PART IV

PROJECT NARRATIVE

MAR 1979

A. TITLE

Research on Attainment of Independent Living Status and Evaluation of Independent Living Centers in California (Rehabilitation Research and Demonstration Grant #15P-59045/9-01)

B. PROGRESS REPORT

INTRODUCTION

This study of Independent Living Centers in California has been undertaken in an effort to examine the functions and efficacy of community-based, consumer-managed centers which were established throughout the state to provide pre-vocational and independent living services to disabled individuals. The purpose of this examination is to determine whether these centers, most of which are supported by State Department of Rehabilitation Innovation and Expansion grant funds, are having a demonstrable impact on the rehabilitation of their clientele and, to delineate the services provided by the centers and the ways in which they interface with other agencies serving the disabled. Additionally, the project proposes to provide historical and descriptive data describing the growth of the centers and their fiscal and organizational structure.

The original application for a research grant was made in 1976, to run from December 1 of that year to November 30, 1979. However, problems presented by the design of the project and later, by securing necessary State approval to begin, necessitated delaying the start of the research until the summer of 1978. The project dates were extended accordingly and the study is currently scheduled for completion in June of 1981.

What follows is a description of the activities undertaken on behalf of the project from July 1978 through March 1979, including a summary of data gathered during this period. This will be followed by a projection of what the project staff hope to be able to accomplish in the next year of the study.

1. Changes in plan: None, since revisions approved in June, 1978.

2. Progress During Current Grant Period (July 1, 1978 - March 31, 1979)

   a. Chronological Summary of Project Activities

      In 1977, anticipating Federal and State approval of the Independent Living Research Project, meetings were held between staff of the State Department of Rehabilitation's Research Section and a six person committee which had been selected by the Coalition of Independent Living Programs* to oversee and assist in the research project. The purpose of these meetings was to reach an accord as to methods to be used in doing research at the centers, and to familiarize the committee with the objectives of the study and gain from whatever insights they could provide the researchers.

      These meetings, held in late 1977 and early 1978, proved very helpful in setting up a research plan that was agreeable to all concerned. Through consultation with the committee, the researchers were able to circumvent problems that could have come up concerning access to centers and their records as well as to gain knowledge about the centers' operations and philosophy which was extremely helpful in planning the research design. As a result of this consultation several changes were made in clarification of the project's objectives (see Appendix A).

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* An organization made up of the Directors of California Independent Living Centers which meets regularly to discuss and address common concerns.

In November of 1977 a list of questions to be asked in preliminary interviews with center directors was drawn up with the assistance of the Coalition Research Committee (see Appendix B). The purpose of these interviews was to be the gathering of historical/descriptive data for the first phase of the study. Shortly thereafter a member of the Research Section staff began going to the centers to conduct these interviews.

In February of 1978 it became apparent that there were going to be problems in gaining the necessary approvals from the state finance agency that would allow the project to officially start. With the energies of the Research Section staff turned to solving this problem, other work on the project was temporarily suspended. Official approval to begin came in June of 1978 and the project dates were changed to run from July 1, 1978 through June 30, 1981.

The next step required was recruitment and hiring of permanent project staff. Preliminary work on the study had been done by State Department of Rehabilitation Research Section staff as time was available, but the project proposal called for a staff working exclusively on the study. Recruitment was complicated by the State government's institution of a hiring freeze, which meant all study staff had to be recruited from persons already employed by the State. Filling the field analyst positions within this constraint was accomplished by diverting three Research Analyst positions in the Research Section to the study. The clerical position had been filled before the hiring freeze began. This left the positions of Project Director and Project Coordinator to be filled. Since it was felt that the Project Director position would not require full time coverage, this was converted to a half time job and filled by the Chief of the Research Section. Recruitment then began for a Project Coordinator.

October of 1978 was devoted to planning and organization. A new time line was drawn up and criteria were selected for deciding which of the state's twenty Independent Living Centers would be chosen as subjects for the study. Once the choice of twelve centers had been made, a meeting of the Coalition Research Committee was called to discuss this decision and explain the rationale behind it (see Appendix C). The committee concurred with the study site selections except for one center which they did not feel would be suitable. Another center was substituted and the study sites were divided between the analysts. When one of the original three analysts transferred to another agency, the remaining two were assigned six centers each.

Interviews for the purpose of collecting historical/descriptive data began in November, 1978 and were completed in January, 1979. The analysts used an interview worksheet containing all the questions that had previously been decided upon (see Appendix D) to insure uniformity of inquiry. In those cases where a Research Section staff person had already visited the center, information from that interview was transcribed onto the worksheet so that only those questions which had not already been answered were asked. The analysts also used these visits to familiarize themselves with the centers and their staffs.

The result of each center interview was a report containing all the pertinent information that had been gathered. This report was sent to the center director with a letter asking that s/he notify the analyst of any errors or omissions. These reports were then used as the basis for compilation of the historical/descriptive data.

Inquiries at the centers revealed that gathering the client characteristic data required by the next phase of the study could not be done as originally planned. The study staff drew up a minimal list

of characteristics that they felt would be important (see Appendix E) and designed a self coding survey form on which the data could be collected (see Appendix F). According to the original plan, these data were to be extracted from files and records at the centers. However, it was found that record keeping systems at the centers were not at all uniform, and in fact varied through the whole spectrum from no demographic data on clients to comprehensive medical/personal histories. An analysis of the data available at each of the twelve centers showed that only two of the selected variables were uniformly available from center records (see Appendix G). From this it was apparent that a new approach would have to be taken to the collection of client characteristics data.

In order to decide on what this new approach would be, study staff did an analysis of alternative data gathering methods (see Appendix H). A meeting of the Independent Living Programs Coalition Research Committee was called in order to discuss the question with them and to get their input as to the best way to gather the data. In general, the Committee concurred with the approach selected by the study staff, which was to gather as much information as was available from each center and footnote the resulting tables to indicate those variables which were not universally obtainable. The study staff then decided on a systematic sample of 100 randomly selected clients from each center as being likely to provide a representative cross section for client characteristics data. Then the center directors were contacted and arrangements made for collection of the data.

Site visits for collecting client characteristics data were arranged and completed during the months of February and March 1979. The analysts made a random selection of 100 files at ten of the twelve

centers in the study. Of the remaining two centers, one was just getting its program under way, so did not have any client files as yet. The other was unable to allow the study analyst access to client files, and could provide the requested data on only 25 cases. This was supplemented by a statistical report prepared for another agency with which the sample could be validated. In the ten centers where the 100 case sample was available, files to be sampled were chosen by ascertaining the total number of records on hand and picking every Nth one, depending on which N would provide a sample of 100. For example, from a file of 400 records, every 4th was recorded; if there were 3,000, every 30th was chosen. Data thus extracted was then tabulated by computer.

During the same time that client characteristics data were being gathered (January-February, 1979) recruitment and hiring of a Project Coordinator was also going on. Mr. C. Eugene Hiehle was hired to fill this position effective March 1, 1979.

The month of March was spent in the tabulation of client characteristics data and writing up the narrative portion of the project's continuation grant application.

b. Summary of Data Collected

The data summarized in this section were gathered by means of personal interviews, usually held with the Director of each center and occasionally augmented by other individuals on the staff who were familiar with the center's beginnings and operations. What follows is a composite view of the twelve Independent Living Centers under study.

EARLY HISTORY

Organizational work for the majority of the centers studied began in 1975, and was done by disabled individuals. While it is often assumed that California's independent living centers are nearly all spinoffs from the Center for Independent Living (CIL) in Berkeley, this was not found to be the case. Only five of the twelve center directors interviewed indicated that their decision to start a center was inspired by the CIL example, and many of the centers did not follow the CIL service delivery pattern.

The impetus for starting a center came from somewhere other than a group of disabled individuals in only three cases. All the other centers were started by variously composed groups of disabled people. Four of these groups were informal, formed by people who found they had similar needs and goals in the course of discussions they had on these issues. Four centers were begun with support of the local chapter of the California Association for the Physically Handicapped (CAPH) while one was instigated by another formal organization concerned with the disabled.

In considering the mechanics of starting up a center, there was wide diversity, not only in the first step taken but in the amount of time that elapsed between the idea and its realization. Those four that were started by committees emanating from a CAPH chapter all began similarly, with these committee members being charged to draw up grant proposals for State Department of Rehabilitation Innovation and Expansion grants. One of these four first undertook a study of an ongoing center before writing up their proposal, but all of them took the grant proposal approach in getting a center started. The one group that had its original proposal denied began providing limited services under the auspices of a local government agency while continuing to reapply for the grant which would eventually allow them to become a full fledged Independent Living Center.

