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REDUCING CALIFORNIA'S SPECIAL EDUCATION COSTS BY IMPROVING
ACCESS TO EARLY CHILDHOOD INTERVENTION:

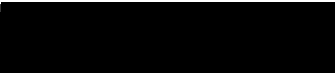
A POLICY REVIEW

A Project
Presented to the
Faculty of
California State University,
San Bernardino

by
Ann Laureen Hennessey


June 2002

Approved by:



Dr. Ann Selmi, First Reader

6/10/02
Date



Dr. Richard Ashcroft, Second Reader

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ABSTRACT

The State of California spends roughly \$3 billion a year to educate its special needs population, ages birth to 22 years. Each year the population grows disproportionately to the general education population, and many school districts are forced to spend general funds to make up for deficits in the special education budgets.

This thesis proposes that more efficient access to early childhood intervention from birth to age 3 years would help reduce the number of school-age children who later need special education services. Early childhood intervention would thereby reduce overall costs of special education, and give all children a better chance at placement in classrooms with their non-disabled peers. The major obstacles to early childhood intervention cited in this study are practices by the managed care industry that limit parents' ability to get help for their children in a timely fashion.

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And, all the parents and teachers at VIP Tots who helped
with the survey.

DEDICATION

For Teresa-Maria Duran

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CHAPTER ONE

INTRODUCTION

Introduction

This master's thesis proposes that the State of California will never rein in special education spending until its special needs population is properly identified and cared for during the critical time period from birth to age 3 years of age. The State of California will spend about \$3 billion educating its special education population this fiscal year (California Department of Education, 2002). Each year the special education budget, a combination of federal and state funds, increases but the money never seems to stretch far enough to meet the needs of California's burgeoning special needs population. Thus, individual school districts often dip into their general education budgets to cover special education needs (Murphy & Picus, 1996).

Proper early childhood intervention means the State of California must work collaboratively with the public and private health industries to insure children get the medical, educational and therapeutic interventions they need in a timely manner. Federal laws already exist mandating these interventions, however, the managed care trend in health care has established some practices that

can delay needed interventions. Pediatricians and hospitals are the main source of referral at the infant and toddler stage. If a doctor does not make the needed referrals at this age, a child usually will not be identified as needing services until the start of public school, at age 5 or later.

Purpose of the Study

This study looks at the importance of early childhood intervention for California's infants and toddlers and how the managed care trend is affecting families' ability to obtain help for their children. The paper examines the problems individual families have in getting insurance and maneuvering through the insurance maze in order to get their children services a pediatrician has deemed necessary. Finally, the thesis suggests changes in state laws that could help families get more timely care for their infants and toddlers.

Significance of the Project

This project is significant now because California's public schools are undergoing vast changes. Graduation requirements are becoming more stringent. In June 2004, California high school graduates will have to pass an exit examination that includes essay writing and algebra. The

public is demanding that schools adhere to statewide academic standards previously viewed as only suggested guidelines. Students in special education are no longer exempted from meeting the same standards as general education students. If California's children with special needs are truly going to be able to compete with their non-disabled peers they must be identified before entering school and receive services as soon after birth as possible.

At the same time California's schools have reached a critical point in funding their special needs programs while the state's special education population, especially those labeled learning disabled, continues to grow by the thousands each year (California Department of Education, 2002). School districts often use money from their general funds to cover special education expenses because the special education budgets are short (Murphy & Picus, 1996). This thesis proposes changes that could help infants and toddlers receive assistance while they are at the stage where the brain may still have the ability to adapt to some disorders and the body may have the ability to alleviate the effects of some disabilities. If children can overcome their disabilities before entering school, or at least lessen the effects of those disabilities,

California can curb its spending, thereby alleviating the need to take money from other educational programs as well.

Assumptions

These assumptions were made while writing this master's thesis:

1. The period from birth to age 3 years old is the most critical time in a child's life for medical, therapeutic and educational intervention. The older the child is when intervention begins, the greater likelihood that damage will become permanent or more severe.
2. Medical, therapeutic and educational intervention during the period from birth to 3 years of age may eliminate the need for or lessen the intensity of special education services needed during the school years.
3. All students have a right to an education.
4. All children have a right to health insurance, timely services and quality health care.
5. Families with children with special needs must have insurance, whether private or public, so the child can receive the often costly medical

and therapeutic services needed to ensure a quality life and to participate as fully as possible in the general education classroom.

6. All parents have a right to services for their children with a minimum amount of stress.

Limitations and Delimitations

Limitations

Constraints in resources, sample size and time placed some limitations on this study. The survey size was limited to 120 parents of infants and toddlers with special needs enrolled in a Hemet, California early childhood intervention program. Parents were given two weeks in March 2002 to return the surveys. Most were returned within that time period but they continued arriving through the end of April, a month later. Twenty-seven, or 22.5%, were returned. A larger survey of parents involved in California's Early Start early childhood intervention program for infants and children with special needs was initially planned. However, the Inland Regional Center's program, which includes Riverside and San Bernardino counties, serves 1,800 children. The cost and time involved in such a survey was prohibitive at the time of this study.

Delimitations

The population surveyed were parents of children with special needs, ages birth to 3 years old, enrolled in either the home-based or the center-based early intervention program at Valley Intervention Program (VIP) Tots in Hemet, California. Parents were asked to respond to questions for their infant or toddler with special needs only. Professionals in the field were also interviewed, in person, by telephone or through electronic mail.

Definition of Terms

The following are definitions of commonly-used terms in this paper:

At-risk of disability: Infants and toddlers with some special circumstances are considered at-risk of disability meaning a disability could surface later although no current diagnosis is known (e.g., toddlers with significant developmental delays). These children are entitled to early childhood intervention services under federal law.

Child with special needs: Any child requiring specialized services to overcome a disability or potential disability.

Children's hospital: A medical center that focuses on the specialized needs of infants, children and adolescents usually under the age of 18. Special considerations are usually taken to lessen the stress of patients and their parents in this setting.

Confidentiality: The concept that medical information is not shared with third-parties outside the physician-patient relationship.

Developmental delay: A documented delay in an infant's progress in one of six developmental areas (speech and language, gross motor, fine motor, cognitive, self-help and social-emotional). Developmental delays can signal potential problems later in life.

Early childhood intervention (ECI): Early childhood intervention is a non-specific term meaning an intervention used to alleviate a problem affecting an infant or toddler. In this paper, the term applies only to children from birth to 3 years of age and is used to mean any medical, educational or therapeutic service or device needed to alleviate the effects of a disability or avert the possibility of one.

Fee-for-service plan: A method of charging for medical services, typically used before managed care. A patient would either pay the doctor's bill or the medical

office would bill the patient later. In the meantime, the patient would submit a claim to the insurance company, usually through the employer's personnel office, for reimbursement.

Genetics testing: Blood tests done to determine a predisposition to a disability, syndrome or other medical condition.

Health maintenance organization (HMO): A medical insurance company that negotiates specific medical fees for an insured party, placing the financial risk on the medical professional rather than the insurance company.

Individuals with Disabilities Education Act (IDEA): Federal legislation that established laws regarding children with special needs and their education. It was amended in 1997 with major additions including language regarding more inclusive environments.

Inland Empire Health Plan (IEHP): A specific managed care plan established by Riverside and San Bernardino counties to better serve Medi-Cal children.

Managed care: Medical health insurance that attempts to keep costs low by setting predetermined reimbursement rates for services and screening what services a patient may receive.

Medi-Cal: California's version of Medicaid, the public insurance for low-income and people with disabilities.

Pediatrics: The area of medicine that deals with infants, children and adolescents under the age of 18.

Preferred provider organization (PPO): A managed care plan that allows members to choose their own physicians. Members usually pay more in premiums and for visits with this plan.

Preauthorization: Written permission granted by the insurance company approving a doctor's recommendation to see a specific specialist or obtain a medical service.

Specialist: A physician who has received additional training in a specific area of medicine. Pediatric specialists focus on a specific area of medicine (e.g., neurology or oncology) but usually only work with children.

Organization of the Thesis

This thesis is organized into three literature review sections addressing the following: 1) the importance of early childhood intervention, 2) the managed care trend in California and 3) genetics testing and confidentiality. A survey of parents of special needs infants and toddlers was conducted. The methodology used in that survey is

outlined in the methodology section. Interviews and information gleaned from the survey are addressed in the findings. Recommendations for addressing concerns raised during the study are outlined in the conclusion. Suggestions for further research in this area follow in the conclusion.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

Chapter Two reviews three areas of the literature relating to children with special needs between birth to 3 years of age. First, the review presents information on the importance of early childhood intervention. Second, the review examines the trend in California toward managed care in the health industry. Finally, the review discusses genetics testing and confidentiality.

