A Cambodian Child with Developmental Disabilities and the Western Health and Welfare System

By

Lisa Ann McPherson Ponce
A.B. (Stanford University) 1980

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Health and Medical Sciences

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, BERKELEY

Approved: .................................................. 5/11/86

Chairman

Date

..........................................................

..........................................................

..........................................................

..........................................................
# TABLE OF CONTENTS

**CHAPTER ONE: INTRODUCTION**  
Methods 1  
Structure and Content of the Paper 2

**CHAPTER TWO: THE SERVICE DELIVERY CONTEXT**  
The Service Delivery System for Developmentally Disabled Children 6  
Overview 6  
Agencies 9  
Regional Centers 11  
Other Programs Affecting S.L. 14  
Income Maintenance: SSI and AFDC 14  
The WIC Program 16  
Medi-Cal 17  
Refugee Services 21

**CHAPTER THREE: THE CASE**  
The Case 25  
Trajectory 35

**CHAPTER FOUR: ANALYSIS OF PROBLEMS**  
Problems of Case Management and Intervention 40  
Medical Services 40  
Housing 42  
Psychological and Social Support Services 43  
Education 44  
Institutional Problems 45  
Lack of Agency Recognition of Cultural Differences 45  
Lack of Adequate Resources 48

**CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS**  
Conclusions 51

Recommendations 54  
Specific Recommendations 54  
For S.L.'s Case Management 54  
Policy Recommendations 56

**BIBLIOGRAPHY** 59
ACKNOWLEDGMENTS

I would like to acknowledge with gratitude the generous and thoughtful contributions of Kate Brown and Thomasine Kushner, without whose encouragement and guidance this paper would never have been written. I am also indebted to Jean Kohn and Neal Halfon for their careful reading of preliminary drafts and many suggestions, which helped to develop and clarify entire sections. To Christopher and Elena Ponce, who provided the support, love, and expert advice which enabled me to survive this process, I owe more than I can say. To these people and the many others who have enhanced my education at Berkeley, I extend my sincere thanks.
CHAPTER ONE: INTRODUCTION

This paper focuses on the condition and care of S.L., a young Cambodian refugee. At four years of age, this child has minimal speech and lacks many functional skills, such as the ability to dress or feed himself. In addition, he exhibits some of the bizarre self-stimulatory and antisocial behaviors associated with autism. Issues surrounding the care of children with mental retardation and developmental disabilities have long been an interest of mine. Learning about S.L.'s case offered the opportunity to explore this interest in relation to a child from a background and culture different from and poorly understood by most Americans.

My experiences with parents of children with chronic disabilities indicate that it is not always easy for families to obtain adequate support services, even under the best of circumstances. Meeting S.L. prompted me to consider the potential difficulty of this task for a Southeast Asian refugee family who has experienced the upheaval of war, persecution, and forced migration, and whose current socioeconomic status is quite marginal. What followed was a six-month period of interviews with S.L.'s family and the service providers concerned with his care.

The questions addressed by this research, then, are:
1) What services exist in the East Bay for children with developmental disabilities?

2) How are language and cultural differences bridged by the service and health care agencies? In particular, what services exist which provide translation and information to immigrants from Southeast Asian countries?

3) What does this child's condition mean to his family and the service providers who treat the child? What are their ideas about etiology, current treatments, and prospects for the future?

4) How do they (service providers and family) work together?

The case of S.L. is the springboard from which these larger questions are examined. Despite the obvious limitations of generalizability and reliability of the case study approach, tracing the trajectory of one family seeking care for their child has valuable lessons for a future health care provider. The purpose of this analysis has not been to provide an exhaustive evaluation of the service system. Rather, it has been an attempt to understand more clearly what it might be like for clients and patients receiving care, particularly newly arrived immigrants.

Methods

Interviews and observations form a major portion of the data for this paper. I was introduced to the L. family by their pediatrician and observed her
interactions with S. and a sibling. S.'s father agreed to share his story when their doctor told them of my interest in how an immigrant family pursues care for their disabled child in America. Once written consent was obtained, two long conversations took place with S.'s father. These occurred at a local museum cafe where Mr. L. often seeks the quiet to study English. Two home visits were made, with S., one sibling, and both parents present. Telephone contact with Mr. L. has been frequent, averaging two times per week.

Professionals directly involved with S.'s care or in charge of the agencies and divisions which oversee such services were contacted by telephone or letter. Interviews lasting from a half hour to two hours were conducted at local hospitals and service centers over a six-month period. Two leaders of the East Bay Cambodian community were also asked about how people with mental retardation were regarded in their country, whether specific commonly held concepts of etiology existed, and what kind of lives such people would typically lead. Several service agency representatives and private physicians declined to be interviewed due to their busy schedules.

Questions were open-ended and addressed the following areas: the child's condition and prognosis; the family's or professional's understanding of the
child's impairments; the family's search for help; the family's or professional's perception of the services being rendered and of their interactions with each other; alternative services the family has sought and may be using in conjunction with Western medicine; and both the family's and the professional's expectations for the child's development. In the sessions with service providers, I was also interested in ascertaining each individual's level of involvement with the family; awareness of the family's situation; the degree to which agencies cooperate and coordinate with others in the care of this child; and whether the child's ethnic status had any perceived impact on the services provided.

I also attended S.'s annual Individualized Educational Program (IEP) meeting, held at the school he attends. This was the only consultation held on S. during the time of data collection, from late November 1985 through April 1986.

All fieldnotes and communications have complied with strict confidentiality standards required by the Committee for Protection of Human Subjects of the University of California.

Structure and Content of the Paper

The paper is divided into five major segments.
The following chapter provides the context for this case history. It summarizes the service systems for developmentally delayed clients and for refugees and outlines how large-scale policies are played out on the local scene. Chapter three focuses on S. and his family; this section reconstructs much of the child's medical history and describes the family's efforts at obtaining services for their son. The paper concludes with an analysis of the problems in the care system pertinent to this case and recommendations as to what might improve service delivery to children like S.L.
CHAPTER TWO: THE SERVICE DELIVERY CONTEXT

The Service Delivery System for Developmentally Disabled Children

Overview

The history of American society's treatment of persons with disabilities has been a bleak one. Disabled children usually were institutionalized, and those who remained at home had agencies ignore their needs and schools refuse to take them. Not until the late 1950s did parents and professionals begin to question prevailing dogma about what "handicapped" children could achieve.

As old myths were dispelled and parent groups organized, attitudes began to change. In 1975, the push for "normalization" was made policy by a Congressional amendment (P.L. 94-103) which stated that people with
developmental disabilities have certain basic rights\(^1\).

Its crucial clauses are:

1. Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities.

2. The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty (P.L. 94-103, 1975 cited in Mulliken and Buckley 1983,\(^3\)).

In that same year, a series of court battles aimed at securing access to public education for children with disabilities culminated in another piece of major federal legislation, P.L. 94-142. This law, titled the Education for All Handicapped Children Act, mandates that an appropriate public education, and all the attendant related services to make that available, be provided children in the least restrictive environment. P.L. 94-142 does not use the word mainstreaming, but its language is quite clear:

---

\(^1\) It should be noted that Section 504 of the Rehabilitation Act (P.L. 93-112), passed in 1973, paved the way for the later, more comprehensive legislation. A simple statement of human rights and non-discrimination, it reads:

No otherwise qualified handicapped individual in the United States...shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.
(1) That to the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped, and

(2) That special classes, separate schooling, or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (Sec. 300.550, Ibid., 22).