The groups which had come together less formally generally took longer to get underway, due to their initial lack of organized structure. The pattern followed by the centers in this category was a sort of "snowball" effect, with two or three individuals discussing the issue together, contacting others and forming a committee to investigate the feasibility and need for a service center for the disabled in the area and moving from there to locate sources of funds and generate community support for the project. Some of these groups were providing informal counseling and referral services out of a private home before they were officially established as a center.

One center grew out of such an informal service provision setting. Disabled individuals who had been voluntarily giving help to others in the community decided to expand their services by formally incorporating and becoming an official independent living center.

Response to requests from the disabled community at large led to the start of two centers. In one case a center was created through the actions of a local governmental entity in response to the recommendations of a task force assigned to address the complaints of the disabled. In another, an independent living service component was added to the services provided to the disabled by a private rehabilitation facility.

Instigation for one center came from a State Department of Rehabilitation Consultant who was familiar with the work being done at CIL and felt such services would help meet the needs of the disabled in his community.

The amount of time that elapsed between the start of efforts to organize a center and the day the center opened officially ranged from 3 months to 3 years, with most centers taking between 7 and 14 months to accomplish the tasks of organizing and locating funding sources.

Most of the centers (9) found their primary source of funding in the State Department of Rehabilitation Innovation and Expansion grants. The

remaining three centers were initially funded by city or county grants. Matching funds for these grants came from five sources: private donations, fund raising events, other community organizations, other private agencies dealing with the concerns of the disabled, or federal CETA programs (which provided staff and salaries).

In most cases, the founders of the independent living centers sought and received help from others in their organizing efforts. Only three centers reported having gotten started with no outside assistance. For the most part, this help came from existing community or governmental agencies concerned with the disabled. Four centers had active backing from a local CAPH chapter in their organizing efforts. Other support came from special organizations serving the handicapped such as United Cerebral Palsy Association or Easter Seals. In eight out of twelve cases other disabled individuals were active in the community at the time the center organizational work was going on. This activity was generally concentrated on specific issues such as removal of mobility barriers, or housing, and was mostly centered in student groups on nearby college and university campuses or in CAPH and other organizations of disabled people.

The various center organizers used one of three methods to determine which service components to include in the initial offerings of the centers. In five cases the service package was determined by what the founding committees felt were the most pressing needs of the disabled community based on their own personal experience and that of other handicapped individuals they knew. Five others determined these needs by means of some sort of survey of the disabled or investigation of problems that had been expressed. In two cases the centers were patterned after CIL and more or less adopted the same service package as CIL was offering at the time, insofar as it was within their ability to do so.

Since the needs of the disabled varied from one community to another, no two centers offered an identical complex of services when they opened. The number of services offered also varied, going from only two (generally consisting of some combination of information, referrals, and counseling) on up to eight separate services. Types of services and the frequency with which they were selected as initial components of center programs are listed below. Since the choice of initial services was dictated by a determination of which needs were most pressing, the list below gives a good indication of the sorts of service gaps the centers were created to fill.

SERVICES OFFERED INITIALLY AT INDEPENDENT LIVING CENTERS

SERVICE*	DESCRIPTION	NUMBER OF CENTERS OFFERING
Attendants	Locating, screening, training and referral of attendants to severely handicapped persons.	9
Advocacy	Assistance in dealing with other agencies serving the handicapped. The most prevalent form of advocacy was in the realm of financial or benefits assistance.	9
Counseling	Mostly peer advising, with some group or family counseling dealing with handling special problems created by disability.	9
Information/ Referral	Information on services available through other community agencies and referral to facilities which could provide services not available at the center.	8
Housing	Surveys to provide lists of accessible housing, other help in locating such housing and referrals.	6
Deaf Services	Special services to deaf individuals such as locating and training sign language interpreters, TTY facilities.	2

* Services are lumped into broad categories. Centers providing each service did not necessarily include all the components listed in the description of the service.

SERVICE	DESCRIPTION	NUMBER OF CENTERS OFFERING
Independent Living Skills	Training in such areas as housekeeping, personal hygiene, and making environmental adaptations to allow an individual to live with minimum assistance from others.	2
Transportation	Help in locating feasible modes of transportation; van transportation to and from the center and center-related services (e.g., benefits offices).	2
Employment	Job and employer listings and referrals.	1
Education	Tutoring; help in locating suitable training or academic education.	1
Recreation	Special programs geared to the handicapped such as swimming, or sports and games using modified equipment.	1
Wheelchair Repair	Either on-site repair service or referral to competent repair facility.	1

GROWTH OF THE CENTERS

While the primary force behind the decision as to what services to offer initially was the question of which needs were most pressing, the selection of these first services was also influenced by the availability of funds and staff. In some cases even services which were considered to have a high priority in terms of need were not included in a center's first offerings because it was not possible to provide them within the constraints of available personnel and finances. Centers were not always given the amount of money requested in their grant proposals, which naturally meant they could not provide all of the proposed services.

Once the centers' operations got under way they were able to add these essential services and eventually two of them were offered at all 12 centers: counseling and attendant services. Other services that were added soon after

the centers became established were transportation (4)*, financial advocacy (2), deaf services (2), information and referral (2), housing assistance (2), employment help (2), newsletters (2), intake evaluation (1), wheelchair repair (1), and rap sessions (1). Many more centers added a number of these components later in their development.

On the other hand, some centers found they had to drop or cut back on some services. Actual delivery of services showed the need for a shifting of priorities in some cases. Services that had been offered to start with but were subsequently eliminated or reduced significantly were advocacy, crisis housing assistance, TTY services for deaf clients, attendant training, and financial counseling. The fact that there are some services that appear both on the list of services added and the list of those dropped illustrates the diversity of service needs between the communities served by the centers.

Besides making shifts in service priorities, a number of the centers found they needed to make other changes in order to best serve their clients. The next phase in the growth of the centers then, was a "settling in" process: establishing and maintaining relationships with other community agencies (public and private), getting out the word of their existence, and experimenting with modifications of their programs.

While no two centers developed in exactly the same way, there were some elements that were common to nearly all the centers: expansion of services in response to expressed needs of the disabled community and increased involvement with other agencies serving the disabled. In some cases expanded services had been planned from the onset but could not be implemented until the basic service model was fairly well established. In others the expansion came as a result of client demand.

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* Numbers indicate the number of centers who added the service to their initial package in the first few months of operation.

In at least four of the centers their early experiences in service provision led to a shift in emphasis as the center began to grow. Two of these mentioned the necessity of having to put more of their efforts into fund raising and community liaison activities than they had originally envisioned doing. While provision of services remained the foremost goal, this goal could not be reached without the practical prerequisites of money and staff to do the job. Some found a partial solution to this problem in shifting from direct provision of services by center staff to referral and advocacy -- directing the client elsewhere for services and acting on his or her behalf in dealings with outside agencies.

Some centers found that by placing more emphasis on evaluation of their clients' needs and capacities they could increase efficiency by focussing more clearly on those areas of assistance that could bring a maximum benefit to the client. Careful evaluation also clarified which clients the center had the capability to help and which would do better by being referred elsewhere.

A number of centers studied ran into administrative problems as they began to grow. Since nearly all the centers were established as consumer-run organizations their leadership and boards of directors were often more idealistic than proficient in skills of management and administration. In some cases this led to reorganization of the administrative structure and more formalization of operating procedures than there had been at the beginning. Most found it necessary to hire experienced professionals for some functions, such as directors, bookkeepers, and fund raising specialists. When this was necessary, an effort was always made to recruit these professionals from among those with physical disabilities whenever possible in order to remain true to the spirit of having the disabled served by the disabled.

As the centers began to grow and become an established part of the community, many of them became a vehicle whereby other private and governmental agencies

could provide necessary services to the disabled population. Seven of the twelve center directors interviewed made specific mention of special projects that they were involved in which were funded or staffed by other agencies. These projects dealt with such issues as accessibility and mobility, compilation of service directories and accessibility guides, community training on awareness of and sensitivity to disability, ombudsman-type services, special programs for the deaf, a drug program, and an adult day health program. The independent living centers were found to be ideal resources through which such projects could be channelled because of the expertise they were developing in dealing with the problems of the handicapped, their contacts with the disabled population, and their growing reputation as providers of services.

In general, keeping in mind that there was considerable variation in the details between centers, it could be said that the first phase passed through by the independent living centers under study was one of defining needs, locating funds and staff to start a center and developing a minimal service package. From there they moved on to expansion of services, reaching out into the community (both in terms of contacts and education) and dealing with the changes brought about in their original concept of their goals and functions by the realities of trying to provide the most effective services to their clients.

CURRENT OPERATIONS

All but one of the twelve independent living centers under study could be described as well established and offering a wide range of services to all physically disabled persons. The one exception to this generalization is a new center established in December of 1978 which has not yet had time to really get under way. However, even this new center has rooted itself firmly in the community by means of the limited services it provided before funds were available for establishing a full scale independent living program. There is no reason to doubt that this center will follow a pattern of growth and

development similar to that of the other organizations and become an integral part of the community's service resources for the disabled.