Importance of Early Childhood Intervention

Give or take a few months, most young children generally follow a prescribed course of development in six areas: cognitive, speech and language, gross motor, fine motor, social-emotional and self-help (Illig, 1998; U.S. Department of Education, 2000). As children develop, they reach what researchers and pediatricians term "milestones," those monumental occasions that usually call for a camera. Infants are expected to begin playing with their own hands, feet, fingers and toes between the third and fifth month and to begin walking between the eleventh and fourteenth months (Furuno, O'Reilly, Hosaka, Inatsuka, Zeisloft-Falbey & Allman, 1988). When an infant does not

reach these milestones within a certain amount of time, pediatricians start looking for signs of an overall delay (Illig, 1998; U.S. Department of Education, 2000). If the delay appears significant (e.g., months pass and the child still does not walk), pediatricians typically will start referrals to specialists and request diagnostic testing such as blood work, magnetic resonance imaging (MRIs) or hearing tests. The pediatrician will attempt to find a medical or environmental cause for the baby's delay so as to chart a course of action. "Developmental delay" is not considered a diagnosis itself; in fact, no one even agrees on the definition of developmental delay (Petersen, Kube & Palmer, 1998).

Developmental delays often cannot be explained easily; in some cases doctors never identify the cause of a significant developmental delay. MRI, a process that allows doctors to see internal tissue, is furthering brain research but so much still remains a mystery.

The roles of nurture and nature are important factors when diagnosing developmental delays. Genetics can predetermine a child's propensity to developmental problems and lower IQs, but researchers are finding the effects of the environment on a child are equally significant (Illig, 1998). Children who live in chaotic

homes or whose parents rarely interact with them are more likely to do poorly in school than children with less stressed homes and parents who engage them early in play. Lack of cognitive stimulation can retard a child's development, especially in the area of speech and language. Research also shows that stress in the home can change the child physiologically (e.g., elevating hormone and neurotransmitter levels abnormally), adversely affecting behavior development (Illig, 1998).

Examples of environmental causes for delays are numerous, and not necessarily the result of poor parenting. One of the latest discoveries is the American Academy of Pediatrics' recent campaign to convince mothers that newborn children should sleep on their backs instead of their stomachs has led to some slight delays in motor development (Davis, Moon, Sachs & Ottolini, 1998). Research indicates that infants who sleep on their stomachs, traditionally done to prevent choking, are more prone to Sudden Infant Death Syndrome (SIDS). Mothers have overwhelmingly heeded the American Academy of Pediatrics advice. Three researchers in Maryland studied 350 infants and found those who sleep on their backs do indeed reach some milestones later than their stomach-sleeping peers, particularly rolling over, tripod sitting, creeping,

crawling and pulling to a stand (Davis, Moon, Sachs & Ottolini). However, "back-sleepers" and "stomach-sleepers" seemed to begin walking at the same time. The researchers concluded that sleep position can affect an infant's development, but that infants sleeping on their back still achieve all milestones within the normal range. The researchers urged pediatricians to use the information to reassure parents rather than give up on the back-sleeping practice.

Researchers have studied the effects of early intervention in treating a child's disabilities for half a century (U.S. Department of Education, 2000). At least a quarter of a century ago, researchers established that a child's disabilities sometimes can be reversed or at least lessened if caught early and the appropriate intervention given. Studies showed that IQ scores could be enhanced with early intervention and that this gain can be sustained over time if intervention is continued into the school years, especially when coupled with family involvement and individualized instruction whether given at home or in a center (Palmer, 1977).

The infant and toddler years are considered so important that national debate continues as to how the federal government can improve the nation's child care

situation so that children in day care are better prepared to enter school (The Future of Children, 2001). Some people are calling for governmental financial support so that parents can take longer parental leaves.

Also indicating the importance of early intervention is the change in the pediatrician's role. In the last 10 years, the pediatrician has become increasingly important in identifying infants and toddlers for early intervention when development appears delayed (American Academy of Pediatrics, 2001). The American Academy of Pediatrics (2001) estimates between 12% and 16% of the nation's children experience developmental or behavioral disorders. The physicians group has called for pediatricians to improve screening of infants and toddlers younger than 2 in hopes problems can be identified before parents complain that a major milestone is missed.

The American Academy of Pediatrics' Committee on Children with Disabilities (2001) has said it is particularly important to identify speech delays early since some delays are caused by hearing loss that may be reversible if caught early enough. Speech delays can also indicate mental retardation or a syndrome that needs treatment.

The Managed Care Trend in California

Early childhood intervention and parental involvement often come in the form of juggled doctors' visits and insurance claims (National Rehabilitation Hospital Center for Health and Disability Research, 2000). Medical insurance can seem an overwhelming maze of bureaucracy. Additionally, one parent is often juggling all this alone. (Heck & Makuc, 2000). The likelihood that an American child with special needs lives in a home headed by a single mother is greater than the national norm for children without disabilities.

Managed Care's Start in California

The 1980s heralded in a new era of medical insurance for many Californians: the introduction of the managed health care system. Employers welcomed HMOs because insurance companies promised to reduce business costs by encouraging doctors to see more patients and focusing on keeping people healthy. Employees often gave up the right to choose a doctor but they and their employers paid less. HMOs also contracted with pharmacies so members could buy prescriptions at a significantly reduced cost as long as the insurance company approved the medicine.

Although HMOs were controversial (Cartland, 1992), they caught on in California. After a decade in the

private sector, HMOs made their way into the public arena in the 1990s through the Medicare and Medicaid programs (Fox, McManus, Almeida & Lesser, 1997; Heck & Makuc, 2000). Both Medicare and Medicaid are federal programs, but states administer them. California state legislators, like others in the country, were looking for ways to save money and still provide mandated health care to the elderly, poor and disabled. In 1994 Medicaid covered about 1.5 million children with special needs throughout the country, and by the end of 1996 more than 75 percent of states served Medicaid children through managed care plans (Fox, McManus, Almeida & Lesser, 1997).

California's Medicaid program, called Medi-Cal, was among those that turned to the managed care industry. In 1993 the California Department of Health Services released its State Strategic Plan for Medi-Cal Managed Care, the plan that changed Medi-Cal from a fee-for-service program to a managed care program (Inland Empire Health Plan, 2001). The state chose 12 counties to create a "two-plan model managed care program" in which Medi-Cal recipients could choose between a mainstream commercial HMO or a "local initiative." The local initiative would be the creation of the county using resources already present in the community. Riverside and San Bernardino counties

formed Inland Empire Health Plan (IEHP), a major Medi-Cal provider in that area (Inland Empire Health Plan).

As the managed care industry gained members it also gained criticism. People felt the insurance industry was dictating who could provide medical care and what level of medical care people could receive. In response to concerns, managed care companies added another type of plan, the preferred provider organization (PPO). Those insured typically pay more for this option but get to choose their own doctors. Currently, it is rare that an insured Californian is not served by one of these two managed care programs.

As part of its cost-containment plan, the managed care industry introduced disease prevention through educational marketing. Before the advent of managed care doctors generally did not have the money to invest in elaborate educational prevention programs (Coalition, 1997). Local and state health departments handled public health issues leaving private physicians to treat problems as they arose in their individual patients. Since preventative medicine was left to the government, intervention opportunities were often lost (Levi, 2000). Today, HMOs have extensive "wellness" programs to keep consumers informed about healthy habits and to encourage

practices such as immunizations and well-baby check-ups to head off major illnesses later.

As efficient as the HMO system appeared, problems surfaced and the California State Department of Corporations found it could no longer handle the volume of complaints (California Department of Managed Care, 2001). In response, the California State Legislature created a new entity, the California Department of Managed Care, which opened in the summer of 2000. The Legislature directed this department to review and investigate complaints about managed care companies, and to enforce the Knox-Keene Act, the California law that delineates managed care regulations. By September 2001 the department had seized its third California HMO due to reported financial mismanagement (Gellene, 2001).

Complaints about managed care continue to come from all sides. Harvard University Professor Arthur Kleinman, in a speech at the University of California, Riverside in 1999, said managed care is destroying the doctor-patient relationship and undermining physicians' ethics (Schwartz, 1999). Most HMOs hire "gatekeepers," companies, which determine if an HMO member should receive the services a doctor recommends, even though gatekeeper rulings are not usually enforced if challenged and the paperwork required

to process preauthorizations is costly (Wojcik, 2000). Preauthorizations are meant to keep costs down by screening out people who do not need to see a specialist; however, almost all HMO clients who want a referral get one. Industry experts called the practice of demanding preauthorizations "a psychological deterrent" and "simply a formality." These practices have helped create an angry backlash in the country.

The battle lines have been drawn but some people are calling for a truce. An editorial writer for the December 2000 issue of American Journal of Public Health urged a collaboration between health and managed care to ensure that patients receive the best that both have to offer (Koplan, 2000). "Ignorance and apathy on one side and ignorance and hostility on the other are not the best recipe for collaboration," the writer noted.

Medi-Cal and Early Intervention

Medicaid primarily serves the poor and disabled 64 years of age and younger. According to the Children's Defense Fund, "there is no single publicly funded program more important to low-income children's access to medical care than Medicaid" (Rivera, 1995).

