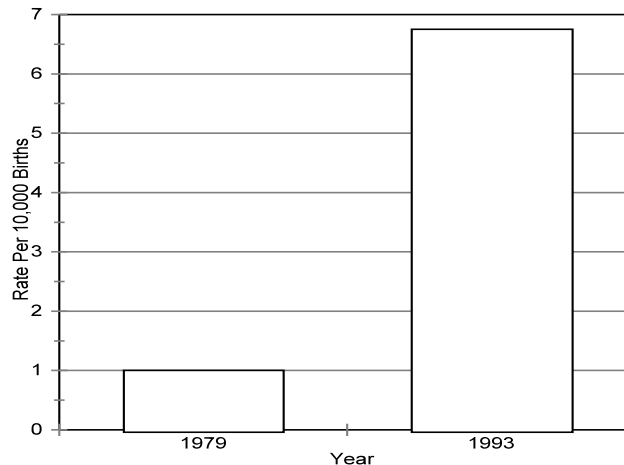


FIGURE 5-C. U.S. Trend in Alcohol-Injured Infants per 10,000 Births

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:⁴⁵

- ◆ 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.

As of July 1995, 4,878 California children were in foster care due to their drug or alcohol exposure *in utero*; they cost California an estimated \$1.7 million each month in direct expenses.⁴⁶

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.⁴⁷

Although blood lead levels in children have decreased approximately 80% since the late 1970s, elevated levels remain more common among low-income children, urban children, and those living in older housing.⁴⁸ 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.⁴⁹ 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.”⁵⁰ 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.”⁵¹ 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.”⁵²

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.⁵³ 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 11.⁵⁴ 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, IQ loss, or physical disability.

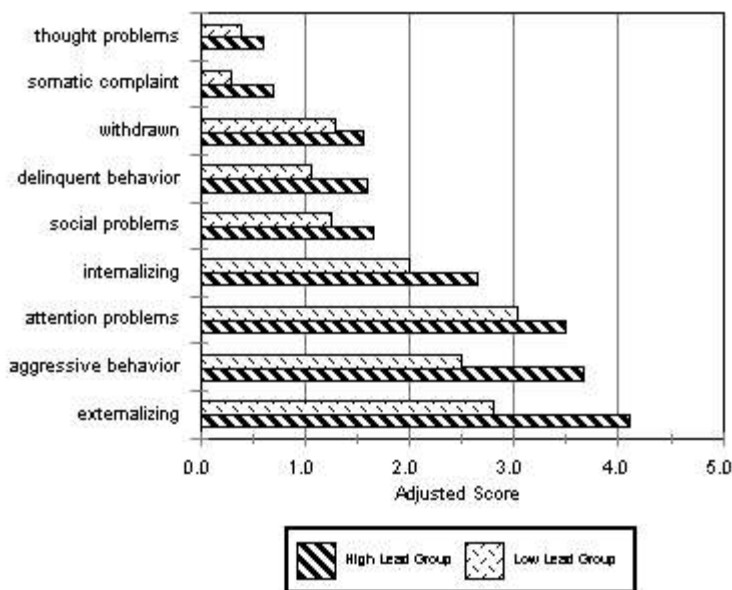


FIGURE 5-D. Bone Lead Concentration and Behavior Correlations

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 10.9% in 1999–2000.⁵⁵ Of the 650,719 special education students enrolled in California public schools during the 2000–01 school year, the disability categories are defined by the Department of Education somewhat differently than the national survey of Figure 5-A above. In addition, the Figure 5-E division includes all those in special education from 0 to 21 years of age (the somewhat smaller population currently enrolled in K–14 special education (excluding preschool) is 612,160 as of 2000-01).

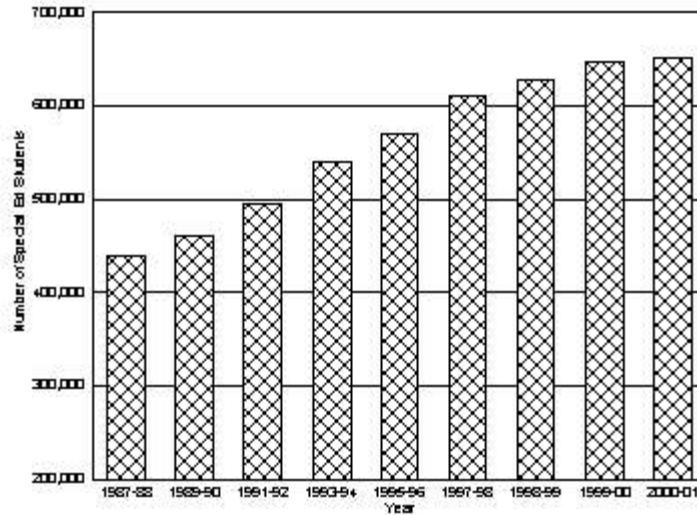


FIGURE 5-E. Number of California Public School Children Enrolled in Special Education, 1987–2001

The California Department of Education operates substantial pre-school programs (see Chapter 6). Its categorization of its special education population from 0 to 21 is as follows:

- ◆ specific learning disability—53.6%;
- ◆ speech or language impairment—25.4%;
- ◆ mental retardation—6.3%;
- ◆ emotional disturbance—3.4%;
- ◆ other health impairment—3.2%;
- ◆ orthopedic impairment—2.2%;
- ◆ autism—2.2%;
- ◆ multiple disabilities—1.0%;
- ◆ hard of hearing—1%;
- ◆ deaf—0.7%;
- ◆ visual impairment—0.7%;
- ◆ deaf/blindness—0.03%; and
- ◆ traumatic brain injury—0.2%.⁵⁶

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.

Seven 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.⁵⁷ It is intended by CDSS to “assist families with disabilities when the barrier to employment is the disability of a child or the adult.”⁵⁸ 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.⁵⁹ The new five-year time limit (60 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.⁶⁰ (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.⁶¹ 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. As noted above, the special education-eligible population, and numbers enrolled, have increased markedly in California over

the past decade. The California Advisory Commission on Special Education is charged with monitoring the system and recommending improvements.⁶²

Although spending for special education is substantial, and has increased, the average amount spent nationally per child in special education is \$688 per child per year, about 12% of the average education cost per child per year. Hence, special education students cost on average nationally 12% more than a non-special education student cost.⁶³ Hence, although substantial in gross, the program is more modest in relation to both need and total public education budgets.