There are two factors which are common to all of the centers: their basic philosophical approach (disabled persons helping other disabled persons attain their maximum potential for independence) and their provision of services to all physical or sensory disabilities. While some centers offer more specialized help to the blind or deaf than others, no center specifically excludes any physical disability from its services. Persons with mental or emotional handicaps are generally referred to other agencies, although at least two centers will accept such individuals as clients if they are also physically impaired.

The service package offered by the independent living centers has expanded considerably since the centers first opened. The list that follows represents services currently being offered by the number of centers at which each is available. A comparison of this list with the one given earlier of initial center services illustrates the dramatic increase in service provision that has occurred in roughly three years of operation.

SERVICE	NUMBER OF CENTERS OFFERING
Attendants	12
Advocacy	12
Personal counseling	12
Information and referral	12
Housing assistance	10
Transportation	8
Special Deaf Services (interpreters, TTY, etc.)	7
Newsletter	5
Employment assistance	5

SERVICE	NUMBER OF CENTERS OFFERING
Group counseling	5
Special Blind Services (readers, braille writers, etc.)	4
Independent Living Skills training	4
Conferences and workshops	4
Wheelchair and equipment repair	3
Social, Recreational Programs	3
Ombudsman, Community Advocate	3
Equipment loans	2
Rap sessions	2

Defining a service unit as a service component multiplied by the number of centers at which it is available, the independent living centers under study have increased the volume of assistance from 612 service units to 2,016, not including as services such special projects as accessibility studies, youth development projects and special, short term training programs that have been provided.

As mentioned in the discussion of initial service offerings, different centers provide different levels of service under many of the general categories listed above. For example, housing assistance at one center may consist of nothing more than a listing of local accessible housing, whereas at another it might include advocacy in tenant disputes, assistance with modifications needed to make an apartment habitable for the disabled client and help in getting into special subsidized housing programs.

All of the centers are currently involved in community work at one level or another. Some of their activities which fall under this category are reciprocal referral agreements with other agencies, community education and awareness programs, and direct assistance in solving community problems that

relate to the disabled. An example of this last category is the center which provides consultation to city planners in connection with compliance with laws pertaining to accessibility regulations in public buildings.

Independent living center services are provided both at the center and by telephone. In some cases, staff are available for home visits when needed. Time taken to provide a service can range anywhere from a 30 second answer to a telephone inquiry to several months of counseling and advocacy to prepare the client for employability and find him or her a job.

Several of the centers offer distinctive programs which are worthy of mention. Some of these are: counseling for the family of the disabled client; a special outreach program in which a bilingual center staff person goes out into the Spanish-speaking community to locate people who might benefit from center services; an adult day health program which helps clients meet social needs while providing them with independent living skills; special rap sessions for persons with low vision; training in sign language for people who wish to work as interpreters for the deaf; self defense classes for the disabled; and a nursing home ombudsman, who deals with problems experienced by clients who are living in nursing or convalescent homes. One center's distinction lies in its emphasis and approach to services. The philosophy at this center is that many applicants for service, particularly those who are newly disabled, need emotional counseling to bring them to an acceptance of their condition before independent living services can do them any good. This center, therefore, addresses the emotional needs of its clients before taking on their physical needs.

As to annual number of clients served, this figure varied from an average of 100 per year to 2,000. However it is difficult to know precisely how many individuals these figures represent, since at some of the centers a count is

kept of new clients only while at others the count represents a service provided. Therefore, one client could conceivably be counted more than once. A rough estimate, based on the number of new applicants served at those centers which keep such records, would indicate that approximately 250 new clients are served annually by each of these twelve centers, on the average. This figure excludes short answers to routine telephone inquiries.

ORGANIZATIONAL STRUCTURE, STAFF AND FUNDING

The wide divergence between the California independent living centers becomes very apparent with an examination of staffing patterns at the centers. The only similarity seen is that each center is headed by a director, but even in this there is variance. Some centers have co-directors having equal authority and responsibility in administrative and program areas; some have these two functions divided between an executive director and an assistant director. In ten of the twelve centers, the original founders are still active as Board members or staff.

The number of full time, paid staff members varies all the way from 3 positions to 63, including staff at all levels: administrative, service delivery, clerical and special projects. The director position is a full time paid job in all but one of the centers. The service delivery jobs (e.g., counselors, advocates, drivers, etc.) are assigned differently at each center, sometimes being performed by full time personnel, sometimes by part time, paid staff and sometimes by volunteers. In general, there is a paid staff person assigned to each program element who either supervises paid or volunteer staff or carries out the function alone, depending on the size of the center and the demand for that particular service. Some full time staff members do double duty, taking responsibility for two program elements.

The twelve centers under study can be divided into two distinct forms of organization. Nine centers are completely autonomous corporations, directed

by their own elected board of directors. The remaining three centers are sponsored by another corporate body and it is the parent organization's board which makes the final decisions on the center's operations.

The Boards of Directors at the nine autonomous centers are composed of anywhere from 8 to 15 persons. In each case it is required that at least half the board members be disabled. The chain of command in decision making generally goes from the Board to the center director to the staff. Depending on staff size, there may be a supervisory level between the director and the service staff. The director has input into the Board's decision, but ultimately the center's policies are made by the Board.

In two of the autonomous centers the Board of Directors acts under direction of the center membership. In one of these centers, the Board or center director makes recommendations or proposals to the membership which must be ratified before they become center policy. In another, the membership elects the Board and makes its recommendations through member committees charged with various aspects of the program. Involved staff members also serve on these committees. Membership in these centers is open to all interested people in the community.

The decision making process in the sponsored centers is similar to that of the autonomous centers in that final decisions are made by a Board of Directors and passed on to the center director for implementation. The difference is that the Board in these cases is not a body charged only with operation of the center, but has responsibility for all the concerns of the parent body, including the center. In one case there is a center advisory board which brings recommendations to the parent board on issues affecting the independent living center.

The primary source of income for ten of the twelve programs under study is State Department of Rehabilitation Innovation and Expansion grant funds.

Income sources are listed below by the frequency with which they are utilized.

CURRENT INDEPENDENT LIVING CENTER FUND SOURCES

FUND SOURCE	NUMBER OF CENTERS USING
I & E Grant	10
CETA grants	7
Individual and business contributions	7
Other Department of Rehabilitation grants	6
Community fund raising events	6
City funds	5
County funds	5
Fees for services	5
United Way*	4
Membership fees	4
Charitable organizations	3
Regional Center fees**	3
Contracts, consultant fees	3
Sponsor support	2
Other State agencies	1
Community service organizations	1

* Community-wide combined charity drive.

** State regulated agencies charged with coordinating and providing services to the developmentally disabled.

All of the centers used a combination of these resources, from as few as four up to twelve. In general, the order of sources listed roughly reflects the dollar contribution made by each. A comparison of these funding sources with those utilized for initial funding (see page 8) demonstrates the extent to which the centers have broadened their financial base since they first opened.

CURRENT PROBLEMS

Even though the independent living centers in California have been successful to some degree in locating sources of financial support for their operations, funds for survival remains the primary problem source in nearly all the centers. Ten of the twelve centers under study receive a major percentage of their funding from State Department of Rehabilitation I & E grants. Eight of these three year grants will expire in 1979, leaving these centers with the necessity for finding alternate sources for a large percentage of their revenue. This problem is exacerbated by California's passage of a ballot initiative (Proposition 13) which severely cut back county and city funds by limiting property taxes. Because of this, funds at these lower governmental levels are more restricted than they had been in the past. The centers are therefore actively seeking financial support from private sources and attempting to work out systems whereby some of their services could be paid for through vendorization to governmental entities such as the Department of Rehabilitation and state supported medical payment plans (Medi-Cal). Some centers have applied for professional fund raisers (Community Resource Specialists) through the State Department of Rehabilitation.

Cutbacks in the federal CETA program have also been felt by some centers, which had some of their staff funded by this means. Some centers have had to cut back or discontinue special projects that had been funded or staffed through the CETA program.

Another problem which springs directly from the shortage of funds is inadequate staff to accomplish all the center's objectives. Nearly all the centers found it necessary to provide fewer services than those contained in their original proposals due to lack of funds to hire all the necessary staff. In nearly all the centers the staff are putting in long hours and still finding

themselves unable to meet all the needs of the disabled in their respective communities. While volunteer help is usually available, it is not as reliably consistent as regular paid staff.