The federal government administers Medicaid, but each state operates its own program by establishing eligibility

guidelines and monitoring services. Because the federal government gives these duties to the states, program benefits and eligibility vary widely across the country (Rivera, 1995; Kaiser Family Foundation, 2001).

The federal government added the Early Periodic Screening, Diagnosis and Treatment Program (EPSDT) to Medicaid in 1967 and vastly expanded its coverage in 1989. This program serves people younger than 21 to prevent and resolve health problems.

Federal law now says that all Medicaid beneficiaries under 21 must get periodic health and dental screenings; receive all recommended immunizations; receive vision and hearing examinations and needed follow-up care; and get preventative, restorative and emergency dental care. Additionally, all beneficiaries must receive well-child check-ups that include health education, and laboratory tests that include checking for lead poisoning in the blood. Their mental and physical development must be charted. As soon as a health professional suspects a problem, intervention must begin without delay. Medicaid staff must help families get that intervention, including helping to locate transportation to appointments and assisting families in setting up follow-up appointments (Rivera, Regan & Rosenbaum, 1995; Fox, McManus, Almeida &

Lesser, 1997). Federal law allows no exceptions to this mandate. However, the law and reality are often two very different things. In California hundreds of thousands of children who qualify for Medi-Cal services go without, often because their parents cannot navigate through the application process. (Inland Empire Health Plan, 2001).

Although Medi-Cal managed care plans such as the Inland Empire Health Plan have created campaigns to get people signed up for health care, the managed care industry has been criticized nationally over the way children with special needs receive care. In many cases states are using health plans that exclude or "carve out" services "that are not likely to be available or perceived as medically necessary in the commercial sector. (Fox, 1997). "Mental health, health-related special education and early intervention services are the most common examples of this," Fox wrote.

California's own Healthy Families state insurance program may or may not exclude mental health care for children depending on which administrator reviews the claim (Healthy Families, 2001). The Healthy Families website advertises medical and dental care but does not mention mental health services. When asked by electronic mail, a Healthy Families representative wrote, "Mental

health coverage is provided by the county mental health department if the child is diagnosed with a severe emotional disturbance. All other coverage is provided by the health provider selected by the applicant and is subject to the limits set by the plan chosen." (J. Buchmann, personal communication, November 26, 2001)

When questioned in a second e-mail regarding the legality of setting limits in light of the EPSDT regulations of Medi-Cal, an unidentified Healthy Families representative contradicted the information provided. The second response said, "The plans do provide all mental health services but children diagnosed with a severe emotional disturbance are also eligible for services via the county mental health department of California Children's Services" (Healthy Families, personal communication, November 27, 2001). California Children's Services is a subsection of the California Department of Health Services.

In some states, health plans require proof that a prescribed service is effective before considering it medically necessary, which might be a problem since "little has been published about the effectiveness of many of the interventions required by children, particularly those with disabilities" (Fox, 1997). A Children's Defense

Fund study indicated that many states' managed care contracts do not determine who is responsible for providing the EPSDT services mandated by federal law (Rivera, 1995). Whether this is a deliberate omission is up to debate; the fall-out is serious all the same. As a result, families can become confused as to what benefits they should be receiving and health care providers are not sure of their responsibilities.

Prolonged delays in providing children screening and follow-up services can lead to a host of subsequent problems (Rivera, 1995). Children may lose their Medicaid eligibility before receiving needed services even though states have already paid the insurance premiums to ensure those children get immediate help. The Children's Defense Fund cites a measles epidemic in Milwaukee in the late 1980s that was traced to children enrolled in HMOs who did not get required immunizations. However, many state contracts do not specify that children must be immunized.

Former U.S. Secretary of Health and Human Services Donna Shalala was concerned enough to make a report to Congress in the fall of 2000 on the relationship between Medicaid's managed care plans and the special needs population (Shalala, 2000). She noted that up to 90 percent of the nation's children suffering from AIDS are

included in the special needs population, as well as many of the children living in foster care or who are homeless.

Medicaid's ability to provide improved health care for the special needs population "is limited and mixed" (Shalala, 2000). One of Shalala's looming concerns was the matter of financial risk; the impact on a medical professional's ability to spend more time with a special needs child. In the past, insurance companies accepted the financial risk; however, managed care transfers this financial risk to the medical offices participating in the plan. If a physician does not see enough patients, that doctor does not get a pre-determined fee. The fee is probably already lower than what the doctor would charge otherwise.

People with disabilities often require more time and special accommodations. Wheelchair access to restrooms, adjustable examination tables, even more time for conversation for a person with difficulty speaking can add time to an appointment and expense to a medical office. Shalala (2000) feared HMO providers may not want to take the financial risk involved in treating people who require more time and accommodations. Indeed, some disabled people have reported that they feel they do not have enough time to ask their doctors questions or explain their situation

because they have limited time in the examination room (National Rehabilitation Hospital (NRH) Center for Health and Disability Research, 2000).

The financial risk issue is one the managed care industry dismisses, attributing fears to sensationalized media reports. As reported on the Inland Empire Health Plan website (2001): Managed care provides a "steady and predictable revenue stream, which enables providers to make appropriate investments in their practices that support disease prevention and management."

Genetic Testing and Confidentiality

The field of genetics has created much debate in the nation lately, especially since cloning animals has become a reality and prenatal genetic diagnosing is rapidly progressing (Henn, 2000). Genetic testing to discover whether "markers" exist in a person's cells that indicate a predisposition to certain illnesses or syndromes is another hotly debated topic, particularly in the medical insurance industry. Genes can determine some aspects of a person's personality traits and intelligence potential (Henn). Genetic testing can sometimes help doctors tell parents whether siblings of the child with special needs could carry an illness or display a disability, and test results can guide doctors in diagnosing a syndrome (Henn).

Genetic testing has also been used to deny people benefits, including insurance coverage (McGoodwin, 1996).

California state law already protects many residents from having to share genetic testing results with insurance companies. Until Jan. 1, 2002, Senate Bill 1146 prohibited state-regulated health insurers and HMOs from denying health insurance coverage or charging more for insurance based on genetic traits without symptoms of an illness or syndrome. Senate Bill 1654 later extended SB 1146's protection by repealing the 2002 ending date.

However, not all of California's insured are covered by the law. When an employer (usually a larger company) self-insures its employees they often have third-party administrators process the claims. The third-party administrators may be governed by state law but the employer that self-insures is not (L. Matocq, personal communication, March 11, 2002). That employer falls under the jurisdiction of the Employee Retirement Income Security Act (ERISA) of 1974, federal law which offers no such privacy protection regarding genetics testing results. The state cannot preempt that law.

Additionally, the California law is not duplicated in all states and some health insurance companies are not

aware of its existence in California (Matocq). This has led to some cases of privacy violation despite the law.

The landmark case in misuse of genetics testing is a class-action lawsuit filed by the U.S. Equal Employment Opportunity Commission against Burlington Northern Santa Fe Corporation (Gottlieb, 2001). This lawsuit, which was the commission's first legal challenge against genetic testing of employees, accused the railroad company of violating the Americans with Disabilities Act (ADA, 1990).

The lawsuit came about after a railroad track-layer developed severe carpal tunnel syndrome, a repetitive stress injury of the nerves running through the hands (Girion, 2001). His wife, a nurse, discovered the railroad company was requiring its injured workers to submit to blood tests. The railroad company was secretly doing the tests to determine if a marker existed, one they thought might indicate a predisposition to carpal tunnel syndrome (Girion). If the marker existed, the railroad company felt it had grounds to deny benefits to workers who could no longer lay track or do any other tasks because their hands were useless. The scientist who discovered the genetic marker was horrified at the use of his discovery particularly since the railroad was wrong in its belief that it could pinpoint such a predisposition (Girion).

The practice of genetic testing to deny benefits, while considered unethical in most medical circles, is not unprecedented. Scientists affiliated with the Council for Responsible Genetics have found more than 200 cases in which healthy people were denied insurance or jobs because genetic tests showed a predisposition to some genetic condition thought to cause illness or medical problems (McGoodwin, 1996). The private insurance companies' lobby group, the Health Insurance Association of America, lists among its top priorities: opposing legislation that restricts the use of genetic information by insurers (Health Insurance Association of America, 2000). The lobbying group has been ranked 25th on Fortune magazine's "Top 25 Most Influential Associations."

Genetic testing and evaluations are often done on infants and toddlers with developmental delays and disabilities, and their parents. Parents may want to know the likelihood that another child might share a disorder, and physicians want to know if something can be done to turn around a child's prognosis. But, genetic tests "do not function as the proverbial crystal ball, enabling their users to look into the future" (McGoodwin, 1996).

