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Attainment of IL [Independent Living] '80

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PROJECT NARRATIVE

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 REPORT1. Changes in Plan

No changes have been made in the plan.

2. Progress During Current Grant Period

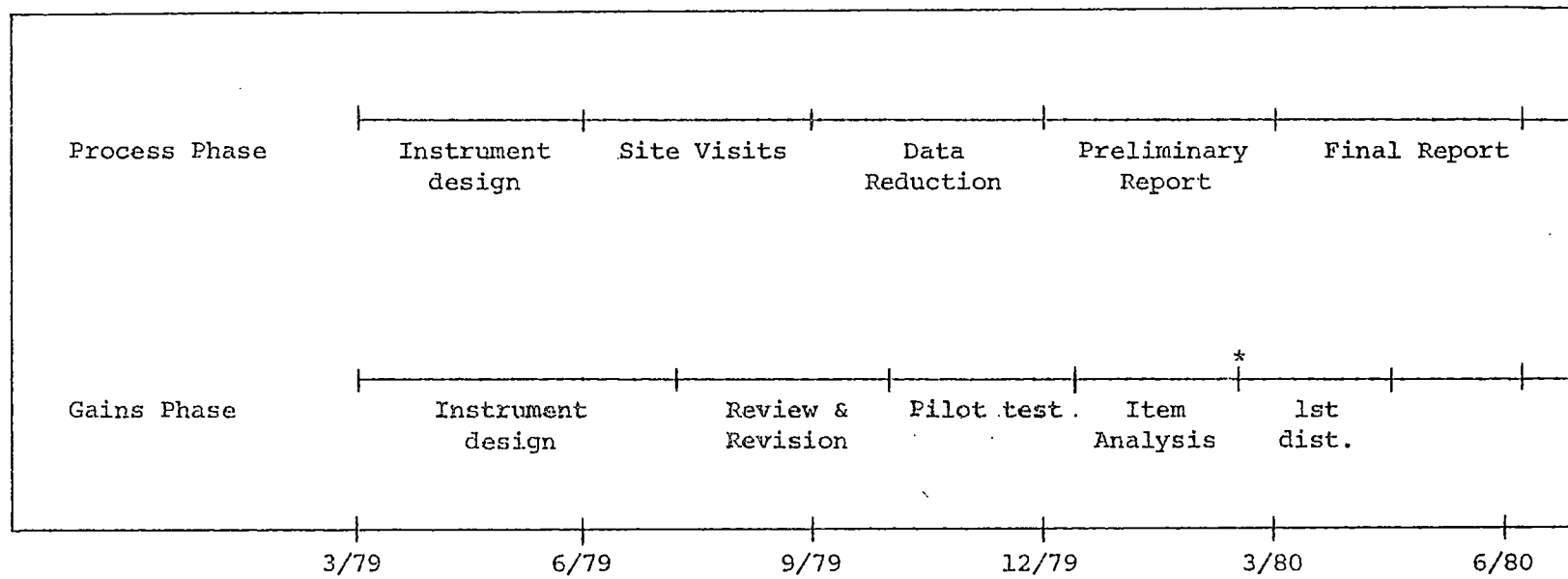
March - April 15:

A preliminary design and timeline for the organization and client outcome portions of the study were created as the new Project Coordinator became familiar with the requirements of the study. A Process Phase of the study was conceived and scheduled for the summer of 1979. The Process Phase was intended to accomplish a rather thorough organizational study of a sample of 12 centers using structured interviews with staff at different levels in the centers and structured examinations of center recordkeeping practices. In this phase, staff role activities, client needs and center organizational problems were to be investigated.

In addition, plans were made for a Client Gains Phase to begin in the late fall of 1979. The Gains Phase is intended to measure client status in a range of Independent Living skills areas at three points in time during the clients' involvement with the Independent Living Centers. A literature review of existing client gains studies began in mid-March.

Instrument development and coordination with both the Research Committee and Department of Rehabilitation management began in late April.

1979-1980 Timeline for the Independent Living Research Study



* Final gains scale version designed with known reliability and demonstrated validity.

April 16 - June 30:

Process Phase: Design and Implementation

In April and May structured staff interviews were designed as were records checklists to be used to inventory the clinical and administrative records used in ILCs. In a May 25 meeting with the Study's Research Committee, the draft instruments were discussed in depth and concurrence & support obtained. Similar support was obtained by the Coalition of Independent Living Centers and the management of the State Department of Rehabilitation (hereafter DR).

During June, site visits were scheduled with each of the 12 centers. Copying and final preparation began in late June (see Appendix A: Process Instruments).

Gains Design

A tentative outline of the dimensions of client gains was proposed to the Research Committee for discussion at the May 25 meeting. The project staff reviewed some of the related research in client gains, noting the heavy past emphasis on employment from which this study must make a departure. An emphasis on IL skills was stressed and feedback from members was gathered to be built into the first draft of the scale. Tentative plans were made for a pilot test of the gains scale in October at the San Diego ILC.

Research staff stressed the need for a broad demographics section to be included in the first application of the scale since there had been no large scale studies of ILC client demographics to date.

Further emphasis was placed on a highly reliable, interval scale which would lend itself to various analytic procedures and which could be used in future effectiveness assessment.

A second Research Committee meeting was scheduled for the fall and a series of meetings with subgroups was proposed to review and revise the gains scale in the interim.

July 1 - September 30:

Process Phase

Site visits for the Process Phase began in July and continued through September. Data reduction and analysis for interview and records checklists began in August and continued through September.

Center status reports were prepared for each ILC which had been visited as requested by the Research Committee.

Gains Phase

Intensive development work on the gains scale draft began in July with a review session by the Gains Scale sub-committee in August.

Subsequent review by various DR research staff resulted in a smooth "pilot test version" of the gains scale.

October 1 - December 15:

Process Phase

The last of the center status reports was completed and an aggregate data tape of the process data was prepared for analysis.

Gains Phase

A pilot test of the gains scale began in late October at the Community Service Center for the Disabled in San Diego (hereafter CSCD). A second substudy to establish validity was carried out at the Dayle McIntosh Center in Garden Grove, CA (hereafter DMC).

CSCD was chosen because of its large client census and the special research aptitudes of key staff in the Center. The pilot study was intended to accomplish the following:

1. to establish procedures for distributing the questionnaire to new clients at intake;
2. to provide a data set on which a factor analysis could be conducted;
3. to do an item analysis of scale items to eliminate items that did not appear to measure anything as well as items that appeared to be confusing to respondents;
4. to provide a "nonindependent" (intake) group for comparison with a group from another center (DMC) preselected for their presumed achievement of independence. This was intended as a basis for measuring the validity of the instrument; and
5. to provide a data set for a Hoyt's Reliability Estimate.

Close contact was maintained with key center staff in order to work out the most efficient procedure for administration of the instrument.

Data collection was completed during early December. Meetings were held on December 6 and 7 respectively with the Research Committee and the ILC Coalition to highlight pilot findings and to plan for implementation of the gains scale in the remaining 11 centers.

December 15 - January 30:

Gains Phase

During late December and early January intensive analytic work was conducted on the pilot test data with the following results:

1. Staff assigned to training center personnel for the full scale implementation developed a set of procedures and a training module for the full study group. Contacts were tentatively scheduled for February, 1980.
2. Factor analysis and item analysis were completed and a more powerful version of the scale was drafted for January 15 review by the Research Committee.
3. A Hoyt's Reliability Estimate* was generated. In this formula, which compares item variance with intersubject variance, the among-subject variance is $\frac{\sum x_i^2}{n} - \frac{x^2}{kn}$ and the among-item variance is $\frac{\sum n_j^2}{k} - \frac{x^2}{kn}$. The residual variance can be obtained by subtracting the among-subject and between-item variance from the total sum of squares or $T-A-B=\text{residual}$. The ratio of the subjects mean square minus the residual divided by the subjects mean square provides the estimate of the reliability or the proportion of among-subject variance accounted for ($n=\text{individuals}$; $k=\text{items}$; $T=\text{total sum of squares}$; $A=\text{among-subject sum of squares}$; and $B=\text{between-item sum of squares}$).

A reliability coefficient of .87 was obtained. Research staff were favorably impressed with this high a reliability navigating, as they were, in such unknown waters. Confirmation of the Hoyt's Estimate will be sought with the full sample using the more traditional test-retest formula corrected for attenuation.