An early problem that the centers encountered has still not been entirely overcome in all cases; that is the need for experienced and knowledgeable administrative staff. Most of the centers' board members and directors started with little or no experience in organizational management. As a result some programs went through periods of floundering and operating on a sort of hit or miss basis. In most of the centers where problems of this nature existed they were eventually recognized and largely solved. Usually it was simply a matter of hiring experienced professionals to fill key administrative positions. However, the early setbacks that occurred as a result of inexperienced leadership have not been entirely overcome in some cases.

The area in which the center operates presents special problems in some cases, mostly in connection with housing and transportation. Some of the centers are located in communities with a unique type of architectural design which presents more difficulty with accessibility than usual. And for those centers which serve a large geographical area, transportation is a serious problem. Clients who are far removed from the center have no way to get there - even if public transportation is available (and it often is not) it is not usually accessible to persons in wheelchairs and sometimes not even to people with less serious mobility problems, such as amputees with prosthetic devices or arthritics who are unable to manage high bus steps without assistance.

The question of accessibility is also raised in connection with locating space for the centers' operations. Several of the center directors mentioned the difficulty encountered in finding quarters that met all the criteria of being large enough at a reasonable cost and accessible, not only to the wheelchair bound but to convenient transportation.

Because the concept of independent living centers is so new, some center directors perceived a problem in dealing with established governmental agencies serving the disabled (such as state rehabilitation counselors). In some of the centers, a satisfactory system of mutual referrals has been set up and a good reciprocal arrangement exists between the "official" rehabilitation service providers and the independent living centers. But in other areas, traditional providers still have considerable reservations about the value of the services provided by the centers and their sometimes unorthodox approach to the rehabilitation of their disabled clients.

In general, however, it would appear that all the centers are working successfully toward solutions to these problems, with the possible exception of the financial one, which seems to be the most pressing of those that exist.

FUTURE PLANS

The majority of the center directors interviewed emphasized fund raising as their most immediate goal for the next year. They planned to concentrate a large proportion of their energies on finding new financial resources in all sectors of the community. Several had grant applications pending with both public and private sources at the time of the interviews, and at least half were working on a fee-for-service schedule to be used in vendorization of services through various public agencies.

The second most prevalent plan mentioned for the immediate future involved some form of reorganization, either of administrative details, staff, or service approach. Two of the centers are planning to move to new quarters as soon as a suitable location can be found.

Other plans for the future deal with expansion of services. Only two of the center directors were satisfied with their current array of services and had no plans in this area other than stabilizing the service package they had currently available. Most of the program components that were mentioned as

being in the center's future plans could be considered "standard" independent living services. That is, things that are seen as a usual part of a full scale program, such as wheelchair repair, legal or financial advocacy, or Activities of Daily Living (ADL) training. Some centers, however, had plans for some innovative programs or special projects that have not been tried in other California centers, such as setting up a transitional living facility (halfway house) or starting a disabled arts program. Some of the more ambitious undertakings were not projected for the immediate future, but were plans the center directors had for implementing only after the basic service package was well established. In all cases, the plans for new programs and expansion of current programs were dependent on the availability of staff and financing.

CLIENT CHARACTERISTICS

As mentioned earlier in this report, it was not possible to extract comprehensive data on client characteristics from center files due to the lack of collection of such information by many of the centers. However, it was possible, by taking as much information as was available at each center, to get a general outline which was sufficient to delineate trends within the various socio-demographic traits under consideration.

Some of the client characteristics the study staff had hoped to be able to tabulate were generally not available at any of the centers. These were job title and hours worked (for those who were employed), education or trade school attendance, secondary disability, and hours of attendant care required per week. None of the centers under study collected these data routinely. While it was possible in some cases to cull this information from notes on case records and inferences, there was still not a sufficiently significant amount of information available to merit reporting it here.

Table 1 gives a general breakdown of data that were available. As the table shows, the largest single category in nearly every case is "not available"; aside from that, there were generally enough available data to at least point to trends, if not to significant patterns. Detailed and uniform client characteristic data will be collected systematically in the next phase of the study, which will give a more definitive profile of the makeup of independent living center clients. A brief analysis of Table 1 by item follows.

Age: Over 75% of the records examined listed the client's age. The figures show that there were few people under 18 served by the center, which is accounted for by the fact that other services are generally available to children and adolescents through schools and other state agencies serving minors. As might be expected, the largest cluster among the age groupings was in the 18-35 category. These people have just "outgrown" the services available to minors and were often seeking such services as attendant care which would allow them to move from a parental home or assistance in furthering their education.

Sex: This variable was almost universally available, since even in those centers where it was not noted specifically on the records, it could be inferred from the client's name or references to "he" or "she" in the case history. As the figures show, independent living center clients were almost evenly divided between the sexes.

Race/Ethnic: Less than half of the records examined (47.6%) yielded information on race or ethnic origin. Of these, the breakdown brought no surprises: whites (other than Mexican) predominated, with Blacks and Mexican/Chicanos being fairly equally represented at 4.0% and 5.2% respectively. The "Other" category included American Indians and such designations as "Puerto Rican" and "Jamaican".

CALIFORNIA STATE DEPARTMENT OF REHABILITATION

TABLE 1 - Independent Living Center Client Characteristics
from a Random Sampling of Project Center Clients
Official Center Start Date to February 1979

Client characteristics as of intake date	Number	Percent	Client characteristics as of intake date	Number	Percent
AGE			LIVING ARRANGEMENTS		
TOTAL, ALL CLIENTS	1,025	100.0	TOTAL, ALL CLIENTS	1,025	100.0
Under 18 years of age	43	4.2	Alone	51	5.0
18-35 years	339	33.1	With spouse and/or children	73	7.1
36-55 years	191	18.6	With roommate(s)	18	1.7
Over 55 years	215	21.0	With paid attendant	14	1.4
Not available	237	23.1	With parents and/or siblings	57	5.6
			Board and care facility, hospital	61	5.9
SEX			Combination of above	9	.9
TOTAL, ALL CLIENTS	1,025	100.0	Not available	742	72.4
Female	515	50.2			
Male	494	48.2	EMPLOYMENT		
Not available	16	1.6	TOTAL, ALL CLIENTS	1,025	100.0
RACE/ETHNIC BACKGROUND			Yes	52	5.1
			No	375	36.6
TOTAL, ALL CLIENTS	1,025	100.0	Not available	598	58.3
Black	41	4.0			
White (other than Mexican)	375	36.6	MARITAL STATUS		
Mexican/Chicano	53	5.2	TOTAL, ALL CLIENTS	1,025	100.0
Asian	15	1.5	Never married	122	11.9
Other	3	.3	Married	74	7.2
Not available	538	52.4	Separated	11	1.1
			Divorced	35	3.4
DR CLIENT STATUS			Widowed	17	1.7
TOTAL, ALL CLIENTS	1,025	100.0	Not available	766	74.7
Not a client	498	48.6			
Currently a client	235	22.9			
Not available	292	28.5			

(continue)

CALIFORNIA STATE DEPARTMENT OF REHABILITATION

TABLE 1 - Independent Living Center Client Characteristics
from a Random Sampling of Project Center Clients
Official Center Start Date to February 1979
(continued)

Client characteristics as of intake date	Number	Percent
REFERRAL SOURCE		
TOTAL, ALL CLIENTS	1,025	100.0
Family and friends	82	8.0
Social worker	27	2.6
Rehabilitation counselor	56	5.5
Medical personnel	52	5.1
Communications media	37	3.6
Other:		
Private agency	79	7.7
Public agency	71	6.9
Center outreach program	47	4.6
Student organization, school	31	3.0
Other unspecified agencies	29	2.8
Lawyer	5	0.5
Not available	509	49.7
SERVICES FROM OTHER AGENCIES		
TOTAL, ALL CLIENTS	1,025	100.0
DR	207	20.2
DR and other agencies	18	1.8
Private rehabilitation	40	3.9
Social services	22	2.1
Other	26	2.5
Not available	712	69.5

Client characteristics as of intake date	Number	Percent
INCOME SOURCE		
TOTAL, ALL CLIENTS	*	*
Employment	48	4.7
Social Security/Public Assistance	614	59.9
SSI	211	20.6
SSDI	47	4.6
Other Social Security benefits	133	13.0
Combined Social Security benefits	44	4.3
Other specified public assistance	21	2.0
Unspecified public assistance	158	15.4
Veterans benefits	33	3.2
Private insurance/pension	76	7.4
Family/personal	74	7.2
Other	14	1.4
No income	5	--
Not available	306	29.9
MAJOR DISABILITY		
TOTAL, ALL CLIENTS	1,025	100.0
Sensory	133	13.0
Orthopedic	532	52.0
Mental	36	3.5
Other	183	17.8
Multiple	45	4.4
Not available	96	9.3

* Total number of clients and percents will not add to 1,025 and 100.0 respectively because there was often more than one source of income.