Within the current year's budgeted amount, 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 to 9. The purpose is to reach those who indicate serious reading problems earlier, when amelioration may be more cost effective.

The 2000–01 budget added \$60.8 million from federal funds to school districts for more consistent decisions between them to provide services—a continuing serious problem. The equalization effort is from two funds: \$33.2 million to districts which spend below the state average in per pupil special education, and \$27.6 million 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.

The Governor's 2001–02 budget 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 are rising faster than K–12 enrollment. Table 5-A indicates slightly increasing or steady spending primarily because we have chosen the conservative adjuster of K–12 enrollment, rather than special education need or caseload. The proposed 2002–03 budget includes \$94.5 million more from Proposition 98 education funds to provide districts with monies consistent with the per pupil funding formula established by AB 602 in 1997 (discussed below). That formula requires a COLA adjustment, which makes up \$77.5 million of the total, the remainder is projected growth.

The current budget received \$97 million in new federal funds to increase the basic spending base (and included in Table 5-A). For 2002-03, the Governor anticipates \$135 million in federal funds, and proposes to reduce general fund commitment by \$112 million of that amount. In addition, he proposes to cut another \$22.6 million to reflect "increases in local property taxes" (attributable to real estate inflation) available to school districts. The taking of these federal and local funds for general fund relief is not without cost.

The four other major new funding additions for 2002–03 are:

- (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 is added for 2002–03, as will be the case through 2010–11 to SELPAs as a result of the settlement of litigation based on state under funding of school districts. The state was obligated to pay to districts \$125 million over 2000–01 and the current 2001–02 fiscal year for prior underpayments. Those underpayments created a dynamic of district avoidance of costs not unlike the problems faced by consumers in managed care systems. Districts denied services to save costs given

the failure of state pick-up. Those districts required to pay from their own sources and who did so saw their other spending obligations suffer. Accordingly, eleven plaintiff districts in two companion cases negotiated this overall increase for statewide application. They also obtained for themselves a one-time \$270 million payment for retroactive and uncompensated special education spending they had incurred (taken from the 2000–01 budget), plus—as noted—\$25 million each year for the next ten⁶⁴ (see discussion of the history of this 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 actually expends less than 15%, placing the burden substantially on the states. Congressional efforts to “fully fund” special education (the full share promised) have encountered Republican opposition and are unlikely to be approved. However, in March of 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 is to be applied entirely to general fund reduction.

	Budget Year						Estimated	Proposed	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-2000	2000-01			2001-02	2002-03
General Fund	\$1,354,594	\$1,720,824	\$1,870,172	\$2,125,891	\$2,256,695	\$2,442,641	\$2,607,658	\$2,714,855	92.5%	4.1%
Federal Trust Fund	\$176,298	\$255,016	\$329,040	\$398,801	\$453,198	\$522,141	\$664,818	\$782,266	277.1%	17.7%
Total	\$1,530,892	\$1,975,840	\$2,199,212	\$2,524,692	\$2,709,893	\$2,964,782	\$3,272,476	\$3,497,121	113.8%	6.9%
Adjusted Total	\$2,615,333	\$2,336,000	\$2,523,053	\$2,790,900	\$2,905,960	\$3,057,703	\$3,272,476	\$3,392,235	25.1%	3.7%

Dollar amounts are in \$1,000s. Sources: Governor's Budgets. Adjusted to K–12 enrollment and deflator (2001–02=1.00). Adjustments by Children's Advocacy Institute.

TABLE 5-A. Special Education

2. Federal Amendments: “1997 IDEA”

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.⁶⁵ 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.

The major funding occurs through “Part B” of IDEA covering school-aged children. The \$3.1 billion nationally appropriated in fiscal year 1997 has grown to \$4.9 billion in the current year. Once that trigger amount is reached, states must “maintain” effort by spending the same per child spent the year before the trigger amount is reached. States qualify for more money by finding more disabled children needing help during the year preceding the trigger year. Less stringent maintenance of effort (minimum spending) requirements also apply to contributions from school districts (and county offices of education).⁶⁶

Part C of IDEA concerns special education programs for infants and toddlers up to three years of age. Funding here was boosted for 1998 from \$220 million to \$400 million nationally. Similarly, funding under Section 619, covering children from three to five years of age, was increased from \$360 million to \$500 million. Although these numbers sound substantial, the original IDEA statute included a minimum guidepost of \$1,500 per annum per child in Section 619 spending (over \$2,000 in current dollars). However, the increased appropriation will bring the total to \$656 per child. The amendments to IDEA also make 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.

3. California’s Special Education Reform Act of 1997

The budget of 1997–98 included “funding reform” (supported by both the former Governor and the LAO).⁶⁷ 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” (SELPAs), 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.⁶⁸ The new system now in its third year, changes allocations more consistent with “population.”⁶⁹ 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 of 2000 redresses some of the prior imbalance, but with a disproportionate reward to the 11 districts who were parties (out of over 1,000 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 of 2000, the Legislative Analyst released her Report on Special Education Facilities Funding. Her study concluded that local authorities should determine facility needs, that the \$2,300 to \$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).⁷⁰

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 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.

6. 1999: Six Vetoed Bills

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.⁷¹ The legislature has enacted little legislation addressing special education or special needs investment in 2000, 2001, and will not enact any measure involving new general fund expenditure in 2002.

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.⁷²

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 well known to HMO or managed care students. An advance budget provided by formula, with the ability to spend as desired what is 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 found and served at a rate which is compensatory for basic average costs (to reduce incentives to avoid proper screening), and would be awarded bonus payments above and beyond out-of-pocket cost based on improvement steps children achieve as measured independently. The more you succeed, the more you receive, with levels above total 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 performance generally.

