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The Center-Satellite System for the Wide-Scale Distribution of Genetic Counseling Services

CHARLES J. EPSTEIN,[1] ROBERT P. ERICKSON, BRYAN D. HALL, AND MITCHELL S. GOLBUS

INTRODUCTION

There is often a discrepancy between the preference for centralization of a specialized medical service on the part of those who are to deliver it and the desire for widespread dissemination on the part of the public who is to receive it. If the service is one which requires significant but limited resources in specialized personnel and facilities, the natural tendency is for it to be located almost exclusively in university-affiliated medical centers. While localization in such centers facilitates the organization of the service, it also acts to aggravate the problem of its delivery. This is particularly the case in areas in which there are large rural populations located at considerable distances from the major medical centers. Precisely this situation was found when we began to organize a genetic counseling unit in northern and central California. In the report to follow, we shall describe the center-satellite system which has been evolved to fulfill the need for both centralization of resources and dissemination of the service.

THE CENTER-SATELLITE SYSTEM

While the concept of community "outreach" programs is not a new one [1, 2], genetic counseling is in many ways uniquely suited for its application. The majority of problems for which counseling is appropriate are not acute in nature. Consequently, the motivation of patients or families to travel long distances or of their physicians to refer them is often insufficient to initiate a visit to a distant counseling center. On the other hand, although special laboratory resources may be required for counseling, it is rarely necessary for the patient to travel to the location of these resources. Availability of appropriate "backup" facilities (laboratory and consultation) at the center and adequate local support make it possible for a single medical geneticist to personally handle most problems at the satellite clinic in the local community. Samples for laboratory analysis (such as

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[1] All authors: Department of Pediatrics, University of California, San Francisco, California 94143.

urine, serum, and blood) are easily transported, as are patients' photographs, pedigrees, X-rays, and other information which may be essential for establishing a diagnosis and making decisions about prognosis and risks.

Critical to the development of an effective satellite program is the existence of a well staffed and equipped central counseling unit. It is becoming generally appreciated that genetic counseling is best carried out by counseling groups or units made up of several individuals with diverse training and skills and having access to the necessary specialized cell culture, cytogenetic, and biochemical laboratory resources. The particular personnel composition will undoubtedly vary from group to group, but because of the critical role of diagnosis as a foundation for accurate counseling, it is essential that one or more appropriately trained physicians and medical geneticists be included [3, 4]. When counseling is being given in one of the community satellite clinics, the counselor is still acting as a member of the central group, and the satellite clinic thus becomes an extension of the center.

Organization

The satellite clinic program established by the genetic counseling group of the University of California, San Francisco, demonstrates that genetic counseling can be made widely available, at reasonable cost and without a sacrifice of quality. The central university-based counseling group, which has developed over a period of 7 years, consists of several physicians (medical geneticists with backgrounds in internal medicine, pediatrics, and obstetrics and gynecology), basic scientists with Ph.D. degrees, a public health nurse, several technicians and secretaries, and an administrative assistant. Of this group, five professionals are directly involved in the satellite clinic program—four medical geneticists and the public health nurse.

A total of 12 satellite clinics have been established, nearly all with the combined efforts of a local National Foundation–March of Dimes chapter and of other community groups. These clinics (listed in fig. 1) are located at various distances from San Francisco, with the nearest (Ross) being 16 miles away and the farthest (Santa Barbara) 340 miles. The closer clinics are usually reached by automobile and the more distant ones by commercial aircraft. Each clinic meets at intervals ranging from once a month to once every 3 months, with the frequency and length of the session being determined by the case load. Some of the clinics are operated in tandem, so that only one trip is necessary to serve two of them (Santa Barbara and San Luis Obispo on the same day; Visalia and Fresno on succeeding days).