Department of Rehabilitation client status: Those who were known to be clients of the State Department of Rehabilitation were outnumbered more than two to one by those who were not Department clients. This is probably explained by the nature of the services offered by these two entities. While Rehabilitation is focussed on vocational assistance, the independent living centers provide services that are not related to employment and are not generally available elsewhere.

Living arrangements: This item was also very sparsely available. None of the centers collected specific information on living arrangements. Information was found in 27.6% of the records by extracting it from case narratives, or in some cases from the client's address when it was given as a hospital or nursing home. As Table 1 shows, the information available showed no significant trends.

Employment: The question of whether the client was employed was answered on only 41.7% of the records. Fifty two of these 427 people (5.1%) indicated that they were working, either full or part time. There was no information given as to the number of hours they worked weekly or the nature of the jobs they held.

Marital Status: Here again, there was very little information available. Only 26% of the records examined gave any indication of marital status. Of these, most were never married (11.9%). Percentages of those currently married and previously married were similar, at 7.2% and 6.2%, respectively.

Source of referral to the center: Clients were referred to, or found out about the centers in a variety of ways. While no one source stood out as providing a major means of referral, the family and friends category was most prevalent, followed closely by private community agencies. The sources listed as "Other" and designated "private agency" included such organizations as United Cerebral Palsy association and other private, non-profit community groups. Under "public agency" are included such things as county mental

health agencies, Crippled Children's Services and other publicly funded social programs.

Services from other agencies: Only 30.5% of the records examined gave any indication of whether the client was receiving services from other agencies besides the independent living center. Of the other agencies listed, the Department of Rehabilitation was mentioned most often, with the balance of the replies fairly evenly divided among the remaining categories with small percentages.

Income: By far the largest source of income reported by the independent living center clients was some form of public assistance (59.9%). The most prevalent form of assistance that was specified was Supplemental Security Income from the Social Security Administration, with other Social Security assistance (SSDI, OASDI) making up the next largest category. In some centers a record was kept only of whether or not the client received public assistance of any kind. These cases were recorded as "Unspecified Public Assistance". Other public benefits included county and state programs, and the listing of "Combination" benefits represents those who received both Social Security Administration payments and other public funds.

Income from employment accounted for only 4.7% of that listed. Private Insurance and pensions provided about the same percentage of income sources as family or personal income. Information on source of income was fairly widely available, being not given on less than a third of the records reviewed.

Data on income amount was very scattered and inaccurate, sometimes listing only public assistance figures with no indication as to whether this was the client's sole source of income. These figures, therefore, were not tabulated.

Major Disability: Information on the nature of the client's disability was almost universally recorded in the center files, although not in any uniform way. In some centers, disabilities were recorded precisely, either by disease (e.g., polio, cerebral palsy) or nature of impairment (e.g., quadriplegic, blind). However, in some cases the categories were more general, such as "mobility impairment" or "semi-ambulatory". Orthopedic disabilities were by far the most prevalent, representing 52% of those recorded. Included in this broad classification were those shown as "quadriplegic" or "paraplegic", non-specific mobility limitations, and specific conditions (e.g., multiple sclerosis, arthritis, polio, amputation).

Sensory disabilities accounted for 13% of those recorded. These included all degrees of vision or hearing loss.

The "Other" category included disabilities related to eight general types of conditions: those involving organ systems (heart, kidneys, etc.), convulsive disorders, cancer, neurological problems (brain damage, stroke, etc.), blood or circulatory disorders, respiratory illness, speech impairment, and unspecified spinal disorders.

The centers' emphasis on physical and sensory disability accounts for there being only 3.5% represented in the categored labelled "mental", which includes mentally retarded, mentally ill, drug or alcohol abusers and those with learning disabilities.

3. Staff Changes

With the adoption of the new research design, an entirely new staffing pattern was developed. These revisions were submitted for approval in June, 1978 and an amended grant award reflecting these changes was issued on July 20, 1978. The Project staff now consists of the following:

Project Director (Research Manager II): Harry Greenblatt

Project Coordinator (Research Program Specialist I): C. Eugene Hiehle

Administrative Assistant: Barbara Jones

Research Analyst: Janet Roberts

Research Analyst: (vacant)

Statistical Clerk: Paulette McQuillan

The Administrative Assistant serves primarily as a Research Analyst, performing the same field and analytical assignments as the other Research Analysts on the staff. In addition, she holds responsibility for arranging meetings, assisting the Project Director in administrative paperwork, and filling the office management function for the project.

Vitae for new key personnel are given below:

PROJECT DIRECTOR - Harry N. Greenblatt

Personal: Born August 13, 1921, Warsaw, Poland

Education: A.B., Sociology, 1948; San Francisco State College

M.A., Sociology, 1951; University of Michigan, Ann Arbor

(Ph.D. Candidate, Sociology, University of Michigan, 1951-1954, completing all course work and doctoral examinations.)

Experience:

1955-1972 - Served as an Associate in research on various projects at the California State Department of Public Health.

Designed, coordinated and conducted research studies in maternal and child health, venereal disease, marriage and divorce, and alcoholism.

Experience: (continued)

1972-1976 - Research Manager II (Social/Behavioral), Human Population Laboratory, California State Department of Health.

Served as Senior Social Research Analyst, planning, organizing and directing epidemiologic surveys in social health. Organizing and carrying out the analysis of relationships between dimensions of social health and numerous independent variables including demographic, behavioral, psychological and other social and cultural factors.

October 1976-present - Chief, Research Section, California State Department of Rehabilitation

Supervise and administer Research and Research Utilization staff within the State Department. Plan, organize and design research studies pertaining to provision of vocational rehabilitation services to the disabled. Provide assistance and consultation to other departmental units on survey research, evaluation, and questionnaire construction. Act as Departmental liaison to other agencies in matters pertaining to research.

A listing of publications and papers is available on request.

PROJECT COORDINATOR - C. Eugene Hiehle

Personal: Born January 24, 1948, Chicago, Illinois

Education: B.A., Philosophy, August 1971; University of Illinois, Chicago

M.A., Psychology, June 1975; California State University, Los Angeles

Experience:

June 1969-June 1972 - Research Assistant, Professor John B. Durant, Evanston, Illinois.

An academic research position requiring an extensive review of the literature in history publications to discern a trend in the use of psychological analysis and typology by historians. Also did research in

Experience: (continued)

educational planning and growth, statistical analysis, survey research and classroom work.

August 1975-August 1976 - Vocational Supervisor/Counselor, Los Angeles Job Corps

August 1977-March 1979 - Research Analyst II, State of California Department of Alcohol and Drug Abuse, Sacramento, California

An associate level position which involved leading an evaluation team of 2-6 persons which conducted a comprehensive, week-long "process evaluation" of drug abuse programs.

PUBLICATIONS:

Hiehle, G. and McDonald, C., A Profile of California Drug Treatment Programs. State of California, Department of Health; April 18, 1978. 11 pps.

Hiehle, G., McDonald, C., and Wilson, T., Drug Treatment in California: The Process Evaluation Study. State of California, Department of Alcohol and Drug Abuse; December, 1978. 173 pps.

4. Inventions and copyrights: None

5. Cost benefit findings: None

C. PROPOSED ACTIVITIES

1. Work Plan for Next Grant Period (April 1979 - April 1, 1980)

The work that the study staff hopes to accomplish in the coming year conforms to the project's revised time line (see Appendix I). It is anticipated that the tasks outlined there for the coming year will be completed, assuming that the vacant Research Analyst position can be filled in April and no unforeseen difficulties occur which might stall the progress of the study.

Generally then, the study staff plans to proceed as follows:

April - June, 1979. Develop survey instruments

During this period the study staff's primary concern will be the development of the instruments that will be needed for subsequent phases of the study. These instruments will be designed to make measurements in five distinct areas:

1. Role activities of staff.

   The project staff will arrange to interview key staff at the centers in order to draw up in-depth descriptions of the functions they perform in their respective capacities. Interviews will be held with volunteers as well as with regular, paid staff members.

2. Examination of organizational problems.

   This aspect of the study will look at such issues as funding, staff turnover, administration, and relationships with referral agencies.

3. Client needs assessment.

   The purpose of this measurement will be to ascertain the service needs of the disabled as seen both by the providers of the services and the clients. Analysis of data thus gathered will show whether the goals of the providers are realistic in terms of meeting felt needs of clients.

4. Client gains measure.

   A primary goal of the project is to determine whether the independent living centers' services have a demonstrable impact on the disabled individuals they serve. Client gain measures will include (but not be limited to) three major categories: health care, personal care, and earnings disincentives. The scales will

be designed to measure any gain that the clients experience that can be directly attributed to the services the center has provided. In order to assure that the client gain scales to be used in the study are feasible for field administration, a pretest of the instrument will be conducted with a small sample panel of clients. If this pretest demonstrates any problems in collection or interpretation of the data, revisions in the form will be made as appropriate.