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. Over half (53%) of all DDS clients are children between the ages of 0–21. Approximately 80,581 children and youth served by DDS programs. Demographically, 58% of DDS clients are male; 45.8% are White, 26.3% are Hispanic, 10.3% Black, 6.1% Asian and the remainder are unknown.⁷³

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.⁷⁴ 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 2.6% of those served are subject to intensive Developmental Center services. Most of those served remain in their local communities, with 66.5% (including most children) living at home, 16.9% in community care facilities locally, 8.6% in partially supported "Independent Living" settings, and 5.4% in "skilled nursing or intermediate care" facilities.⁷⁵

	Budget Year					Estimated	Proposed	Percent Change	
	1989-90	1997-98	1998-99	1999-2000	2000-01	2001-02	2002-03	'89-'01	Proposed
General Fund	\$543,591	\$537,509	\$706,380	\$910,746	\$1,127,094	\$1,879,134	\$2,007,363	245.7%	6.8%
Federal Trust Fund	\$6,871	\$44,172	\$44,336	\$46,864	\$50,058	\$47,604	\$48,153	592.8%	1.2%
Reimbursements (Medi-Cal)	\$535,558	\$1,072,396	\$1,158,657	\$1,248,125	\$1,380,356	\$803,592	\$808,951	50.0%	0.7%
Other	\$8,310	\$2,425	\$2,954	\$4,470	\$4,975	\$7,449	\$4,549	-10.4%	-38.9%
Total	\$1,094,330	\$1,656,502	\$1,912,327	\$2,210,205	\$2,562,483	\$2,737,779	\$2,869,016	150.2%	4.8%
Adjusted Total	\$1,732,271	\$1,897,769	\$2,127,442	\$2,389,179	\$2,654,771	\$2,737,779	\$2,762,997	58.0%	0.9%

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

Adjusted to California population and deflator (2001-02=1.00). Adjustments by Children's Advocacy Institute.

TABLE 5-B. Department of Developmental Services

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 58% 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 is now in the final year of a four year plan to more aggressively and effectively treat clients. That plan involves 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 in Table 5-B.

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 2002.⁷⁶ California uses Social Services Block Grant funds to support DDS' regional centers.⁷⁷

b. Regional Centers Account

The Regional Center line items account for two-thirds of DDS’ total departmental budget. As Table 5-C indicates, this account as adjusted has increased markedly from 1989–90 to the current budget in 2001-02. 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 has received meaningful additional state investment from general fund sources during the Davis Administration, \$138 million in 1999–2000, another \$150 million in 2000–01, and a significant \$562 million in current 2001–02. Real growth has occurred in these regional community center operations of DDS, as public officials attempt aggressive early intervention to avoid more costly institutionalization.⁷⁸

	Budget Year						Estimated 2001-02	Proposed 2002-03	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01			'89-'01	Proposed
General Fund	\$501,392	\$469,030	\$498,809	\$659,835	\$799,307	\$949,782	\$1,511,771	\$1,645,128	201.5%	8.9%
Dev. Disab. Prog. Dev. Fund	\$3,759	\$1,817	\$2,123	\$2,353	\$3,846	\$2,934	\$2,052	\$2,052	-45.4%	0.0%
Federal Trust Fund	\$5,804	\$41,030	\$43,427	\$43,578	\$46,176	\$49,487	\$46,924	\$47,513	708.8%	1.3%
Reimbursements (Medi-Cal)	\$30,413	\$548,007	\$642,770	\$709,060	\$788,300	\$902,076	\$530,843	\$533,232	1645.4%	0.5%
Dev. Disab. Services Account	\$0	\$20	\$30	\$30	\$30	\$1,000	\$2,900	\$0	-	-100%
Total	\$541,368	\$1,059,904	\$1,187,159	\$1,414,856	\$1,637,659	\$1,905,279	\$2,094,490	\$2,227,925	286.9%	6.4%
Adjusted Total	\$877,077	\$1,216,347	\$1,331,621	\$1,543,058	\$1,742,695	\$1,958,605	\$2,094,490	\$2,156,518	138.8%	3.0%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets.
Adjusted to California age 0–19 population and deflator (2001–02=1.00). Adjustments by Children’s Advocacy Institute.

TABLE 5-C. Community Services, Regional Centers

Regional Center population has increased from 157,475 in 1999 to 171,430 currently.⁷⁹ It is projected to 182,230 in 2002–03.⁸⁰ Much of the increase has been to accommodate that growth and inflation. That growth and higher service use rates accounts for \$148 million in the proposed year.⁸¹ Aside from that factor, total spending is scheduled for decrease.

The large shift in funding within Table 5-C in the current year from Medi-Cal reimbursements and to the general fund involves a \$346 million accounting change, where money previously attributed to DHS’ state match required for Medi-Cal, and is now attributed directly to DDS. That shift does not represent a substantive change. That accounting adjustment is also reflected in the proposed budget numbers for 2002–03.

Another \$5.6 million was expended in current 2001–02 for the second of three phases to implement a statewide accounting and monitoring system; the five year project will eventually cost \$14 million in general fund monies. Related to this expense was a major addition in proposed 2002–03 of \$108.7 million for “Purchase of Services” improvement. The concept is to spend monies to assure statewide standards across all 21 Regional Centers, including consultation with stakeholders to assure efficient administration of the \$2.16 billion expended for the Community Services Program.

In current 2001–02, \$9.2 million was budgeted for additional Regional Center staff to expand the “Special Incident Reporting System,” intended to bring the state into compliance with federal requirements (which have been waived under the state’s “Home and Community Based Services” program. The federal jurisdiction, with substantial basis, expects the community focus to include investment and documentable results as compared to the institutionalization option. The state’s approach is supported by advocates for the disabled, but with the caveat that it not become a bureaucratic means to “dump” persons in-need (particularly children and parents) into local facilities where they may be

mistreated or untreated, and may also be unmonitored. The 2002–03 budget adds a token \$2 million to this account—intended to “assure compliance with federal requirements under the waiver.”

Two other new spending proposals for 2002–03 are of importance:

(1) The budget proposes \$20.4 million to improve the method of deciding how and when consumers are transferred from Developmental Centers into “community placements.” One agenda of the additional money is to stimulate the departure of persons no longer needing more expensive services into what the Governor’s Budget terms with favor “the least restrictive environment.”⁸² Beginning in 2002–03, such movement will involve a detailed assessment of the services necessary to support individuals in community placements.