Some people shy away from genetic testing because they think the results might be used against them by third

parties (McGoodwin, 1996). Without such testing patients and doctors may act without all the information that could be available. Some researchers have dismissed insurance companies' claims that, financially, they cannot be expected to insure people at risk of genetic disorders. McGoodwin (1996) calls the complaints "hard to take seriously" since "there is no epidemic of genetic conditions."

Jecker (1993) debated the role of the insurance industry in maintaining the nation's health. Medical insurance in the United States is not an entitlement program; insurance companies are not obligated to insure people with poor health in their futures. On the other hand, Jecker asked what responsibility the government takes on if people cannot obtain employment because of genetic testing results. Jecker also questions the practicality of confidentiality. Genetics testing affects entire families, not individuals. It could be difficult for one member of a family to maintain privacy if others in the family willingly publicize the test results.

Summary

The review of the literature demonstrates current thinking in each of three areas: early childhood intervention, insurance trends and genetic testing. The

review demonstrates that, although medical professionals as well as researchers tend to believe early intervention into possible disabilities is the best approach to heading off serious problems, financial obstacles exist that may keep children from receiving the help they need.

CHAPTER THREE

METHODOLOGY

Introduction

This study is a mixture of qualitative and quantitative approaches. It relies on a review of the literature for background and policy history, and uses interviews with experts and a survey of parents to add personal insight.

Much of the literature review did not provide specific information on the population studied for this paper, birth to age 3 years. The review also gave opinions of those working in the insurance and medical fields but, for the most part, did not focus on the insured's thoughts. The survey, and subsequent quantitative analysis, was necessary to attempt to fill those gaps.

Development and Design

This is a qualitative policy research study that reviews California's special education spending. The study suggests what could be done to improve early childhood intervention practices so to decrease the number of school-age children who need special education funding.

An open-end questionnaire was designed for this study. The director of Valley Intervention Program (VIP)

Tots Preschool in Hemet, California and a California State University, San Bernardino professor with expertise in early childhood intervention read over the survey and suggested revisions. The survey was then distributed by the director of VIP Tots to individual teachers with instructions to have parents complete the forms anonymously and return them within a one-week period.

Surveys were collected by teachers and returned to the VIP Tots director's office where they were filed for pick-up for this study. After two weeks, VIP Tots' teachers sent out a reminder asking for any outstanding surveys. The surveys contained questions about insurance and the parents' encounters with the medical and insurance professions. A copy of the actual survey is located in Appendix A of this study; the results are found in Appendix B. A copy of the results was also given to the VIP Tots program to use for in-service planning.

Population Surveyed

The population surveyed for this study was a group of 120 parents of children with special needs, ages 0 to 3 years old, enrolled in early intervention classes at VIP Tots in Hemet, California. The children's diagnoses ranged from at-risk of disability to more severe disabilities such as cerebral palsy or autism. All but three of the

respondents were mothers or female guardians. The survey did not specify who should fill out the survey, other than requesting a parent or guardian.

Treatment

The written comments received through the survey were grouped according to subject and tallied onto a blank survey form. The comments were then examined for emerging patterns, such as a theme emerging among the comments or an overwhelming number of similar responses to a question. After identifying themes, the data was scanned to determine if the respondents gave any background for their beliefs and experiences.

Data Analysis Procedure

Data gathered from the survey were tallied for each question. Numeric responses were averaged and the mean score reported. In the case of the average wait to see a specialist, only the responses that gave a specific wait time were averaged to determine a mean. Those who said they could get an appointment immediately were not included but that information was listed in the survey results in Appendix B. Yes and no questions were tallied to indicate how many people responded each way. Narrative responses were listed as direct quotes.

Special education budget and enrollment figures were also analyzed. The California Department of Education provided budget figures for four years, from 1998-99 to 2001-02 (J. Williams, personal communication, March 19, 2002), and the corresponding cost-of-living adjustment (COLA) percentages (Williams, March 25, 2002). Enrollment data were retrieved from the Department of Education website (2002). Figures for children, ages 0 through 22 years old, served by the state Department of Education were used. These figures were collected on Dec. 1 of each fiscal year.

California's special education budgets are made up of mostly state money and some federal funding. For this paper, only the state contribution was used to analyze state spending. The tables in this thesis show the federal government figures as well to give the reader an idea as to how much money the federal government contributes. The mean amount spent per child with special needs each fiscal year was calculated by:

1. Multiplying the cost of living adjustment by the state contribution amount.
2. Subtracting the resulting amount from the state contribution. This was done to determine if any additional money was budgeted to special

education each year aside from the traditional increases to pay for rising costs of existing services. Additional money was budgeted each year.

3. The balance was then divided by the number of students with special needs, ages 0 to 22 years old, served by the California Department of Education according to figures found on the department's website. Breakdowns were also given for categories such as children enrolled in public schools and for school-age children only. This age range was chosen because some students with special needs attend non-public schools paid with state money, and some children younger than 5 and older than 18 are enrolled in state-funded special education programs.

The per-student spending mean should only be viewed as a tool to compare year-to-year spending; it is not the actual amount schools receive per special education student. Assembly Bill 602 (1997) set up the current special education funding system. Specifically, school districts receive special education funding based on total number of students enrolled in their schools, general and special education combined. The state sets a percentage of

expected special education students. Districts with exceptional numbers of special needs children may apply for more money.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

This section begins with an analysis of special education spending in California. Next, it identifies the annual increase in special education enrollment and spending on special education programs. Finally, this section discusses results of the survey administered to parents of infants and toddlers with special needs.

Money for California's special needs education programs, for students birth to age 22 years of age, comes from a combination of funding from the state's general fund and, to a much lesser extent, from federal funds. These funds are used even if a child is not enrolled in a public school. The state is responsible for providing special education services to children whose school districts have consented to enrollment in private schools and in non-public placements due to severe special needs.

This section also discusses the survey results and interviews with experts. Both the survey results and interviews revealed several areas of need for parents of children with special needs, areas of which some parents may not even be aware. The areas of concern are broken down into five subsections.

Presentation of the Findings

Special Education Financing Analysis

As previously stated in the methodology section, special education spending in California was analyzed to give a general per-student spending figure for each year since the 1998-99 school year (see Table 1). These figures were compared to each previous year to demonstrate that California has allocated more money to special education

Table 1. California Special Education Funding: 1998-2002

Fiscal year	State funds	Federal funds	Cost-of-living adjustment (COLA)	State funding without COLA	Special education enrollment, ages 0-22	Mean spending per student
2001-2002	\$2.6 billion	\$665.7 million	3.87%	\$2.5 billion	Not available	Not available
2000-2001	\$2.44 billion	\$522 million	3.17%	\$2.44 billion	650,719	\$3,749.70
1999-2000	\$2.26 billion	\$453 million	1.41%	\$2.26 billion	646,191	\$3,448.10
1998-1999	\$2.06 billion	\$399 million	3.9%	\$2.06 billion	628,848	\$3,146.44

Source: California Department of Education. (2002)

each year in addition to the annual cost-of-living adjustments. However, many school districts still struggle to keep special education spending from overflowing into the general fund (Murphy & Picus, 1996).

California's special education population grows each year, as does the entire student population. However, the state's special education growth usually outpaces the overall growth.

An analysis of the enrollment shows the percentage of special education students grew every year since 1985-1986, the first year the California Department of Education lists in its web site enrollment data, until the year 2000-2001, the last year listed.

In 2000-2001, the actual numbers of students in special education grew but the percentage compared to overall population dropped. Between 1985-1986 and 1999-2000 California's growth averaged a mean of 19,658 more special education students each year. By comparison, California's special education population grew by 4,528 students between 1999-2000 and 2000-2001. The statewide enrollment figures show a specific decrease in special education enrollment of children ages 3-11 and 18-21 between December 2000 and December 1999.

The reason for this change is not clear. Enough data does not exist to determine if this is a trend, and the information may not be statistically significant, according to one California State Department of Education research analyst (J. Parker, personal communication, April 17, 2002.) Likewise, the apparent trend of increasing percentages of special education students in previous years could be due to a number of factors "that would be very difficult to analyze" (Parker, April 17, 2002). Those factors could include "greater awareness of special education, better identification process or method for students, increased skill levels for personnel, to name a few" (Parker).

The amended Individuals with Disabilities Education Act (IDEA) was signed into law in 1997. The amended IDEA, among other things, calls for greater inclusion of special needs students into the general education classroom. The percentage decrease in 2000-2001 might reflect greater participation in regular education, although it is unlikely this would be the sole reason.