5. Client characteristics

Socio-demographic items will be included in a client questionnaire that will yield a comprehensive view of these characteristics through the client sample.

In designing these instruments, an effort will be made to combine the areas of inquiry so as to minimize the number of times respondents need to be approached. (Project staff hope to be able to gather staff and organizational data through one interview form and design another that can be administered to clients that will cover all the information to be asked of them.)

July - August, 1979

It is anticipated that the analysts will be able to start interviewing center staff for the process evaluation phase of the study in June. These visits will continue through July and data should be ready for analysis by August.

The pilot version of the gains scale should be ready for pretest by the middle of July. It is planned to administer the pretest instrument at a center not included in the study sample.

September - December, 1979

Analysis of preliminary data from clients is expected to begin in late September, after a second application of the gain scale early in the month.

In mid-December the final version of this measure should be ready for application.

January 1980 - March 1980

This period will be largely taken up with preparation of the project's second progress report, which will include a detailed description of center operations drawn from the process evaluation instrument.

2. Proposed changes in project: None

3. Research Utilization Plan

a. Relevance of the Project to the rehabilitation field.

Outcomes of this research will be useful to both consumers and providers of services to the disabled. Copies of reports prepared as part of the first year's work have been sent to the individual centers to provide them with an organized history and description of their activities which they can use in the preparation of funding grants and solicitations. Each center has been provided with a breakdown of its own client characteristics as compiled from the sample drawn for the Project. These data will be useful to the independent living centers in two ways: to give them a broad picture of the sorts of people who apply to them for services, which will enable center staff to determine whether any program changes or shifts in emphasis might be indicated; and, to provide them with the sort of representative demographic data that is required by some potential funding sources.

However, it is not only the independent living centers themselves who will benefit from having the information the Project will make available. Data from this study will be useful to professionals in various disciplines who provide services to severely disabled persons (e.g., medical, social welfare, transportation planners) in giving them some clear guidelines on which to base future planning.

Additionally, the instruments and scales developed as part of the Project are expected to have wide applicability to all research into problems and needs of severely disabled people, especially the client gain scale. Measurement of client gain has long been given a high priority in the rehabilitation field. If this Project can create such a scale with tested validity it will be of immeasurable value to those who are working to improve rehabilitation services to the disabled.

As for the rehabilitation clients, they will be served by a comprehensive knowledge of what independent living centers have to offer them, as well as by awareness of the shortcomings of the services offered by the centers. They will thus be enabled to make more intelligent choices as to where their felt needs might best be met.

b. Changes that might be suggested as a result of Project outcomes.

Independent living centers are an alternative approach to helping disabled people function in society with a minimum of outside assistance. In the event that this project shows that the concepts and methods by which the centers operate are more effective in helping the disabled to lead productive, non-dependent lives, it will mandate a new approach to services to the disabled. If the premises on which these centers operate are shown to produce a greater number of functioning, productive people than methods used heretofore it will be obviously beneficial to society in general, not just the disabled population, to adopt those premises in the provision of rehabilitation services. Current emphasis in rehabilitation is on vocational services. The independent living centers set higher priorities on the client's social and day to day living needs. Some of their services are prevocational or directly related to employment, but for the most part they are concerned with meeting whatever needs their clients might feel whether they have any relationship to employment or not. Under

this philosophy, a client need not be placed in a job to be considered rehabilitated -- s/he need only be enabled to function in the community with minimal assistance from others. Should this research show this to be a valid concept in terms of the alleviation of human suffering and benefit to the society in lifting some of the burden of meeting the survival needs of the disabled, broad policy and program changes would have to be made. These changes could take the form of restructuring existing public programs along the lines taken by the independent living centers or having public funds diverted into support and expansion of independent living centers.

c. Plan for dissemination of research results.

It is anticipated that results of this research will be disseminated on at least three levels: to public rehabilitation professionals; to private agencies serving the physically disabled; and to interested members of the general public. Public rehabilitation professionals will be notified of the outcomes of this research by the publication of monographs under the auspices of the California State Department of Rehabilitation. These monographs will be distributed to all state rehabilitation agencies as well as receiving wide distribution within the State of California. Additionally, they will be sent to Research and Training Centers throughout the country.

Any scales or measurement instruments created as a part of this research will be provided to other researchers, who will be notified of their availability through the same sources as the monographs are distributed.

The independent living centers in California are receiving regular reports of findings as the Project progresses. Additionally, these findings will be made available to other private agencies serving the

disabled and to groups or individuals interested in starting new independent living centers.

Articles based on outcomes and findings of this research will be submitted for publication in appropriate journals dealing with rehabilitation and services to the disabled.

Cost estimates for printing and distribution of monographs in the upcoming grant year are as follows: printing - $350 maximum; postage - $300. These costs can be absorbed within present budget limitations and will not require any increase in expenditures.

APPENDIX A

Statements of Research Objectives

Independent Living Research Study - R&D Project, 15P-59045

December 1976 Statement in Original Application	Augmented Statement as of June 1978
A. To identify and describe the developmental patterns of independent living centers.	A. To identify and describe developmental patterns of independent living organizations (ILOs) relative to: 1. Group and organizational structure 2. Leadership and management 3. Goal formation and expression 4. Environmental pressures 5. Inter-organizational relations
B. To describe the social and recreational needs of the severely disabled clients of the independent living centers.	B/C. To describe the socio-demographic characteristics of the severely disabled people (both developers and users of services) in ILOs; to describe their service needs and the extent to which the services provided by ILOs and other agencies in the community are able to meet estimated service needs: 1. Social and recreational needs 2. Advising and counseling needs 3. Housing and personal attendant needs 4. Mobility and transportation needs 5. Financial aid and social service need 6. Advocacy and legal needs 7. Medical, physical and occupational therapy needs (including appliances) 8. Vocational counseling, education, training and placement needs
C. To describe the characteristics of the severely disabled clients of the independent living centers, with emphasis on their service needs and the degree to which their local community agencies are able to meet their needs.	
D. To describe the functions of "peer counselors" within the independent living centers.	D. To describe the role-activities of service providers within ILOs, including: 1. Peer counseling/advising providers 2. Developers and providers of housing and attendant referrals 3. Advocacy providers 4. Training providers 5. Other service providers

(Continued)

Independent Living Research Study - R&D Project, 15P-59045

December 1976 Statement In Original Application	Augmented Statement as of June 1978
	E. To describe apparent outcomes of and impacts on the participants from their activity in ILOs in the areas of: 1. Health care 2. Personal and household care 3. Social relations and participation 4. Vocational preparation and placement 5. Economic support
	F. To describe ILO activities which respond to and cope with organizational problems of: 1. Financial support 2. Recruitment of staff 3. Leadership, organization and planning 4. Internal communication and relations 5. External communication and relations

APPENDIX B

INDEPENDENT LIVING PROJECT RESEARCH STUDY

INITIAL INTERVIEW TOPICS

1. How long this center has been going as such; what stage of development the respondent(s) see its being at in their own terms; what kind of people it especially serves or doesn't serve.
2. What was and is going on organizationally in the area on the part of disabled people as a background for the center organization; the agency or organizational base, if any, on which it started.
3. The founders and how they got together; description and some biography of the founders.
4. What activities or services came first chronologically; subsequent additions; changes in direction or emphasis, if any.
5. What change, impact, needs to fill or other difference the center can make and wants most to make.
6. Activities currently offered and available; community advocacy events now in progress; number and frequencies.
7. The people who do the work: staff, volunteers, officers, committees, board members; the hours and frequency of these people's work; pay or other compensations.
8. How decision making and problem solving needs get taken care of; examples, especially how hard ones are handled.
9. What an ILP has to be careful of, pitfalls discovered, false directions and misinformation to beware.
10. How the bills get paid: ways to put together funding that have and haven't worked; the current basis for staying afloat and ideas being developed.

APPENDIX C

CRITERIA FOR CHOICE (of 12):

VARIATION IN:

1. Rural-suburban-urban
2. City size
3. Time established
4. Age of majority of clients
5. Autonomous or sponsored

(?) 6. "Special" disability emphasis

(?) 7. Economic level of clients

(?) 8. Range of services

(?) 9. Source of funding
   --original
   --current

(?)10. Number of clients served

(?)11. Size of staff

(?)12. "Catchment" area
   --number of political jurisdictions

Suggested Site Selections - Independent Living Research Study

Twelve Independent Living Centers have been tentatively selected as primary sites for the Independent Living Research Study. Choice of these sites was based on the following criteria:

1. With study staff cut back to 3 analysts, it was felt that the maximum number of sites to be studied in depth would be 12, assigning 4 centers to each analyst.