4. Staff of the Dayle McIntosh Center were asked to select "independent" clients and to make a single-blinded approach by merely inviting subjects to participate in a study of independent living centers. The mean score of DMC scales returned ($N=15$) was compared with the mean of the CSCD intake clients ($N=37$) using a t-test. The results were significant in the predicted direction at the .01 level (see Appendix B: Summary of Validity Findings).

* Hoyt, Cyril J., Test Reliability Estimated by Analysis of Variance. Psychometrika, 1941, 3, 153-160.

January 16 - February 28:

Process Phase

An analysis and report of the aggregate data of the Process Phase began in late January. Appendix D is a preliminary report of the Process Phase.

Gains Phase

At a January 15 meeting of the full Research Committee, the revised gains scale was submitted to an all-day review. Many simplifications of language were proposed and a decision was made to produce a separate "deaf translation" of the scale to permit easier interpretation by deaf clients, who often have less well developed verbal skills.

In ensuing weeks, a final version of the gains scale was created after further review by departmental staff involved with ILCs. A small contract was also let with a local organization recommended for their expertise in working with the deaf. A final version for deaf clients was received on January 31, 1980.

Scheduling of initial visits to the remaining 11 ILCs was completed in early February and all visits were made during February.

A strategy for client follow-up has been developed and a mechanism for paying clients to complete the rather lengthy questionnaire has been set up to ensure a reasonable response rate.

It is anticipated from the pilot study results that the gains survey will have returns from 65-75% of all first contact ILC clients in sample centers during the period February 15 - March 21, 1980.

A brief feasibility study is currently being conducted to explore methods of selecting a control group for the Gains Phase from among DR's 08 closures. The demographic returns from the February distribution of the scale would be used to create sampling strata for random selection from the State's client masterfile.

Considerable time was spent by the Project Director and ILRS staff on the separate evaluation of 11 Independent Living Centers partially supported by AB 204, a State law enacted for one-year funding of centers whose I & E Grant support was terminated. Nine of these centers are in the sample of 12 contained in the research study. The hasty evaluation was contracted to Berkeley Planning Associates, but ILRS staff were involved in each stage, particularly in the Department of Rehabilitation report to the Legislature and Governor, to be submitted March 31, 1980.

Although the AB 204 evaluation had imposed upon it an egregious time constraint (November, 1979 - March, 1980) there is valuable information on the nine "overlapping" centers that will supplement the Research Study (see Appendix F: Berkeley Planning Associates Evaluation of California's ILCs -- Executive Summary).

3. Staff Changes

During the grant year, a vacant Research Analyst position was filled and two other positions vacated during the year were filled by research staff having strong analytic background. This shift reflects the need for a more technically oriented team for the gains phase during which multivariate analyses will be conducted.

The following resumes are for the three Research Analyst I positions on the Independent Living Research Project. The half-time Director, Harry Greenblatt, the Project Coordinator, Gene Hiehle and the Statistical Clerk, Paulette McQuillan remain the same as in the most recent Project Narrative.

PAGES 8-10 OMITTED:

(Resumes for Albert P. Bradley, Andrew P. Lasser and Paula Bayer, Research Analysts).

4. Inventions and Copyrights - not applicable
5. Cost Benefit Findings - not applicable

C. PROPOSED ACTIVITIES

1. Work Plan for Remainder of Current Grant Period

April - June 1980

During the first quarter of the last grant period, staff will study the feasibility of selecting a control sample from the DR masterfile of 08 closures, analyze the returns from the first distribution of the client gains scale and distribute the second gains scales to the pilot study group in San Diego.

The following specific objectives are planned:

Objectives	April	May	June
1. To maintain contact with centers to resolve distribution problems.	15		
2. To conduct 2nd distribution of gains scale in San Diego pilot center (including follow-up).		15	
3. To finalize the Process Aggregate Report.	30		
4. To complete sampling design for Gains control group and to conduct first mailout distribution (including follow-up).		15	
5. To analyze data returned from first gains distribution including control sample.			1
6. To do preliminary analysis of change data from pilot study group.			1
7. To generate 2nd reliability estimate (test-retest) using pilot data.			15

July 1 - September 30, 1980

During the summer quarter, it is anticipated that project staff will plan and carry out the second full scale distribution of the gains scale, prepare and conduct a second mail out to the control group and prepare demographics profiles for each center in the study group.

The specific objectives are:

Objectives	July	August	September
8. To prepare for 2nd full scale distribution.	15		
9. Second full scale distribution.	15		30
10. Dissemination of demographic profiles & gains analyses to those centers who request them.	20		
11. Second mailing of control group scales (including follow-up).		15	30

October 1 - December 31, 1980

Intensive analysis of the first interval of client gains will begin during this period. Also the gains of the control sample will be assessed and statistical tests will be used to compare the two groups. A Research Committee meeting will be held to review preliminary findings.

The specific objectives are:

Objectives	October	November	December
12. Intensive analysis of gains data.			15
13. To analyze control group gains.	30		
14. To prepare for and conduct Research Committee meeting to present final pilot data.			15 30

January 1 - March 30, 1981

During the last reporting period the final distribution of gains scales will be made, a preliminary report of findings will be prepared along with the project narrative, further gains data analysis will be made and presentations of preliminary findings will be made for DR and other research groups.

The specific objectives are:

Objectives	January	February	March
15. Final distribution of gains scales.		15	
16. Preliminary report of findings and progress report.	15	25	
17. To analyze second interval of change.		15	30
18. To prepare reports and presentations of preliminary findings to DR and other research groups.		15	15

April 1 - June 30, 1981

Between April 1 and June 30 of 1981, analyses will be completed and final reports will be prepared.

2. Proposed changes in project: None
3. Research Utilization Plan

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.

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 pre-vocational 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.

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: PROCESS PHASE INSTRUMENTS

CENTER

PROCESS INTERVIEW
(STAFF)

POSITION TITLE

DATE

HOURS/WEEK

Part I - Program

A. Goals and Objectives

Goals are defined as what the program is trying to accomplish; they express broad, general aims. Objectives are specific aims which are time limited and measurable. Services are those activities performed for or with the clients which help you to accomplish your objectives and goals.

1. What are the major goals of the Center?

2. Do you have any specific objectives drawn up, such as having a certain community problem solved by a given date, or training a measurable number of attendants?

B. Target Group

3. Are there any rules as to the people the Center will or will not give services to (admission criteria)?

___ yes

___ no (skip to #5)

4. What are they?

5. What are the characteristics of the clients who come to the Center? (age, sex, disability, and ethnicity) (not a typical client, but range)

C. Needs and Services

6. What sorts of needs do the people who come to the Center generally have?
(list needs below)
7. What services does the Program provide? (list below)
8. Which staff member provides each service? (match service to names
written on list, ask about remaining names, list new ones)

NEEDS

SERVICES

STAFF

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

D. Roles and Functions

9. Are staff members grouped into working components or sections in the Center?

___ yes

___ no (skip to #11)

10. What are these components or sections?

11. You mentioned that your job is _____. Could you describe your basic duties and responsibilities?

At any given time, what is the approximate percentage of clients in the following categories:

16. Clients who come in on a fairly regular basis (weekly, monthly, bi-monthly)?

_____ %

17. Clients who come in on an irregular basis (at varying intervals)?

_____ %

18. Clients who phone in on a one time only basis?

_____ %

19. Clients who drop in on a one time only basis?

_____ %

Part II - Recordkeeping

20. Does the Center maintain client records in a way that allows a person to distinguish between a new client and one who has received services before?

___ yes

___ no (skip to #22)

___ don't know (skip to #22)

21. How is this done?

22. Are records kept on every individual who receives services, both walk in and phone in?

- ☐ yes (skip to #24)
☐ no
☐ don't know (skip to #24)

50. Are there procedures to assure client confidentiality?

- ☐ yes
☐ no (skip to #53)
☐ don't know (skip to #53)

51. What are these procedures?

52. Do all staff members know about them?

- ☐ yes
☐ no
☐ don't know

Part III - Staff Recruitment, Orientation and Training

53. How do you usually advertise job openings at the Center?

54. After someone has applied for a job opening, what steps are taken before they are hired?

55. Who ordinarily interviews job applicants?

- | | |
|--|--|
| ☐ Center Director only | ☐ Center Director and other staff |
| ☐ Center Director and Board | ☐ Other (specify) _____ |
| ☐ Board only | _____ |

56. Are there written personnel policies:

- | | |
|--|---|
| ☐ no (skip to #58) | ☐ on salaries? |
| ☐ on working hours? | ☐ on firings? |
| ☐ on vacations? | ☐ other (specify): |
| ☐ on sick leave? | _____ |
| ☐ on holidays? | _____ |
| ☐ on benefits? | ☐ don't know (skip to #58) |

57. Are these written policies given to new staff members?

- ☐ yes
☐ no
☐ don't know

GO TO NEXT PAGE, ASK #132-135.