Essentially, these bills and the cumulated precedents set by the courts meant that the schools would have to design programs to meet the unique needs and capacities of children with disabilities, that these children would have their needs assessed appropriately before placement, and that necessary services which could assist children to benefit from schooling would have to be provided. The legislation lists appropriate ancillary services as including "transportation...developmental, corrective, and other supportive services..." (Sec.3010.13, Ibid., 32).

Given the magnitude of their task, the schools have made great strides toward attaining the goals outlined in this legislation. Yet, compliance with the many provisions of the law has been uneven. Considerable obstacles exist which make implementation difficult. For example, the supply of qualified personnel to work with disabled children, particularly infants, toddlers, and older adolescents, was quite inadequate at the time of
these bills' passage. Compounding this, Mulliken (1983) suggests, was academia's failure to meet the challenge of the new requirements by neither intensifying nor developing special education curricula for teachers.

For all of Congress's political advocacy, the most significant impediment to implementation remains financial. As Mulliken (1983) pointedly observes, "at no time has Congress sufficiently funded the program, nor does it seem likely that it will, given the climate of retrenchment that began in 1981" (p. 18).

**Agencies**

In the United States, at least five federal agencies have major responsibilities for the developmentally disabled and mentally retarded. Subagencies directed by Health and Human Services include the Department of Rehabilitation. Other important regulators of service under the Health and Human Services Secretary are the Public Health Service, which houses the Maternal and Child Health division, and the Health Care Financing Administration which administers Medicaid. The Departments of Education, which oversees the Office of Special Education and Rehabilitation Services, and Transportation are also important. Each arm of the government considers its territory to be independent and
channels funds without much coordination. This sets up the potential for gaps and duplications at lower levels.

On the state level, many of the same dilemmas of heterogeneous criteria and dispersed responsibility for services exist. The State Department of Developmental Services, along with the Departments of Rehabilitation, Education, Health and Human Welfare, and Social Services, oversees most of the programs affecting people with mental retardation and developmental delays in California. In addition, there is a governor-appointed State Council on Developmental Disabilities whose purpose is to ensure that the "legal, civil, and service rights of persons with developmental disabilities" are upheld (California State Welfare and Institutions Code, Division 4.5, Lanterman Developmental Disabilities Services Act, Section 4520). Under this council, thirteen Area Boards act as regional monitoring and advocacy groups. In the Bay Area, Area Board V reviews the services available in San Francisco, Marin, Alameda, Contra Costa, and San Mateo counties.

The Department of Developmental Services (DDS), currently has jurisdiction of over 410,000 clients (Charles Calavan, personal communication, March, 1986). Developmental Services is especially important to children such as S.L. because it is this agency which contracts with a system of "regional centers" responsible
for the case management and coordination of all needed services for persons whose developmental disabilities are diagnosed before the age of eighteen.

Regional Centers

The Lanterman Mental Retardation Act (later amended and renamed the Lanterman Developmental Disabilities Services Act) created California's regional center system in 1966. Since then, it has grown from two pilot programs to twenty one organizations which provide or secure services for over 67,000 clients throughout the state (Assembly Office of Research 1984). The Regional Center of the East Bay is the youngest of these facilitator agencies, having split off from San Francisco's Golden Gate center ten years ago. Each center is administratively independent and is run by a community based board of directors. Therefore, policies vary among centers. However, all centers are required by law to perform the following functions for developmentally disabled individuals and their families:

1) Perform initial entry evaluations within fifteen working days following a request for assistance;
2) Establish the diagnosis and complete assessment via testing and interviews within sixty days after intake;
3) Develop an Individualized Program Plan (IPP) within sixty days after the assessment; and
4) Assign a Program Coordinator to implement and monitor the program plan (What Is A Regional Center? Client Education Pamphlet 1985).
Charles Calavan, supervisor of the Regional Center of the East Bay's northern Alameda county area, handles the assignment of cases in Oakland and Berkeley. Mr. Calavan portrays the process which prospective clients undergo as one which conforms closely to the state minimum requirements. Typically, a family fills out a four-page application asking for an in-depth medical history. If it seems probable that the client is appropriate or if the family continues to request an evaluation, an assessment counselor, usually a social worker, will then meet with the family. An M.D. and a psychologist may be called in to see someone if the social worker deems such an evaluation necessary. For most clients, however, the physician and psychologist write reports on clients based on the initial professional's review. A manager at Mr. Calavan's level will then transfer the case to a program coordinator (case manager) responsible for developing a workable Individualized Program Plan and ensuring that necessary services are rendered by appropriate providers. These case managers may be employees of the regional center or cooperating subcontractor agencies. To remain in compliance with the Department of Developmental Services, these coordinators must see clients who live at home at least once a year at the mandatory annual update of the IPP. Quarterly visits are required for those clients in
out-of-home placements (personal communication, April, 1986).

At the Regional Center of the East Bay, the client-case manager ratio is 67 to 1. As of April 1985, this regional center's caseload included 4,534 active clients residing in the community, 788 clients in state hospitals, 214 high risk infants, and 840 pregnant women considered to be at high risk for delivering a child with disabilities. One hundred and eighty six persons were in the process of diagnosis and evaluation in the third week of April (Ibid.). No ethnic breakdown data for clients are kept by the regional center, but a delegate agency, Asian Community Mental Health Services (ACMHS), estimates that it served 127 Asian and Southeast Asian clients in 1985 (Lum 1985). ACMHS is the usual subcontractor to whom the regional center refers all Asian clients. According to Ester Wong, as of May 2, 1986, ACMHS was responsible for the case management of over forty Chinese clients, thirteen Filipino clients, as well as nine Japanese, eleven Korean, twelve Laotian, ten Vietnamese, and five Khmer clients. (The rest of this agency's 350 clients are non-Asian.) Asian families with a member speaking adequate English, however, are managed by other authorized vendors, due to the limited staff and large caseloads of ACMHS.
Other Programs Affecting S.L.

Income Maintenance: SSI and AFDC

The Supplemental Security Income/Disabled Children's Program was a 1976 amendment to the federal cash assistance program which makes direct payments to people who are poor and over sixty-five, or are blind or otherwise permanently disabled. This amendment expanded eligibility rules to include handicapped or seriously ill children.

Hobbs, Perrin, and Ireys (1985) claim that making such children SSI beneficiaries was intended to ensure the provision of comprehensive care to those with chronic conditions. However, these critics report that states vary widely as to what percentage of theoretically eligible children actually receive benefits, and suggest the program falls far short of its goals.

For the children it does serve, the SSI program is not generous. In 1979, 67 percent of the children on SSI received a federal grant averaging $158 per month; the other 33 percent received both federal and state support, which together average less than $225 per month per child...As it exists now, the SSI program contributes little to financing care for chronically ill children. Although it provides direct payments to families and makes some recipients eligible for Medicaid, the SSI program touches only a few children with a chronic illness (Hobbs, Perrin, and Ireys 1985, 224).

Recent local statistics bear out this assessment. Children such as S.L. currently receive less than $300 per month (Weir 1985).
Like SSI, Aid to Families with Dependent Children (AFDC) is a major cash assistance program which evolved out of the Social Security Act of 1935. It provides income to children in single parent families as well as those in two-parent households whose major wage earner is unemployed, incapacitated and unable to work, or, as one welfare worker put it, "frequently absent."