Local interest and support and adequate facilities are, of course, essential, and the establishment of several of the earlier clinics was determined primarily by these factors. As the number of satellites has increased, geography has assumed greater importance, and the locations of the new clinics have been chosen to bring genetic services to major population areas distant from San Francisco. The ultimate aim is to have a network of satellite clinics so situated that virtually any

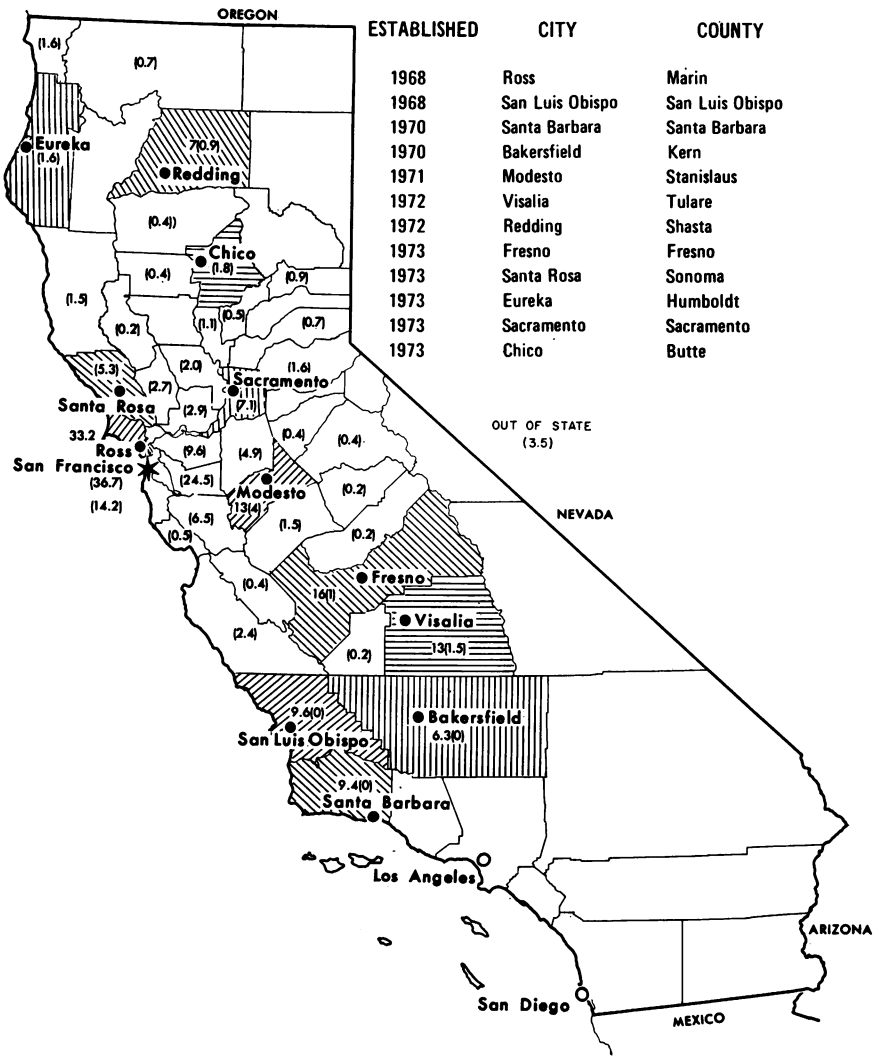

FIG. 1.—Map of California showing the center (*star*) and satellite clinics (*closed circles*) and the year of initiation of each satellite clinic. The number of patients seen per year in the center and satellite clinics combined are shown for each county. For those counties *without* a satellite clinic, the number of patients per year seen in the center in San Francisco is shown in parentheses. For those counties *with* satellite clinics (*shaded*), the total number of patients per year seen *after* initiation of the satellite clinic is shown first, followed in parentheses by the number per year seen in the center *prior* to that time. For the Ross clinic in Marin County, no number is shown in parentheses since the center and the Ross satellite were essentially contemporaneous in origin. This figure is based on the total number of patients seen through June 30, 1973, and does *not* include the patients seen at the recently established satellite clinics in Santa Rosa, Eureka, Sacramento, and Chico.

person in northern and central California would be no more (and preferably less) than 2 hours by automobile from a counseling center.

At the time most satellite clinics were established, many National Foundation–March of Dimes chapters and all local health departments were organized on a county basis. The clinics thus became essentially county genetic counseling clinics. Recently, however, there has been a tendency for those clinics located in sparsely populated areas to cover adjacent counties as well, thereby obviating the need to have a separate clinic in each county. The same result has been achieved in another way by alternating the locations of what were originally the Ross and Redding clinics with newer ones at Santa Rosa and Chico, respectively, thereby making functional "couples" of Ross/Santa Rosa and Redding/Chico clinics.