58. Is employee performance regularly evaluated?

- ☐ yes
☐ no (skip to #60)
☐ don't know (skip to #60)

59. How often are staff members evaluated?

- ☐ every 6 months
☐ yearly
☐ other (specify) _____

60. Does the Center have an orientation program for new staff?

- ☐ formal program ☐ no orientation (skip to #62)
☐ written orientation information
☐ informal tour
☐ combination of above

61. What does it include?

62. Is training provided to all staff members on an ongoing basis?

- ☐ yes ☐ selected staff only
☐ no (skip to #69)

63. Who decides on the training policies (who is to go, what training, etc.)?

132. Do you have a formal grievance procedure?

- ☐ yes
- ☐ no
- ☐ don't know

133. How are staff grievances or disagreements with policy usually handled?

- ☐ formal written grievance procedures
- ☐ informal discussion
- ☐ taken to Board through Center Director
- ☐ taken to Board through someone else (who? _____)
- ☐ taken directly to Board
- ☐ don't know
- ☐ other (specify): _____

134. Is there a way for staff to relate directly to the Board of Directors on a non-grievance issue?

- ☐ yes
- ☐ no (return to previous page, #58)

135. How can they do this?

RETURN TO PREVIOUS PAGE, #58.

64. Where are training programs usually given?

- ☐ at the Center
☐ at outside training facilities
☐ both
☐ other (specify) _____

65. For those training programs held here at the Center, are they developed and lead by other staff members or by trainers from outside the Center?

- ☐ staff members
☐ outside trainers
☐ either
☐ both in combination
☐ not applicable

67. Does the Center: (1) provide time off or (2) pay fees for special courses employees wish to take?

	Time off	Pay fees
Yes		
No		
Don't know		

68. What training courses have you attended in the past year?

69. Are there areas in which you would like to be trained or get more training than you already have?

- ☐ yes
☐ no (skip to #71)

70. What are these areas?

Part IV - Lines of Authority and Staff Communications

71. Is your work supervised or do you work independently?

☐ supervised

☐ work independently (skip to #73)

72. Who supervises you?

73. Do you supervise anyone on the staff?

☐ yes

☐ no (skip to #75)

74. Who do you supervise?

75. Are the lines of authority in the Center clear to you (i.e., who is in charge of what)?

☐ yes

☐ no

76. Are regular staff meetings held?

☐ yes

☐ no (skip to #80)

77. How often are they held?

78. Who attends the staff meetings?

☐ all staff

☐ selected staff members (specify if possible): _____

79. What is usually discussed at those meetings?

80. Do you have a good idea of what the center is planning for the future?
___ yes
___ no
81. Are you kept informed of policy changes, personnel changes, Center activities, etc.?
___ yes
___ no (skip to #83)
82. How are you kept informed?
___ informal conversation ___ written notices sent to each staff member
___ planned meetings ___ notices posted in the Center

Part V - Referrals

83. For which services do you usually refer clients to other agencies?
(use list on page 2, write "r" next to service)
85. Do you have a list of the places you refer people to regularly?
___ yes (may I have a copy?) Verified: ___ yes ___ no
___ no
86. How are these referrals made? Do you just give out a name and phone number, or do you call the referral agency and have them contact the client?
87. Are many of the Center's clients referred here by other community agencies or organizations? (get example)
___ yes Examples: _____
___ no _____
88. Outside of direct referral from other agencies, how do people usually learn about the Center?
___ communications media ___ Other (specify): _____
___ family/friends _____
___ center outreach program _____
___ don't know

89. What forms of tangible support and assistance does the Center receive from the community?

☐ financial ☐ volunteers
☐ donations of office space ☐ other (specify) _____
☐ donations of furniture & supplies _____

GO TO NEXT PAGE, ASK #136.

90. Does the Center have a program to advertise its existence and services?

☐ yes
☐ no
☐ don't know

91. Are any special efforts made to reach special target groups, such as elderly, minorities or people in convalescent hospitals and rehabilitation centers?

☐ yes
☐ no (skip to #93)
☐ don't know

92. Describe these efforts.

93. Is there a program that provides center services somewhere away from the center, such as a staff member stationed at another location?

☐ yes
☐ no
☐ don't know

94. What about community education on disability? Is the Center involved in any programs such as a disability awareness program?

Part VI - Organizational Structure and Problems

B. Organizational problems

103. Does the Center have any problems finding and keeping qualified staff?

	Finding	Keeping
Yes		
No (skip to #106)		
Don't know (skip to #106)		

136. Do you know of any changes that have occurred in the community because of the Center's presence here (e.g., more busses for the disabled, curb cuts, etc.)?

RETURN TO PREVIOUS PAGE, #90.

104. Why does the Center have this problem?

Finding: _____

Keeping: _____

105. What efforts have been made to deal with the problem?

106. Does the Center face any difficulties in the community?

___ yes

___ no (skip to #109)

___ don't know (skip to #109)

107. What are they?

108. What is being done to deal with these difficulties?

109. Do staff members have any problems with agencies in the referral network?

___ yes

___ no (skip to #112)

___ don't know (skip to #112)

110. What are they?

111. How are these problems dealt with?

114. Do you have any funding plans for the future?

☐ yes

☐ no (skip to #116)

115. What are those plans?

120. Does the Center have any other major problems that we haven't mentioned?

121. What do you see as the biggest problem the Center faces today?

122. What is the primary focus of present planning activities?

☐ new and/or expanded service programs (specify) _____

☐ expanded facilities _____

☐ expanded outreach program _____

☐ new staff _____

☐ more and different client groups (specify) _____

☐ other (specify) _____

123. Are there any changes you would like to see made that might improve the Center's program?

☐ yes

☐ no (end interview)

124. What are those changes?

Client Records Checklist

(To be used on a sample of 8 randomly selected records to include all counselors)

	Yes	No	A If yes, tally where used appropriately	B Not applicable to individual client	*C.L.
1. Does the program have a standard intake form? (IF NO: skip to #4)					
2. What information is it designed to capture?					
a. Date of intake					
b. Name of client					
c. Address of client					
d. Phone number					
e. Birthdate and/or age					
f. Sex					
g. Ethnicity					
h. Marital status					
i. Social Security number					
j. Type of contact (drop-in, phone)					
k. New or returning client					
l. Source of referral					
m. Nature of disability					
n. Living arrangement					
o. Source of income					
p. Amount of net monthly income					
q. Employment (are you employed?)					
r. Highest grade completed in school					
s. Trade, business, or professional school					
t. Presenting problem -- needs					
u. DR client (counselor's name and phone)					
v. Other (specify) _____					

3. Overall level of consistency: _____

* $\left(\frac{A}{N-B}, \text{ Criterion} = .75 \right)$ Met criterion? yes no

4. At what level does the program draw up a formal Service Plan?

- a. Never (skip to #6) c. Sporadically
b. Severe problem cases only d. Always

For b, c, or d, which of the following are included:

	Yes	No	A If yes, tally where used appropriately	B Not applicable to individual client	*C.L.
a. Counselor's name					
b. Client's goals					
c. Services planned to achieve goals					
d. Time frames					
e. Indication that client actively participated in forming the plan					
f. Periodic notations of progress or revision of goals					
g. Are plans filled out within 30 days of the first contact with the client					

5. Overall level of consistency: _____

* $\left(\frac{A}{N-B}, \text{Criterion} = .75 \right)$ Met criterion? ____ yes ____ no

6. Does the client file contain release of confidential information forms, signed by the client, for any instance in which information has been given to an outside agency or person?

yes no

7. Does the Center have locked files for client records?

yes no

8. Does the program have separate forms for specific services?

yes no

9. What are they?

[illegible]