Alameda county estimates that over 60,000 of its residents receive AFDC money every month. The latest county social services report, published in December, 1985, indicates that 3,287 of these women and children were refugees (Weir 1985). Social security cards and proof of legal residence for aliens are strict requirements for participation.

AFDC permits families to earn some income from other sources. The current income ceilings allow $533 for one child; this goes up to $1,473 for a family of seven, with increases of $150.00 per child thereafter. These numbers represent 185 percent of established AFDC federal need standards. Subsidies from other programs and free rent are counted as income. Eligibility rules also limit "personal and real property", like bank accounts, to $1,000 dollars. One car, however, is considered exempt if its net market value is below $1,500 (Kathy Belding, AFDC program specialist, personal communication, April, 1985).
According to the Alameda County AFDC program specialist, families of seven with no other income receive $982 in monthly aid payments. Since S.L. and his father both receive SSI monies, they are not counted as part of the family for computation-of-aid purposes. Therefore, funds supplied by AFDC to this family are the same as would be given a family of five: $796.

The WIC Program

During the late 1960s, several major surveys focused attention on the problem of hunger and malnutrition in the United States (McCormack 1980). These studies reported that lower socioeconomic status and minority citizens showed high rates of anthropometric deficits and deficiencies in caloric and iron consumption. Other work showed indices of poor nutrition such as prevalent obesity and diets high in fat and salt intake among the poor. The World Health Organization and other international advocacy groups highlighted the interactions between malnutrition and the lack of social stimulation, linking poor academic achievement with a vicious cycle of poverty, hunger, poor health, and environmental deprivation (Pham and Sun 1983). Political pressures engendered by these studies led to the creation of the Women, Infant, and Child (WIC) program in 1972. Also known as the Special Supplemental Food Program for Pregnant and Lactating Women, WIC is under the
administrative auspices of the U.S. Department of Agriculture. WIC's purpose is to provide vouchers for specific foods, such as milk, cheese, eggs, juices, and infant formula. WIC's mandate includes nutritional education classes as well (McCormack 1980).

Although the L. family has received WIC vouchers for almost three years, the family has received little nutritional information. The Berkeley and Oakland WIC programs do not employ Southeast Asian translators. The L's utilize their vouchers for few of the items for which they were intended. Rice, fish, juices, fruit, and Khmer wine are the L.'s staples. Like other Southeast Asian families in the Bay Area, the L's sometimes trade these vouchers in Vietnamese and Chinese groceries for highly regarded ceremonial foods or cash (Pham and Sun 1983).

 Medi-Cal

Medi-Cal is California's version of Medicaid, the federal program which pays for medical services for the poor. Hobbs, Perrin, and Ireys (1985) nicely summarize
this program and its applicability to children with the following statement:

Also known as Title XIX of the Social Security Act, Medicaid is the single largest public program which supports health care for children who live in poverty...Medicaid is designed to pay for medical services delivered primarily to individuals who are enrolled in two welfare programs: Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI)...In 1980, the program spent $24 billion, of which $4.2 billion was spent on children. Fifty-five percent of the total amount was contributed by the federal government; most of the rest, by state governments. Although the federal Medicaid law furnishes general guidance to the states and establishes specific regulations, the program is primarily administered by state authorities. (207-208)

When passed in 1965, Medicaid was designed with a payment scheme which resembled that of the recently enacted Medicare program for the elderly. Historically (i.e., before Diagnostic Related Group (DRG) based payments and the other cost cutting strategies greatly altered government reimbursements in the early 1980s), benefits under these programs were modeled after traditional hospital insurance to which a physician services plan was attached. Direct reimbursements for services were made to hospitals and doctors. Although Medicaid's payments were always tied to a rate schedule rather than what providers actually billed, Butler et al. (1981) indicate that medicine's inflationary spiral and the burgeoning of the program pushed reimbursements beyond the state's capacity. These researchers likened
the governmental programs to that of a "credit card" system where providers essentially charged the government whatever they wanted, and were usually reimbursed without much control.

While Medicaid has always given states considerable leeway in deciding what services to cover, it does mandate inpatient care, lab services, and at least one program oriented toward preventive health care for children--the Early and Periodic Screening, Diagnosis, and Treatment program (EPSDT). Meisels (1983) reports that the Code of Federal Regulations sets forth the minimum services which the state Medicaid programs must cover in order to comply with the law. These are:

1) recording of health and developmental history;
2) developmental assessment;
3) immunizations appropriate for age and health history;
4) physical examination;
5) assessment of nutritional status;
6) vision testing;
7) hearing testing;
8) laboratory procedures appropriate for age and population groups; and
9) dental services

This is an ambitious list of objectives. Yet, surprisingly, documentation of the number of children served by the program, the exact breakdown of services billed under its auspices, and how much the program has cost through the years is not available.
Indeed, in a scathing review of this program, Meisels refers to EPSDT as the "largest and most expensive public secret in the human services domain" (Ibid., 268). He sharply criticizes officials for neglecting to conduct studies which "measure its impact, demonstrate its effectiveness, or determine its ratio of cost to benefit..." (Ibid., 268).

Because no systematic documentation of the program exists, only rough estimates have been made of EPSDT's scope and effectiveness. In 1977, almost ten years after the program's inception, one Michigan county survey of community health services indicated that less than half the sampled physicians, early childhood professionals, and parents with eligible children knew of EPSDT's existence. Meisels also cites reports which estimate that only 16 percent of the nation's eligible children actually receive screening services (Foltz 1982 cited by Ibid., 268-269).

Local statistics available to the public do not separate EPSDT program services from other Medi-Cal outlays. Approximately $3.9 million was allocated for Medi-Cal expenditures in the 1985-1986 Alameda county budget. A case count performed in September, 1985 showed that 94,939 county residents were beneficiaries of the program at that time (Weir 1985).
Refugee Services

Since the passage of the Refugee Act of 1980, California has been the site for resettlement of one third of newly arriving refugees into the United States. Over 80 percent of these have been Southeast Asian. Secondary migration into the state of refugees dependent on welfare programs continues at a high level (Office of Refugee Services 1985).

Census data indicate that 5.3 percent of the state's total population is Asian. According to the executive director of Asian Community Mental Health Services, Rodger Lum, this group represents the fastest growing ethnic minority group in the U.S. (Lum 1985). A recent report written by Mr. Lum cites an increase of over 133 percent among Asians from 1970 to 1980 and attributes most of this growth to immigration (Ibid.). This report also indicates that the 1980 census counted only 4,483 Southeast Asian refugees among 116,535 Asians residing in Alameda and Contra Costa counties. Mr. Lum asserts that 23,000 Southeast Asian refugees is a more realistic estimate of this area's current Southeast Asian refugee population, since a large influx occurred after 1979 (Ibid.).

Mr. John Tran of the Central Intake Unit for Refugees in Alameda county corroborates this information,
reporting that as of September 1985 there were over 15,000 officially recognized refugees residing in the county, 8,000 of whom were participating in cash assistance programs. Mr. Tran also stated that another 9,000 refugees live in Contra Costa County. Fifty-four percent of the total number of refugees are Vietnamese, 30 percent are Lao or Laotian, and approximately 6 percent are Cambodian. Most of the Southeast Asians live in the Oakland/Berkeley area (personal communication, April, 1986).