(2) The new budget proposes an additional \$17.2 million for children with autism. The Governor’s Budget notes, consistent with the condition indicator discussion above, that “the number of children autism diagnoses is increasing steadily.” Importantly, the Governor’s 2002–03 publicly acknowledges the value of early and intensive intervention for this population.⁸³

The May Revise 2002 cut the Regional Center general fund totals of Table 5-C by a significant \$184 million, arguing that these funds will be provided by equivalent new federal funding, \$106.7 million from additional consumers under the Home and Community-Based Services Waiver, and \$70.9 million from Title IV-E funds used for Child Welfare Services Emergency Assistance Case Management activities to “free up TANF dollars” that will somehow be allowably deposited in the Table 5-C account. Given the predicted pressure on TANF funds during 2002–03, it is unclear how this transfer is accomplished without subtraction.

2. DDS Developmental Centers

The other major DDS account funds developmental centers, and makes up roughly one-third of DDS’ total departmental budget. 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.⁸⁴ The centers together 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 3,660 as projected for 2002–03. The *Coffelt* Settlement required the devolution of at least 2,000 patients within five years of its 1994 issuance, which the state met 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 intensive care centers.

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.

The DDS development center devolution turns current clients (and leaves future ones) to the 4,000 community care facilities (CCFs) at the local level—which have been under increasing pressure over the past decade.

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 has been fairly constant (in the \$38–\$46 million range) from 1989 to 1998. However, general fund increases were committed in large measure during that year. This major spending increase starting in 1998 reflects

the four-year plan discussed above to change services from passive warehousing to active treatment. The budgets since 1998, including general fund increases, reflect the implementation of that plan, which has included 43 new Developmental Center positions

The new funds are required due to the aging plant housing existing patients. As the Governor notes 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.”⁸⁵ Accordingly, the budget includes money to study renovation, and adds \$3.7 million to fully staff the new Sierra Vista facility in Northern California.

However, developments during the current year have undermined the ambitious four year plan of 1998. The federal jurisdiction “decertified” the Sonoma Development Center, and the certification of the Agnews Center and the Sierra Vista Center were delayed. As a result of that decertification, the federal jurisdiction found the state out of compliance with federal standards, and withheld federal monies. In 2000–01, \$36.5 million was subtracted as a federal penalty. During current 2001–02, the Secure Treatment Program at Porterville was decertified and the Canyon Springs facility suffered a certification delay. The result was a \$13.7 million penalty in the current year’s budget. It is unclear what may be assessed during proposed 2002–03, but although no funds are reserved for such an assessment, the record of the last three years is not promising.

Most of the substantial change within Table 5-D represents a \$255 million shift from Medi-Cal reimbursements to general fund obligation. However, as discussed above with regard to the Regional Centers, this shift represents an accounting change rather than an increase in general fund commitment. The total budget expended represents a adjusted decline of 26.6% from 1989 to the current year, and an additional 4% decline as proposed for 2002–03. Most of the reduction reflects caseload decline, and spending per patient has in fact increased. However, the pattern of releasing large numbers of persons requiring less attention has left the much smaller group of patients who require more intensive treatment per person.

	Budget Year						Estimated	Proposed	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01	2001-02	2002-03	'89-'01	Proposed
General Fund	\$42,199	\$40,412	\$38,351	\$46,133	\$111,103	\$177,030	\$366,839	\$361,739	769.3%	-1.4%
Federal Trust Fund	\$1,067	\$735	\$745	\$758	\$688	\$571	\$680	\$640	-36.3%	-5.9%
Reimbursements (Medi-Cal)	\$505,155	\$494,134	\$429,626	\$449,597	\$459,825	\$478,280	\$272,749	\$275,719	-46.0%	-1.1%
Other	\$4,541	\$315	\$272	\$571	\$594	\$1,041	\$2,497	\$2,497	-45.0%	0.0%
Total	\$552,962	\$535,596	\$468,994	\$497,059	\$572,210	\$656,922	\$642,765	\$640,595	16.2%	-0.3%
Adjusted Total	\$875,312	\$629,290	\$537,302	\$552,973	\$618,545	\$680,582	\$642,765	\$616,923	-26.6%	-4.0%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets. Adjusted to California population and deflator (2001–02=1.00). Adjustments by Children’s Advocacy Institute.

TABLE 5-D. Developmental Centers

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.⁸⁶ 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 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.⁸⁷

The Governor's decision in his May Revise of 2002 to remove all funding for the analogous “System of Care” program in the Mental Health account bodes ill for the future of this program, an approach strongly supported by disabled and child advocates (see discussion below).

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 is projected at 765,952 for 2002. The blind portion (also including children) amount to approximately 21,000 persons and has been relatively stable year to year. The remaining persons in the total projected caseload of 1,126,400 for 2002–03 are in the “aged” third 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 and as projected, caseload growth approximates population increase.⁸⁸

Maximum SSI/SSP payments in calendar 2001 for the aged and disabled in California are \$712 per month for an individual or \$1,265 for a couple. For a blind person the 2001 maximum was \$771 and \$1,466 for a blind couple. Of this total, \$531 and \$796, respectively, come from the federal treasury (the SSI share). COLA adjustments in January of 2002 and January of 2003 will put the disabled maximums above to \$759 and \$1,347, respectively as of 2003. All of these increases will come from a federal COLA increase to the federal share.

On the one hand, California has among the highest benefits under this program, because of its SSP supplement. Its maximums are from \$100 to \$150 per month higher than other populous states due to

this state contribution. However, the increase is largely consumed in the higher median rents applicable in California (see Chapter 2 data). Moreover, California applied no COLA to its share from 1994–95 to 1999-00, and after three years of inflation adjustment, has now stopped such increases to match inflation for the current 2001–02 and projected 2002–03 year. Accordingly, the overall COLA increase for the disabled to be applied in January 2003 is 1.8% to the federal portion, or 1.34% overall. It is likely that California rents and other basic costs for the severely disabled attempting to live independently (or to care for children who require their attention at home) will increase by more than this amount.