ADMINISTRATIVE RECORDS CHECKLIST

	Yes	No
1. Accurate, up-to-date organization chart.		
2. Filing system index		
3. Correspondence, memoranda, minutes:		
a. Files of outgoing correspondence If yes, how are they ordered? (alphabetically by subject, chronologically) _____		
b. Files of incoming correspondence If yes, how are they ordered? (alphabetically by subject, chronologically) _____		
c. Files of interoffice memoranda If yes, how are they ordered? (alphabetically by subject, chronologically) _____		
d. Minutes of Board meetings		
e. Minutes of staff meetings		
4. Funding reports:		
a. Copies of funding narratives from grant applications. If yes, list services proposed from the most <u>recent</u> narrative or contract: _____ _____ _____ _____		
b. Department of Rehabilitation quarterly reports. If yes, please specify: _____ _____ _____ _____		

(continue)

Page 1 of 2

ADMINISTRATIVE RECORDS CHECKLIST
(continued)

	Yes	No
5. Personnel records:		
a. Personnel policy manual		
b. Job descriptions		
c. Staff work schedules		
d. Applications for employment (forms)		
e. Written staff orientation procedures (guideline or checklist)		
f. Written staff training policy (under what circumstances center will pay or give time off, training contact person, etc.)		
g. Written staff performance evaluation guidelines		
h. Written grievance procedures for staff		
6. Client records:		
a. Written admissions criteria		
b. Written instructions for doing intakes		
c. Special forms for specific client services (e.g., attendant forms, housing requests, etc.) If yes, please specify: _____ _____ _____		
d. Written grievance procedures for clients		
7. Services		
a. Itemized services list with services descriptions		
b. Listings of available services or people to provide services (e.g., available attendants, accessible housing, etc.) If yes, please specify: _____ _____		
c. Standard form for summarizing services delivered by service and client disability. If yes, does it record any other information? If so, what? _____ _____		

APPENDIX B: SUMMARY OF VALIDITY FINDINGS

Validity Study

As mentioned previously, during November 1979 the client gains scale yielded a reliability estimate of .87. Later in January 1980 a study was undertaken to determine the gains scale's validity. It was hypothesized that a group of clients having a known high level of independence (concurrent validity) would obtain higher scores on the scale than a group of new clients (San Diego intake clients). In order to test this hypothesis, staff of another Southern California ILC (the Dayle McIntosh Center) were asked to select people in their Center who were known to be highly independent. The people selected were not told why they were chosen. The staff then asked them to fill out and return the questionnaire. The scores of the McIntosh group were compared to the San Diego group.

A t-test for difference between two independent means was applied to the data extracted from the two groups. Results were significant (.01), and in the direction hypothesized. The computational results based upon 50 variates, are reported below.

<u>GROUP</u>	<u>N</u>	<u>VARIANCE</u>	<u>MEAN</u>
McIntosh	15	804.0523810	213.9666667
San Diego	37	663.7590090	196.3648649

$$t = \frac{213.9667 - 196.3649 - 0}{2.2896939}$$

$$t = 7.69$$

$$(t_{.01} = 2.660)$$

CONCLUSION: The probability of selecting from two populations with means that differ by more than 17 is considerably less than 1%. The difference between the means is sufficient to warrant the conclusion that one is higher than the other.

APPENDIX C: BRIEF HISTORICAL SKETCH OF THE
INDEPENDENT LIVING MOVEMENT

Independent Living Research Study

A Historical Sketch of the Independent Living Movement

The Independent Living Movement is the result of the struggle of people with severe disabilities to participate fully in society. Historically, the severely disabled have been condemned to a sequestered existence in private homes, or in hospitals and institutions for the disabled. With the advance of medical technology, more of these people began to survive the crisis, only to be faced with barriers to mobility and participation, which left them facing a lifetime of unreasonable struggle and impoverished opportunity.

Unfortunately, social awareness grew more slowly than medical technology, and it wasn't until 1920 that legislation appeared; in the form of P.L. 66-236 or the Smith-Fess Act, providing public acknowledgement of the dilemma the disabled were facing. The Smith-Fess Act authorized placement, counseling, and training services for the physically handicapped, but no provision was made for those to whom the goal of employment was not attainable. In terms of today's population figures, this left 3.3% or 6.8 million people without public recognition; 2.6% of all working age adults, 17.1% of the elderly, and 2% of the children.

Those who were not covered by the Smith Fess Act were forced to remain under institutional care, and were in essence denied any means of self direction in their lives, their daily routine being dictated by the needs of the institutional staff. As their numbers grew, along with general population expansion and advancing medical technology the need for representation and public acknowledgement became critical.

In 1959 HR bill 361 was proposed; the bill would have provided services for those to whom employment was not a goal. The bill, however, was not passed. The issue then, became not only one of need, but also of the denial of the disabled person's civil rights. At this juncture, the striving for legal recognition became a movement, gaining momentum toward the late sixties. In 1968 one of the first legal breakthroughs occurred with the passage of P.L. 90-480, or the architectural barriers act, which stated that public buildings must be designed or altered to be accessible by the disabled person. In early 1973, HR 8395 (Title V) was passed, and became known as the 1973 Rehabilitation Act. The bill

contained several provisions of crucial importance to the disabled; 1) It mandated that the most severely disabled were to receive first priority in service under Title V; 2) It extended new statutory rights to the disabled through Sections 501 to 504 which mandated the development of affirmative action programs and banned discrimination due to a physical disability on federally funded projects. Additionally, Title V created the architectural and transportation compliance board. Because the implementation of the new law was proceeding too slowly, the American Coalition of Citizens with Disabilities (ACCD) helped organize coast to coast demonstrations in an effort to hasten compliance with the terms of Title V.

In 1974, Title V was amended to create P.L. 93-516. Two key phrases were inserted which gave legitimacy and impetus to the independent living movement. The first phrase asserted that it is essential that recommendations be developed to insure that all people with handicaps be enabled to live their lives independently; and the second called for a complete integration of all handicapped people into normal community living, working and service patterns. Title V soon became known as the civil rights act of the disabled. In 1978 President Carter signed P.L. 95-602. Title VII of P.L. 95-602 offered the first comprehensive services for independent living, defined as services appropriate under vocational rehabilitation and any other services necessary to achieve the goal of independent living. Title VII deemphasized employment as a goal, and authorized 150 million dollars for independent living programs in 1980, although subsequent appropriations reduced the figure to 15 million dollars.

Independent Living

The early independent living centers established their roots within academic communities. In 1962, separated by 2000 miles, two independent living centers based in academic communities evolved. The first, a modified home near the University of Illinois' Champaign/Urbana campus, received four severely disabled individuals who were transferred from a nearby nursing home. The second, established at the student health center of the University of California's Berkeley campus received two severely disabled individuals. The establishment of these two centers marked the formal birth of the current independent living movement.

The independent living movement is in reality a social movement as well as a new treatment paradigm. It involves a change in which people view themselves and their possibilities. The movement is actually the expression

of this change, the evolution of ideas into concentrated and directed action. Independent living has come to be seen as a viable alternative for those people to whom vocational goals are not immediately applicable. The movement has had its basis in two main sources; from within the community of the disabled, springing from their efforts to seek a more fulfilling life in an able bodied world, and through the efforts of rehabilitation professionals to reach disabled persons for whom a vocational goal is unrealistic.

The Philosophy of the Independent Living Movement

Central to the philosophy of the independent living movement (ILM) are the principles of demedicalization and reduction of dependency. It is the philosophy among those involved in the movement that:

- 1) The management of medically stabilized disabilities should be demedicalized.
- 2) Those who know best the needs of the disabled and how to provide for them are disabled persons themselves.
- 3) The needs of disabled persons can be met most effectively by comprehensive programs which provide a variety of services.
- 4) Disabled people should be integrated as fully as possible into the community.
- 5) The disabled consumer should play the major role in determining his/her service plan.

Along with this basic philosophy there exists a certain core of attitudes which have played a major role in directing the development of the ILM. It is typical of consumer operated programs to be protective of their autonomy, and apprehensive about any bureaucratic control. It is feared that bureaucratization of the program would reduce their capacity to deliver services by greatly increasing paper work responsibilities as well as threatening consumer control. For this reason, there is a resistance to the involvement of both Federal and State rehabilitation agencies in center operations. An additional factor which also evolved from the community based profile of the centers is the orientation toward a non-profit mode in the delivery of services.