About the same time the IDEA reauthorization took place, the state began tightening high school graduation requirements, requiring more extensive yearly testing of students and demanding certain performance standards of

its classroom teachers which has led to massive changes in teaching styles. General population dropout rates were not available for the years 2000-2001 and 2001-2002. However, prior year figures show a constant decrease in dropout rates ended between the 1998-99 and 1999-00 school years (Table 2). Special education dropout rates were not available so it is impossible to determine whether the change in special education enrollment was linked to an increase in special education dropout rates. It is

Table 2. California's Dropout Rates, High School Population

Year (Data collected in October)	4-Year Derived Rate	One-Year Rate
1991	20%	5.2%
1992	19%	5.0%
1993	18.5%	4.8%
1994	17.1%	4.4%
1995	15.3%	3.9%
1996	13.0%	3.3%
1997	11.7%	2.9%
1998	11.1%	2.8%
1999	11.1%	2.8%
2000	Not available	Not available
2001	Not available	Not available

Source: California Department of Education. (2002). www.cde.ca.gov.

unlikely the dropout rate would account for the decrease in special education enrollment in ages 3 to 11 years since preschool and elementary school children do not usually drop out of school, but it is possible that more special education students are choosing to leave school at age 18 rather than staying longer to finish a high school diploma.

Survey and Interview Findings

Genetics Testing

Findings demonstrate a 22.5% return rate of those surveyed for this study. The information gleaned from those who returned surveys indicate a fear and frustration among some parents of children with special needs, one that a California State Senate consultant in this area says is valid (L. Matocq, personal communication, March 11, 2002).

Most of the children with special needs and their families in this study have not undergone genetic testing, evaluation and counseling but many parents expressed concern that the information remain private if testing is ever done. They fear for their children's futures. They know their children need medical insurance and they believe insurance companies will cancel their contracts.

They also fear their own employers could find a way to fire them if the genetic test results are known.

Nine parents (33.33%) said they have had genetic testing or consultation done. All but eight respondents said they would not want insurance companies to gain access to their children's genetic testing results; 19, or 70.37%, opposed allowing insurance companies access. One of the eight did not respond and one of the eight parents was unsure. Those who said they did not oppose releasing results to insurance companies appear to be unaware of the risks or why insurance companies want that information. "I think that would be a good thing for the people that need it," one parent responded. Another said, "I didn't know the insurance companies couldn't get results. It doesn't really matter to me."

The survey's open-ended questions provided respondents with the opportunity to explain their ideas and many did. Many felt their insurance companies would not cover their children's expenses if the companies had full knowledge of the problem. One woman wrote, "Where will that stop? The purpose of insurance is for unforeseen problems. The result of genetic testing should be kept private! If we allow insurance companies to have these results, before long they will be passing laws allowing

insurance companies to mandate these tests as they sign on new clients. If we let insurance companies know, will some day our employers or possible employers be entitled to these results? We could be refused employment because we have a predisposition to having a child with special needs. We all know how much more time a special needs child takes. Who would want to hire someone knowing they have that type of obligation?"

The potential for abuse is "huge" and growing, according to one expert in the field (Matocq). The advent of the state newborn and prenatal screening programs, intended to catch problems as early as possible, could lead to more struggles with insurance companies for coverage (Matocq). In-vitro fertilization clinics can already screen for genetic disorders before implanting a fertilized egg into a woman. Genetics technology "is just rapidly advancing," said Matocq, a consultant with the California State Senate's Select Committee on Genetics, Genetic Technologies and Public Policy.

Obtaining Medical Reports

Most of the respondents (20, or 74.07%) said they did not have problems getting copies of their children's medical records; however, comments written on the surveys would appear to prove otherwise. For example, some who

said they did not have problems getting the records added that they did have to know how to maneuver through the medical provider's system and, although they did not have to fight to get the records, they did have to wait weeks before they arrived. Five respondents, or 18.52%, said medical providers charged them for copies of their children's records: Loma Linda University Children's Hospital, Scripps Memorial Hospital La Jolla and an unnamed doctor's office. One person who was charged for records did not say who wanted payment. In one case a parent reported being charged \$10 per page. Four respondents, 14.81%, said they have never tried to get medical records or reports written about their child's condition and treatment. Those who had never requested or received copies of their children's medical records and reports listed their children's disabilities as at-risk of disability, speech delay, brain damage and bronchial pulmonary problems.

Pressure Against Receiving Services

The survey asked parents if the stigma of special education had resulted in pressure from family or friends to delay seeking intervention. Six respondents, or 22.22%, said they had faced some pressure from family and friends; 19 respondents, or 70.37%, said they faced no pressure and

two (7.41%) did not answer. Several said their families and friends are extremely supportive of their attempts to get help for their children. Some of those who faced pressure to discontinue services described the experiences.

"Absolutely," one parent answered. "Many people said that. Including doctor, family and strangers we would meet. It was crazy. You may be scared to admit it but you know when your child isn't developing normally."

Another mother described how her child's paternal family took her to court and attempted to gain custody saying her child's cerebral palsy was "all in my head." She won the custody battle. A third mother told how her sister-in-law tried to reassure her that her son was "just slow" because he was born prematurely. Another was told her son's language skills were delayed because he was a boy.

Service Delays

According to the survey results, the major reasons a child cannot see a specialist in a timely fashion are required preauthorizations that must be processed before an appointment can be made and a lack of pediatric specialists. Most of the 27 people responding to the survey said they had to wait for appointments for

specialists. The mean is two months, five days to see a specialist. An appointment with a pediatric neurologist can take six months, according to one person. Three people gave no specific answer to whether they had to wait, one said the child had never seen a specialist and three said they do not have to wait.

The first obstacle most parents face is the preauthorization, the written permission they must obtain from their insurance companies before their child can see a specialist. The pediatrician's office, acting as the insurance company's gatekeeper, must get the insurance company's written permission for the parent. One parent said the wait for permission to make an appointment is about two weeks. One mother said an appointment can be made before the preauthorization is processed but the parent runs the risk of having a procedure denied and having to then reschedule an appointment until the matter can be resolved.

"When my son had a seizure I had to wait over a month to get the referral OK'd to get a CAT scan and EEG," one mother wrote of her son with cerebral palsy. Another parent told of bringing the child to the doctor for a required shot only to find out the insurance company had denied permission. Parents sometimes cannot get prescribed

medications either. "We should have to pay \$10 for a generic prescription and \$15 for a regular prescription," wrote one mother of a child with Down syndrome. "Instead, on several occasions, I ended up paying well over \$25 for one prescription and on three occasions the prescription couldn't even be filled because the HMO wouldn't cover it. We pay good money - well over \$400 per month for a family of four to have coverage - and most of the time we aren't even covered."

Doctors' offices are becoming sticklers for paperwork. A mother wrote, "There are ways to schedule appointments prior to approval but now I'm even having a difficult time doing that. I have even offered to fax them a notarized agreement for my husband and I to pay for services ourselves if insurance denied it and they still wouldn't make the appointment. That day I got approval but if I hadn't I would have driven to the hospital and spoke to whoever I had to in order to get his testing scheduled. It is time consuming and you must be diligent and organized to get all the evaluations and testing done on your child. There wasn't a day that went by in the first months of his evaluations and testing that I wasn't on the phone trying to get approval, status, appointments, seeing if any earlier appointments cancelled so that we could

have their spot. Very emotional and difficult time. In one month alone he had 19 doctors' appointments!"

Once written permission is granted the task is getting an appointment. Pediatric specialists are in short supply, especially in California, according to parents and some experts interviewed for this study. Some lay the blame on California's heavy reliance on managed care coupled with the high cost of living (L. Silvia, personal communication, December 26, 2001).

Children's Specialists of San Diego, the 130-member physicians group for Children's Hospital San Diego, has unsuccessfully tried to hire a pediatric neurosurgeon for five years (Silvia). The physicians group has offered the job to three candidates. They all turned it down. The reasons given were cost of living in the San Diego area, the working pace required by the managed care industry and lack of teaching and research opportunities.

Specialists leave medical school with \$200,000 to \$400,000 in student loans (Silvia, 2001). At Children's Hospital San Diego they can expect to earn \$120,000 to \$130,000 a year and pay a premium for housing. According to Silvia, the East Coast offers another incentive over San Diego: more medical universities where specialists can teach classes and conduct research. "While you have UCSD

(University of California, San Diego), it still doesn't compare to Harvard or BU (Boston University)," said Silvia, chief operating officer for the pediatric specialists' group at Children's Hospital San Diego. Findings demonstrate that Children's Hospital Boston, the nation's largest pediatric medical center, is Harvard Medical School's primary pediatric teaching hospital, and most of the hospital's physicians also teach at Harvard (Children's Hospital Boston, 2001).

Silvia (2001) estimates about 40% of the children receiving medical care from Children's Hospital San Diego qualify for Medi-Cal. Doctors who treat Medi-Cal patients then bill the state for reimbursements at state-capped rates. When medical offices start writing off bills their staffs must make up the shortfall in other ways. A common practice is to increase the number of patients doctors see per day, both to meet quotas set by insurance companies and to bring in enough money to meet payroll. In some Children's Specialists of San Diego offices, 150 infants and children are seen per day (Silvia).