Seven clinics meet at county health department facilities, four at community hospitals, and one at a university hospital. Most clinics have public health nursing support from the local county health department. Scheduling for the clinics is generally done locally by officials of a local health agency (e.g., directors of public health nurses, medical directors of regional centers of the mentally retarded, the supervisor of crippled children services), by a hospital nurse (in one), or by the public health nurse of the central clinic. These individuals accept referrals from local physicians and health agencies as well as from interested families directly. The referrals are screened to ensure their appropriateness for genetic counseling.

The Sacramento clinic deserves special mention since it represents a unique type of collaborative effort between two different campuses of the University of California—San Francisco and Davis. While its general mode of operation is similar to that of the other satellites, it acts more as a specialized genetic consultation clinic rather than as a general counseling clinic. In addition, it serves as a center for the training of medical students, house officers, and other medical and allied personnel at the medical school of the University of California, Davis, and in the Sacramento area.

Each clinic is operated by one of the medical geneticists from the central clinic (except for Ross/Santa Rosa in which two participate), and each geneticist is responsible for two to four of the clinics. On the average, each physician spends 1–1½ days a month at the satellite clinics and a roughly equal amount of time in preparation and follow-up work. Postdoctoral fellows and genetic assistant trainees also participate in some of the clinics, and, when possible, medical students are involved in the evaluations and observe the counseling sessions.

Operation

Prior to the establishment of each clinic, the geneticist who will be responsible for its operation meets with members of the local medical community, most often the county medical society, local pediatric society, or the community hospital staff. These groups are involved in initiating and assisting in the establishment of the satellite clinic. The purposes of the meeting are to enable the geneticist and

local physicians to meet with one another, to explain the purposes of genetic counseling in general and of the clinic in particular, and to outline the mechanisms for referral. The ultimate success of a satellite clinic is heavily dependent on the acceptance by the local medical community of both the satellite clinic concept and the geneticist from the distant medical center. Although such acceptance is usually rapid and positive, it has occasionally been slow and cautious. The geneticist also meets with the individuals who will be involved in the local scheduling and arrangements, as well as with the public health nurses who will be seeing the patients and their families. The nurses are instructed on how to obtain pedigrees and family histories, and all are informed about the types of information which will be required and the kinds of problems considered appropriate for evaluation and counseling. Since the full local clinic staff is not always organized prior to the inception of a clinic, it is sometimes necessary to give these instructions after clinic operations have begun. As the numbers of satellite clinics and attendant personnel have increased, it has become desirable to hold annual meetings at the central unit to enable the personnel from the different units to become better acquainted and to benefit from the experiences of others.

Although the precise operation of each clinic varies, the following pattern is generally followed. After referrals are made, each family is visited by a public health nurse prior to attending the clinic. The nature of the problem is assessed, and a detailed pedigree and family history are obtained. All available medical and other relevant information is assembled and forwarded to the responsible geneticist 1–2 weeks before the scheduled date of the clinic. This provides an opportunity to determine whether additional information is necessary and whether special supplies or equipment need to be brought. At the actual clinic session, the public health nurse presents the information which she has obtained and then participates in further evaluation and counseling. In some instances, and this has been encouraged, physicians who have referred cases will themselves be present at the clinic session and may present the medical aspects of the case. The geneticist examines each case and carries out the initial counseling. If necessary, blood for chromosome studies or blood and/or urine for specialized biochemical studies is obtained and brought back to San Francisco for analysis and interpretation. Whenever possible, other laboratory studies and specialty consultations which may be required are obtained locally, with the results forwarded to the geneticist. Upon the geneticist's return to the center, the difficult cases seen at a satellite clinic are presented to the entire staff of the central counseling group and discussed. The geneticist then prepares a report which is returned to the local clinic official and the referring person or agency. Preparation of a final report may await the completion or receipt of laboratory studies, consultations, or other material and, if necessary, the reevaluation or recounseling of the patient or family by the geneticist at a subsequent visit. The public health nurses may conduct follow-up interviews or visits with the family and assist them in interpreting the counseling and in making and implementing whatever decisions are required. The role of these nurses cannot be overemphasized. Their preparatory work prior to the

clinic, their participation in the counseling session, and their follow-up afterwards are key elements in insuring that the clinic will be efficient and effective in its operations. A letter to the family restating the diagnosis and counseling is valued for the written record it provides. Such letters frequently prevent misunderstandings and are sometimes used by the patients to communicate with geographically distant relatives or to show to physicians who are unacquainted with their problems.