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.⁸⁹ New guidelines eliminate references to the “comparable severity standard,” the “individual functional assessment,” and “maladaptive behavior.”⁹⁰ 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.⁹¹

New guidelines implemented by the Social Security Administration include a set of “medical listings.”⁹² 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.⁹³ The Social Security Administration had until February 22, 1998 to accomplish all of the redeterminations.⁹⁴ 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.⁹⁵ 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. 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.⁹⁶

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.⁹⁷

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. However, for children with the affliction, 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.⁹⁸

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.⁹⁹ 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, new Social Security Commissioner Kenneth Apfel promised an independent review of the termination and denial pattern.¹⁰⁰ 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.¹⁰¹ SSI children are automatically eligible for Medi-Cal. In some states, the Medi-Cal status of SSI-terminated children is ambiguous. The Governor has 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.¹⁰²

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.

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	1,103,400	1.6% higher
2002-03	1,126,400	2.1% higher

Source: Governor’s Budget Summaries

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

As discussed below, 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.¹⁰³

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 groups¹⁰⁴—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. As with the similar sunset for state-only food stamps for post 1996 arrivals, the Governor's current year budget as it was proposed would have allowed the sunset to terminate even the limited CAPI coverage for the disabled described above, affecting about 1,400 disabled persons, including several hundred children, and coverage for another 700 persons who would

be eligible during the current year. 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 cost of the CAPI program under its now permanent, expanded state-only terms, is \$61.3 million as revised in May 2002.¹⁰⁵

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.

	Budget Year					Estimated	Proposed	Percent Change	
	1989-90	1997-98	1998-99	1999-2000	2000-01	2001-02	2002-03	'89-'01	Proposed
State (SSP) Total	\$2,215,736	\$2,026,301	\$2,243,056	\$2,501,786	\$2,555,829	\$2,822,338	\$3,050,033	27.4%	8.1%
SSI (direct fed.)	\$1,804,170	\$3,595,258	\$3,842,155	\$3,993,844	\$4,135,308	\$4,428,914	\$4,616,665	145.5%	4.2%
Total Benefits	\$4,019,906	\$5,621,559	\$6,085,211	\$6,495,630	\$6,691,137	\$7,251,252	\$7,666,698	80.4%	5.7%
Adj. Total Benefits	\$6,959,757	\$6,690,190	\$7,018,815	\$7,152,000	\$6,938,673	\$7,251,252	\$7,397,699	4.20%	2.0%

Dollar amounts are in \$1,000s except average benefits as noted. Sources: Governor’s Budgets. Adjusted to California population and CPI-U (2001–02=1.00). Adjustments by Children’s Advocacy Institute.

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

E. Mental Health

In October of 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.¹⁰⁶ 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.”¹⁰⁷ 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 estimates 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 condemns 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 are 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 Report noted that the current annual turnover of mental health professionals exceeds 30%).¹⁰⁸

As discussed below, the Governor's budget proposal for 2002–03 would implement none of the recommendations. In general, the budget document moves in the opposite direction. For example, the rescission of the 2001 Medi-Cal compensation increases for mental health professionals (only granted after years of accumulated reductions from inflation) will not advance #6 above. Similarly, the other five recommendations are not meaningfully reflected in the proposed 2002–03 budget.

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 a result of the funding decline, with the degree of reductions unclear.¹⁰⁹ The problem of fragmented local cuts was 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.¹¹⁰ 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) increase at 5–8% 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.¹¹¹ 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.¹¹² 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 \$2,027.¹¹³ 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. Belshé* contends that EPSDT screening (see Chapter 4) makes available “wrap-around” 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.¹¹⁴ And foster care children use a highly disproportionate 41% of Medi-Cal mental health dollars spent on children.¹¹⁵

Underlying all of these concerns is the matter of Medi-Cal rates discussed in Chapter 4. As noted above, the proposed and long overdue increases in those rates for mental health professionals was suspended in the Governor’s May Revise of 2002. That suspension necessarily restricts supply and affects time available for children. The compensation reductions from Medi-Cal have accumulated through years of attrition, as the state has failed to match inflation. The impact of such broadly framed compensation reductions falls most heavily on children as those least able to advocate articulately for their own treatment, or to search out providers.

3. AB 377 “System of Care” Programs

The Children’s System of Care Program (CSOC)¹¹⁶ (also known as “the Ventura model”) is a mental health program model administered on a county-wide level, designed in a collaborative fashion,¹¹⁷ and targeted to seriously emotionally disturbed children under the age of 18 who are being served by more than one public agency.¹¹⁸ 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.

The Department of Mental Health (DMH) believes that a “system of care” approach not only results in better care, but—if implemented in all counties—could save California \$171 million.¹¹⁹ 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.¹²⁰

	Budget Year						Estimated 2001-02	Proposed 2002-03	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01			'89-'01	Proposed
General Fund	\$5,297	\$13,496	\$20,354	\$24,354	\$26,354	\$41,841	\$39,759	\$35,578	650.6%	-10.5%
Federal Trust Fund	\$5,806	\$12,511	\$12,511	\$12,511	\$0	\$0	\$0	\$0	-100.0%	0.0%
Total	\$11,103	\$26,007	\$32,865	\$36,865	\$26,354	\$41,841	\$39,759	\$35,578	258.1%	-10.5%
Adjusted Total	\$17,122	\$27,873	\$34,720	\$38,356	\$27,124	\$42,396	\$39,759	\$34,790	132.2%	-12.5%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets. Adjusted to California age 0–9 population and deflator (2001–02=1.00). Adjustments by Children’s Advocacy Institute.

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

Where there is 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?

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.

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. As Table 5-G depicts, this account has been essentially flat from 1989. Its coverage had expanded from 26 counties to 43 in 1997–98.¹²¹ 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. The current 2001–02 budget retracted slightly from this level. Although the proposed 2002–03 figure above indicates an additional 10% retraction, the Governor startled advocates in May 2002 by proposing its entire termination. Hence, the budget would eliminate this promising approach for child treatment. It is an approach that lacks a highly organized constituency of agencies or providers. Indeed, because it may require competition and some measure of accountability among currently organized social service providers, political support is weak.