2. In order to obtain a representative sample of ILPs that would encompass their various characteristics, such as funding sources, types of services offered, area served, etc., such characteristics were listed (insofar as data was available) and choices made to cover as wide a range of differences as possible.

3. Representation from all areas of the state was also taken into consideration with half of the choices being made in the northern end of the state and half in the south. In each of these geographic divisions five well established ILPs and one fairly new one were chosen.

APPENDIX D

IL CENTER INTERVIEW WORKSHEET

1. First organizational efforts (date and description)

2. Official opening as an ILP

3. Organizational and other activity going on among disabled people in the area

WORKSHEET - 2

4. Other groups or organizations which helped get Center started

5. Initial funding

6. Founders: Brief biographical sketch

Why he/she started an IL Center

Still active in the Center?

WORKSHEET - 3

7. First services offered and why these were chosen

8. Subsequent services added; when and why

9. Services dropped; when and why

10. Stages passed through in development; description of current stage

WORKSHEET - 4

11. Center distinctions: People served (or not served)

Approach or emphasis

Types of activities or services

12. Services offered: Types (including referrals)

Numbers

WORKSHEET - 5

13. Staff: Paid (full/part time), volunteer, outside funded, disabled/able-bodied

14. Description of service area

15. Organization - autonomous or sponsored

16. Chain of command - decision process

17. Current funding

WORKSHEET - 6

18. Types of records kept

19. Future plans

APPENDIX E

Demographic and Health Status Characteristics

Demographic

- Age
- Sex
- Race-ethnic
- Length of stay in county, California

Living style

- Married/single
- Family composition
- Living arrangements
  - i.e., with parents, alone, with attendant, with own family, with roommate(s), institutionalized

Economic

- Income
- Source of income
- Employed/not employed
- Job title
- Public assistance

Independent Living Programs

- How long with ILP
- Referral source

Other Agencies

- Department of Rehabilitation
  - Past, current, or never a client
- Services from other organizations, e.g., V.A., Social Security, Easter Seals, Cerebral Palsy Associations, etc.

Health Status

- Disability
- Any other disabilities
- Attendant Care
- Mobility

Education

- Education level completed
- Any specific education, e.g., vocational, business, etc.

Communication

- Ability to communicate, e.g., sign, foreign language

Research Section
10/78

APPENDIX F

CLIENT DATA

1. Intake date:

   (7-12) __ __ / __ __ / __ __

2. Date of birth:

   (13-18) __ __ / __ __ / __ __

3. Sex:

   (19)
   ___ 1. Female
   ___ 2. Male
   ___ 3. Not available

4. Race-ethnic background:

   (20)
   ___ 1. Black
   ___ 2. White (other than Mexican)
   ___ 3. Mexican/Chicano
   ___ 4. Asian
   ___ 5. American Indian
   ___ 6. Not available

5. Residence:

   (21-28) City: _____
   (29-30) County: __ __

6. Marital status:

   (31)
   ___ 1. Never married
   ___ 2. Married
   ___ 3. Separated
   ___ 4. Divorced
   ___ 5. Widowed
   ___ 6. Not available

7. Living arrangements:

   (32)
   ___ 1. Alone
   ___ 2. With spouse and/or children
   ___ 3. With roommate(s)
   ___ 4. With paid attendant
   ___ 5. With parents and/or siblings
   ___ 6. Board and care facility
   ___ 7. Not available
   ___ 8. Other (please specify):
   (33-40) _____

8. Income:

Source (check all that apply)		Amount (monthly)	
(41) ___	1. Employment	(42-45) $	__ __ __ __
(46) ___	2. SSI	(47-49)	__ __ __
(50) ___	3. SSDI	(51-53)	__ __ __
(54) ___	4. State/county benefits (55-62) (specify): _____	(63-65)	__ __ __
(66) ___	5. Veteran's benefits	(67-69)	__ __ __
(70) ___	6. Private insurance	(71-73)	__ __ __
(74) ___	7. Family	(75-77)	__ __ __
(78) ___	8. Amount given, no source	(Card 2) (7-10)	__ __ __ __
(11) ___	9. Not available		

9. DR Client Status:

   (12)
   ___ 1. Never a client
   ___ 2. Currently a client
   ___ 3. Past client
   ___ 4. Not available

10. Employed:

(13) ___ 1. Yes
___ 2. No
___ 3. Not available

IF YES:

(14-19) Job title: _____

How long:

(20-21) __ __ years
(22-23) __ __ months

Hours:

(24) ___ 1. Full-time
___ 2. Part-time

11. Education level:

(25) ___ 1. 0-8 years
___ 2. Some high school
___ 3. High school graduate
___ 4. Some college
___ 5. College graduate
___ 6. Post graduate
___ 7. Not available

12. Trade, Business, Vocational school:

(26) ___ 1. Yes
___ 2. No
___ 3. Not available

13. Major Disability:

(27-34) _____ (description) (35-37) __ __ __ (code)

14. Secondary Disability:

(38-45) _____ (description) (46-48) __ __ __ (code)

(49-56) _____ (description) (57-59) __ __ __ (code)

15. Average hours of attendant care per week if needed:

(60-62) __ __ __

16. ILP referral source

(63) ___ 1. Family/friends
___ 2. Social worker
___ 3. Rehabilitation Counselor
___ 4. Medical personnel
___ 5. Communications media
___ 6. Not available
___ 7. Other (please specify)
(64-71) _____

17. Services from other agencies:

(72) ___ 1. Yes
___ 2. No
___ 3. Not available

IF YES, please specify agencies

(73-80) _____

APPENDIX G

Client characteristics	Independent living centers											
	1	2	3	4	5	6	7	8**	9	10	11	12**
Age	✓	*	✓	✓	✓				✓	✓	✓	
Sex	✓	✓	✓	✓	✓				✓	✓	✓	
Race-Ethnic			✓	*	✓					✓	✓	
Residence: City	✓	✓	✓	✓	✓				✓	✓	✓	
Residence: County		✓	✓	✓	✓				✓	✓	✓	
Residence: Length of time												
Marital Status	*	*	✓	*	✓				✓		✓	
Living Arrangement		*	✓	*					✓	✓	✓	
Income: Source	just PA		✓	✓	✓				✓		✓	
Income: Amount					✓				✓		✓	
Employment: Job	*			✓					✓		✓	
Employment: How long				*					✓		no	
Education	no			*					✓		✓	
Disability	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Hours of attendant care per week	*	✓	✓	*		✓	✓		✓	✓	*	
ILP Referral Source	*	*	✓	✓	✓	✓	✓		✓	✓	✓	
DR client	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Services from other agencies	*			*			✓			✓		

* Inconsistent

** Not known

PROBLEM: Desired client characteristics data are not available in the records at all centers. It is therefore impossible to extract this information uniformly for the first report to HEW.

ANALYSIS OF AVAILABLE ALTERNATIVES

In deciding what sort of data collection to settle for in the absence of the ideal, several objectives were used for screening alternatives. Some of these objectives were considered "musts"; others were "wants" (i.e., desirable, but not absolutely essential). Any alternative that failed one "must" test was discarded immediately.

The "musts" were:
- Data gathering and analysis completed by 3/1/79
- Method involves no increase in staff
- Client confidentiality maintained
- Minimum disruption of center activities

The "wants" were:
- As wide a client sample as possible
- As wide a selection of variables as possible

The alternatives considered are discussed below, showing how well each met these criteria.

ALTERNATIVE 1: Minimal data

Data on type of disability and service provided is available from all centers' records. This data could be extracted by allowing DR Research Study staff access to center records to make a simple tally of these two items. This could be accomplished by one analyst and one clerk working one day at each center.

This method meets all the "must" objectives, but would yield very little in the way of client characteristics data. We would end up with nothing more than a distribution of center clients by disability.

ALTERNATIVE 2: Random sample questionnaire

The self-coded form that has already been designed could be administered with minor alterations to a randomly selected cross section of center clients. This would involve allowing either Study staff or someone on the center staff to pull a list of names and addresses from the center files, approaching these individuals and asking them to complete the questionnaire.

This idea was discarded as infeasible as it could not possibly be done by the deadline.

ALTERNATIVE 3: Extract data from I & E Data Collection Form

This would involve compiling data available at DR and, for those subjects who are DR clients, extracting as much additional information as is available from the Client Master File. This would yield comprehensive data on DR clients only.

While this plan would have the advantage of not having to bother the centers at all to get data, it has the serious disadvantage of including a biased sample (i.e., Rehabilitation clients only).

ALTERNATIVE 4: Intake survey

Have the client characteristics questionnaire (or those portions of it not covered on the center's own intake forms) filled out at the center for each new client for one month.

This alternative was discarded on two grounds: it would require too much assistance from center staff and it was doubtful that it could be done by deadline.