EVALUATION

There is no easy means for assessing the effectiveness of the satellite clinic program which has been outlined above. The questions of numbers and types of patients seen will be discussed below, as will the altered geographical distribution of families receiving genetic counseling. However, a few subjective impressions will be presented at the outset. While every attempt is made to make access to the central clinic available to all, irrespective of socioeconomic status, there is no question that the patient population is essentially middle class in nature, with a small admixture of less affluent families drawn principally from the clinic populations of the medical center and its affiliated hospitals. In the satellite clinics, on the other hand, the mix tends to be broader, particularly in those which are located primarily in agricultural areas. One factor, of course, may be that because of the sponsorship by local National Foundation–March of Dimes chapters, no charge has been made for counseling in the satellite clinic. However, this does not appear to be the whole or even the main explanation; publicity, geographical proximity, ease of access, and education of the local physicians and public health nurses and their identification with the clinic are all undoubtedly involved. The prospect of traveling to and receiving counseling in the more informal atmosphere of a community clinic is considerably less forbidding than is that of a long journey to the large and impersonal medical center in the "big city" with its attendant traffic and parking problems.

Patient Statistics

Examination of the presumptive or final diagnosis of the patients seen at the satellite clinics indicates that a wide range of problems are seen and that the satellite clinic case load is similar in composition to that of the central clinic. The major diagnoses at the satellite clinics have included congenital malformations of all types, meningomyelocele, hydrocephalus, and congenital heart disease (28%); mental retardation, seizures, and/or cerebral palsy (16%); Down syndrome (11%); other known genetic or cytogenetic disorders (8%); eye and ear defects (4%); diabetes (3%); and counseling without a definitive diagnosis (29%).

The location of each of the satellite clinics is shown in figure 1, as are the year of opening and the numbers of patients per year seen by the combined center and satellite clinics before and after the start of each clinic. For convenience, all of the data are presented on a county basis since, as already stated, each clinic has tended to serve principally the county in which it is located. It

is quite clear from these data that the number of cases seen for genetic counseling increases remarkably in counties where a satellite clinic is located. For instance, although situated only 80 miles from San Francisco, Stanislaus County, in which the Modesto clinic is located, was represented by only 14 cases at the central clinic and one at another satellite when a satellite clinic was started there late in 1971. From then until June 1973, 25 cases were seen from the county at the satellite clinic while only one more has been seen at the central clinic. Similar increases in the number of patients seen per year are noted in each of the other clinics which were started 1 or more years after the central clinic. Since it was established shortly after the central clinic, it is not possible to carry out the same type of comparison for the Ross clinic. However, it is of considerable interest that although it is just across the Golden Gate Bridge from San Francisco (and is predominately a "bedroom" suburb), patients have found it more convenient to attend the clinic in Ross than in San Francisco—125 cases since the satellite clinic was started in 1968 versus 45 cases at the center over the same period of time.

Taken as a whole, a total of 1,098 patients have been seen at the central clinic or one of eight satellites (not including Santa Rosa, Eureka, Sacramento, or Chico) during the 5-year period between July 1, 1968, and June 30, 1973. Of these, 295 (27%) were seen at one of the satellite clinics. However, this figure is to some extent misleading in that the number of patients seen in the satellites is still increasing rapidly while the load of the central clinic, *not* including visits for amniocentesis and consultations for prenatal diagnosis, which are now handled in a special clinic, has remained relatively constant. For the year 1973, 264 patients (216 families) were seen in the central clinic (exclusive of prenatal diagnostic problems) and 210 cases (185 families) in all of the satellites, giving a satellite to total case proportion of 44.3%. If the 107 prenatal diagnostic procedures carried out in San Francisco during the same year are also included in the central clinic figure, the fraction of cases of all types seen in the satellite clinics becomes 36.1%. As long as the great majority of amniocenteses are done in San Francisco, this percentage is likely to remain relatively constant.

We do not have specific data to prove that the increase in the total number of patients evaluated and counseled as a result of the establishment of satellite clinics could not have been achieved in the central clinic alone by an intensive educational program coupled with an extensive referral system. However, our assessment of the patient-related factors of time, distance, expense, and reluctance to go to a large medical center leads us to believe that only a small fraction of the patients seen in the satellite clinics would actually come to the central clinic. As a matter of fact, consideration of the size of the population residing in the various areas served by the central and satellite clinics suggests that, if anything, there is relative underutilization of even the central clinic by individuals living quite nearby. This observation, coupled with socioeconomic considerations, may lend support to the suggestion that even *within* the metropolitan area of the central clinic, satellite clinics may be necessary to most effectively reach the population that could benefit from genetic counseling services.

