PREVENTION

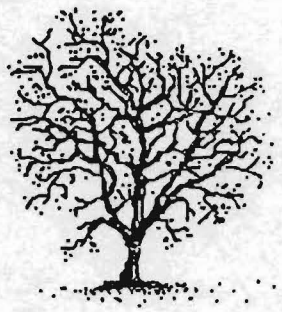
The Regional Center Experience

July 1985 to December 1988

Department of Developmental Services
Gary Macomber, *Director*

Community Services Division
Ken Nelsen, *Deputy Director*

Office of Prevention
Julie Ann Jackson, *Chief*



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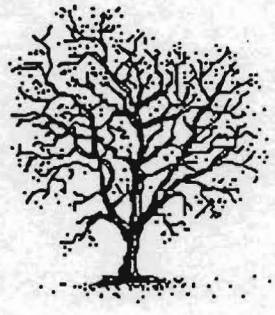

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INTRODUCTION

Prevention of developmental disabilities and birth defects is a top priority of the Health and Welfare Agency and the Department of Developmental Services (DDS). Since 1983, significant new program and resource commitments have been directed at this prevention initiative. One of the key elements of the initiative has been the development of regional center prevention programs. The purpose of this report is to chronicle some of the major achievements and provide important client and service data collected during the program's first three years.

In 1983, DDS launched the prevention initiative as a major priority of the new administration. The goal of the prevention initiative is to ensure that all infants born in California are able to develop to their full potential and, to the extent possible, are free of birth defects or other developmental disabilities.

One of the first actions of the new administration was to establish the Office of Prevention within the DDS' Community Services Division.

Following that, a special Prevention Task Force was appointed in January 1984 by Health and Welfare Secretary David Swoap. The task force assisted the Office of Prevention in the development of the first comprehensive statewide prevention plan, Prevention 1990: California's Future - A Plan for the Prevention of Developmental Disabilities and Birth Defects. One of the major recommendations of this plan was the development of early intervention and genetic prevention programs and staffing in the regional centers. This recommendation acknowledged the regional center role in service delivery and coordination for the developmentally disabled and recognized the importance and potential advantage of a regional center prevention program.

Regional centers have offered prevention services for many years. The Lanterman Developmental Disabilities Services Act, the legislation under which regional centers are defined, includes the provision that prevention services are accorded priority equal to all other basic regional center services.

In FY 1985-86, DDS' funding proposal for regional center prevention "teams" was included in the approved state budget. Each regional center received an allocation which was sufficient to provide three new staff positions: Prevention Coordinator, High Risk Infant Case Manager, and Genetic Associate. Funding for these positions has continued in each subsequent fiscal years.

PROGRAM ORGANIZATION AND ADMINISTRATION

The Community Services Division is responsible for the DDS prevention program. Through the Division's Community Support Branch, annual contracts are negotiated with each regional center. The three prevention staff positions are included among the resources provided for the center's program operations. Additional case management staff are funded on the basis of the estimated number of clients; high risk infant clients are accorded equal credit in this process. Funding for purchase of services, likewise, relates to the client caseload and is based on past per capita expenditure patterns.

The Children and Adult Services Branch, Office of Prevention provides statewide program direction, planning, and technical assistance to the regional centers.

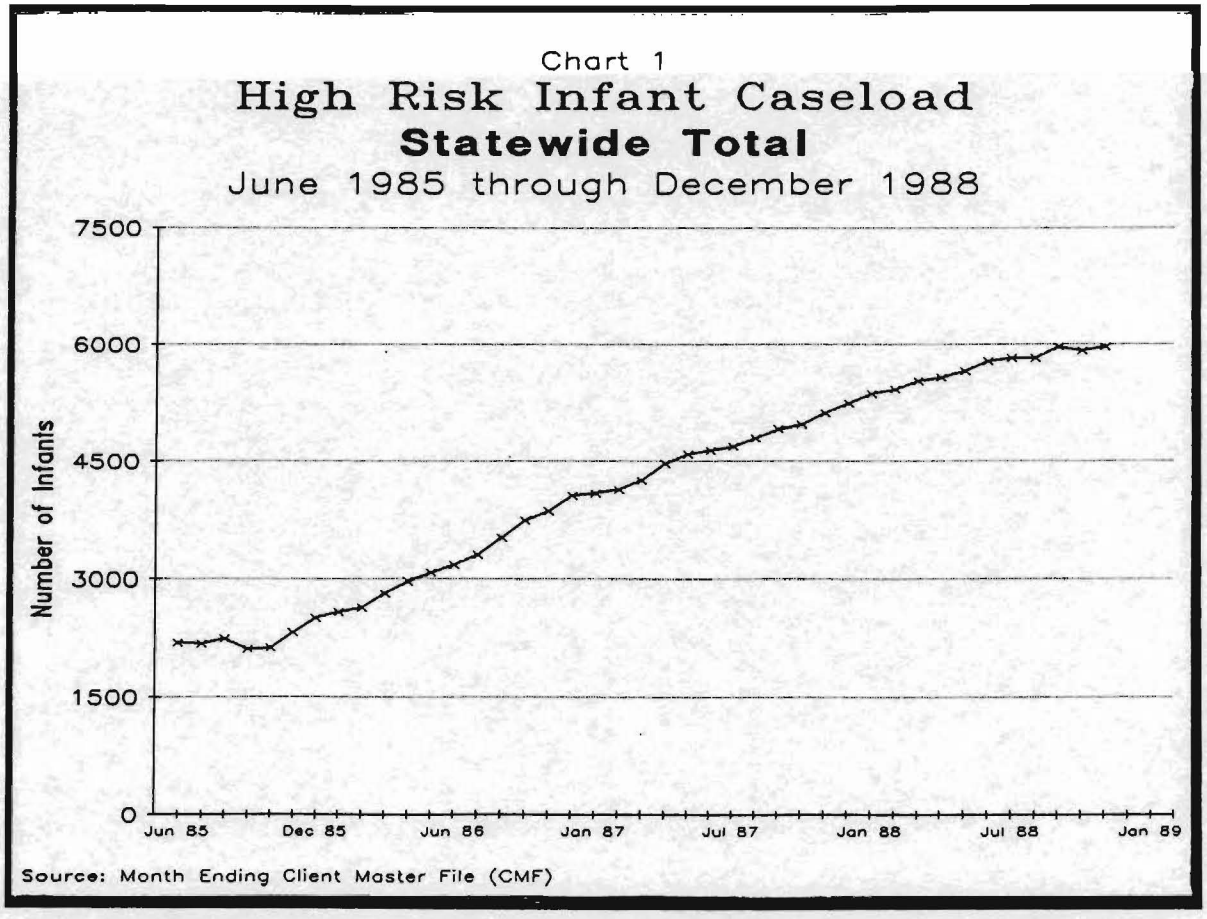
Under the terms of its contract with DDS, each regional center is required to develop, implement, and maintain an annual plan for the provision of prevention services. The plan describes the prevention goals and objectives which are established for the fiscal year, and the various activities which will be undertaken to complete them.