The Focus of the Independent Living Movement

The IL movement, having had its early start in the academic community, has developed through the energy of the younger individual, and has evolved a focus upon the older adolescent and the younger adult. Within the movement, the older adult appears to be under-represented at present. Well represented are the young middle class white population. Minorities and individuals with age related degenerative disabilities are not well represented. The concentration of the IL movement is upon individuals with; a) spinal cord disorders; b) muscular dystrophy; c) cerebral palsy; d) multiple sclerosis; and e) post polio conditions. Some centers are equipped to handle deaf and blind individuals. The mentally retarded and the emotionally disturbed are generally referred elsewhere unless they also possess an accompanying physical disability.

Goals

By focusing on limitations to a person's major activities, the ILCs have developed a social role definition of disability. This social role definition has played a major part in directing the goals of the movement. The principle of the individual assuming the responsibility for directing his/her life is basic to the IL movement. Additionally, the principles of participating actively in the day to day life of the community, and an emphasis on allowing and expecting the disabled person to function as autonomously as possible are central to the ILM.

Along with the development of a philosophy and central goals, several environmental factors have arisen which are central to the independent living movement. The first is attendant care. Because the disabled individual often requires assistance providing for personal needs, attendants are central to the IL movement. The role of the attendant in the ILC differs from the medical model in that the client directs the attendant in the performance of duties rather than the reverse. Currently, there exists a critical shortage of well trained personal care assistants.

A second important factor is transportation. Many of the disabled do not have personal transportation available to them, and so depend on means provided by the community. In many locations, accessible transportation is not available, and in most areas where it is available it is expensive.

A third issue, by no means less critical than those previously mentioned, is the current shortage of accessible housing, and barriers to accessibility within the community. Universally, independent living centers have directed a substantial part of their energy and resources to the training of attendants, provision of community based transportation, development of accessible housing, and removal of architectural barriers within the community.

Definition of Independent Living

A review of literature related to independent living has yielded several definitions of the movement. Essentially, the cores of the definitions are the same, though each takes a slightly different focus. The following are four provisional definitions offered by individuals central to the IL movement. According to Don Galloway, Executive Director of the Governor's Council on the Handicapped, Denver, Colorado, "Independent living means understanding the various components of society that affect ones life so that s/he can use them to meet his/her needs". Dr. Jean Cole, former director of New Options in Houston, Texas, offers a dual faceted definition; that of assuming responsibility for directing one's own life, and participating actively in the day to day life of the community. Lex Friedman, New Options Research Director, defines Independent Living as the ability to live independently of nursing homes and institutions. Judy Heumann, Deputy Director of CIL Berkeley and a current spokesperson of the movement defines independent living broadly. "To us independence does not mean doing things physically alone. It means being able to make independent decisions.. it is a mind process not contingent upon a normal body. It is the ability to take on the major responsibility for determining ones own lifestyle."

Three Major Models of Independent Living Centers

ILCs have evolved into three major service types. First is the community-based, consumer controlled service model. Patterned after CIL Berkeley, these centers are essentially non-residential independent living training centers. Operating from a central location, they generally provide attendant referral (occasionally attendant training), housing referral, peer counseling, advocacy counseling, training in mobility and the maintaining of a household. The aforementioned list of services is by no means exhaustive, however they are core services found in practically all ILCs.

The second model is the ILC offering brief transitional living facilities, similar to the New Options program of Houston, Texas. These programs offer

a series of training modules crucial to the attainment of independent living. The services offered are essentially the same as in the non-residential centers, however, the client has the opportunity to reside in a closely supervised environment and practice the skills they are learning.

The third model is of an ILC offering long term housing, similar to the Boston Center for Independent Living. Again, this is transitional living in that the client is taken from a state of dependency to independence, through a series of training modules somewhat more lengthy than those involved in a project such as Houston's New Options.

APPENDIX D: PRELIMINARY SUMMARY OF PROCESS FINDINGS

Independent Living Research Study

Preliminary Report of Process Analysis

During the summer of 1979, a series of site visits were made to 12 of California's Independent Living Centers in an effort to gather specific data about organizational structures and service delivery systems. Structured staff interviews and records inventories were used in each Center. The following brief summary report highlights these "process" findings with some discussion of the relationship between this groundwork phase of the study and the more analytically involved gains phase which is now in progress.

Independent Living in California

In terms of services and delivery pattern, the design of most California ILCs is similar to CIL in Berkeley. The majority of them are community-based, and offer the core services of attendant referral, counseling, advocacy, and housing referral, and are non-residential in nature. The typical profile of the center, however, may have developed through a process of evolution rather than emulation, as only five of the 12 center directors interviewed for the process phase of the current study indicated that the development of their center was inspired by CIL.

Consumer control and distrust of service agencies (such as the State of California's Department of Rehabilitation) is typical of the California ILC, and is an expression of a deeper commitment to a self determination which challenges the dominance of the "professional" and professionally oriented service patterns.

Due in part to the growing pressure from the disabled to legitimize the independent living movement as a legal entity, Ed Roberts, the founder and former director of CIL Berkeley was appointed to the directorship of California's Department of Rehabilitation. In 1975 Roberts reemphasized services to the severely disabled as mandated by the 1973 Rehabilitation Act. Roberts used rehabilitation resources to offer more governmental support for IL programs. The State Department of Rehabilitation announced that more than \$700,000 would be available to ILCs in the form of Innovation and Expansion grants. This resulted in 10 grant applications averaging \$72,000 each; nine were funded during the first year. Although 1974 was the first year the independent living centers were funded through the Department of Rehabilitation (with federal I & E money), some groups were providing informal counseling and referral services out of a private home, before being officially established as a center.

Organizational work for the majority of the ILCs contained in the current study began in 1975, and was done by disabled individuals. The amount of time that generally elapsed between the beginning of efforts to organize a center, and the day the center opened officially, ranged from three months to three years, with most centers taking between 7 and 14 months to organize.

Funding

Following the provision of the 1974 Innovation and Expansion (I & E) grants, most centers received their primary funding through the Department of Rehabilitation, although matching funds came from a number of sources: a) private donations; b) fund raising events; c) community organizations; d) private agencies; e) CETA grants; and f) special organizations serving the handicapped such as the United Cerebral Palsy Association and the Easter Seals Society.

The I & E grant funding which supported the centers was due to expire in 1979. This led to the passage of AB-204 (Chapter 191, California Statutes of 1979) as an emergency measure to maintain services formerly provided through the I & E grants. AB-204, which was approved on July 2, 1979, provided 1.8 million dollars in funding for ILCs for fiscal year 1979-80. These funds were targeted for both the maintenance of current ILCs and if feasible the establishment of new ones. AB-204 defines an independent living center as:

- A private, non-profit organization
- Controlled by a Board of Directors, the majority of whom are disabled
- Staffed with individuals trained to assist the disabled in achieving social and economic independence; such staff to include as large a proportion of disabled individuals as is practicable

AB-204 further provides for core services of independent living centers, services to include, but not limited to:

1. Peer Counseling
2. Advocacy
3. Attendant Referral
4. Housing Assistance
5. Other referrals

The bill further states that independent living centers are not to be operated in conjunction with residential centers, as residential centers are

AB 204 further provided for program evaluation by a source outside of the Department of Rehabilitation, and for the provision of monthly client counts from funded centers. Centers have been providing such demographics, and an outside evaluation has been carried out by Berkeley Planning Associates (see Appendix F for executive summary).

Attendants and AB 124

Because the issue of attendants is central to the independent living movement, a word on California's attendant care program is in order.

The attendant care program in California began during the 1950's. In most cases the disabled person had to secure his or her own attendant through funds provided by SSI directly to the client. This worked well for those who were able to deal with the problems of finding, hiring and often training attendants, except for the problem of delays in receiving checks for payment. The program obviously did not work well for those who were unable to secure their own attendants.

In 1974, the In-Home-Supportive-Services Program was included in SSI, whereby the states had the option of providing an attendant care program, or allowing the counties within the State to administer their own programs through local social services offices. With this program, the problem of duplication of services arose. In-Home-Supportive-Services were provided through the county social service programs at the same time Home Health Aides for the acutely ill were provided through Medi-Cal; the duties of the two types of workers were not clearly differentiated. This lack of a clear division of duties led both to the problems of important services not being provided, and funding being wasted. In an attempt to rectify this situation, California, in September, 1979, enacted AB1124. AB 124 authorized pilot projects to provide attendant care under Medi-Cal as the duties of the attendant care provided by social services were limited in scope. AB 124, in effect, combines the attendant services of the personal care assistant and In-Home-Supportive-Services in four pilot counties.