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.¹²² Under federal law, a child assessed as “seriously emotionally disturbed” (SED) is entitled to mental health services as necessary to receive appropriate public education.¹²³ 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. The Legislative Analyst reports that, in fiscal year 1994–95, 16,300 children “diagnosed” as SED were enrolled in special education programs in schools. While not all of these children necessarily receive AB 3632 services, any child in that group could eventually qualify for them.

The state provides a portion of the funds for AB 3632 outpatient and day treatment services.¹²⁴ But the counties end up being 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 is paid for by the state.¹²⁵

As reflected in Table 5-H, the contribution by the state in unadjusted dollars decreased by \$3 million from 1989 to 1994, and has remained frozen since then. As the table indicates, the funding pattern has led to an adjusted 52.2% drop in the funding provided by the state for services to these children. 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%,¹²⁶ almost three times the overall school enrollment gain rate. Hence, the 51.8% reduction from 1989–90 to the 2001–02 budget may understate somewhat actual decline *vis-a-vis* the children eligible for services. The proposed 2002–03 budget would eliminate state contribution entirely.

	Budget Year							Estimated 2001-02	Proposed 2002-03	Percent Change	
	1989-90	1995-96	1996-97	1997-98	1998-99	1999-00	2000-01			'89-'01	Proposed
Total (General Fund)	\$15,116	\$12,334	\$12,334	\$12,334	\$12,334	\$12,334	\$12,334	\$12,334	\$0	-18.4%	-100.0%
Adjusted Total	\$25,824	\$15,316	\$14,582	\$14,150	\$13,635	\$13,230	\$12,721	\$12,334	\$0	-52.2%	-100.0%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets.
Adjusted to K–12 enrollment and deflator (2001–02=1.00). Adjustments by Children’s Advocacy Institute.

**TABLE 5-H. Assessment, Treatment, and Case Management—
Special Education Pupils (AB 3632)**

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).

5. “Early Mental Health Initiative” (EMHI)

The Early Mental Health Initiative was one of the “prevention” initiatives which the Governor outlined

upon taking office. The program’s goal is 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.¹²⁷ 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.

	Budget Year							Estimated 2001-02	Proposed 2002-03	Percent Change	
	1989-90	1995-96	1996-97	1997-98	1998-99	1999-00	2000-01			'89-'01	Proposed
General Fund	\$0	\$11,674	\$12,000	\$15,000	\$15,000	\$15,000	\$15,000	\$15,000	\$15,000	-	0.0%
MH Primary Prev. Fund	\$(234)	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	-	0.0%
Asset Forfeiture Distrib. Fund	\$1,571	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	-	0.0%
Total	\$1,337	\$11,674	\$12,000	\$15,000	\$15,000	\$15,000	\$15,000	\$15,000	\$15,000	1021.9%	0.0%
Adjusted Total	\$2,062	\$12,899	\$12,861	\$15,847	\$15,607	\$15,438	\$15,199	\$15,000	\$14,668	627.4%	-2.2%

Dollar amounts are in \$1,000s. Sources: Governor’s Budgets. Adjusted to California age 0–9 population and deflator (2001–02=1.00). Adjustments by Children’s Advocacy Institute.

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

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.¹²⁸

To date, 434 programs serving 155,000 children have been funded. The program currently serves 45,000 children in 271 schools.¹²⁹ The size of the average grant has fallen from \$59,000 in 1992–93 to \$53,000. The budget for this program has increased from \$1.3 million in 1989 to \$15 million in the current fiscal year (Table 5-I), and is proposed at the same raw number level, for an adjusted decrease of 2.2% for 2002–03.

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 have increased dramatically, from \$25 million in 1995–96 to \$150 million in 1998–99 to \$315 million in the current fiscal year and \$440 million in 2001–02. This dramatic 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. The Governor notes that despite the increase in this separated-out account it “has not yet stabilized nor reached its peak utilization.”¹³⁰

Consistent with that judgment, the Governor proposed an important \$133.7 million increase in EPSDT reimbursement for 2002–03, a 31.6% increase in its total budget from the current year.¹³¹ However, the May Revise then subtracted \$35 million from this addition, arguing that it would be made up through a “county requirement to fund 10%” share of cost for program growth. As discussed in Chapters 1, 2 and 4, it is unclear how counties can afford the pick-up of any funding given state cuts, a lack of revenue generating authority, and increasing state mandates across a host of programs—particularly those in the health care area.

7. Homeless Mental Health Services

As discussed briefly in Chapter 2, the 2001–02 budget includes \$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 January 2002–03 budget proposed \$65.6 million for the program, but the May Revise cut it back to its current level of \$56.5 million.

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, 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 fiscal year 1991–92. As Table 5-J indicates, adjusted funding has decreased from \$7.3 million in 1989–90 to \$5.9 million last year, with an increase in the current year to \$6.9 million and a proposed reduction to \$5.9 million, a 16.5% proposed year reduction after close to flat real spending over the past decade. 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 2001-02	Proposed 2002-03	Percent Change	
	1989-90	1996-97	1997-98	1998-99	1999-00	2000-01			'89-'01	Proposed
Total (all federal funds)	\$5,490	\$5,350	\$5,825	\$5,881	\$5,981	\$5,601	\$6,894	\$5,874	25.7%	-14.8%
Adjusted Total	\$7,286	\$5,780	\$6,231	\$6,186	\$6,217	\$5,691	\$6,894	\$5,759	-5.4%	-16.5%

Dollar amounts are in \$1,000s. Sources: Governor's Budgets.
Adjusted to deflator (2001-02=1.00). Adjustments by Children's Advocacy Institute.

TABLE 5-J. 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, some increases for EPSDT, some SSI state coverage to those denied help federally (CAPI), and maintenance of most accounts.