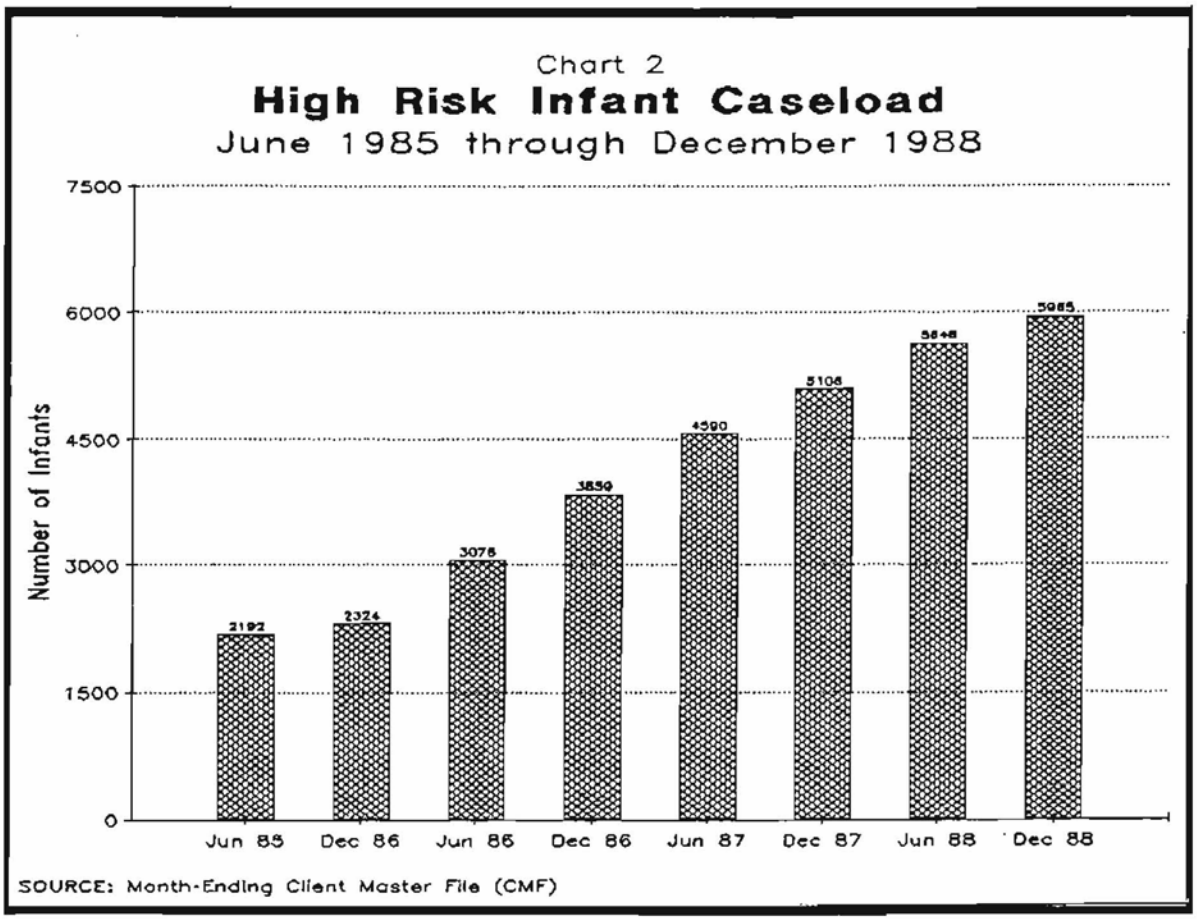
In addition, regional centers report prevention client data. Information collected on high risk infants is reported to DDS on the Prevention High Risk Infant Report (HRI). Caseload and purchase of service data are maintained as part of the Uniform Fiscal System (UFS), a standardized, automated accounting and information system, and reported. Data regarding genetics services clients are reported on the Parents at Risk Report (PAR). Data contained in this report are derived from all of the aforementioned sources.

HIGH RISK INFANTS

Caseload

In June 1985, regional centers were serving 2,192 high risk infants. When the new staffing allocations were received, some centers were fortunate to hire new staff immediately. Most, however, went through a period of recruitment before locating and hiring qualified prevention staff. As a result, the high risk infant caseload did not increase for several months. In December 1985, the caseload rose to 2,324 and began an upward trend which has continued to the present. In December 1988, the number of high risk infants receiving regional center services was 5,965. Please refer to Chart 1 and Chart 2.





An important measurement of the success of the regional center prevention program is the increased caseload. Prevention services must be considered as an investment which will repay dividends in the form of reduced caseloads of developmentally disabled clients in future periods. In addition, prevention services have proven effective in reducing or ameliorating the severity of disabilities among the diagnosed caseload.

During this three year stretch, the high risk infant caseload has grown by nearly 200 percent. In comparison, the monthly number of developmentally disabled clients, as determined by the count of active Client Developmental Evaluation Reports (CDER), has increased by only 22.7 percent over the same time. Chart 3 offers

an illustration of the difference in the rate of increase between the high risk infant caseload and that for the developmentally disabled clients. If the prevention goals are fully realized, the rate of increase in the CDER caseload will diminish in the future.