Managed care companies encourage general practitioners to screen patients wanting to see a specialist to keep costs down. Silvia, in an interview, said he believes the practice is not working because the

industry has not attracted enough pediatricians to act as "gatekeepers," and the current industry practice forces pediatricians to rush through appointments. Medical schools tell prospective doctors to expect to see one child every seven minutes, a rate reinforced by insurance companies. Doctors do not have the time to make follow-up telephone calls, to check on parents to make sure they take a child to the laboratory to get needed blood tests done, to ensure a child returns for a follow-up visit. They do not have time to discuss problems in-depth with a parent and wait for a child - one who may be afraid or disabled as well - to give needed information. If a doctor could spend 10 to 20 minutes on a child "maybe, maybe it would work," Silvia said.

However, a Michigan State University expert in medical ethics (H. Brody, personal communication, January 28, 2002) doubted even that is enough time. "In our family practice center at MSU we try to keep our standard minimum appointment at 15 minutes and often feel rushed," Brody wrote in an electronic mail message. "I cannot see doing an adequate job on a child and parents with special needs or disabilities in a seven-minute visit, personally. Seven minutes is enough for a simple sore throat or earache, possibly, but not for one of these complex cases."

In a telephone interview, a Blue Cross/Blue Shield representative said the pediatric specialist shortage extends throughout California and people living in rural areas are especially hard hit (L. Mee, personal communication, February 19, 2002). Silvia (2001) suggested the shortage might, at least partially, be artificially created by the Residency Review Committee for Pediatrics, the accrediting organization for U.S. training programs in pediatrics (Silvia).

The committee's executive director (M.A. Parsons, personal communication, January 14, 2002) denied limiting the number of pediatric specialists and noted the American Board of Medical Specialties has approved a new subspecialty area in developmental-behavioral pediatrics due to the "substantial number" of physicians with training in that area.

Treatment Based on Type of Insurance

A final problem that surfaced during this study is an inequality in children's health care. Physicians may say they do not judge a patient by the insurance card but survey results and interviews indicate the front office staffs in medical offices do make such judgments. A baby with congestive heart failure had to wait for care while her mother looked for someone who would accept her Inland

Empire Health Plan (IEHP), a Medi-Cal provider for San Bernardino and Riverside counties, according to one survey response.

Another mother, M. Kuechler, described in an interview how type of insurance played a significant role in her children's ability to access health care (Kuechler, personal communication, January 31, 2002). She has given birth to three children, one still-borne. She has used private insurance, Medi-Cal and gone without insurance and said she noticed the differences. "I just feel like, when I have Medi-Cal or IEHP (a form of Medi-Cal), I'm treated differently" than with private insurance, she stated.

With the private insurance, obstetrician visits were "always quick and easy," the mother reported. Under Medi-Cal she reported waits up to 3 1/2 hours for a sonogram, a routine diagnostic procedure to determine if a pregnancy is proceeding as it should. The mother said that she asked the sonogram technician for copies of her developing baby's pictures but the technician refused. In comparison, the mother reports that, with private insurance, "we walked right in and we got tons of pictures." The technician actually gave her a video, edited to music, of the developing child.

When the mother became pregnant for the third time she had Medi-Cal and found the obstetrician she loved did not accept Medi-Cal patients. She found a doctor who would accept her insurance but the doctor made her wait hours for scheduled appointments and she reported that he seemed "cold." The experience adversely affected her feelings about her pregnancy, she said. The fetus died unexpectedly, shortly before the due date, and the woman had to go through induced labor to deliver her deceased daughter. The mother received a call from the obstetrician's office a couple months after an emotional funeral. The office worker wanted to know why she had missed her appointments with the doctor.

Her remaining two children do not have special needs, but they catch the colds and flu that all children catch. She kept them on Medi-Cal when her employer provided her with private insurance since she could not afford the additional premiums. She would have had to pay \$300 for each family member, money she did not earn as a blackjack dealer. She discovered Medi-Cal had dropped her children when she took her son to the emergency room with a 103° fever in the middle of the night. The hospital staff told her a doctor would see her son but she would have to pay for the emergency room visit. She took her child home. The

mother still does not know why her children were dropped from Medi-Cal but she eventually got them signed up again through the Inland Empire Health Plan (IEHP). In the six weeks waiting for IEHP to process her application the woman paid \$500 for doctor visits and medicine. When her IEHP membership card finally arrived she called her pediatrician to get her children's immunizations updated. The office manager told her the children, established patients, would no longer be able to see the doctor. He was accepting no more IEHP children under the age of 6 years. The office manager referred the family to the county health department..

This story appears to illustrate the problem Medi-Cal patients can face when physicians do not want to accept the reimbursement rates set by the State of California. People with private insurance sometimes face the same problem when their physicians no longer accept the reimbursement rates set by managed care companies. Such was the case this year with the pediatric specialists who work at Children's Hospital San Diego's clinics (Silvia, 2001). They terminated their contract with Blue Cross because they felt the reimbursements were too small. Blue Cross sent letters to its members 30 days before the contract ended warning them they would have to find other

doctors (Mee, 2002). Those with PPO options, plans that allow the insured to choose their own doctors, could keep their Children's Specialists of San Diego doctors but would have to pay more.

Discussion of the Findings

Survey respondents generally ranked their insurance provider as "at least adequate" and overwhelmingly said they "have not experienced problems" getting records from their child's health care providers. The majority of respondents said they did not feel pressured by family or friends to rethink the medical care and early intervention they are getting for their special needs child. Only three had ever appealed a decision made by an insurance company. Almost two-thirds of the respondents said their health insurance plan had never delayed services for their child. On the other hand, some respondents reported that some medical care providers are charging parents for medical records. One of those named was Loma Linda University Children's Hospital, one of the major providers in the Riverside-San Bernardino county area for children with special needs. Parents reported having to wait weeks just to get referred to a specialist and for permission to request an appointment - even though a pediatrician had deemed an appointment necessary. When asked about genetic

testing the overwhelming majority of respondents said they would not trust their insurance companies with such information and some would not trust their own employers either. Some responses to questions seemed to show parents lacked understanding about insurance issues. For example, three people listed California Children's Services as their child's insurance provider. However, California Children's Services is a state agency not an insurance company. In another example, some people did not appear to know why an insurance company would want results of genetic testing.

The survey results would seem to indicate that many parents of children with special needs are accepting their situations as normal rather than fighting their medical providers and insurance companies for more access to reimbursements, records and services. The study does not show why this would be true. A possibility could be that parents are too busy trying to care for a child with special needs to spend time and energy fighting institutions. Or, parents may not know what is available or what services they should be receiving.

Summary

The findings for this study tend to be favorable toward the insurance companies in that parents generally

appear to accept their insurance companies' practices. However, several concerns were expressed that should be addressed and remedied so that California's children with special needs can get the help they need. The major concerns addressed are: genetics testing and confidentiality, obtaining medical records, pressure for parents to delay intervention, service delays due to required preauthorizations and a shortage of pediatric specialists, and unequal access to health care by all children.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

Introduction

This study suggests that the State of California may want to determine whether the managed care industry's practices affect the ability of families to get early intervention for their children with special needs. Additionally, it suggests California's early intervention programs may need to make a greater effort at reaching out to people who do not know what services their children should receive.

Conclusions

California's special needs children are coming under more scrutiny in the classroom. The State of California is demanding that they perform equally to their non-disabled peers on a high school exit examination starting June 2004 and in coursework that now must meet statewide standards. The push is for general education placement as much as possible so that children with special needs are "included." These are legitimate goals but California must make sure the support exists to help children with special needs succeed. Without proper support in the early years of life, the state could just as well succeed in denying

massive numbers of disabled people a public education as students drop out or sit in classrooms without comprehending or fully participating. One of the most important things the State of California can do to prevent this from happening is to eliminate obstacles parents face in getting their infants and toddlers with special needs identified and served before they reach school-age.

The following recommendations are made to the California State Legislature:

1. Review the insurance industry's practice of requiring written preauthorizations from pediatricians before referring an infant or toddler to a specialist or laboratory. Time is of the essence and the referral process should be efficient. If a contract between a pediatrician and an insurance company already exists preauthorizations may not be needed.
2. Prohibit medical care providers from charging parents for their initial copy of all medical reports, including charts, evaluations, referrals and recommendations. Medical organizations and hospitals should be required to give a parent a copy of any report also sent to the pediatrician in a timely fashion.

Parents should not be required to request the records. Any copies after the first could carry a charge to cover copying and handling expenses only.

3. Require self-insured companies operating in California to notify their employees that their health care plans fall under the federal Employee Retirement Income Security Act's jurisdiction and what that entails, including wording that genetic testing results can be obtained by the insurer.
4. Include mandatory training in identification of disabilities and developmental delays in infants and toddlers in all preschool licensing programs, special education teacher training programs and school nurse programs so that more parents become aware of available services and the importance of early intervention. The training would include public resources available and referral procedures. Special education teachers would be required to discuss identification of infant and toddler disabilities and delays as part of the high school special education

student's transition plan since many learning disabilities appear to be genetic. School nurses would be expected to instruct pregnant teenagers on how to identify potential problems in their own children and teach them where to go for help.