Analysis of Costs and Time

The effectiveness and value of a program which makes services available to persons who would not otherwise receive them cannot be judged solely, or even primarily, in financial terms; however, economic considerations cannot be ignored. We have, therefore, attempted to calculate and compare the costs of delivering counseling services to patients in the central and satellite clinics (table 1). These must be considered only as estimates since it is impossible to quantitate all of the many and often hidden or intangible aspects of a process as involved as genetic counseling or of institutions as complex and diffuse as university hospitals and county public health departments. The various items of physician, nurse, and secretarial time are computed on the basis of equivalents, and the efforts of many different individuals are summed together. No estimates of overhead expenses (meeting locations, equipment, supplies) are included since most of the necessary data are not obtainable.

Although the cost per patient and *total* physician time per patient are approximately the same for both the central and the satellite clinics, the nurse time, secretarial time, and physician time with patients are all higher in the central clinic. The higher nurse time represents the greater time spent by the central clinic public health nurse in follow-up visits with families, in scheduling and clinic coordination, and in patient-related teaching activities. Similarly, the greater secretarial time is largely related to the need for having a secretary available almost full time to handle the telephone inquiries and general correspondence of the central clinic. With regard to physician time with patients, the difference between central and satellite clinics results from two factors. One is the greater time devoted to patient-related teaching activities in the central clinic. The other is that a shorter time is actually devoted to each patient in the satellite clinics than in

TABLE 1

FINANCIAL AND TIME REQUIREMENTS PER YEAR FOR PROVIDING GENETIC COUNSELING SERVICES

	CENTRAL CLINIC		SATELLITE CLINICS	
	Time (Hr)	Cost ($)	Time (Hr)	Cost ($)
Patients	264	...	210	...
Families	216	...	185	...
Physician time with patients	816	10,908	698*	9,888†
Physician transportation costs	...	...	...	1,605
Public health nurses or equivalent	1,600	11,261	672	4,860
Secretaries	1,400	5,585	600	2,425
Total	4,296	27,754	2,365	18,778
Cost and total physician time per patient	3.1	105	3.3	89

NOTE.—These calculations are based on case load figures for the calendar year 1973 using salary scales applicable in October 1974. The times listed represent the best estimates as judged by the physicians and nurses involved and represent only time actually devoted to the provision of services; teaching and research time are *not* included. The cost of physician travel time has been computed at the same rate as physician time with patient.

* 206 hr (30%) of this time spent in travel.

† $2,977 (30%) of this cost represents reimbursement to physicians for time spent in travel.

the central clinic. Because of the relative infrequency of the satellite clinic sessions, there is a tendency to make the patient scheduling considerably tighter than at the central clinic.

FUTURE PROJECTIONS

Our 6-year experience with satellite genetic clinics has led us to the conviction that genetic counseling services of this type can and should be organized on a statewide and nationwide basis. To estimate the number of centers and clinics that would be required, the following rough calculations based on statistics applicable to the state of California have been made. Since the population of California is about 10% of that of the United States, multiplication of these estimates by 10 would make them appropriate, at least in order of magnitude, for the whole country. (Geography and demography can alter the details of the projections.)

The number of births in California in 1971 was approximately 330,000. Using these figures as a basis, it is estimated that 13,200 infants (4%) will be born each year with a pathologic condition wholly or partially genetic in origin [5]. In about half of the cases, or 6,600, the condition will be a serious one associated with physical disability, mental retardation, and/or shortening of life. Each of these families constitutes an appropriate subject for genetic counseling, even if the affected individuals were to die early in life. Furthermore, with a population of approximately 20 million, there already exist in California about 400,000 individuals (2%) with a significant genetically determined condition. This figure might be reduced somewhat by early death of affected persons, but it seems reasonable as an overall estimate. Of this group, about 150,000 will be of childbearing age (18–44 years). If it is assumed that counseling is warranted for these individuals or families of childbearing age and that this counseling is carried out over a 20-year period, approximately 8,000 cases would require counseling each year. Thus the sum of new serious cases and existing cases (spread out over 20 years) would be about 15,000 per year. If utilization of counseling services is arbitrarily calculated at 50% of the potential load, the annual case load for counseling in California will be 7,500 cases per year.