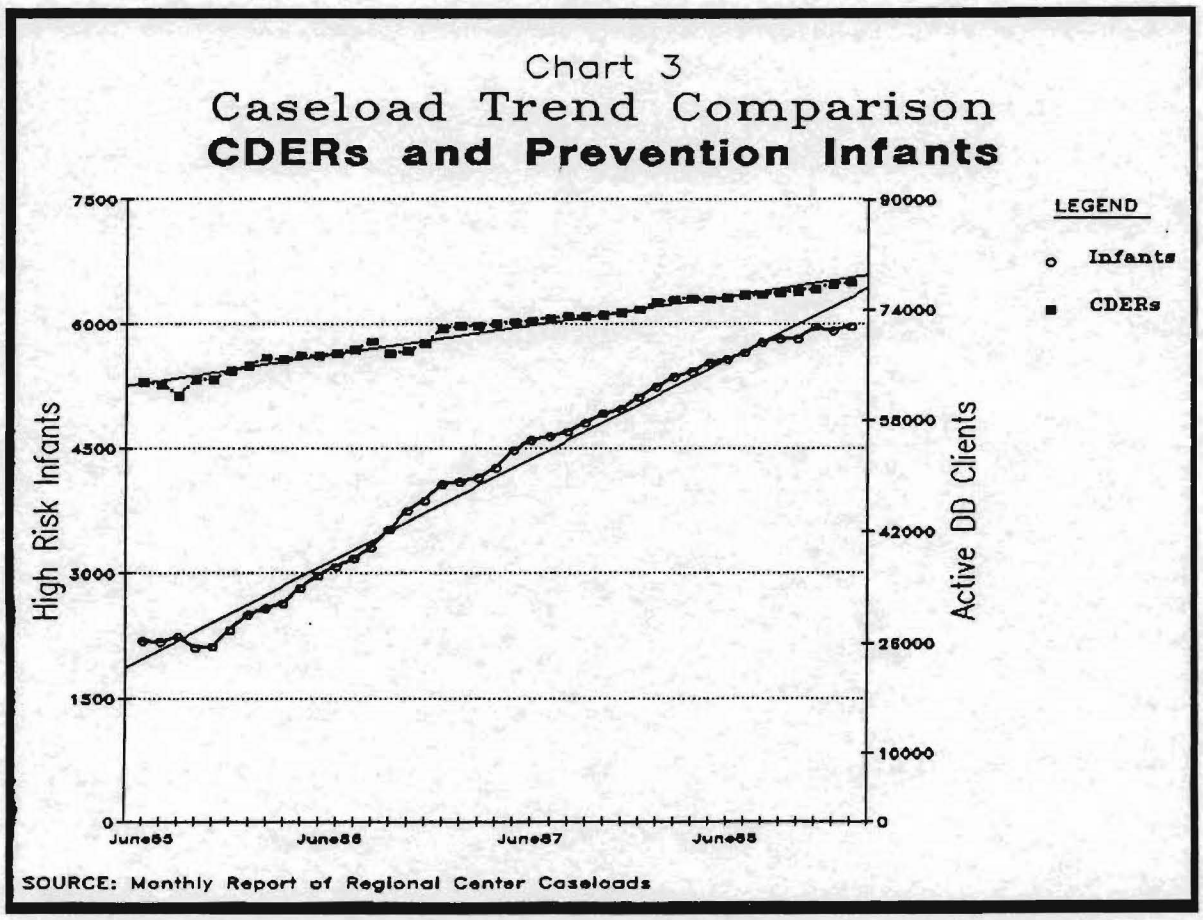
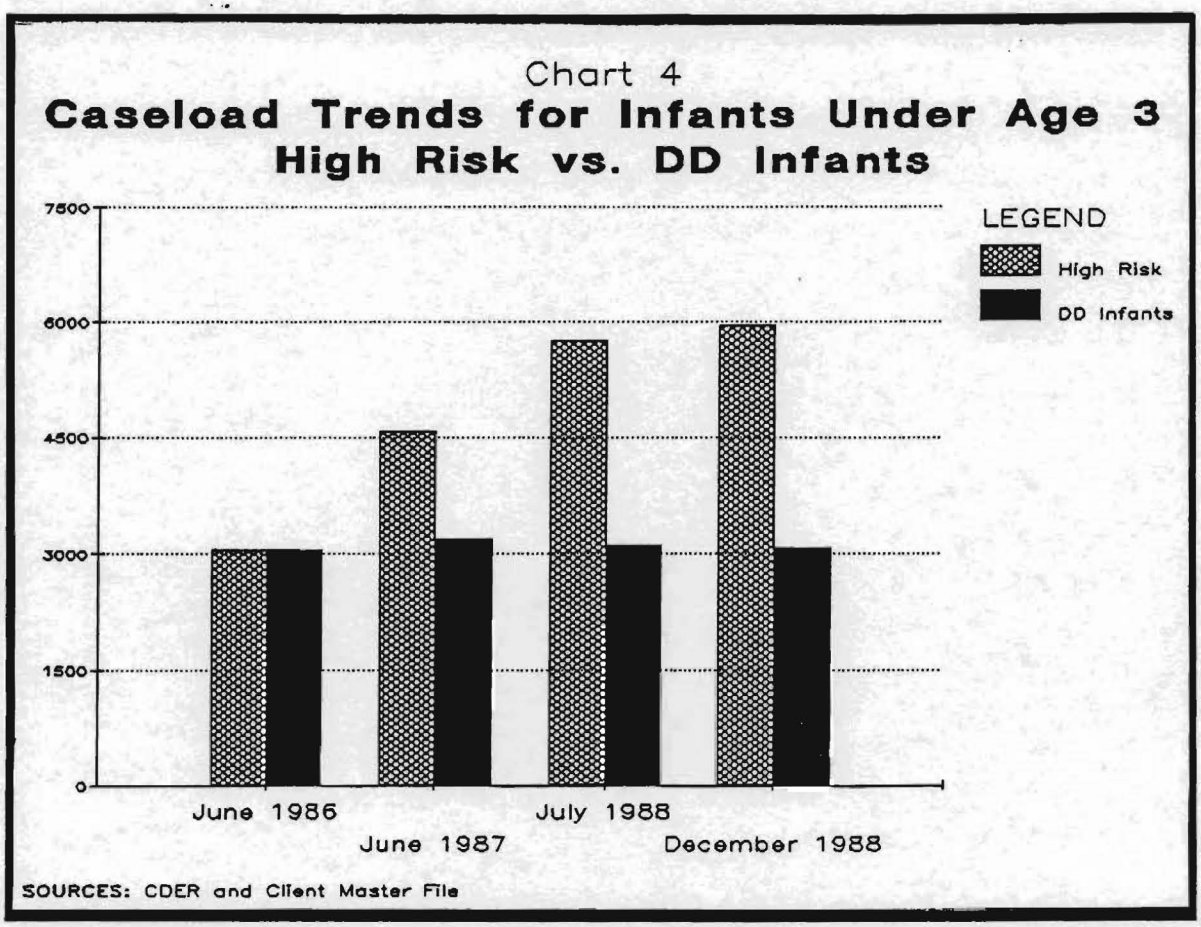


Chart 4 , perhaps, offers an early look at what the prevention activities may already be accomplishing. In this visual, the number of high risk infants, who, as defined in the Welfare and Institutions Code, must be under age 36 months, and the developmentally disabled caseload for the same birth to 36 month age category are plotted. In contrast to the steep increase for the high risk group, the number of developmentally disabled children under 36 months has remained remarkably stable over the past three years. This may be interpreted an early sign of prevention's success in reducing the incidence of developmental disabilities, particularly in light of the advancements in sophisticated medical technology which has

allowed for life-prolonging interventions at increasingly younger ages.

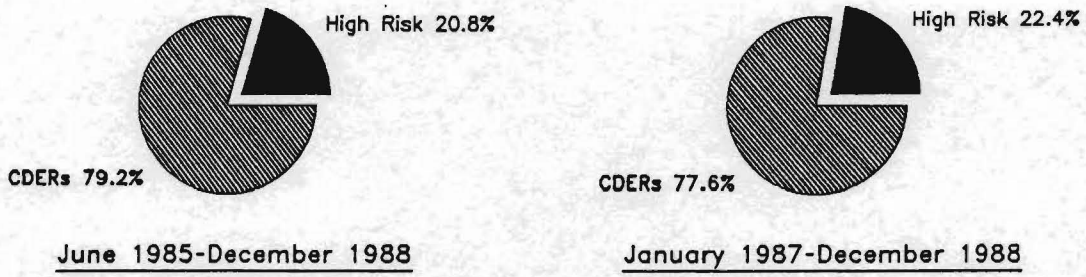


Illustrated differently, of the total caseload growth since June 1985, high risk infants account for 20.8 percent. Since January 1987, the percentage is slightly larger, 22.4 percent. This means that nearly 1 of every 4 new regional center clients over the past two years was a high risk infant. As this trend continues, the mix of the regional center client caseloads will change. With that change will come significant future staffing and services resource implications. This comparison is shown in Chart 5 on the following page.

Chart 5

Components of Total Caseload Increase

High Risk Infants vs CDER Clients



Data as of December 1988 Client Master File

The growth trends have varied according to regional center area. The table on the following page indicates the high risk infant caseload changes between June 1985 and December 1988. Those regional centers which had well established and active prevention programs prior to establishment of the prevention "teams" may not have grown at the same rate as those which started new programs. It is important to remember that the table only purports to compare the regional center rates of high risk infant caseload increase. It is not a reflection on the regional center itself, its program, or the quality of services delivered by the staff.

TABLE 1

Regional Center High Risk Infant Caseloads

Regional Center	*June 1985*	*December 1988*	*Percent Change*
Lanterman	17	229	1247.1
Golden Gate	44	229	420.5
San Diego	113	290	156.6
Far Northern	46	231	402.2
Alta California	140	518	270.0
San Andreas	59	179	203.4
Tri-Counties	69	237	243.5
Central Valley	167	257	53.9
DDC - Orange	187	400	113.9
Inland Counties	334	338	1.2
Redwood Coast	56	164	192.9
North Bay	86	170	97.7
Kern	52	147	182.7
Eastern Los Angeles	49	350	614.3
South Central Los Angeles	86	328	281.4
Harbor	141	302	114.2
Westside	27	321	1088.9
Valley Mountain	76	281	269.7
North Los Angeles	171	393	129.8
San Gabriel / Pomona	121	304	151.2
East Bay	151	297	96.7
Total	2192	5965	172.1

High Risk Infant Program Qualifying Criteria

In order to receive regional center prevention services, applicants must meet established eligibility criteria. While professional judgement plays a major part in determining eligibility for prevention services, the criteria have been determined to be predictors of increased risk for developmental disability. The factors are used in the client review and become the basis for establishing regional center prevention service eligibility.