5. Use television and radio advertising and brochures in English and other languages to dispel fears about seeking intervention for developmentally delayed infants and toddlers. Brochures and trainings would be available in senior centers as well since grandparents often act as their grandchildren's babysitters in an unlicensed setting.
6. Establish a state-funded insurance program that parents can temporarily rely upon if their own pediatrician or pediatric specialist refuses to accept a parent's insurance. This would enable a child to continue services with the same doctor while giving the parent time to chart another course of action. The program would be similar to Medicare's "Medigap" program in which a private insurance company fills in the gaps when Medicare falls short.

This program would act in reverse. Public insurance would fill the gaps where private insurance falls short.

Recommendations

The following recommendations are made for future researchers on this topic:

1. Further analysis of the California Department of Education's special education enrollment, funding and dropout rates should be done in fall 2004 to determine the effect of the high school exit examination and tougher statewide graduation requirements on the special education population.
2. A telephone survey of the parents of Inland Regional Center's 1,800 Early Start clients in Riverside and San Bernardino counties should be done to get a more in-depth look at parents' views on their insurance coverage and related issues.
3. A study should be done on several groups of past and current Early Start children, beginning now, to determine whether early intervention helped them graduate despite the tougher high school requirements.

Summary

California spends roughly \$3 billion a year educating its special education population, a group that grows by the thousands each year. Early childhood intervention, medically and educationally, is California's best bet for special needs children and the state's taxpayers alike. Medical and educational intervention should start before the state's children reach their third birthday if California is to close the gap between regular and special education students in school.

APPENDIX A
VALLEY INTERVENTION PROGRAM
(VIP) TOTS SURVEY (BLANK COPY)

SURVEY OF VIP TOTS PARENTS WITH CHILDREN AGE 0-3

This survey is being conducted by Ann Hennessey, a graduate student at California State University, San Bernardino, to gather information for a master's thesis. The thesis is that the California Department of Education could cut special education spending if more children in the birth to age 3 range were identified for early intervention programs and services were provided in a timely fashion. The thesis looks at the effect managed care has on identifying and serving those children in California.

You are not asked to give your name or identifying information because this survey is anonymous. If you have any questions or wish to verify that this survey is being done for a master's thesis you may call Dr. Ann Selmi at California State University, San Bernardino at 909-880-7244. VIP Tots is cooperating with this survey and will receive the results of the survey. If you are interested in the results you may contact VIP Tots for a copy or call Ann Hennessey at 909-654-4220.

Please return the survey to your child's teacher within the next week.

If you need more room to write, please use the back of the survey pages.

Please remove this cover sheet from the survey and keep it for your records.

Thank you for your help.

SURVEY OF VIP TOTS PARENTS WITH CHILDREN AGES 0-3

Please do not write your name or any identifying marks on this survey. This survey is anonymous. Please answer the questions for the child attending VIP Tots who is age 0-3 only.

1. Are you a single parent or are both parents in the home? _____
2. Are you female or male? _____
3. How old is your child? _____
4. What is your child's disability/diagnosis? (If undiagnosed, please state.)

5. Who is your insurance provider?

6. Do you have an HMO (you must get your doctor's permission to go to other health care providers), a PPO (you choose your own doctors), or other (please state)? _____
7. At what age was your child first identified for early intervention services? _____

8. Who identified the child? _____
9. Have you had genetic testing or consultation done?

10. How would you feel if laws changed so that insurance companies would get the results of that genetic testing?

11. Have you ever had problems getting copies of your child's medical records or reports from a medical provider? Describe.

12. Has anyone ever charged you for copies of your child's medical records or reports? _____ Who charged you? (private medical office, hospital, etc. If hospital, please give the name of the hospital.)

13. Has anyone in your family or circle of friends tried to convince you that you should not get services for

your child because your child will "grow out of it"
or something similar? Describe.

14. Have you ever had to appeal a decision from your
insurance company or Medi-Cal provider? _____

15. Rate your happiness with your insurance company or
Medi-Cal provider using a scale of 0-5, 0 meaning you
are very displeased with the services and 5 meaning
you are extremely happy with the services.

16. Has your insurance company or Medi-Cal provider ever
delayed services to your child? Describe.

17. How long does your child have to wait to get an
appointment with a specialist? _____

18. Anything you would like to add?

APPENDIX B
VALLEY INTERVENTION PROGRAM
(VIP) TOTS SURVEY RESULTS

SURVEY RESULTS

Demographics

Population surveyed: Parents of special needs children age 0-3 attending either the home instruction or center-based program at VIP Tots in Hemet, California.

Number surveys returned: 27

Number surveys sent out: 120

Percentage of response: 22.5%

Date of Survey: March 8, 2002 through April 12, 2002

Questions

1. Are you a single parent or are both parents in the home?

a. Single: 5 (18.52%)

b. Both: 22 (81.48%)

2. Are you female or male?

a. Female: 24 (88.89%)

b. Male: 3 (11.11%)

3. How old is your child?

a. Average age: 21.70 months (1.81 years)

b. Age range: 9 months to 35 months

4. What is your child's disability/diagnosis? If undiagnosed, please state. (Numbers do not add up to 20 because some respondents listed more than one condition.)

- a. Mental retardation: 1
- b. Congestive heart failure: 1
- c. Down syndrome: 4
- d. Bronchial pulmonary: 1
- e. Hallerman-Streiff syndrome: 1
- f. Cerebral palsy: 5
- g. Speech delays: 7
- h. Autism: 1
- i. Brain damage: 1
- j. At-risk of disability: 2
- k. Developmental delay: 4
- l. Hydrocephalus: 2
- m. Gross motor delays: 1
- n. Undiagnosed: 0
- o. Did not state: 1

5. Who is your insurance provider? (Numbers do not add up to 20 because some respondents listed more than one insurance provider.)

- a. California Children's Services: 3

- b. Medi-Cal: 9
- c. Blue Shield/Blue Cross: 6
- d. PacifiCare: 3
- e. IEHP: 3
- f. HealthNet: 1
- g. United Health Care: 1
- h. Aetna: 1
- i. Tricare: 1
- j. Kaiser Permanente: 1

6. Do you have an HMO, PPO or other? (Note: Medi-Cal and the military provider may or may not be run as an HMO or PPO but respondents did not specify.)

- a. HMO: 13
- b. PPO: 4
- c. Other:
 - i. Medi-Cal: 7
 - ii. Military provider: 1
 - iii. HMO with PPO option: 1
- d. Did not state: 1

7. At what age was your child first identified for early intervention services?

- a. Average age: 9.46 months
- b. Age range: prenatal to 2 years

8. Who identified the child? (Numbers do not add up to 20 because some respondents listed more than one category. Some categories may overlap; these are the categories given by respondents.)

- a. Neurologist: 3
- b. Doctors: 6
- c. VIP Tots: 3
- d. Inland Regional Center: 6
- e. Parent: 2
- f. Pediatrician: 3
- g. Nurse: 2
- h. Hospital: 3

9. Have you had genetic testing or consultation done?

- a. Yes: 9 (33.33%)
- b. No: 18 (66.67%)
- c. Did not state: 0

10. How would you feel if laws changed so that insurance companies would get the results of that genetic testing?

- a. Opposed: 19 (70.37%)
- b. Not opposed: 6 (22.22%)
- c. Did not state: 1 (3.7%)
- d. Not sure: 1 (3.7%)

11. Have you ever had problems getting copies of your child's medical records or reports from a medical provider?

- a. Yes: 5 (18.52%)
- b. No: 20 (74.07%)
- c. Did not state: 2 (7.41%)

12. Has anyone ever charged you for copies of your child's medical records or reports?

- a. Yes: 5 (18.52%)
 - i. Loma Linda University Children's Hospital:
.2
 - ii. Scripps Memorial Hospital La Jolla: 1
 - iii. Doctor's office: 1
 - iv. Did not state: 1
- b. No: 22 (81.48%)

c. Did not state: 0

13. Has anyone in your family or circle of friends tried to convince you that you should not get services for your child because your child will "grow out of it" or something similar?

a. Yes: 6 (22.22%)

b. No: 19 (70.37%)

c. Did not state: 2 (7.41%)

14. Have you ever had to appeal a decision from your insurance company or Medi-Cal provider?

a. Yes: 3 (11.11%)

b. No: 24 (88.89%)

c. Did not state: 0

15. Rate your happiness with your insurance company or Medi-Cal provider using a scale of 0-5, 0 meaning you are very pleased with the services and 5 meaning you are extremely happy with the services.

a. Average rating: 3.31

16. Has your insurance company or Medi-Cal provider ever delayed services to your child?

- a. Yes: 10 (37.04%)
- b. No: 17 (62.96%)
- c. Did not state: 0

17. How long does your child have to wait to get an appointment with a specialist?

- a. Mean wait time: 8.65 weeks (2.16 months)
Calculated without no-wait responses.
- b. Range: No wait to six months
- c. No. responded that child does not have to wait:
.3
- d. No. marked not applicable: 1
- e. No. giving no specific answer: 3

Comments written as part of survey results:

1. How would you feel if laws changed so that insurance companies would get the results of genetic testing?

- a. I feel it is unnecessary because paperwork probably shows diagnosis somewhere anyway, and extensive explanations of testing is not needed for billing or breaking privacy rights.
- b. OK I guess.