Characteristics of Sampled Independent Living Centers

The purpose of the process phase of the Independent Living Study was to delineate California Independent Living Centers (ILC) in terms of organizational and service delivery factors, recordkeeping, staff and client characteristics,

hiring and orientation of new staff, as well as fiscal issues and program planning.

Selection of Sites

Because of constraints in terms of time, money and the availability of staff, it was determined that the most effective procedure was to draw a sample representative of a cross section of California ILCs rather than to survey the operating characteristics of all programs in the state. Twelve sites were chosen for variation in 12 strata:

- Location (rural, suburban, urban)
- City size
- Period of establishment (early period of the movement, middle, or recently developed)
- Age of the majority of clients served
- Whether the program is autonomous or sponsored
- Whether service patterns are geared toward serving special disabilities
- Social/economic status of clients
- Range of services provided
- Sources of funding
- Number of clients served
- Number of staff employed
- Political catchment area

Client Demographics

As a supplement to the process data, client demographics were drawn from records kept by the centers and examined in the process sample. Information yielded by this method indicates that among the twelve sample centers, the largest number were from 18-35 years of age; the sexes are evenly divided, middle class whites predominate, with latinos and blacks representing 5.2% and 4% of the sample, respectively. The largest single source of income for clients on whom records were kept was some form of public benefit such as SSI or SSDI. Of the clients represented, approximately one-fifth were referrals from the Department of Rehabilitation.

Program Structure and Development

All programs included within the process sample are nonresidential in nature, and provide services not generally related to employment. The programs, however, do not specifically preclude the provision of employment related services. Provision of services to the physically disabled was emphasized, and programs tended to refer persons with emotional or mental handicaps, or substance abuse problems, to other agencies.

All programs took a grant proposal approach to getting started; generally in the form of Innovation and Expansion (I & E) Grants, Comprehensive Employment and Training Act (CETA) grants, and business or foundation grants.

The California independent living centers which were included in the sample either had developed autonomously or were sponsored by a parent organization. During the time that has elapsed since the first progress report, at which time many of the centers included in the study were just completing organizational efforts, three elements of the developmental process have become apparent which seem to be common to most emerging centers. First is the general expansion of service offerings in response to the expressed needs of the community. Secondly, with increased growth there tends to be greater involvement with other agencies providing services to the disabled. This increased involvement has led to the development of quite an extensive referral network, which is common to all sample ILCs. Additionally, as centers were primarily community based and consumer run, the individuals responsible for the organizational effort often did not have the necessary training in administrative and management skills, and centers therefore ran into administrative problems as they grew.

The basic philosophical approach of the disabled helping the disabled, provision of services to all physical or sensory disabilities and a basic distrust of all bureaucratic agencies in general are elements which appear to be common to sample ILCs.

The Board of Directors

The directives of State legislation in selection of Boards of Directors follow the pattern set by all sample centers. ILCs are controlled by a Board of Directors, at least 50% of whom are disabled. In general, the chairperson of a center's

Board of Directors is disabled. The following are characteristics of the Boards of Directors which have emerged from the process component of the study:

- The Board of Directors is generally not involved in the center's daily operational activities.
- The Board has definite duties which involve policy creation.
- The center staff felt that the Board of Directors is generally helpful, although there are some problems with them.
- The Directorship tends to differentiate its activities through the establishment of committees.
- There appear to be channels of communication for the staff to relate directly to the Directorship.
- Board members are generally recruited from the business and professional community, from staff and friends of the Board of Directors, or by word of mouth from among those within the disabled community.
- Members are aware of the Independent Living Movement.

Goals of ILCs

All centers within the sample study appear to be in agreement about major goals. Primarily, the center's goals are to help people with physical disabilities to live as independently and productively as possible; to live their lives apart from institutions within the working world and to participate in the community. A second goal, that of filling the gaps in the social services system is felt to be of great importance. A third goal common to all study centers is the provision of services to the severely disabled who are considered to be unemployable. A sampling of staff within the study centers has indicated that these goals are generally known to them and that they are in agreement with them, although some staff have indicated concern as to whether their attainment is measurable.

Provision of Services

The ILCs contained in the sample universally appear to be dynamic organizations, dynamic in the sense that they are in a continual process of the development and refinement of service areas and delivery patterns. Initially,

various organizers used one of several methods to determine which service components to include in their first offerings. Service components were frequently developed through the assessment of the most pressing needs of the disabled community, based on personal experience of the center organizers. Alternatively, many centers took a survey approach to the assessment of need, or patterned themselves after CIL in Berkeley, adopting CIL's service components and delivery methods.

Initially, the sample centers offered a basic core of services which included attendant referral, advocacy counseling and peer counseling. Later, with continued expansion, information and referral were added as services. In some cases, even services regarded as having high priority were not included in the centers' first offerings because it was impossible to provide them within the constraints of personnel and funding. It has generally been the pattern that additional services were added as centers became more firmly established. At this point, roughly half (51%) of the process respondents indicate plans for expanded services, and 25% of respondents indicate plans for expanded facilities.

In an attempt to determine if the core of services offered by the centers was consistent with the needs of the clients, center records were examined for frequency of service provision and center staff were questioned as to the needs of clients with whom they had contact. This method produced two lists of services by frequency. To these two lists, services offered and serviced needed, a rank order correlation measure (Spearman's Rho) was applied; the result was a Spearman's Rho of .504. Considering the sample size ($N=56$) and the fact that many of the programs are still in the formative stage of development, the indication is that services offered are fairly well aligned with services needed. Many of the rank order dissimilarities between the two lists evolve from differences in services such as equipment loan and repair, and housing services, both of which are expensive to provide, and for which formative programs do not have the funds or personnel.

<u>Services Offered</u>	<u>Rank of Provision</u>	<u>Rank of Need</u>
1. Independent Living Skills	1	1
2. Attendant Care	2	1
3. Counseling Services	2	2
4. Benefits/Finances	2	2
5. Advocacy (Personal)	2	5
6. Legal Services	3	11
7. Community Services	3	7
8. Transportation	4	4
9. Employment Services	5	6
10. Recreational/Education	6	9
11. Advocacy (Department of Rehabilitation)	7	9
12. Housing Services	7	10
13. Equipment Loan	7	10
14. Equipment Repair	8	8
15. Blind Services	8	7
16. Information and Referral	9	3
17. Deaf Services	10	11

Center Staff

When Centers first began their operations, often one staff member would perform several roles. Typically, as the center grew, differentiation of duties occurred and specialists were generally employed in four main areas of service provision: attendant recruiting, peer and advocacy counseling, housing surveys, and information and referral. Depending on center size and funds available, specialists in other areas of service provision were added. The number of full-time paid staff employed by study centers varies from 3 to 63. The composition of this staff is also varied. Some of the staff is paid for by grant money which is provided to the center to cover cost of operations, while other staff is provided through CETA funding. Additionally, most centers also depend on volunteer assistance from the community. Currently, centers report that there exists a critical shortage of experienced and knowledgeable administrative staff.

During the process phase of the study, center staff as well as the directorship were interviewed with regard to their personal role in the provision of services and any additional training which they felt was necessary for more efficient service delivery. Center staff appear to know what their particular

Duties are, as well as who is responsible for the various service areas. The most frequent response indicated that they would like to receive additional training, generally in the areas of program skills and administration.

The ability to secure quality staff is crucial to the operation of an organization. For this reason, center directors were interviewed in an attempt to discern the method by which they recruit staff. It was found that job openings are advertised in basically six ways: a) through newspapers; b) employment agencies; c) through organizational newsletters; d) through the use of mailing lists and flyers; e) through school employment agencies; and f) through word of mouth. In spite of the rather thorough canvassing, the universal comment by center directors was that qualified staff are very difficult to find, and, once recruited, they were difficult to keep because of low pay. In general, the decision to hire a particular individual is made conjointly by the center director and staff.

The area of personnel policy was also considered to be of great importance to the operation of a center. It was found from the process inquiries that, in general, centers do provide written policy manuals to staff, which contain several organizational elements common to all centers; including a statement of philosophy, a statement of lines of center authority, a schedule for job performance evaluation and an outline of grievance procedures.