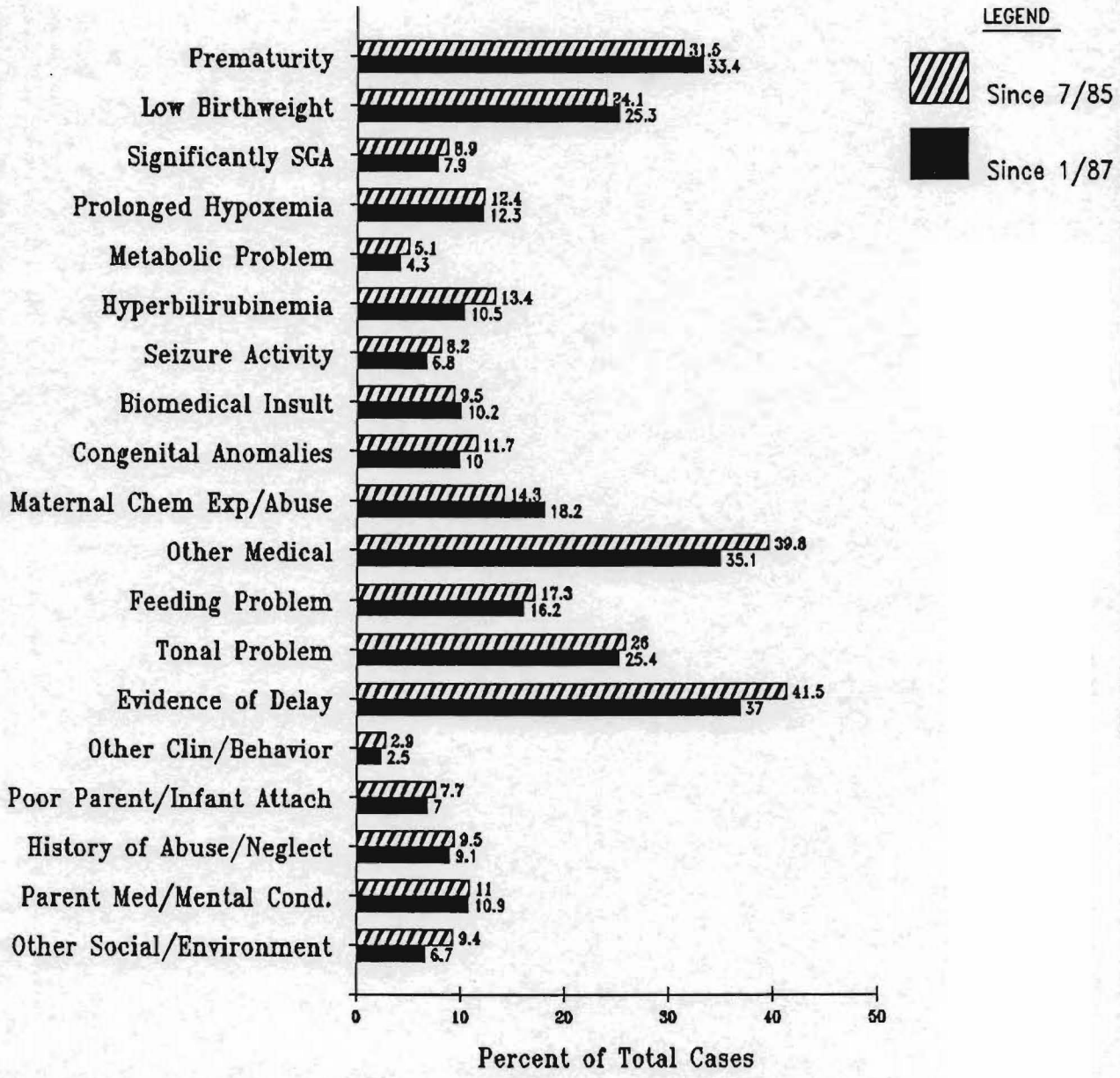
The pictorial on the following page, Chart 6, displays the factors used to evaluate the potential high risk infant clients. In addition, the chart shows the percentage of infants who met the various indications of risk. Infants may meet more than one risk factor. Most, in fact, meet several or more. As a result, the percentages in the table do not add to 100 percent, reflecting the fact that infants may meet a set of risk factors.

Chart 6 compares the experience over the entire three year period with that of the past 24 months since January 1987. Of particular significance is the increase in infants whose mothers were substance abusers or chemically exposed; over the entire three years, 14.3 percent of the infants met this risk factor, while during the past 24 months the percentage has increased to 18.2 percent. Prematurity and low birthweight are still the major factors which qualify infants for this program. In general, medical complications have been the major factors in delaying infant development. In the future, the Office of Prevention will investigate some of the other medical factors in an effort to gain a better understanding of the number and type of specific medical problems which are placing infants at risk of developmental disabilities.

Chart 6

High Risk Infants

Indications of Risk



Data as of January 1989 High Risk Infant file update

Infant Client Characteristics

The following pages report the characteristics of the infants and genetics clients served by the regional center prevention programs.

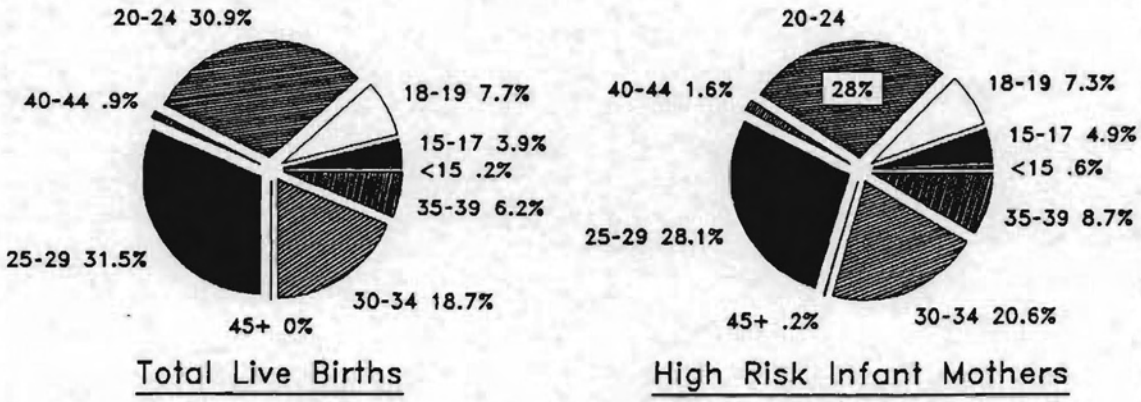
The majority of the infants are born to women aged 20 to 29. Teenage pregnancies account for approximately 13 percent of the high risk infants. Teenage pregnancies, according to the 1983 vital statistics data, account for only about 11 percent of all births in California. Women over age 30 delivered about 26 percent of all infants in 1983; in comparison, the same age group accounted for about 31 percent of the high risk infants. Of all live births, women over age 40 accounted for less than 1 percent; this age group gave birth to nearly 2 percent of the high risk infants.

Chart 7

High Risk Infants

Mother's Age at Delivery

(in Years)



Data as of Jan 1989 update; Live birth data from vital statistics records.

About 6 percent of the infants have been the offspring of a developmentally disabled mother. Services to disabled parents is a major program emphasis. Chart 8 illustrates the share of DD mothers and indicates the other disabilities apparent among the mothers. This chart, however, also shows that three-quarters of the infants are born to mothers without an apparent disability.

Chart 8

High Risk Infants

Disability Status of Mother

Total-since July 1985

Since January 1987

Data as of January 1989 High Risk Infant file update.