California is faced with the challenge of providing assistance to refugees in the face of shrinking allocations for this population within federal and state budgets. The Department of Social Service's Office of Refugee Services supervises the administration of all resettlement related programs. Its stated goal is to "promote economic self-sufficiency within the shortest possible time after a refugee's entrance into California" (Office of Refugee Services 1985, 1). Accordingly, 85 percent of its funds are allocated to programs directly related to employment. These include Vocational Training, Job Placement/Job Follow-up, On-The-Job-Training, Skill Upgrading, and other training and placement services. English language classes are an integral part of these programs; indeed, instruction and eligibility for AFDC and other direct financial support
for refugees hinge upon participation in job training programs. Central Intake Units within county welfare departments are responsible for enforcing this policy.

Medi-Cal benefits for this special category of recipients are paid for by the national Office of Refugee Resettlement. These funds are channelled first through the Department of Social Services and then through Health Services, which ultimately directs medical assistance programs and contracts with local providers.

Ordinarily, Medi-Cal does not pay for medical and dental examinations and laboratory tests for asymptomatic recipients. However, due to the possibility of refugees' exposure to many communicable diseases in camps and countries of origin, Medi-Cal does reimburse for such services provided to refugee families. Federal allotments for preventive health measures for refugees are paid directly to the state health agency by the U.S. Department Health and Human Services. This program is charged with providing services in the following areas:

1. Case location/outreach;
2. Health assessment;
3. Control and prevention of TB and other communicable diseases;
4. Referral and follow-up;
5. Health education/counseling;
6. Support services;
7. State coordination and technical assistance.2

2 Health and Human Services' Indochinese Refugee Assistance program reimburses states for social support services to eligible refugees under Title XX of the Social Security Act. According to an Indochinese Refugee
The state, in turn, distributes this money to public health jurisdictions with large numbers of refugees.

In Alameda county, for example, welfare workers typically refer refugees to designated county health clinics or private providers for health assessment and any necessary treatment. Most Southeast Asians are sent to Central Health Clinic, Highland Hospital, or Asian Health Services in Oakland, where translation in several languages is available. In addition, Refugee Health Project, a consulting group staffed mostly by refugees, receives federal and state support to implement an array of educational and technical assistance programs for both health providers and refugees themselves (Anita Fong, personal communication, March, 1986).

Action Center report, the services allowed under the program include: "Information; referral to appropriate resources; assistance in scheduling appointments and obtaining services; counseling to...help [refugees] understand and identify their health needs and maintain or improve their health" (Indochinese Refugee Assistance Program directive, cited by Robinson 1980, 17).
CHAPTER THREE: THE CASE

The Case

There have been two major periods of migration from Southeast Asian countries into the U.S. within the last decade. The first wave of refugees arrived in 1975 and 1976. This group generally consisted of Vietnamese professionals or military personnel who were well-educated, familiar with Western ways, and often had family or political connections in America. The second wave of refugees began arriving in 1979, after the Vietnamese invasion of Cambodia in January of that year. This second group is much more heterogeneous in its ethnic origins, its literacy, languages, and health status (Muecke 1983b).

The situation of the L. family is reflective of the second influx of refugees. They arrived in the U.S. in late 1981, when S. was twenty-seven days old. Like so many of the Southeast Asians who entered America after 1979, the L. family had escaped the chaos of civil war and the subsequent invasion and genocidal campaign of the Vietnamese and lived in Thai and Philippine camps for years.
S.'s family is Khmer, rather than Chinese Cambodian or Cham, two other quite distinctive Cambodian ethnic groups now in the U.S. The Khmer are the indigenous people of Cambodia who are thought to have "moved into Southeast Asia, probably from Southern China, before the start of the Christian era" (Poole 1969, 8). Much of the Khmer's cultural heritage derives from the ancient traditions of Buddhism, Brahminism, and Animism (Ibid). Before the Communist insurgency against Sihanouk led to civil war and Pol Pot's attainment of power in 1975, the Khmer comprised over 85 percent of Cambodia's population (Osborne 1979).

The L.s lived in a relatively large city, although both parents were raised in villages. S.'s father went through primary school and speaks some English. S.'s mother is not literate and does not yet speak any English, although she attends classes and is beginning to understand some words. S. has four living siblings, ranging in age from 12 years to two months. Four other children died from diseases in Cambodia. He is the only surviving son.

S. was born in a Philippine transit center for refugees. Both parents indicate the pregnancy to have been "normal and healthy." Mr. L. reports that Mrs. L. had more foods available in the camps during her pregnancy with S. than she had during previous
pregnancies, and had no trouble with eating or weight loss. Mrs. L. denies any history of infection or trauma, and claims that S.'s birth was an uneventful home birth attended by a Cambodian midwife. After the birth and the ritual burial of the placenta, Mr. L. took S. and Mrs. L. to the center's hospital for examinations. Both parents recall that S. was put on a scale there and weighed over 3.0 kg. It was discovered that S. had been born with conjunctivitis and a white cast (congenital cataract) in the left eye. It is not known how the conjunctivitis was treated. Mrs. L. spent two days at this facility before returning to their quarters with their son.

The L.s' apartment is in a run-down section of Oakland near the bus station. The building is badly in need of repair: ceilings and walls are cracked, the linoleum is disintegrating, and there is no glass protecting many of the upper story windows. The L.s living conditions are cramped. Eight people live in their small apartment, which consists of a living room (about 9' by 12'), an ante-room containing two double beds pushed together, and a small efficiency kitchen. In addition to the five children and two parents, there is a 17 year old uncle. This "uncle" is not related to the
family in our terms, but has been befriended by the L.s and has lived with them intermittently for three years.³

The L.s first became concerned that S. was not developing normally when he did not talk or walk at the age of about one year. In fact, S. did not walk until he was about 18 months old.

Because of their worry, S.'s parents took him to see Dr. V., a Vietnamese practitioner in Oakland. Dr. V. told the L.s that S. was "fine" but a little slow for an 18-month old. Mr. L. reports that S. was not taken to a doctor before that time because the child had no serious illnesses. He also denies that any welfare or refugee service personnel ever told him S. should be getting

³ According to May Ebihara, an anthropologist who has lived among the Khmer, the practice of including "fictive kin" in a household is very common. Adopted relatives, called "towaa", assume all the bonds and duties of other family members. Affection, pooling of resources, and mutual assistance are important aspects of Khmer family life. The Khmer do not have the type of lineages or clans found among the Vietnamese and the Hmong. Rather, like Americans, they recognize a circle of relatives via blood and marriage on both the mother's and father's sides of the family. The degree of contact varies among individuals within family groups, but social interaction, visiting, attending ceremonies, loaning money, and giving shelter and support to relatives in need—including those who are orphaned, destitute, or disabled was a traditional norm and expectation. Mutual assistance and the sense of obligation to a wider network of relatives continues here in America and is considered by Ebihara to be a significant and adaptive way for refugees to reconstitute some kind of family structure in America and cope with traumatizing losses and difficult economic circumstances (Ebihara 1985, Conference on Cambodian Mental Health).
well-baby checks as an infant. Unfortunately, this is impossible to verify.

Mr. L. reports that he does not really understand when or how S.'s problems began. Once, Mr. L. off-handedly alluded to the notion of karma as being a possible cause for S.'s condition, but quickly retracted this, saying that this is "only what some people in my country believe". As a general rule, Mr. L.'s statements concerning the possible etiology for his son's disabilities reflect Western biomedical explanations he has received from doctors in this country. Mr. L. describes his son as having "brain damage". He often refers to S. as "crazy", unattentive, and as having "bad behaviors." S. throws tantrums and breaks things at home, according to his father, when frustrated. S. attempts to climb out of windows, runs until he hits walls, and often laughs and cries without apparent reason. As far as Mr. L. can remember, this has always been so.