A similar estimate can be carried out for prenatal diagnosis. We believe that prenatal diagnostic services can also be organized on a center-satellite basis and are presently investigating this possibility. Each year, about 4,100 women 40 years and older and 15,000 between 35 and 39 years of age have children in California. Of the resulting infants, approximately 95 (50 and 45, respectively) with Down syndrome can be expected. Again, arbitrarily assuming 50% utilization, the number of pregnant women over 40 and over 35 years of age to be tested will be 2,000 and 7,500, respectively.

Based on the experience of our genetic counseling unit, it is estimated that a comprehensive counseling unit including satellites can handle approximately 1,200 new and existing cases per year, excluding prenatal diagnosis. This estimate would require the utilization of approximately the following *full-time personnel* or *personnel equivalents:* two physician–medical geneticists (with special training), one

postdoctoral fellow or trainee, two public health nurses, one genetic associate, two secretaries, one cytogeneticist, two cytogenetic technicians, and one biochemical technician. This list refers only to personnel equivalents required for the delivery of patient-oriented services and does *not* include any allowance for teaching, public service, or research-oriented activities. Since it is unlikely that any person, particularly a professional in an academic institution, would spend all of his or her time in the direct provision of services, the actual number of persons involved would be considerably greater. On the basis of currently applicable costs, the total cost would be $189,000 per year or $158 per patient, not including supplies, equipment, or overhead. This is higher than our estimates in table 1 because of the inclusion of laboratory personnel and of a postdoctoral fellow and genetic associate.

To conduct a prenatal diagnosis program based on the center-satellite model, with all laboratory work being carried out in core laboratories at the center, the following personnel equivalents would be required to service a load of 1,000–1,250 cases per year: one obstetrician with training in amniocentesis, genetic counseling, and cell culture techniques; 0.5 cytogeneticist; two cytogenetic technicians; one cell culture technician; and one secretary. Again, it must be kept in mind that the efforts of more than one person would likely be involved to make up the full-time equivalent of, for example, the obstetrician. Based on current figures, such services would cost about $103,000 or $85–$93 per case, not including supplies, equipment, or overhead.

Given the total projected load of cases in California of 7,500 per year for counseling and 2,000–7,500 for prenatal diagnosis, it is concluded that a series of about six or seven comprehensive and centralized genetic counseling and prenatal diagnostic units, each with up to 10–15 satellite clinics (the exact number depending on the geographic area covered by each central unit), could handle the requirements for the essential genetic counseling services which can be reasonably projected for the next decade. In addition to the services already delineated, these units, with extra help in the form of genetic associates or public health nurses, would be able to provide the counseling backup (but *not* the laboratory services) for the wide-scale population screening programs which are likely to become more common in the future. Extrapolating to the whole of the United States, it is estimated that the genetic counseling needs of the nation could be met, with high quality services, by approximately 60–70 centralized counseling units working in conjunction with 600–900 satellites. It is of interest, therefore, that center-satellite genetic counseling systems similar to the one described here have recently been initiated in Colorado, Wyoming, and Pennsylvania, and more limited systems are in operation elsewhere [6–8].

SUMMARY

A 6-year experience with a center-satellite system for the provision of comprehensive genetic counseling services to a large geographical area is described. A series of 12 satellite genetic clinics established throughout northern and central

California have brought genetic counseling services to within a 2-hour drive for most patients. These satellite clinics are largely organized by local groups (such as National Foundation–March of Dimes chapters and county health departments) but are backed by the personnel and resources of the center at the University of California, San Francisco. Assistance is generally provided by county public health nurses who collect medical records from referring physicians and pedigrees from the family. Specimens for cytogenetic or special biochemical studies are brought back to the center, but, if possible, other laboratory determinations, radiological investigations, and specialty consultations are obtained locally. Follow-up counseling may be provided by the public health nurses, and a written summary is sent to each patient or family. The socioeconomic spectrum of the patients seen at the satellite clinics is much broader than at the central clinic, and the establishment of a satellite clinic results in a great increase in the number of cases seen from the area in which it is located. Physician time per patient and cost of services per patient are substantially the same in both central and satellite clinics. Based on population figures applicable to the state of California, it is estimated that approximately 60–70 comprehensive counseling centers, each with up to 15 satellites, could adequately provide for the foreseeable genetic counseling needs of the United States.

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