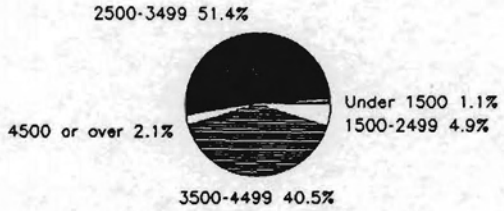
Most of the infants have birthweights between 2500 and 3499 grams, or approximately five and a half to seven and a half pounds. Infants whose weight was less than 1500 grams (3.3 pounds) account for 26.9 percent of the infants served in the past three years. This percentage has increased during the last two years to nearly 29 percent. As seen in Chart 9, however, only 1.1 percent of all infants born in California are under 1500 grams, and only 6 percent are under 2500. Almost 55 percent of the high risk infants served since January 1987 were under 2500 grams.

Chart 9

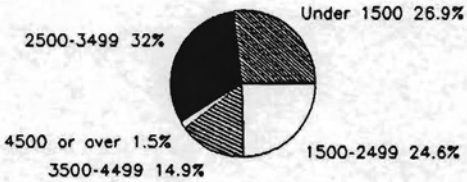
High Risk Infants

Birthweight

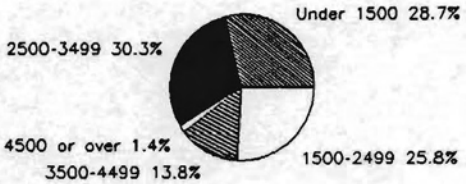
(In Grams)



All Births in California



Since July 1985



Since January 1987

Data as of January 1989 High Risk Infant file update

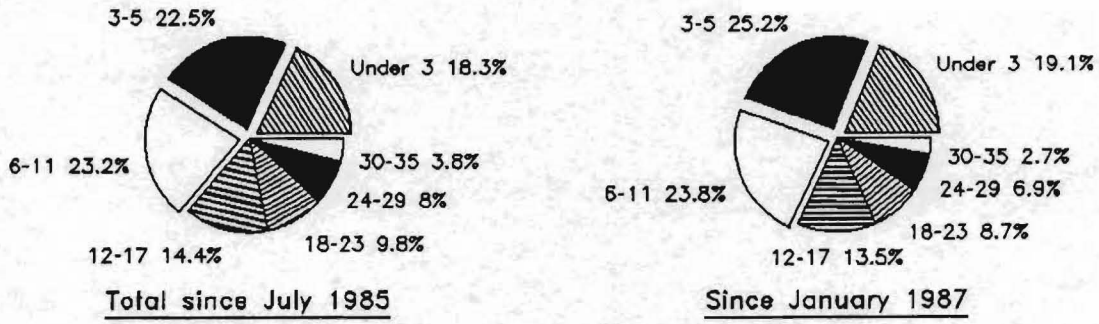
It is important to identify potential problems early. Early intervention services usually are most effective if the problems are identified at an very young age. As seen in Chart 10, 64 percent of the infants are identified and receive regional center attention prior to one year of age. Since January 1987, this has increased to 68.1 percent, which indicates that regional centers recognize the importance of an early identification and service to these infants.

Chart 10

High Risk Infants

Infant Age on Initial Intake Date

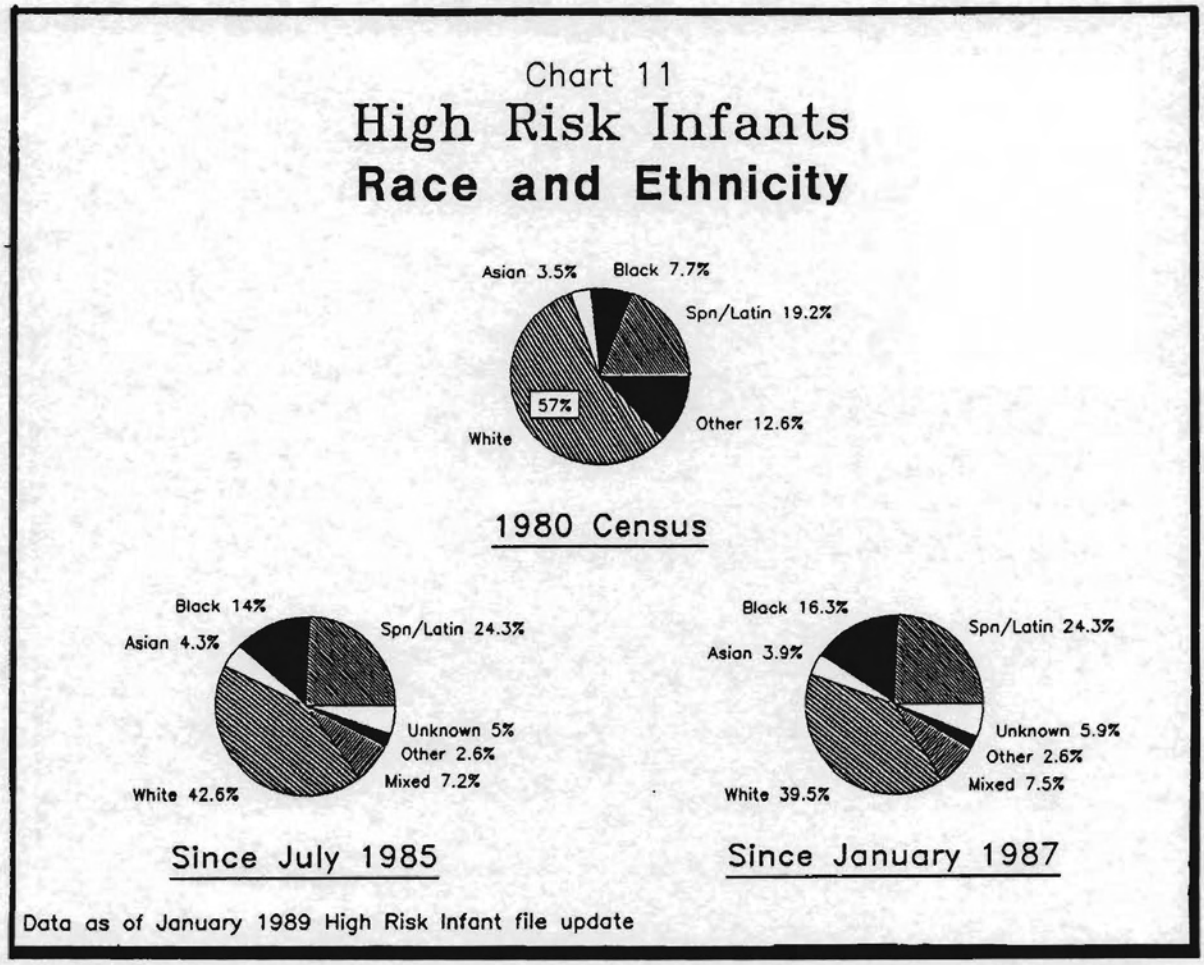
(In Months)



Data as of January 1989 update. Age calculated on date of initial report.

The various racial and ethnic groups are well represented in the high risk infant caseload. While the most of infants are white, non-hispanic (42.6 percent), the representation of spanish/latin (24.3 percent) and blacks (14.0 percent) are higher than for the population as a whole. Furthermore, their share of the high risk infant caseload is increasing, particularly blacks; since January 1987, blacks have accounted for 16.3 percent of the infant cases.

Chart 11, on the following page, indicates the race/ethnic group representation for high risk infants compared to the 1980 Census for California. Note that each race and ethnic group shown is greater than the representation in the total population. This is an indication of the effective outreach provided by regional centers to the the state's diverse population.



Services to Infants

Some services to prevention clients are provided by regional center specialist staff, such as the High Risk Infant Case Manager, nurses, physicians, therapists, and others. Other agencies, however, are a large and active part of the prevention service delivery process. Regional centers may arrange for the services either through other public agencies or by purchase from private vendors. Only about 50 percent of the high risk infants, however, have required purchase of services.