Countering these increases is a long list of cuts, including the rescission of 2000-01 Medi-Cal rate increases for psychiatrists and psychologists, the abolition of the important System-of-Care program, and a long list of described accounting shifts which are actually disguised reductions to vulnerable populations. These cuts take one of two forms, general fund reductions supposedly to be compensated through higher federal contributions, or delegation of spending obligation to counties. Some of the federal monies claimed may be so credited, some will not. Almost all of the county deferral is ephemeral given the now desperate condition of local governments, particularly in the health care area.

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 or 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. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Disabilities Affect One-Fifth of All Americans; Proportion Could Increase in Coming Decades* (Washington, D.C.; Dec. 1997) at 1 and 8 (hereinafter "*Disabilities Affect One-Fifth of All Americans*").
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3. National Information Center for Children and Youth with Disabilities, *Attention-Deficit/Hyperactivity Disorder* (April 2001) at 1 (available at www.nichcy.org).
4. 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).
5. 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.
6. Luke Tsai, M.D., *Pervasive Developmental Disorders*, Briefing Paper FS20, National Information Center for Children and Youth with Disabilities (January 1998) at 12–13.
7. See National Information Center for Children and Youth with Disabilities, *Autism/PDD* (April 2000) at 1 (available at www.nichcy.org).
8. 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%.
9. See Autism Society of America count, reported and discussed in Scott LaFee, *Mental Blocked*, S.D. UNION-TRIB., Jan. 8, 2002.
10. Senate Committee on Budget and Fiscal Review, *Overview of the 2002–03 Budget Bill* (Sacramento, CA; Jan. 2002) at 3-19.
11. *Id.*
12. *Disabilities Affect One-Fifth of All Americans*, *supra* note 1, 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).
13. In California, the Department of Finance reports that in 1995, 9.2 million Californians were between the ages of 0–17. 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 1.004 million children. Rebecca T. Craig, *What Legislators Need to Know About Children's Mental Health*, NAT'L CONF. OF STATE LEGIS. (1990) at 3.
14. California Department of Mental Health, *California Department of Mental Health* (October 1998) at 12.
15. Centers for Disease Control and Prevention, *Suicide in the United States* (January 28, 2000) available at <http://www.cdc.gov/ncipc/factsheets/suifacts.htm>.
16. 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.
17. 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).
18. See Chapter 4 at Table 4-C (1995 California Leading Causes of Child Death by Age Groups).
19. Centers for Disease Control and Prevention, *Mental Retardation Among Children* (October 1999) (see www.cdc.gov/ncbddd/fact/mrfs.htm).
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24. Patricia Winget, *Reading Initiative May Decrease Special Ed Referrals*, *The Special Edge*, Resources in Special Education, Vol. 12, No. 1 (Spring 1999) at 1.
25. National Information Center for Children and Youth with Disabilities, *Traumatic Brain Injury* (Feb. 1999) at 1 (see www.nichcy.org).
26. National Information Center for Children and Youth with Disabilities, *Traumatic Brain Injury* (Fact Sheet #18) (March 2000) at 2 (see www.nichcy.org).
27. National Information Center for Children and Youth with Disabilities, *Cerebral Palsy* (May 2000) at 1 (see www.nichcy.org).
28. National Information Center for Children and Youth with Disabilities, *Down Syndrome* (April 2000) at 1 (see www.nichcy.org).
29. National Information Center for Children and Youth with Disabilities, *Epilepsy* (April 2000) at 1 (see www.nichcy.org).
30. National Information Center for Children and Youth with Disabilities, *Spina Bifida* (April 2000) at 1 (see www.nichcy.org).
31. 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.
32. 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.
33. 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.
34. 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.
35. 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).
36. *Id.* at 852–54.
37. *Id.* at 851.
38. 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.).
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41. *Id.* Note that the American Lung Association reported the level nationally at 20.4% in 1990. The decline to 13.6% by 1996 is significant, but given the ability of nicotine and carbon monoxide to pass through the placenta, remains of great concern. It is unclear, given increases in smoking by young women through the 1980s and 1990s, whether the decrease from the 1990 level to 1996 reflects lower smoking incidence, or lower self-reporting from increased recognition of the hazards posed to their children and the self-guilt an admission implies. See *Smoking and Pregnancy*, Fact Sheet, American Lung Association, April 13, 2000 (available at www.lungusa.org/tobacco/pregnancy_factsheet.html).

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48. 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).
49. California Department of Health Services, *Lead Hazards in California's Public Elementary Schools and Child Care Facilities* (Sacramento, CA; 1998).
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52. See *Our Children at Risk*, *supra* note 50, at 13.
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54. *Id.* at 367 (Table 5).
55. California Department of Education, Special Education Division, *Special Education Programs in California: A Statistical Profile* (see www.cde.ca.gov/spbranch/sed/stat_prof/index.htm#intr) at Table 1.
56. *Id.* at Table 7.
57. California Department of Social Services, *Proposed Redesign of the Welfare System: Detailed Program Description* (Sacramento, CA; Jan. 10, 1996) at 3.
58. *Id.* at 23.
59. *Id.* at 23–24.
60. *Id.* at 24.
61. 20 U.S.C. § 1400 *et seq.*, Pub. L. No. 94–142, Individuals With Disabilities Education Act (IDEA), formerly known as the Education of All Handicapped Children Act. For an excellent reference on special education rights, see Eileen L. Ordovery and Kathleen B. Bounty, *Educational Rights of Children with Disabilities*, Center for Law and Education (1991).
62. See *California Advisory Commission on Special Education, Annual Report 1997–98*, eds. Patricia Wiinget and Elissa Provance (1998).
63. Office of Special Education, *FY 2000 Budget Request* (Washington, D.C.; 1999) at 1 (see www.ed.gov/offices/OSERS/fy2000.html).