Referrals and Outreach

Because referral and outreach programs are the core of an organization's ties with the community, a discussion of such programs was determined to be an essential inclusion to the process phase of the study. Referral and outreach abilities generally increase as an organization becomes firmly established. This has been found to be true of the current project's ILCs. Centers generally possess referral agency lists, and frequently receive clients who have been referred from other agencies. From the results of the process interviews, several elements have been determined to be common to sample ILCs. Most centers have public relations programs which are focused on special groups. Additionally, centers frequently offer a community education program. Clients often have become aware of the centers' activities through these programs, the media, and friends or family. Although most programs have extensive outreach and public relations programs, services are generally offered only through the center. Finally, with respect to referrals, centers generally report satisfactory referral experiences, although some report having problems in terms of communication and availability.

Community relations is also an element important to the successful operation of an independent living center. The most frequent forms of tangible support received from the community were furniture, supplies and volunteers. Often major community changes have occurred in response to the center's presence, of which the most frequently occurring is an increase of community awareness of the activities. This commonly results in enhancing community accessibility and participation.

Although in general community relations appear to be good, some centers report problems in this area. The most frequent problem is that of individuals within the community stereotyping the ILCs and their clients. The lack of community accessibility rates a large mention as a problem, and the problems of complaints, poor reputations resulting from biased views of consumer based organizations, and of the centers' being viewed as crisis rather than service agencies were mentioned.

Admission Policies

Another major factor in the operation of a center is that of the policies relating to the provision of service. Central to this policy are the admission criteria for determining exactly which clients the center will serve. It was found that centers tend to have standard intake forms for use in obtaining demographic data on clients. Further, the use of these forms is governed by standardized intake rules. Within particular centers, special training is often provided regarding intake procedure and criteria, and typically several of the staff members are qualified to process intakes. Centers generally keep confidential records on clients, and identify clients who are new to the program. Centers don't necessarily write service plans for clients; however, when they are written the client takes an active part in the process. Once a client has been accepted for services, case notes are kept indicating activities and progress. In many cases, there are follow-up procedures for clients to see that problems have been resolved.

Universally, centers keep files on their clients, for both active and inactive cases. Quite often the files are not centralized, but rather kept separately by the various specialists in charge of specific service areas. All files are confidential and the staff is informed of the policy. Files usually include any follow-up on the client as well as referrals to other agencies.

Statistics and Demographics

Along with the process elements, this study examined the records of sample centers to determine the types of statistics and demographics summarized for use in reporting to the Department of Rehabilitation, other granting agencies, and for use in program planning. Generally, the centers summarized client demographics such as age, sex, and type of disability. Also summarized are type and number of service hours rendered. ILCs do not, however, appear to summarize referrals to and from other agencies. Because of the complexity involved in centers' funding and recordkeeping, most centers utilize the services of a professional bookkeeper. Occasionally centers have been audited.

Organizational Records

In addition to the types of records kept for clients, the study examined the types of organizational records kept on center activities. The following is a list of the number of centers, based on an N of 12, keeping such data.

Organizational Records Maintained

N = 12

<u>Type of Record</u>	<u>Number of Centers</u>
Funding reports from grant applications	12
Job descriptions	12
Minutes of board meetings	12
Files of incoming correspondence	12
Files of outgoing correspondence	12
Written grievance procedures for staff	11
Services list with services description	11
Dept. of Rehabilitation quarterly reports	11
Personnel policy manual	10
List of services given by disability	10
List of services and people who provide them	10
Unique forms for special client services	10
Staff work schedules	10
Accurate, up-to-date organizational chart	9
Files of interoffice memoranda	8
Minutes of staff meetings	8
Written staff evaluation guidelines	7
Written staff training policy	6
Written admission criteria	6
Applications for employment	5
Written staff orientation procedures	5
Written instructions for doing intakes	5
Filing system index	5
Written grievance procedure for clients	2

Problems and Future Considerations

During the course of the process phase, we spoke with many people involved with the independent living movement. Some were quite open about future plans, as well as the problems which the centers were facing; several of which were of a magnitude sufficient to warrant mention.

One of the greatest problems is that of community accessibility. Although recent legislation has dictated items such as curb cuts and architectural modifications for accessibility, there still remains a critical shortage of housing and accessible transportation. Many of the sample centers have devoted a significant portion of their energies to the development of accessible housing lists, and attempts at the provision of accessible transportation. The majority of center representatives expressed the desire to be able to provide transportation, but it is an expensive venture, and in most cases limited funding has hampered their efforts.

Cash flow is also a major problem; as centers grow, increased staffing and funding become a necessity. Most centers currently are facing a funding shortage and as a result are preparing a fee for service delivery pattern, as well as establishing plans for increased funding in the forms of community contracts for service, foundation grants and community grants and assistance.

Additional problems in the form of a critical personnel shortage, and a lack of office space have frequently been mentioned. The centers are on the whole doing quite well in terms of dealing with their problems. The majority of respondents indicated that fundraising was a possible avenue to their immediate objectives, since most wish to expand their services in response to an increased community need. Several of the centers, in addition to the above, have mentioned that as a future consideration, they wish to reorganize their centers, adding more services with specialized staff to provide them.

Future Research

At the point of this writing, the client gains phase of the Independent Living Research Study has begun. The instrument has been developed and pilot tested with clients from one of our sample centers. To demonstrate validity, the scores of intake clients were compared to clients who have achieved known levels of independent functioning. The instrument has proven to be useful in terms of its reliability and validity.

It is expected that a comparison of process results with outcome scores of the gains phase will enable the study team to determine the effect organizational factors have on client gain.

Scale

During the course of the process phase of the study two of the original sample centers ceased operation. In an attempt to determine possible factors which lead to center failure, a regression equation was developed using nine variables relating to critical areas of center functioning; the criterion variable being center success or failure. The equation turned out to have considerable predictive value ($R^2 = .85$).

The scale was composed of the following variables:

- x1 = Is it difficult to find qualified staff?
- x2 = Is it difficult to keep qualified staff?
- x3 = Are personnel policies given to new staff?
- x4 = Is job performance regularly evaluated?
- x5 = Are there problems with referral agencies?
- x6 = Are there problems with the community?
- x7 = Are there plans for expanded service programs?
- x8 = Are there plans for new staff?
- x9 = Is training provided to staff?

Correlations with criterion variable (center failure):

(x1= .8996	x5= .545)
(x2= .440	x6= .570)
(x3= .391	x7= .590)
(x4= .155	x8= .839)
(x9= .142)	

<u>Proportion of Center Staff</u> <u>Indicating A Problem Area</u>										
CENTER	X1	X2	X3	X4	X5	X6	X7	X8	X9	CM ⁺
A	.83	.33	.40	.17	.40	.33	.50	.83	.17	.40
*B	.80	.50	.00	.00	.60	1.0	.40	.60	.60	.49
C	.00	.00	.00	.00	.33	.33	.33	.00	.00	.12
D	.67	.33	.43	.71	.57	.43	.29	.71	.00	.44
E	.75	.00	.75	.00	.00	.60	1.0	1.0	.40	.45
F	1.0	.00	.33	.25	.50	.75	.50	.75	.00	.41
G	.00	.00	.33	.33	.25	.25	.25	.00	.00	.18
H	.33	.00	.00	.25	.25	.00	.00	.67	.75	.25
*I	1.0	1.0	.00	.00	.67	.33	1.0	1.0	.00	.50
J	1.0	.25	.67	.50	.75	.67	.67	1.0	.25	.58
K	.60	.60	.00	.00	.40	.60	.20	.20	.00	.34
L	.50	.25	.00	1.0	.25	.33	.25	.75	.75	.40
MEAN	.68	.30	.24	.27	.41	.47	.45	.63	.24	.39
S.D.	.3119	.3115	.2810	.3245	.2141	.2667	.3084	.3652	.3054	.1358

*Indicates Centers which have failed

+ = Center mean

APPENDIX E: DEMOGRAPHICS SURVEY
FROM CLIENT GAINS PHASE

General Information

1. Year of birth: 19 ____
2. Sex: ☐ Male
☐ Female
3. Ethnic background: (check one)

☐ Black	☐ Native American (American Indian)
☐ Hispanic	☐ Asian
☐ White, other than Hispanic	☐ Other (specify: _____)
4. Marital Status: (check one)

☐ Never married	☐ Separated
☐ Married	☐ Divorced
	☐ Widowed
5. Where do you live? (check one)
☐ Central city
☐ Suburban area
☐ Rural area
6. What is your current living arrangement? (check one)
☐ Live alone
☐ With a spouse or close friend(s)
☐ With dependent child(ren) and spouse
☐ With dependent child(ren) without spouse
☐ With adult son or daughter
☐ With parent(s)
☐ With other family
☐ With paid attendant only
☐ In institutional setting (hospital, convalescent home,
rehabilitation facility)
☐ Other (specify): _____
7. How long have you lived in this setting?
____ years, ____ months
8. In what setting did you live before your current arrangement? (Use
categories from #6 if possible.)