Chart 12 indicates the types of services required by high risk infant clients. Medical and developmental/psychological assessments are the services most often required. This clearly supports the concept that medical complications often are associated with delay in child development. Psycho-social assessments, parental counseling, and parenting education, in addition, are frequently needed as part of the infant service plan, since family considerations often strongly influence infant development. Also of interest is the relative stability of the infant services requirements over the three year period. The service category with the greatest increase during the past two years has been nursing assessments, reflecting the trend to in-home service and family support.

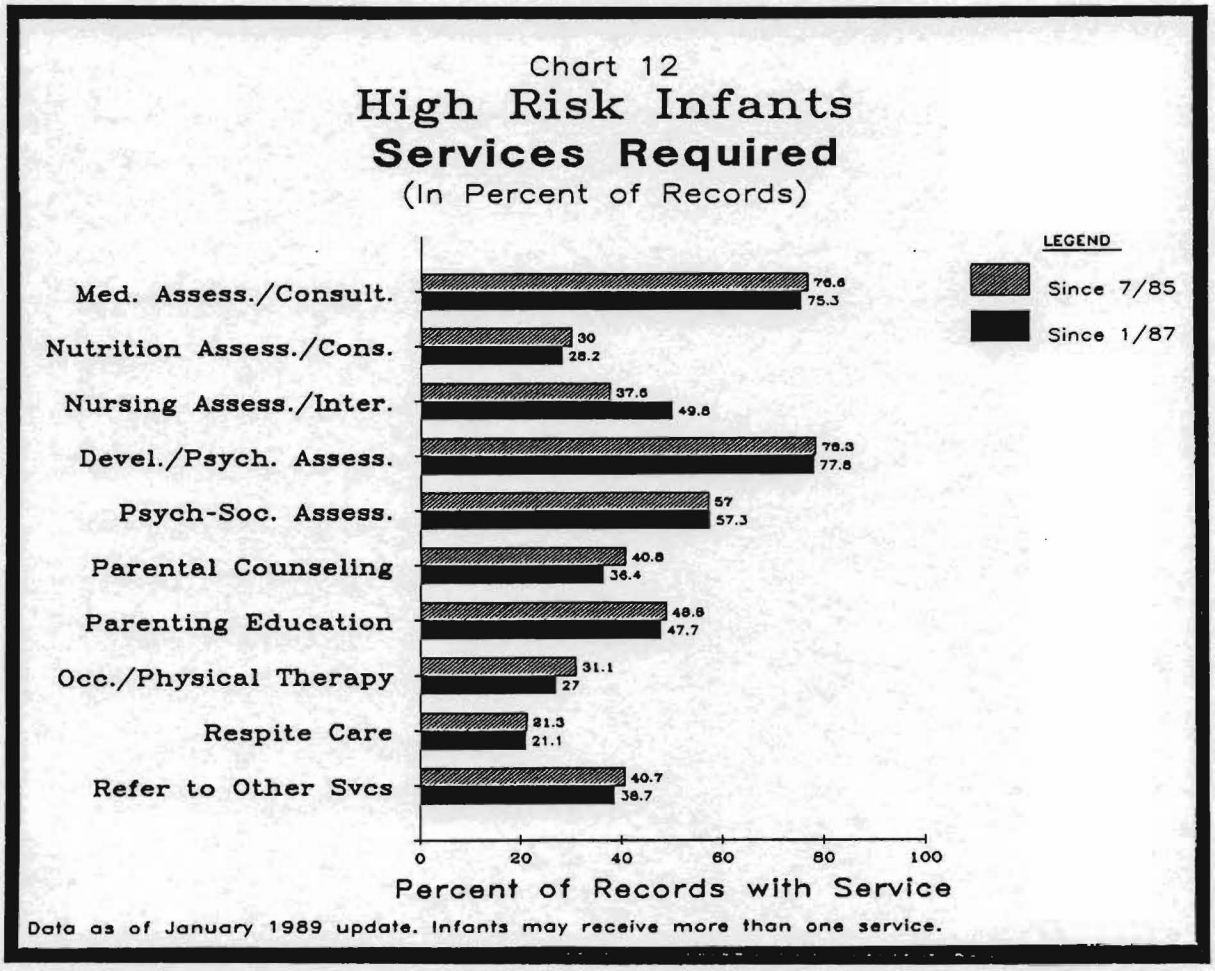


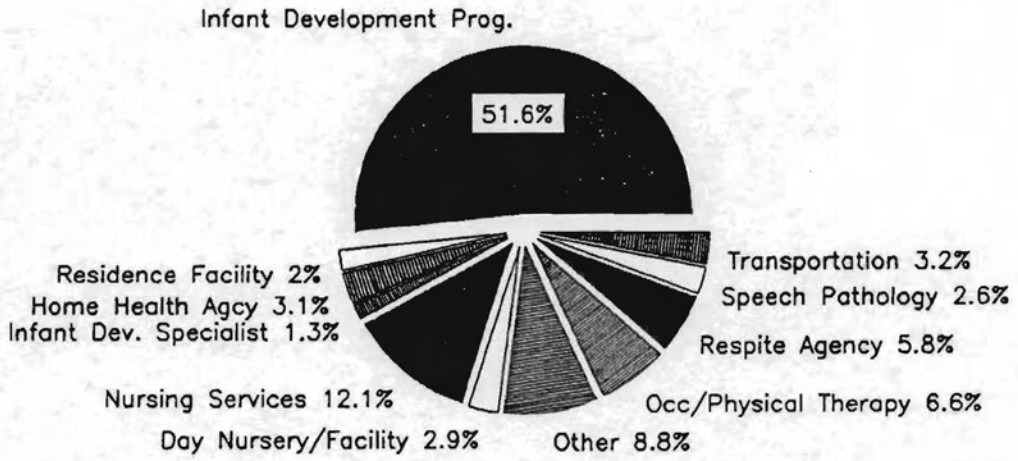
Chart 13 shows the pattern of the regional center service purchases for high risk infants during FY 1987-88. Infant development programming accounts for the majority of service purchases. Spending for nursing services, in large part, reflects specialized respite care provided to medically fragile, technology dependent infants who reside in their parents' home. Respite accounts for a very small share of expenditures.

Chart 13

High Risk Infants

Purchase of Services Patterns

Fiscal Year 1987-88



SOURCES:Uniform Fiscal System, POS and CMF files

Infant Outcome

As mentioned earlier, a major part of the DDS prevention program goal is to ensure that all infants are able to develop to their full potential. For many high risk infants, the services provided by the regional center prevention program may be the essential component which permits realization of full potential.

Limited information about the case disposition is collected for high risk infants when the regional center closes the case. The information presented reflects the various reasons why the infant cases were closed. The first chart presents the entire experience to date. During the more than three years that this program has been operative, over 5,000 infant cases have been closed. About one-third no longer required regional center services. One-quarter continued to receive services as developmentally disabled children. Many (nearly one-quarter) moved or were not located for other reasons.