Dr. V. referred the parents to the local hospital where I first saw S. when he was almost three. Several practitioners there noted then that S.'s level of functioning was low for his age. It was apparent that the child had no language, and could not undress himself. At the age of four, he was still not toilet-trained or able to feed himself with a spoon.
I met S., a sibling, and his parents while observing physician-client interactions at an outpatient clinic of a local pediatric hospital which offers translation services to its clients in Vietnamese, Khmer, Laotian, Chinese, and Tagalog. S. and his sister were at the clinic for check-ups. S. attracted attention immediately by running out of the examining room, discarding his paper gown, and racing down the halls as his family waited to see the physician. He managed to escape from the clinic again after being weighed. Fortunately, the physician was free to see him once he had been guided back to his family.

The only utterances S. made during this session were cries of unhappiness at being held still for the physician's examination, and giggling and gurgling noises. He pointed and grabbed at things to indicate what he wanted. Throughout the examination, he exhibited a developmentally inappropriate short attention span (less than a minute), impulsiveness, and hyperactivity. Yet, S. displayed some imitative ability (he put the physician's stethoscope in his own ears and placed the diaphragm on his chest), was able to follow short commands from his father delivered in Cambodian, and could engage in some parallel play behaviors with his sibling.
Close to the end of this session (which lasted over 50 minutes), S.'s father asked the physician about doing an EEG. What follows is a short excerpt from the transcript of that interaction:

Mr. L: I think, uh want that he should have a EEG too, you know to see if something can be done to the brain

Mr. T: Uh, he has not had any seizures though that we are aware of?

Mr. L: no

Dr. T: Right, uh we could do that and um I...sometimes Dr. R. will do that when he sees a child Oh Oh my goodness (to child now sliding off table)

Mr. L: The problem is that I want to get EEG because he never never remember what I told him, you know, and after that he forgot all the words I say.

Dr. T: Oh, unfortunately the EEG is most useful when there is a seizure problem in telling us about the seizure. Um, it does not tell us about the structure of the brain and so I don't think it would help S. It would not help [Dr. R.] to give him some medicine, there's no medicine that we have for this situation.

Mr. L: OK, um...And Dr. R. has given S. a kind of medicine that he said could help, but S. is just the same

Dr. T: When I say there's no medicine what I meant I guess is that there's no medicine to make his brain change and to develop more or faster, to make it work any differently. Sometimes there are medicines to calm the activity...the medicine did not help [S.], is that right?...

Mr. L: That's right.

(Mr. L then brought up the school's concern that S. may have an intestinal parasite, since they had noticed blood in the stool.)

Dr. T: Well, OK, we'll take a look...OK..I share your frustration in some ways, you know. This is a kind of problem that is very hard to deal with here. I think it may be easier for you in your country where there are other families--

Mr. L: -yes it is-

Dr. T: -to help care, and it's hard here I think having one in a small apartment...um but I will speak with the other doctors and maybe give you
a call back if there's anything new they have
to offer him and as he gets bigger to have him
in special schools that will try to help him.
I think that is our best hope. OK?

Mr. L: OK.

It was this interchange which stimulated my interest
in following S.L.'s case. Mr. L. apparently requested an
EEG because he thought it would reveal what was wrong
with S. The physician gently explained that an EEG was
sometimes helpful in diagnosing seizure disorders and
other brain problems, but inappropriate for S.'s
condition. She emphasized that she and others would
continue to work with S. and offer support, but also
indicated both at this point and later that "cure" for S.
was not a realistic expectation.

In my discussions with Mr. L., I learned that he
continues to hope for vast improvements in his son's
intellectual capacity. He repeatedly expressed the wish
that "the doctors should help S., give him some
medicines...because he don't listen to what I say... he
always forget" (fieldnotes, February, 1986).

S.'s medical record lists a diagnosis of pervasive
developmental disorder. This diagnostic category falls
within a broad spectrum of rare, somewhat idiosyncratic
"waste-basket" syndromes in which there is a strong
clinical impression of mental retardation, but the
individual cannot be evaluated by standardized
intelligence tests due to severity of impairment or resistance to the testing structure.

There are several references in S.'s medical record to an "autistic" quality to S.'s behaviors. One practitioner wrote that the child "follows inner directions not related to the reality of other people in the room." Another commented that the child exhibits frequent echolalic and imitative sounds.

Mr. L. has continued to be concerned about the possibility of sensory deficits. He also complains that S. "doesn't understand what I say...I don't know if he hears." The hospital's audiologist has performed tests on S., and although her assessment is inconclusive, she thinks S. has conductive hearing loss for low and middle pitches bilaterally. In addition to the hearing specialist, S. has been seen by an ophthalmologist, since he often brings objects very close to his face and may be having trouble seeing them. The assessment here was that S.'s cataract probably did not impair vision in any way, but that the child did have an astigmatism in that left eye. S. was prescribed glasses, but refuses to wear them.

A congenital dysmorphology has been noted by a physician at the pediatric hospital. It is this clinician's impression that S. has "odd dermatographics" on both hands, which resemble a single palmar crease. No
other such deviations have been noticed, and the significance of this observation is not known. S.'s only other outstanding health problems are the uncorrected myopia and chronic otitis media, the latter of which was severe enough to require a myringotomy with bilateral tube placement in 1984.

S. has also been seen by a psychiatrist and a psychologist. The psychologist described S. as "distractible and uncooperative" during her evaluative play session and suggested the child was engaged in "provocative limit testing." S. was noted to have poor hand eye coordination on a number of tasks (geometric form board, crayons, peg board—all performed at the 20 month level), but it was unclear whether this was due to lack of motivation and distractibility or actual fine motor problems. S. repeatedly rubbed his stomach with the blocks he was given and engaged in other "self-stimulatory and perseverative behaviors." S.'s vocalizations were sparse, although he did engage in some imitative sounds. It is the psychologist's opinion that S. is not primarily autistic because he shows glimpses of appropriate contact with the environment. As is characteristic of the pervasive developmental disorder diagnosis, S. is difficult to assess because he doesn't comply with the testing structure.
It is also possible that S.'s reactions to this situation are partially a function of his lack of exposure to toys and other materials used in the tests. The home visits I made revealed that the L. children do not possess any blocks, balls, coloring books, or other playthings. Mr. L. says that he does not have enough money for such items, and thinks that S. would break them if they were present in the apartment.

Trajectory

S.L. was accepted as a regional center client in November, but had no case manager assigned until March, just within the mandatory state deadlines. Because Asian Community Mental Health Services was handling over its capacity of clients during this period and the original intake worker deemed Mr. L.'s English to be adequate, S.'s case was assigned to another agency.

On March 5th, Mr. L. told me of a letter he had received the day before from the regional center asking him to contact a specific social worker at this agency. Mr. L. indicated that he had tried calling once, and was told that the social worker was out of the office. Mr. L. said that he was not sure if he would try calling again. When asked why, Mr. L. responded "I don't know. This lady, I don't know who she is." I explained that
this person probably would be in charge of getting services for S., and asked Mr. L. for permission to call her for an interview.