64. 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.
65. H.R. 5, Pub. L. No. 105-17, the IDEA Improvement Act of 1997.
66. For example, local jurisdictions can escape the maintenance of effort requirement where enrollments decline, special education staff or high cost students leave or graduate, or prior expenses represent atypical, one-time purchases.
67. 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.
68. While a discussion of this proposal is beyond the scope of this *California Children's Budget*, advocates in the area of special education should familiarize themselves with the proposal, see LAO 1996–97, *supra* note 51, at E-79. A copy of the report—*New Funding Model for Special Education: Final Report* (November 1995)—can be obtained from the Legislative Analyst's Office.
69. AB 602 (Poochigian and Davis) enacted on October 10, 1997 (Chapter 852, Statutes of 1997).
70. Elizabeth Hill, Office of the Legislative Analyst, *Special Education Facilities Funding Report* (Sacramento, CA; Jan. 3, 2000) at 1, 13–14.
71. See AB 395, AB 645, AB 953, AB 1020, SB 156, and SB 867. For a brief summary of the measures and the Governor's veto messages, see *Cost-conscious Davis Vetoes Several Special Education and Related Bills*, California Special Education Alert, Vol. 6, Iss. 4 (Nov. 1999) at 5.
72. Office of Special Education and Rehabilitative Services, *Assessment of California Special Education Performance*, U.S. Department of Education (Washington D.C.; May 1999).
73. Department of Developmental Services, DDS Information Services Division, *Consumer Fact Book* (Sacramento, CA; Aug. 1999) at 12 (hereinafter "*DDS Fact Book*") (see www.dds.cd.gov/factstats/main/factbook98.pdf).
74. CAL. WELF. & INST. CODE § 4512.
75. *DDS Fact Book*, *supra* note 73, at 12.
76. See Legislative Analyst's Office, *Federal Welfare Reform (H.R. 3734): Fiscal Effect on California* (Sacramento, CA; Aug. 20, 1996) at 19 (hereinafter "*Fiscal Effect on California*").
77. *Id.*
78. See discussion in Legislative Analyst's Office, *Analysis of the Budget Bill 1999–2000* (Sacramento, CA; Jan. 1999) at C-72.
79. See *Governor's Budget Summary 2001–02*, *supra* note 64, at 160.
80. Office of the Governor, *Governor's Budget Summary 2002–03* (Sacramento, CA; Jan. 2002) at 185 (hereinafter "*Governor's Budget Summary 2002–03*").
81. *Id.*
82. *Id.* at 186.
83. *Id.*
84. Office of the Governor, *Governor's Budget 1996–97* (Sacramento, CA; Jan. 1996) at HW-74.
85. *Governor's Budget Summary 2000–01*, *supra* note 64, at 128.
86. *In Re Roger S.*, 19 Cal. 3d 921 (1977).
87. Office of the Legislative Analyst, *Analysis of the Budget Bill 1999–2000* (Sacramento, CA; Jan. 1999) at C-75-78.
88. *Governor's Budget Summary 2002–03*, *supra* note 80; see esp. Figure HHS-24 at 198.
89. See *Fiscal Effect on California*, *supra* note 76, at 9.

90. 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*").
91. *Sullivan v. Zebley*, 493 U.S. 521 (1990).
92. See *New Rules for Children's SSI*, *supra* note 90, at 1–2.
93. *Id.* at 5.
94. *Id.*
95. 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).
96. 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.
97. Prepared Statement of Robert E. Cooke, MD, Before the Senate Finance Committee/Social Security and Family Policy Subcommittee (July 7, 1998).
98. 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.
99. For an interesting discussion of the issue, see David Lash, *Cease Fire*, L.A. DAILY J., Jan. 22, 1998, at 6.
100. See Robert Pear, *Social Security to Help Children Regain Their Disability Benefits*, S.D. UNION-TRIB., Nov. 16, 1997, at A-1.
101. See Barbara Vobejda, *Review Ordered on Cutoff of Disability Aid to Children*, WASH. POST, Dec. 18, 1997, at A-1.
102. 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.
103. See Chapter 2, Table 2-M.
104. Balanced Budget Act, Pub. L. No. 105-33.
105. Office of the Governor, *Governor's May Revise 2002–03* (Sacramento, CA; May 2002) at 53, see also discussion in *Governor's Budget Summary 2002–03*, *supra* note 80, at 198–199.
106. California Little Hoover Commission, *Young Hearts and Minds: Making a Commitment to Children's Mental Health* (Sacramento, CA; Oct. 2001) (hereinafter "*Young Hearts*").
107. *Id.*, at i.
108. *Id.*, at i - xix.
109. California Mental Health Directors Association, *CMHDA Interim Report on Realignment* (June 11, 1992), *passim* (hereinafter "*CMHDA Interim Report*").
110. California Mental Health Planning Council, *Effects of Realignment on the Delivery of Mental Health Services* (Jan. 1995) at 8.
111. 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.
112. Figures on file at the offices of the Children's Advocacy Institute, 5998 Alcalá Park, San Diego, California; survey was conducted in 1992–93.
113. Medi-Cal Policy Institute, *Mental Health Services in Medi-Cal*, Medi-Cal Facts, Number 10 (April 2001) at 2.
114. *Medi-Cal Mental Health Managed Care*, *supra* note 111, at Attachment B.

115. 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).
116. AB 377 (W right) (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.
117. 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).
118. CAL. WELF. & INST. CODE § 5600.2(c).
119. California Department of Mental Health, Managed Care Implementation, *California Public Mental Health System Overview* (Sacramento, CA; Oct. 1993) at 9.
120. *Medi-Cal Managed Mental Health Care*, *supra* note 111, at 32–33.
121. See Office of the Governor, *Governor's Budget Summary 1998–99* (Sacramento, CA; 1998) at 23.
122. CAL. GOV'T CODE § 7572.5.
123. 20 U.S.C. § 1412(b)(2) (Individuals With Disabilities Act); CAL. EDUC. CODE § 56500 *et seq.*
124. 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.
125. *CMHDA Interim Report*, *supra* note 109, at 7.
126. Office of the Legislative Advocate, *Overview of the Governor's Budget 1995–96* (Sacramento, CA; Jan. 1995) at E-45.
127. California Department of Mental Health, *Early Mental Health Initiative* (Sacramento, CA; Jan. 1, 1993).
128. *Id.*
129. Office of the Governor, *Governor's Budget Summary 1997–98* (Sacramento, CA; Jan. 1997) at 33, 116.
130. *Governor's Budget Summary 2001–02*, *supra* note 64, at 156.
131. See *Governor's Budget Summary 2002–03*, *supra* note 80, at 183.