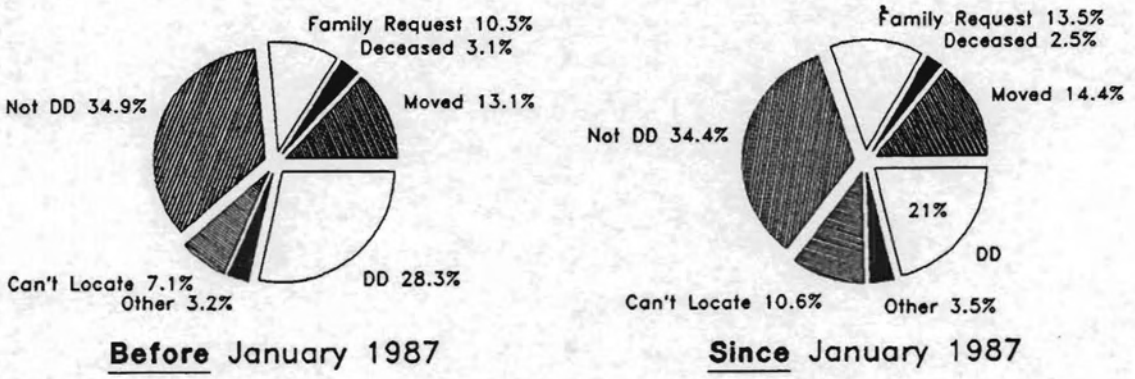
The following chart separates the records into pre- and post-January 1987 periods. As viewed in Chart 14, it appears that a smaller percentage of the infant caseload were retained in the developmentally disabled caseload during the past two years. About the same percentage are considered to no longer require regional center attention.

Chart 14

High Risk Infants

Status of Closed Cases

Before and After January 1987



Before January 1987 **Since** January 1987

Data as of January 1989 High Risk Infant file update.

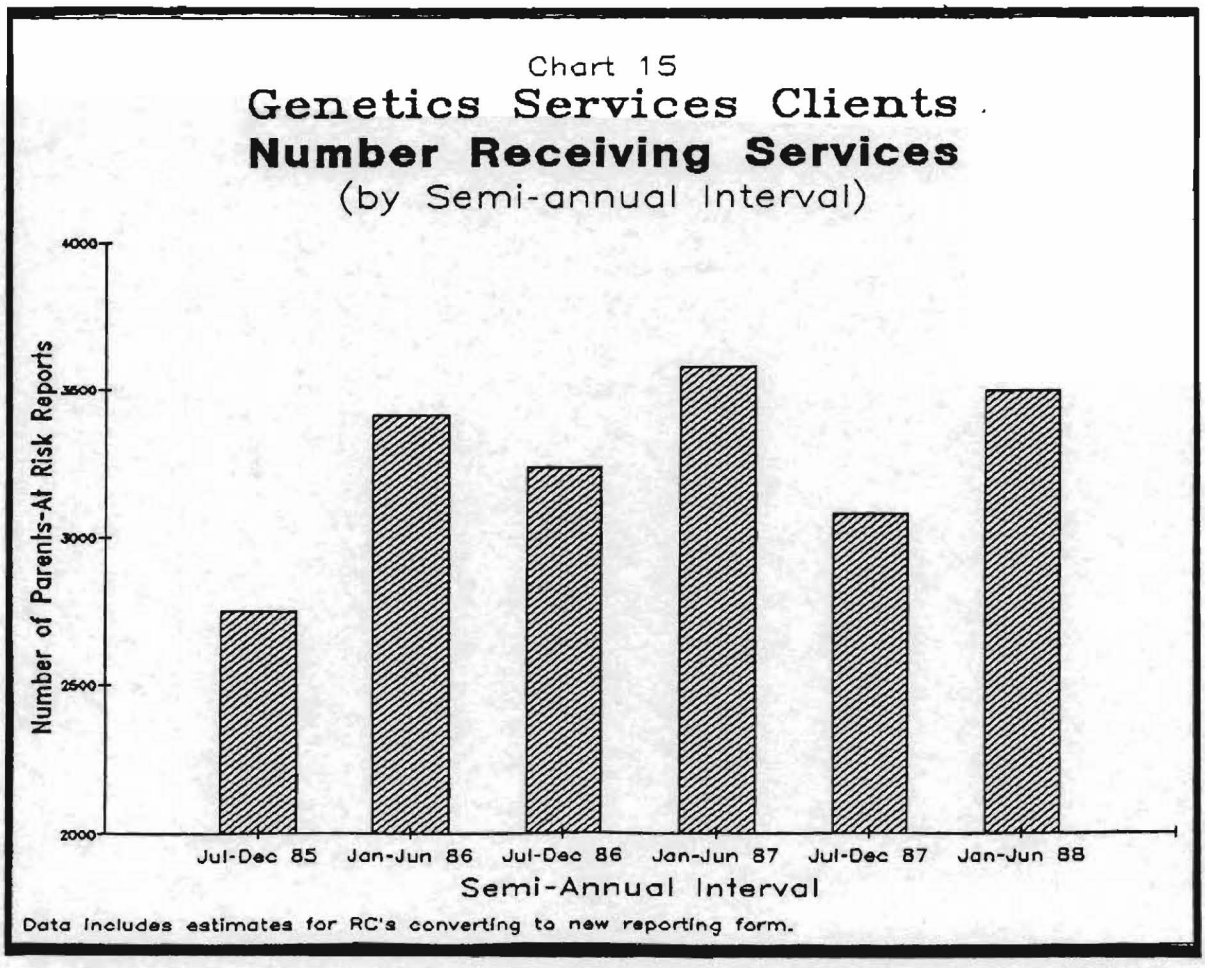
More cases are closed as a result of infant movement and the families' decision not to continue with regional center service. Cases closed because of family relocation or family request will be given special attention during the next year. It is believed that the increase is related to the large gain in children of substance abusing women. Experience has shown that these families are mobile and reluctant to seek services.

The data do not provide conclusive evidence regarding the effectiveness of the regional center services and those of collaborating agencies in reducing the extent and severity of developmental disability outcomes among high risk infants. Further specialized studies are necessary in order to make an accurate and reliable assessment of the effectiveness of early intervention services in producing desirable outcomes. In addition, as mentioned previously, early intervention services have proven to be effective in ameliorating the extent of an infant's disability. Some infants, who, in the absence of services, might have become severely disabled may instead only require future treatment of a mild handicapping condition.

GENETICS SERVICES CLIENTS

Caseload

The number of genetics clients has also risen. As measured by the number of Parents at Risk reports received from the regional centers, the client trend appears to indicate a gradual increase. Since genetics client cases generally are opened and closed within a few months of the service action, it is more difficult to define and measure the "caseload". However, the timing and pattern of the assessment reports appears to indicate the growth trend. Chart 15 provides an estimate of the number of genetics services clients, as determined by the counts and timing of the Parents at Risk reports, by six month intervals since July 1985.



The chart clearly indicates that the typical genetics services client is a woman who has achieved an age at which childbirth presents elevated risks. This experience has been consistently validated over the course of the program.

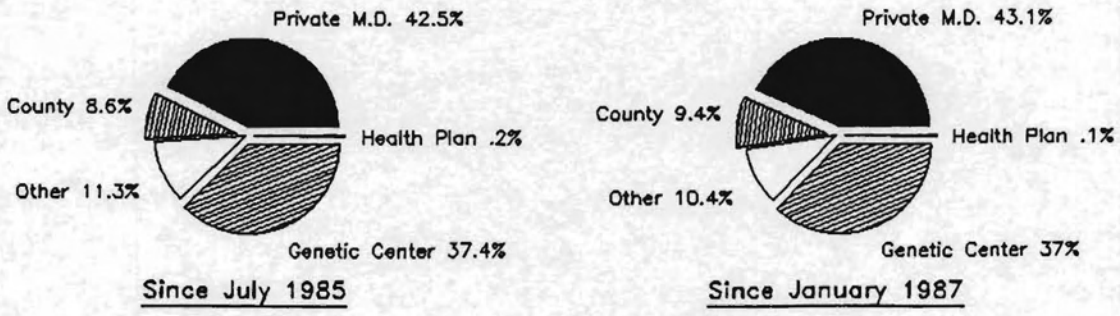
Genetics Services Client Characteristics

Chart 17 displays the various sources of the genetics client referrals. Private physicians are the largest source and have increased since January 1987. Genetics centers, which are affiliated with the Department of Health Services' Genetics Disease Branch, have accounted for 37.4 percent of the referrals to regional center programs.