ALTERNATIVE 5: Take a sample from what's available

All available data on 100 randomly selected clients would be collected from each center's files by the study staff, filling in as many of the variables as are recorded in the records. This could be accomplished in two days (maximum) at each center by one analyst and one clerk. The compilation of this data would be footnoted by each item to indicate the number of centers from which it was available.

This plan was tentatively selected as meeting all the "must" objectives and most closely meeting the "wants". While it would yield scattered data, there would be more information from a wider sample than any of the other alternatives.

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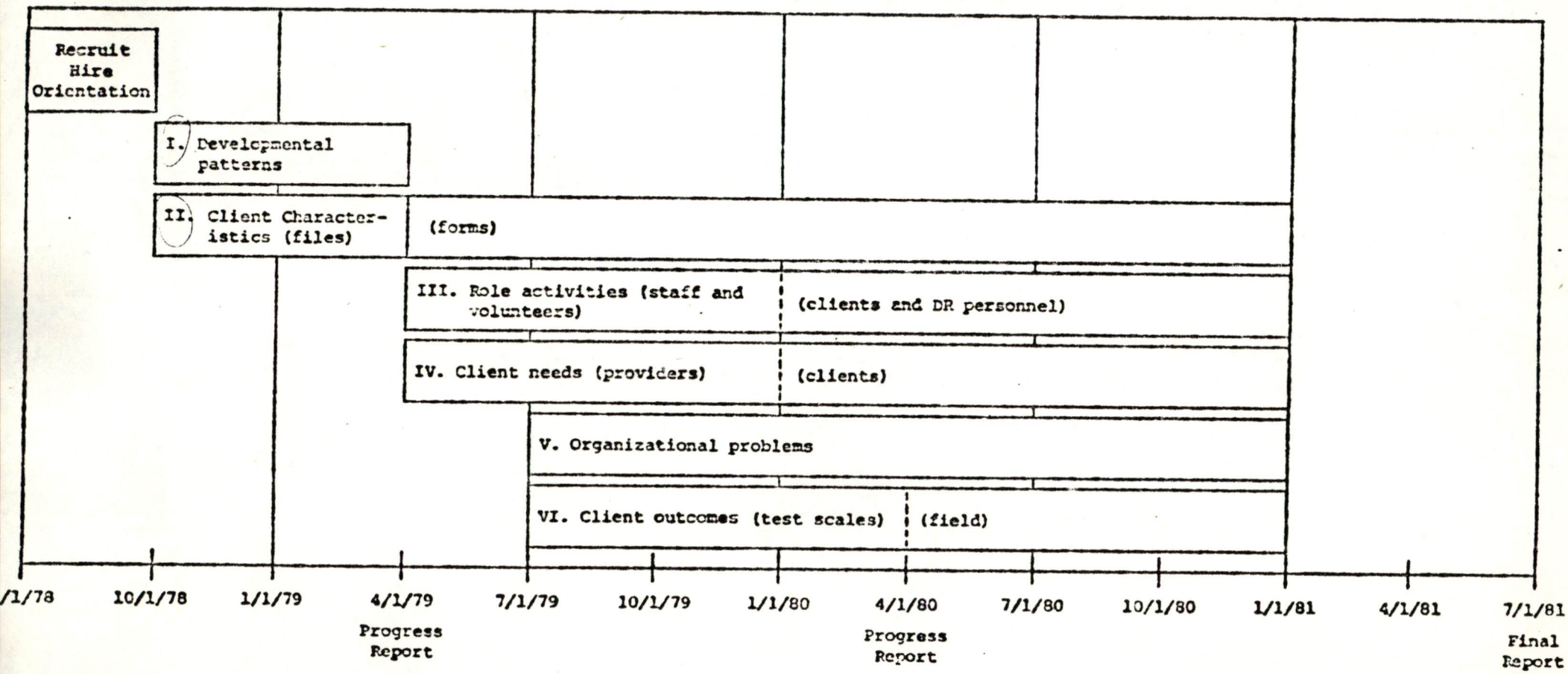
TIMELINE: INDEPENDENT LIVING RESEARCH STUDY



Research Section
August 14, 1978

Independent Living Research Study - First Progress Report

EXECUTIVE SUMMARY

The first year of the Independent Living Research Study was devoted to planning and laying groundwork for initial field interviews and gathering historical and descriptive data from twelve independent living centers statewide. A capsule of the descriptive data gathered from the centers is attached.

Data were collected in two steps by two research analysts. The historical and descriptive information came from focussed interviews with center directors and staff. Client characteristics data were taken from files at the centers. Because of the wide variation in record keeping systems between centers, it was not possible to obtain all the information on client characteristics that the study staff had originally planned to collect.

Historically, it was found that the majority of the centers began their organizational activities in 1975 and that this work was undertaken by disabled individuals. Nearly all had help from other community sources and/or the Department of Rehabilitation in their initial organizing efforts.

Number of services offered originally ranged from two to eight, with the most pressing needs having been in attendant problems, advocacy, and counseling. As the centers grew, the service package expanded to include 18 separate services, four of which are offered at all of the centers (attendants, advocacy, counseling, information/referral). The amount of services rendered has more than tripled in the average three years of center operations.

Not only did the service package expand with growth of the centers, so did their involvement in the community. All have developed close ties with various organizations and agencies in their communities, both public and private. These ties are manifested in mutual referrals and assistance in fund raising.

Getting an accurate count of clients served by the centers was complicated by the fact that some centers counted services provided while others counted individuals served. Figures produced, therefore, ranged from 100 to 2,000 annually. An estimate of the number of clients drawn from available data yielded an average of 250 new clients a year per center.

Organization and staffing patterns of the centers are summarized on the attachment. Generally, each staff member serves one or more program areas, either providing services, supervising those providing services, or both.

The biggest problem now facing the independent living centers is that of funding. With Department of Rehabilitation I & E grants nearing the end of their term, centers which have been largely supported by this means are searching out other sources of financing, some with the help of Departmental Community Resource Specialists. CETA program cutbacks have also put a crimp in some center budgets. Other problems that were mentioned were lack of administrative and managerial skills, and dealing with other agencies serving the disabled.

In the area of future plans, primary emphasis was given to fund raising efforts. Other plans mentioned included administrative reorganization and expansion of services.

Client characteristics data that were drawn from center records are summarized on pages 26 and 27 of the report. A totally accurate picture of client characteristics was not obtainable because of the variation in record keeping systems between centers. The figures given represent the best information available from a sample of 100 cases per center at ten centers. A composite average center client drawn from this limited data would be a white female between the ages of 18 and 35, who is orthopedically disabled, not a client of the Department of Rehabilitation, and whose primary source of income is some form of public assistance, primarily from the Social Security Administration.

The project is currently keeping up with its time lines. Activities proposed for the next grant year are based on the expectation that the project will proceed as currently designed. These activities will be: development and administration of survey instruments to study client characteristics, client needs and client outcomes; and field interviews on role activities of staff and organizational problems.

The research utilization plan for study outcomes includes dissemination of data collected to rehabilitation professionals at all levels by means of monographs and journal articles. Additionally, scales and instruments developed in the course of the study will be available for use by other researchers.

BJ/RS 032379

Capsule Description of 12 Independent Living Centers Under Study

Primary source of initial funding	State Department of Rehabilitation Innovation and Expansion Grants (9); City or County grants (3).
Current funding sources (each center uses from 4 to 12 of these sources)	Department of Rehabilitation I & E grants (10); CETA grants (7); contributions (7); other Department of Rehabilitation grants (6); community fund raising (6); city and county funds (5); other fees and grants (1-5).
Initial services offered	Attendant-related (9); advocacy (9); counseling (9); information and referral (8); housing services (6); special deaf services (2); independent living skills training (2); transportation (2); and employment, education, recreation, wheelchair repair (1 each).
Services currently offered	Attendant related (12); advocacy (12); counseling (12); information and referral (12); housing (10); transportation (8); special deaf services (7); employment (5); special blind services (4); independent living skills training (4); conferences and workshops (4); wheelchair and equipment repair (3); social, recreational programs (3); ombudsman, community advocate (3); equipment loans (2); rap sessions (2).
Types of disabilities served	All centers provide services to any person with a physical or sensory disability. Mentally disabled persons are generally referred elsewhere, except at 2 centers where they are accepted if also physically disabled.
Number of clients served	On an average, roughly 250 per center per year.
Number of staff (full-time, paid)	Range: between 3 and 63; most have around 15 or 20.
Description of area served	4 urban; 5 urban/suburban; 1 largely rural; 1 suburban; 1 mixed.
Organizational structure	All are incorporated; 9 are autonomous, 3 are sponsored and under the direction of a larger organization.
Board of Directors structure (9 autonomous centers)	8 to 15 persons, at least half of which are physically disabled.

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