I telephoned this agency the following week to learn that "some internal reorganization" had shifted the responsibilities of several caseworkers, including that of S.L.'s case. The worker who would pick up the case was about to go on vacation, and asked me to call back in two weeks. I made several attempts to do so, only to miss this particular social worker because he was out in the field. Mr. L. never attempted to call him. In mid-April, the social worker informed me that S.'s file would be reviewed the following week and that I should call back then. At that point, I was told that S.L.'s case had been sent back to the regional center for reevaluation. The worker said his reasons for rejecting the case centered around the fact that his agency would not be able to provide translation services, which would essentially exclude S.L.'s mother from direct participation in any formal discussions or decisions about her son.

As of April 21st, S.L. still had no case manager. Both the original intake worker and the area director at the regional center feel that holidays, vacations, and the large caseload of the regional center have combined to delay the assignment of this particular case. An
educational consultant familiar with the regional center feels that the fact that the center's client rights advocate was away on maternity leave was a factor contributing to the long processing period. Another view was expressed by a worker at Asian Mental Health Services. This person reported that the assignment of the case to another vendor is representative of the regional center's reluctance to reroute non-Asian clients, even when a case comes up where an Asian family could benefit from being a ACMHS client (fieldnotes, April, 1986).

Mr. L.'s relative inactivity vis-a-vis the regional center may also have been an important factor stalling L.'s assignment to a case manager. My interactions with Mr. L. have led me to believe that Mr. L. is somewhat depressed. Mr. L. repeatedly complains of head and back pain, which he says keeps him from working. However, Mr. L. cannot describe the pain, localize it, remember under what circumstances it began, or recall how long he has had it. While it is inappropriate to make any judgments about the nature of Mr. L.'s pain, it is important to note that the pain coincides with times of difficulty for Mr. L. During the six month period of data collection, this pain often kept him from venturing outside his apartment and keeping appointments. Although Mr. L. expresses worry over S.'s welfare and future, his
attempts to deal with agencies regarding the care of his son are sporadic. Sometimes he says that he forgets appointments or the names of the people and places he is supposed to contact. For example, The IEP meeting I attended was rescheduled twice because Mr. L. did not show up.

Mr. L.'s reticence to make independent telephone calls or visits to the regional center also stems from fear that asserting himself would somehow affect his son's treatment. He prefers instead that physicians, and others with whom he is familiar, make arrangements and give him directions to follow.

When interacting with physicians, teachers, and other American professionals whom he does not know well, Mr. L. does not express his opinions. He nods or murmurs agreement, but will not ask questions of his own. At the IEP meeting held at S.'s school, Mr. L. remained quiet as S.'s teacher read through the list of goals she and S. would work toward during the next school year. S.'s teacher accomplished her agenda quickly and efficiently, but never asked for Mr. L.'s input. Once she had come to the end of her document, she asked if Mr. L. had any questions and indicated that if he was satisfied he should sign the necessary forms. Although he signed immediately, on the way home, Mr. L. asked me several questions about the purposes of certain tasks S. would be
working on in school. He had understood the teacher's English but not the concepts which she was trying to get across.

During that meeting, S.'s teacher introduced Mr. L. to an Oakland school district speech pathologist. This consultant, who was called in because of S.'s continued lack of verbal skills, promised to determine S.'s eligibility for her services within the next two months. It is not clear whether Mr. L. has heard from her. Mr. L. maintains that he has not received any calls or letters about S. from the school since early March.

**Postscript**

When told of the regional center's delay, one of the physicians at the pediatric hospital's Center for Child Development wrote the person in charge of assigning case managers, asking for a conference between S's caregivers. Soon thereafter, in the last week of April, S.'s case was reassigned to ACMHS. S.'s new case manager has arranged to meet with the L. family for the first time on May 9th.
CHAPTER FOUR: ANALYSIS OF PROBLEMS

Problems of Case Management and Intervention

It is not surprising that Mr L. finds seeking services for his son an overwhelming task. Navigating through the confusing and fragmented patchwork of programs available for the developmentally disabled is made especially difficult because S.'s needs are complex and cut across many agencies' capabilities.

S.L.'s needs for service may initially seem to be minimal. S. already receives SSI benefits, medical care, and instruction in a class for the severely disabled. With more careful examination, however, the services' deficiencies in meeting S.'s needs become apparent. In this section, the problems I have found to be most pertinent to this child's care will be reviewed and analyzed.

Medical Services

S. receives his medical care from a large pediatric hospital in the San Francisco Bay Area. This tertiary center offers diagnostic and therapeutic services in every discipline of medicine and trains a large cadre of medical students and residents. In such a setting, house
officers, medical students, and nurses rotate periodically through individual clinics. S.'s medical records indicate that he has been seen by at least five different physicians in Asian clinic, an outpatient primary care clinic with available translators. In addition, he was evaluated by various specialists elsewhere in the hospital. Although the four professionals I spoke with here were familiar with and concerned about S.'s case, no provider had specific responsibility for S.'s care.

These staff members voiced frustration with the lack of continuity in their patient relationships and the consequent limitations in the types of support they could offer families such as the L.s. Time constraints adversely affected their interactions. They considered financial constraints, however, to be the most significant barrier to giving the L.s more time and attention. Because the hospital is not reimbursed for the time its staff members spend talking with families and evaluating or coordinating information and services for a child, there are financial disincentives to performing these functions. This lack of reimbursement has led to reduced staffing in the hospital's social service department.

The two professionals associated with the hospital's developmental unit (who tested S., established his
working diagnosis, and directed his parents to the regional center) have had their own hours reduced. Each agreed that the hospital's professionals should follow their cases closely and act as patient advocates to procure community services, but felt that this did not always happen because of many other competing responsibilities. Moreover, each felt this task was better left to agencies designed for this purpose, that is, regional centers.

Housing

Housing is a primary concern for S.L. and his family. As do many refugee and minority families, the L.s live in sub-standard, unsafe, and crowded conditions. The apartment rents only to Cambodians and Laotians, but the neighbors have little interaction with the L.s., due in part to S.'s disruptive behaviors.4

4 The close relationships which occur between Cambodian families do not appear to extend to the larger Cambodian community. Although they express a strong sense of loyalty for and identity with their homeland, neighbors in the L.'s apartment building do not form a tightly knit enclave. Sayonn Sok, a Cambodian woman who has worked as a teacher and translator in mental health facilities, feels that this is a consequence of old regional differences and suspicions as well as how busy most of her countrymen are scrambling to survive (fieldnotes, April 21, 1986).

According to this informant, Cambodians in the East Bay are not highly organized. Activities rarely involve the cooperation of the community as a whole. Temple centered activities are the most significant form of social contact with other Cambodians. Certain leaders have started fledgling organizations aimed at assisting
The L.'s isolation is compounded by fear of harm from junkies and drunks who frequently use the apartment's entrance to get high. Mr. L. has been mugged twice at the front door, and therefore monitors his children closely. As already described, the L. children do not play outside. Mr. L. picks his children up from school, and once inside, the children do their homework, watch television, and play in the upper story halls. S. spends most of his time in the L.'s apartment because he is teased and hit by other children in the building.