Chart 17

Genetic Services Clients

Referral Source

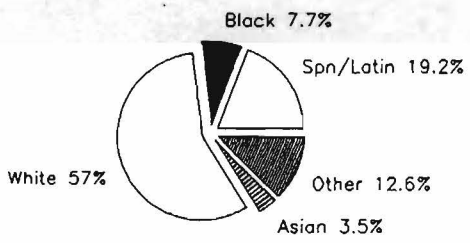


Data as of January 1989 Parents-At-Risk file update

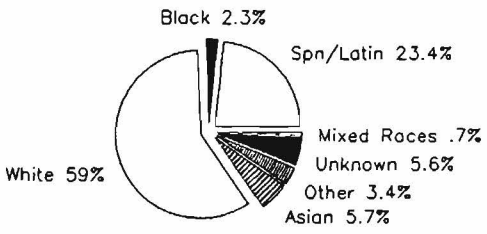
The racial and ethnic composition of the regional center genetics services caseload is, with the exception of blacks, in balance or exceeding their representation in the overall population. Despite active community outreach efforts, blacks still only account for less than 2.5 percent of the genetics services caseload. This percentage, as evidenced by the data for the past 24 months, does not appear to be changing. Chart 18 provides the comparative of the total program experience, and that of the past two years, with the 1980 state census.

Chart 18

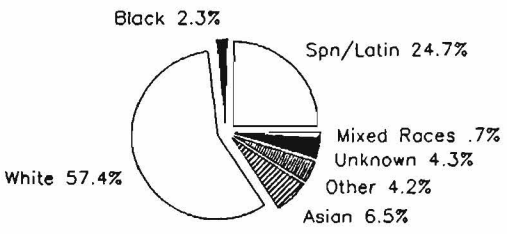
Genetic Service Clients
Race and Ethnicity



1980 Census



Total since July 1985



Since January 1987

Data as of January 1989 Parents-At-Risk file update.

Services Provided

As reflected in the client data provided earlier in Chart 16, most of the genetics services clients are women of advanced child-bearing years. Regional centers assist in arranging for the various pre-natal diagnostic tests and other associated services, and either provide subsequent counseling or arrange for follow-up client counseling through a genetics center or other qualified source.

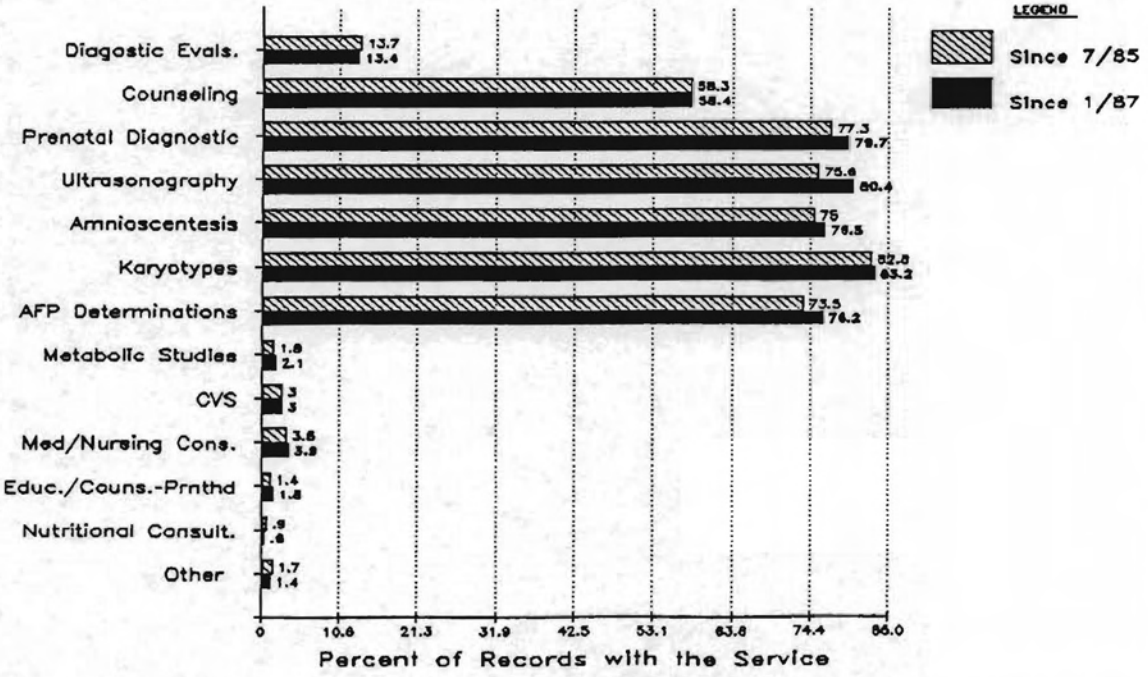
The following illustration indicates the various services and diagnostic tests provided to regional center genetics service clients. More than 75 percent of the clients receive prenatal diagnostic services, such as the ultrasonography, amnioscentesis, karyotying, and alpha-fetoprotein determinations. Regional center services usually entail completing a genetic pedigree, diagnostic evaluation, and counseling - both prior to and after the tests are performed.

Chart 19

Genetic Services Clients

Services Provided by Other Providers

(In Percent of Records)



Data as Jan 1989. Records may indicate more than one service was provided.

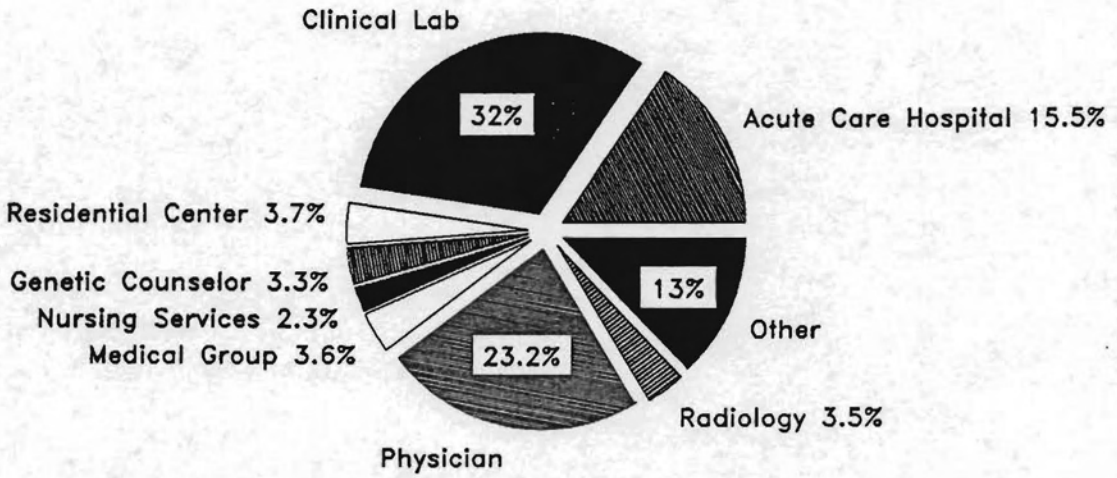
The pattern of services purchased in Fiscal Year 1987-88 clearly reflects the prenatal diagnostic procedures required for the genetic services clients. Clinical laboratories, physicians, and acute care hospitals accounted for more than 70 percent of the FY 1987-88 expenditures. These represent the typical providers involved in pre-natal diagnostic tests.

Chart 20

Genetic Services Clients

Purchase of Service Pattern

Fiscal Year 1987-88



POS Pattern

SOURCE: UFS, Purchase of Service files