- c. I think that would be a good thing for the people that need it.
- d. ? (Respondent wrote a question mark.)
- e. Where will that stop? The purpose of insurance is for unforeseen problems. The results of genetic testing should be kept private! If we allow insurance companies to have these results, before long they will be passing laws allowing insurance companies to mandate these tests as they sign on new clients. If we let insurance companies know, will someday our employers or possible employers be entitled to these results? We could be refused employment because we have a predisposition to having a child with special needs. We all know how much more time a special needs child takes. Who would want to hire someone knowing they have that type of obligation?
- f. I wouldn't mind.
- g. I would not like it. (Three similar responses.)
- h. I think the more insurance information the insurance companies get, the less they cover expenses. I would not support a law like this. (Three similar responses)

- i. No, thank you. I wouldn't agree.
- j. That would be so wrong! It might make it hard for him to ever get private insurance later in life!
- k. I would not like that. It is not necessary for insurance companies to know about genetic testing.
- l. I didn't know the insurance companies couldn't get results. It doesn't really matter to me.
- m. I wouldn't want it. First, insurance companies are always looking for a reason to deny your claim. If they knew regional center already did it, then they wouldn't be as open to doing testing on their own. Second, I don't want regional center and insurance doing the exact same tests because that would be a waste. But, to have two facilities working on my child is more thorough. You get second opinions and you get choices of services to pick the best one. For a very young child where diagnosis was uncertain it is very beneficial.
- n. I don't feel that it would be fair to people who carry "bad" genes. I do not think you should be

refused insurance because of what you might get later in life.

o. I have a problem with it. I do not want there to be future issues for denying coverage as a result, and there definitely could be if the information was released.

p. I think that should be confidential information, and it should be up to the parents whose hands that information gets into.

q. I'm not in favor of that.

r. I feel that might be an invasion of privacy. The presence of genetic predisposition does not mean the disability or illness will appear so it is unfair for insurance companies to insure or not based on that.

s. I don't know.

t. I wouldn't trust them to be fair in insuring someone that they knew had positive genetic testing results.

u. I would not like that.

v. I would not care.

2. Have you ever had problems getting copies of your child's medical records or reports from a medical provider?

- a. No. It's just a matter of going through the hospital or doctors' procedures to get them. It's a pain but necessary because I don't want others to be able to get his confidential medical records.
- b. I have never asked for any.
- c. Yes. It has been going on six weeks to receive copies from medical providers.
- d. I haven't had problems, except for the wait. Sometimes it takes more than two weeks.
- e. Except for it taking up to two weeks, sometimes longer, I've never had to fight to get it.
- f. Haven't tried.
- g. Yes, the doctor's office wanted to charge me \$10 a sheet.
- h. No. I have always been the one to provide any relevant reports and results to new specialists.
- i. No problem.
- j. No problems so far.
- k. No, I've never needed them.
- l. No -- haven't really needed to yet.

3. Has anyone in your family or circle of friends tried to convince you that you should not get services for your child because your child will "grow out of it" or something similar?

a. Absolutely. Many people said that. Including doctor, family and strangers we would meet. It was crazy. You may be scared to admit it but you know when your child isn't developing normally.

b. Yes. My child's entire biological father's family, to a point they took me to court over it, then tried to get custody saying it was all in my head. (I won.)

c. No. My family and friends are very understanding and supportive.

d. Yes! My husband's sister's baby is the same age and she thinks (my son) is just slow because he was born at 36 weeks.

e. Yes. (Respondent did not elaborate.)

f. Often my oldest has helped show others how important early intervention is and because of intervention my youngest is now almost completely age-appropriate.

- g. No way! Any help offered to my child is fully supported by family and friends.
- h. No. Family and friends are very supportive of our early intervention efforts.
- i. Not so much trying to "convince" but lots of people tend to want to ignore or deny that there is a problem and this saying (that the child will grow out of it) is very popular!
- j. Yes. They said that for a boy not to be talking at 2 1/2 (years) is normal.
- k. No. Everyone sees and understands what he needs.

4. Have you ever had to appeal a decision from your insurance company or Medi-Cal provider?

- a. Almost, then another report came in and they approved treatment.
- b. No, but I have had to pay for things myself in order to get them in a timely fashion.
- c. Yes. Different insurance. HealthNet.
- d. Yes, often. But, persistence usually wins.

5. Rate your happiness with your insurance company or Medi-Cal provider using a scale of 0-5, 0 meaning you are very displeased with the services and 5 meaning

you are extremely happy with the services. (Only comments are listed here.)

a. Sometimes it's hard to get approval from the HMO but overall they have given us the testing necessary and approved all the specialists I have wanted to see.

b. I am (rating) 3 pleased with their testing of my child. I am only (rating) 1 pleased with the available treatments for my child. If it wasn't for the regional center I don't know where my child would be. I guess I'd be fighting with insurance a lot more.

6. Has your insurance or Medi-Cal provider ever delayed services to your child? Describe.

a. The closer he gets to (age) 3, the longer they take and the more denials I get. That's because they know that the school districts kick in at 3.

b. Yes, due to waiting list for specialist.

c. I have had to pay for things myself in order to get them in a timely fashion.

d. Only on X-rays and some medications.

- e. Yes. One time they did not approve a shot and had to reschedule.
- f. Not to my knowledge.
- g. When my son had a seizure I had to wait over a month to get the referral Okayed to get a CAT scan and EEG.
- h. Yes, takes a long time to get referrals to things.
- i. Yes. We were unable to find a pediatrician that would accept her because of the insurance company.
- j. The only problem with delaying of service is the wait time for referrals. It is about two weeks.
- k. Yes. Testing for a mitochondria DNA mutation after numerous requests from specialists was ultimately paid for by regional center 2 ½ years after the first request.
- l. No. Kaiser has been very helpful and willing to accommodate our requests for referrals to different specialists.
- m. Not that I can remember but it happened to "me" lots when I was pregnant.

7. How long does your child have to wait to get an appointment with a specialist? (Only comments listed. Answers that only gave a time period are not listed but were averaged to determine a mean waiting period.)

- a. Depending on the specialist and severity of the need, between two and six weeks. Only a five-day stay in a hospital for multiple tests took longer but I got it approved on my HMO with no out-of-pocket costs at a hospital they did not have a contract with by showing medical need.
- b. He doesn't have to wait.
- c. Depends on how long the referral takes.
- d. Immediately.
- e. Neurologist - six months.
- f. Doesn't.
- g. Not long. Depends on open time slots and my schedule.
- h. She has never needed a specialist.
- i. Three to six months on average. Way too long!!
- j. Six to eight weeks. There are ways to schedule appointments prior to approval but now I'm even having a difficult time doing that. I have even offered to fax them a notarized agreement for my

husband and I to pay for services ourselves if insurance denied it and they still wouldn't make the appointment. That day I got approval but if I hadn't I would have driven to the hospital and spoke to whoever I had to in order to get his testing scheduled. It is time consuming and you must be diligent and organized to get all the evaluations and testing done on your child. There wasn't a day that went by in the first months of his evaluations and testing that I wasn't on the phone trying to get approval, status, appointments, seeing if any earlier appointments cancelled so that we could have their spot. Very emotional and difficult time. In one month alone he had 19 doctor appointments!

8. Anything you would like to add?

- a. Hope this helps!
- b. Good luck!
- c. I feel sorry for the families with these insurance companies that provide HMO and do not care and give the same services as PPO!

- d. The HMO companies need to inform their customers of the medications covered and not covered. We should have to pay \$10 for a generic prescription and \$15 for a regular prescription. Instead, on several occasions, I ended up paying well over \$25 for one prescription and on three occasions the prescription couldn't even be filled because the HMO wouldn't cover it. We pay good money - well over \$400 per month for a family of four to have coverage - and most of the time we aren't even covered.
- e. We've already (after one month or so) begun to see some results due to the VIP Tots/Early Start programs. Our daughter is beginning to catch up developmentally, and we can see this in many small ways. The program is really helping us to know how to work with our daughter in areas that need development. I definitely support your thesis!!
- f. Good luck! It would be great if more people were aware of the early intervention program. I did not know until recently and called right away after a friend informed me and my son qualified. I was very appreciative of the help they are

giving him and that it is being done now while he is still so young. I know that another problem is that lots of people who do know about the program are either too selfish or lazy to get their child the help they need or they have too much pride to admit that their child has a problem. So unfair to the child!

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