Psychological and Social Support Services

Another matter for concern is the question of Mr. L.'s psychological status. Mr. L. is the family's negotiator with the outside world. If S.'s welfare is to be optimized, then Mr. L.'s situation must also be assessed. A physician and social worker interviewed at the pediatric hospital feel that the family, particularly Mr. L., has difficulty accepting the fact that S. has

Cambodians with language skills and job placement. These efforts, however, have suffered from infighting and lack of cooperation. As this Cambodian observer put it "everyone wants to start their own group. People refuse to help each other because one person doesn't like XXXXX or wants to be in charge. They won't come to meetings if XXXXX is there." Despite these rivalries, open dispute and disagreement are rare. Sok claims that although someone might disapprove of another person and say so behind their back, they would never directly confront that person with negative feelings unless that person were a close relative (Ibid.).
little hope of achieving the functional capacities of a normal child. These two professionals indicated that Mr. L. has had the child's diagnosis explained to him thoroughly on several occasions. They were not surprised by Mr. L.'s request for an EEG and reported that he had made similar requests for interventions over the past year. One of these professionals thought that Mr. L.'s behaviors signified denial and disappointment. This pediatrician knew of Mr. L's back pain and hypothesized that it is a somatic symptom of depression.

This issue requires particular sensitivity, given the stigma attached to mental health and psychiatric diagnoses by many Southeast Asians. The need for skill and discernment is stressed by research suggesting that "somatization, the expression of distress through bodily symptoms, emerges as a factor separate from depression" (Beiser 1985, 282). Yet other recent reports indicate that post-traumatic stress disorders and depressive symptoms are particularly prevalent in Cambodians (Cohon 1981; Kinzie 1983; Lin 1979). Therefore, the traumatic life events of Cambodians such as Mr. L. and the ongoing stresses of existence in America merit some attention, if only as a preventive measure.

Education
S.'s educational program is a focus of worry for Mr. L. He has repeatedly expressed disappointment in S.'s lack of progress. S.'s IEP meeting in April confirmed that S. had not demonstrated any significant improvements in fine motor, verbal, or social skills over the past year.

The school which S. attends offers instruction to severely disabled students between the ages of 3 and 21 years. S.'s class, which is staffed by a teacher and an aide, has ten students. Their problems and ages vary significantly, but most have conconsiderable intellectual and communication deficits. Mr. L. thinks that the class is too large for S. to receive enough individualized attention. He also worries that S. is learning crude gestures from older students. Mr. L. did not feel comfortable expressing these apprehensions to S.'s teacher.

Institutional Problems

Lack of Agency Recognition of Cultural Differences

The regional center's long delay in assigning S.L. a case manager is in part a function of its lack of recognition of the need for culturally sensitive services. The suggestion that the system neither recognizes nor responds to the clinically relevant
disparities between the L. family's language and culture and that of most Americans comes from direct service providers themselves. Esther Wong, the director of ACMHS's developmental program, reports a good deal of underutilization of services by immigrant and refugee populations due to a host of access and cultural barriers.

Ms. Wong expressed some frustration at the discrepancy she perceives between the needs existing in Southeast Asian refugee families and the services available to them. She indicated that many of the Asian refugees find it difficult to understand the American welfare and aid system. The societies from which they came generally did not have parallel social service systems. Help was something which came from family and neighbors rather than the government. Wong said that many clients are afraid to utilize services, feeling stigmatized and scrutinized by the array of offices, forms, and other trappings of bureaucracy which inevitably face them.

In many of these cultural groups, confusion is compounded by a very different sense of time. Wong's social workers find it troublesome just to monitor appointments for many of these clients, who show up hours late, if at all. Supervising medications and prescribed exercises is also problematic, given the lack of context
and experience some clients have for such regimens. Non-acceptance and non-compliance are the rule rather than the exception.

The lack of adequate translation services is another serious problem. ACMHS employs six case managers (four full-time, two part-time) who follow over 350 families which have a member with developmental disabilities. Approximately 25 percent of this caseload is comprised of Chinese nationals, Filipinos, other Asian and Pacific Islanders, and Southeast Asians. However, while the agency has caseworkers who are Chinese, Filipino, Korean, and Japanese, none are Southeast Asian, nor do any of these staff members speak any of the Indochinese languages or dialects.

While translation services do exist at ACMHS, they are not part of the contract between this agency and the regional center. The translators used by case managers are actually paid to work at an outpatient mental health clinic also run by ACMHS. This means that translators are difficult to obtain, since their services are in great demand. When they are available, at least a week's advance notice is necessary to insure that there will be a translator present for any particular meeting or appointment. Also, translators do not travel out of the Asian Resource Building to make home visits.
Wong also said that it is often hard to get other service workers to make home visits and cited the example of a respite care organization whose director would not allow her personnel into several apartments where clients live because of poor and unsafe construction. (The building in this instance happens to be across the street from the building where the L. family lives.) These families, then, go unserved because they can not get to an out-of-home respite facility without taking the better part of their day to do so.

**Lack of Adequate Resources**

Insufficient financial resources and inadequate staffing are major impediments to offering culturally appropriate services to small groups, such as Southeast Asian families. Equally detrimental is the uncreative, seize mentality of some service professionals (often described as "burn-out"), which is fostered by dwindling resources, mounting paperwork, and lack of time.

Supervisors have many competing responsibilities, and caseloads are too large for individual program coordinators to give the kind of attention they would like to individual clients. Under these conditions, the needs of any particular case cannot be given high priority. S. and his family represent difficult clients because their needs are more extensive than can be easily
met by the regional center's list of preapproved vendorized services.

For S. and his family, it is not that tertiary care centers or other specialized services are unavailable. Rather, as suggested by Stein and Jessop (1985), access needs of urban, low income, and minority families are far more complex:

The most pressing aspects of [inner city children with chronic disabilities'] problems are not the concrete and technical ones that can be delivered and evaluated in ways comprehensible to policy makers and the public but the more intangible social, psychological, and economic services that are harder for the uninvolved to see as important, harder to deliver, and once delivered, harder to evaluate. These problems have proven to be more intractable than specific technical problems, particularly to simple financial solutions. Moreover, they are not remediable through quick interventions, and they may take a very long time to move toward even partial solutions (p. 392).

Over the last six months, I have attempted to identify the problems this Cambodian family has encountered in dealing with the Western health and social service systems as it has tried to find care for their disabled son. Although S.'s parents have done quite well in many respects, they lack the skills and knowledge that would help them find the best possible programs for him. This is a case manager's function.

At first glance, the task of procuring and overseeing services for S.L. may seem deceptively simple. S. already receives SSI benefits, attends a special school program for the severely disabled, and has access
to good medical care. A more careful examination, however, makes apparent the areas where S. does not fare very well—and where a case manager might make a difference. In the following chapter, recommendations are made for appropriate interventions in this case. Also offered are associated policy recommendations for social service administrators which I see as necessary to improving access and availability of services to persons of different languages and cultures.
CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

Conclusions

It is customary at this point in a thesis to emphasize the limitations of a work's scope and methodology and warn of the caution necessary in drawing conclusions from its findings. In keeping with this tradition, it should be noted that this work's sample consists of a single case found by chance, which makes it difficult to assess whether or not it is representative of others. Reliance on interview data has its own inherent methodological weakness. Interviewees often develop response sets to questions, and give information they perceive researchers want to hear. In addition, although the methods employed were that of a participant-observer, both time constraints and fear for personal safety in the neighborhood where the L. family lives precluded the immersive field work upon which anthropologists usually base their research.

Nevertheless, through my contact with S.L. and his family, I learned a little of what it means to belong to some of the least favored groups in our society—that is, living in an inner city slum, being a member of an ethnic
minority, having little income and little knowledge of English. It has been difficult to convey the complexity of the problems facing the L.s. I am still trying to understand the frustrations they face daily. That they are very poor, live in substandard housing, have five children to raise, and lack both fluency in English and experience dealing with the norms and expectations of American society amount to considerable burdens.

Further complicating these disadvantages is S.'s profound mentally handicapping condition. Previous chapters have outlined the difficulties imposed by this combination of problems and the need for appropriate intervention and active case management. Effective case management poses unique challenges in complex cases such as S.L.'s. As Hobbs, Perrin, and Ireys (1985) observe:

Chronic conditions require focusing on the individual as a person rather than on a specific symptom or illness. The progress and care of the individual with a chronic condition requires clinicians to consider the entire physical and social environment as relevant (p.388).

Thus, case managers involved with persons with chronic disabilities must have a considerable diversity of expertise. Traditional pathology-centered models of intervention do not apply because of the lack of possibility of cure as well as the variety of services needed to optimize the functional capabilities of the client.
A case manager, then, must 1) be familiar with available services and ensure that the family has access to him or her; 2) have a concept of the child as an individual; 3) know the physical and social environment in which the child lives; 4) be aware of the total needs of the family yet keep conflicting priorities in perspective; and 5) synthesize a coherent and realistic plan.

I see an essential role for case managers as advocates who foster coping skills in clients and their families. Such relationships can only evolve over time, therefore continuity of care should be a primary feature of case management. It is always important, however, that someone be identified to act in this capacity and that pertinent information be passed along when changes in case managers do occur.

If the tenets of case management just outlined are to be met, S.L.'s case manager will have to address the problems facing his family which have already been identified. Active interventions are supported. A basic assumption of the recommendations made for case management, however, is that families have a right to be involved in their children's care and that such involvement is in the best interests of children. The recommendations are offered in light of service providers
being facilitators rather than usurpers of parental decision-making.

Recommendations

Specific Recommendations For S.L.'s Case Management

1) It is my view that the case manager should become well acquainted with S.L.'s diagnosis, functional capacities, and family situation. Accordingly, I feel a careful review of S.'s records, site visits at the home and school, and consultations with S.'s physician and other service providers will be necessary.

2) A translator should be involved in all interactions with the family to ensure that each party understands the other. The provision of translation services will allow Mrs. L. to be an active participant in discussions and plans concerning her son. It is also important to recognize that the presence of an interpreter can have its attendant difficulties. Accuracy of interpretation is often difficult to verify. Families may be embarrassed to talk about sensitive issues, or the translator may feel the need to alter statements so that his or her cultural group appears in the best light. These potential problems may be lessened if the translator is the same person over time, is
acceptable to the family, and agrees to maintain strict confidentiality.

3) Among the case manager's priorities should be the development of a close working relationship with the medical professionals involved with S. Although no one physician is in charge of S.'s case, the collective knowledge of the medical and social work staff who have worked with S. offers important insights into the dynamics of the L. family situation. Further, a case manager who maintains lines of communication with the medical team and community providers is in better position to gather and share information and call for meetings that could aid in refining S.'s diagnosis and treatment options.

4) The appropriateness of S.'s educational program requires evaluation. S. should be observed in the classroom. If an environment with greater potential for individualized attention exists, S. should be transferred. At the very least, the case manager should alert S.'s teacher about Mr. L.'s concerns and arrange sessions where they can be explored. Since Mr. L. has little understanding of S.'s classroom activities, it is important that better communication be established between S.'s parent and teacher.

5) Housing and mental health issues also need assessment. After the case manager visits S. in the home
environment, has some opportunity to interact with the L.s, and appraises the stresses which bear on the family's care of their son, referrals to agencies dealing with these respective areas should be made. In this regard, it is likely that it will be necessary to act as an intermediary and also provide translation services.

These recommendations assume that the case manager will have the bilingual, bicultural translation services and other resources necessary to develop a strong relationship with the L. family. Unfortunately, given the services currently available and the working conditions of social service personnel, such an idealistic scenario is unlikely to be realized. The service system for the developmentally disabled has yet to implement strategies which would reduce existing linguistic and cultural barriers to its programs. Increasing the future availability and accessibility of services to immigrant and refugee families with a developmentally disabled member is the aim of the following systemic recommendations.

Policy Recommendations

At the state level, efforts should be directed by the State Office of Developmental Services. This agency recently established a research division whose responsibilities entail identifying and establishing
priorities for direct service as well as research related to developmental disabilities (California Department of Developmental Services 1985). I suggest that the following items be included in these priorities:

1) Conducting or authorizing epidemiological research aimed at estimating the number of families who are eligible for the department's services and have special cultural or linguistic needs;

2) Directing research efforts toward defining service needs in these populations;

3) Developing programs to address these service needs and assure their implementation; (Central to these efforts will be the training of bilingual and bicultural paraprofessionals to participate in outreach, intake, assessment, and translation)

4) Designing curricula to inform case managers and counselors about clinically relevant cultural information regarding the different immigrant and refugee groups in their catchment areas. Similarly, educational materials should also be designed to acquaint the potential client in these groups with the facilities and services available to them.

The recommendations listed are but preliminary groundwork which might lead to improvement of services for families such as the L.s. Fundamental to the actualization of this goal is a substantive commitment of
financial, administrative, and other resources.

Recommendations which call for better coordination and services tailored to individual needs have almost become stock features in work advocating social service reform.

It may sound facile, but I believe that it is morally imperative that the system address the problems of clients like S.L. and institute such reform.
BIBLIOGRAPHY

Alberman, Eva

American Psychiatric Association

Assembly Office of Research

Beiser, Morton

Butler, Louis, Paul Newacheck, Dyan Piontkowski, Aileen Harper, and Patricia Franks

California State Department of Developmental Services

-----


Calhoun, Sarah
Carlin, Jean E., and Burton Z. Sokoloff

Chandler, David P.

Cohen, Donald J., Fred R. Volkmar, and Rhea Paul

Cohon, J. Donald

Cox, D.

Faust, Shotsy, and Robert Drickey

Ebihara, May

Gaines, Rosslyn

Galazka, Sim S., and J. Kevin Eckert
Herskovits, Melville J.

Hobbs, Nicolas, James M. Perrin, and Henry T. Ireys

Kazuk, Elyonor

Keesing, Roger M.

Kinzie, D., and S. Manson

Kleinman, Arthur

Kleinman, Arthur and Leon Eisenberg

Lin, K.M., L. Tazuma, and M. Masuda

Lum, Rodger

McCormack, Michael K.
Meisels, Samuel J.  

Muecke, Marjorie  

1983b In Search of Healers--Southeast Asian Refugees in the American Health Care System. Western Journal of Medicine, 139:835-840.

Mulliken, Ruth K. and John J. Buckley  

Office of Refugee Services  
1985 Refugee Assistance and Services Orientation. Sacramento: California Department of Social Services Publications.

Osborne, Milton  

Pham, Tanh and Richard Sun  
1983 Governmental Policies and the Effectiveness of the WIC Program for the Southeast Asian Refugee Population in the Bay Area. Health and Medical Sciences Department, University of California, Berkeley. Photocopy.

Poole, Peter A.  

Regional Center of the East Bay  
1985 What Is A Regional Center? Educational Pamphlet. Oakland: Regional Center of the East Bay.

Richardson, Steven A.  
Robinson, Court

Simmonds, Stephanie, Patrick Vaughan, and S. William Gunn

Stein, Ruth E., and Dorothy Jones Jessop

Weir, Jack