9. Education: (circle the highest grade completed)

grade school	1	2	3	4	5	6	7	8
high school	9	10	11	12				
college	1	2	3	4				
graduate school	1	2	3	4				

10. Have you ever had, or are you now taking, the following types of training?

☐ Trades (mechanical, electrical, plumbing, etc.)☐ Vocational (bookkeeping, clerical, cosmetology, etc.)☐ Professional (specify): _____11. If you are not currently employed, how long has it been since you worked?

_____ years, _____ months

☐ I have never worked.12. If you are currently employed, how long have you been working?

_____ years, _____ months

13. Are you a veteran?

☐ yes☐ no

14. Do you have a driver's license?

☐ yes☐ no15. If you have regular access to a car or van, who usually drives it?

(check one)

☐ I don't have regular access☐ a family member☐ a friend☐ a hired driver☐ I drive it

16. At what age did your disability occur? (check one)

☐ at birth☐ first 5 years☐ 6-15 years old☐ 16-25 years old☐ 26-35 years old☐ over 35 years old

17. Is your disability the result of military service?

☐ yes☐ no

18. What is the nature of your primary disability? (Put #1 in the appropriate box below.)

DISABILITY:ORTHOPEDIC:

- ☐ Amputation
☐ Arthritis
☐ Multiple sclerosis
☐ Muscular dystrophy
☐ Post polio myelitis
☐ Spina bifida
☐ Spinal cord injury
☐ Stroke
☐ Cerebral palsy
☐ ALS (Lou Gehrigs)
☐ Other (including Parkinson's, scoliosis, ataxia, osteoporosis, orthogryposis, etc.)

GENERAL MEDICAL:

- ☐ Brain injury
☐ Diabetes
☐ Kidney disorder
☐ Respiratory disorder
☐ Seizure disorder
☐ Liver
☐ Heart or circulatory
☐ Other congenital specify: _____
☐ Other injury specify: _____

PERCEPTUAL:

- ☐ Dyslexia
☐ Speech disorder (includes aphasia)
☐ Visual impairment/blindness
☐ Hearing impairment/deafness

LEARNING/EMOTIONAL:

- ☐ Emotional problem
☐ Learning problem
☐ Alcohol or drug problem

19. Please check (✓) other disability(ies), in the appropriate box(es) above.

20. Do you have an attendant at this time?

- ☐ yes
☐ no

21. Are you a new client at the Center or have you received services before?

- ☐ new client
☐ received services before from the Center

22. If you are an ongoing client, how many times have you been there? (check one)

- ☐ 1 - 2 times
☐ 3 - 4 times
☐ 5 or more times

23. How did you find out about the Center and its services? (check one)

- ☐ School
☐ Newspaper
☐ Radio or TV
☐ Friends, family
☐ Medical person or health agency
☐ Another disabled person
☐ Governmental agency (specify): _____
☐ Other (specify): _____

24. Why did you contact the independent living center? (Check all that apply.)

- ☐ To get help in improving my housing situation
- ☐ To get help in dealing with my landlord
- ☐ To find an attendant
- ☐ To meet people
- ☐ To talk to people with similar problems
- ☐ To get advice from a counselor
- ☐ To find out about other places to get help
- ☐ To get help in dealing with an agency
- ☐ To get legal help
- ☐ To get help in finding a job or job training
- ☐ To get help in dealing with an employer
- ☐ To get a special device or piece of equipment (e.g., wheelchair, eating aid, ramp, TTY, brailier, etc.)
- ☐ To get a piece of equipment repaired or modified
- ☐ To get a ride
- ☐ To find a reader or interpreter
- ☐ To get mobility training
- ☐ To get communication assistance (message relay service)
- ☐ Other (specify): _____

APPENDIX F: BERKELEY PLANNING ASSOCIATES
EVALUATION OF CALIFORNIA'S ILCs -- EXECUTIVE SUMMARY

EXECUTIVE SUMMARY: EVALUATION REPORT ON THE STATE'S INDEPENDENT LIVING
CENTERS

Berkeley Planning Associates has conducted a study of the eleven Independent Living Centers included in funding under AB 204, which supports a portion of activity in these centers. Information for this study was obtained from a client survey mailed to a systematic random sample of center clients, from site visits to each of the participating centers, and by telephone and personal interviews with community service providers and administrators, and Department of Rehabilitation staff. The study was limited to specific questions in the authorizing legislation, and was conducted in the months of November 1979 through mid-February 1980.

Centers participating in the study were:

Good Shepherd Center for Independent Living	Los Angeles
Westside Community for Independent Living	Los Angeles
Disabled Resources Center, Inc.	Long Beach
Darrell McDaniel Independent Living Center	Van Nuys
Community Service Center for the Disabled, Inc.	San Diego
Dayle McIntosh Center for the Disabled	Garden Grove
Resources for Independent Living	Sacramento
CAPH Service Center	Fresno
San Francisco Independent Living Project	San Francisco
Center for Independent Living	Berkeley
Community Resources for Independence	Santa Rosa

Findings from the study, related to each legislative question, are summarized here.

The Number and Description of Disabled Individuals by Disability, Who
Receive Services from the Independent Living Centers

An estimate of up to 18,000 clients served annually was compiled from interviews with center staff and information from their records. The centers serve clients with a wide range of disabilities. Users in wheelchairs account for over one-half of the client population, a number significantly higher than the national or state prevalence of wheelchair users in the disabled population as a whole. Approximately one-fifth of the

clients are elderly, and the educational profile shows that the clients are as well, or better educated than the general population. A large percentage of the clients receive public income assistance, supporting lifestyles where living alone or as a couple predominates as the living situation. Few of the clients live in institutions or group homes.

The Range of Problems Presented by the Individuals Served and the Services Provided in Response to Those Problems

A part of the service concept of centers is that clients may receive several combined services as a part of a casework process, where a peer counselor assists the client in bridging gaps left by public agencies, serves as a role model, and helps clients solve problems through peer counseling; on the other hand, clients may be using centers for only one service. In the analysis, we see that both these patterns exist. One-third of the questionnaire respondents indicated that they received help in one service area only; another third reported using help in four or more areas.

Clients indicated that advice from a counselor was the service most frequently sought and most frequently received, although no one service stands out as a predominant single service. Counseling relates closely to other social needs, such as a person with similar problems to talk to, or the chance to meet people. Services such as housing, attendants, and transportation are more isolated in that many clients may use these services alone, rather than the complete program of center counseling and referral. In most areas of service need, there was a high probability (at least 70%) of being helped by the center.

The Number of Individuals Who Moved from an Institutional Setting to a More Independent Setting by Type of Setting

At least two-thirds of centers' housing service efforts are directed toward maintaining disabled individuals in non-institutional settings, rather than deinstitutionalization. Of respondents living alone when they first contacted the center, and who subsequently received assistance finding new housing, 93% were still living alone at the time of the survey, compared with 77% of those who received no housing service from the center.

During the same interval, an average of 24 months, 28% of the respondents had changed their type of housing situation, resulting in a 10% increase in those living alone, a 28% decrease in those living with parents, a 47% increase of those living with roommates, and a 61% decrease of those living in institutions.

Of the clients who reported the centers had provided them with help in looking for a new place to live, 65% reported the centers had a positive impact on their housing situation.

The Number of Individuals Who Entered Vocational Rehabilitation or Employment

Employment services are a major service area in only four of the eleven centers. The employment situation for working age clients improved slightly after contact with the centers, with 8% of those unemployed and not looking for work when they came to the center reporting full- or part-time work now. The unemployed not looking for work still account for 60% of the clients in the sample, however. Twenty-five percent of the working age disabled clients indicated that they were unemployed but looking for work.

The centers report a strong relationship with the Department of Rehabilitation. All centers have a counselor regularly in the center, and over 40% of clients have a rehabilitation counselor now. Over 70% of those clients receiving employment-related service reported positive effects or help with finding a job or help with an employer.

The Impact of the Services on Medical and Supportive Service Costs

Expenses to provide support services, for those living independently, are difficult to estimate, due to the inability to capture all the social costs of delivering publicly provided services, and the lack of specific information on the expenses incurred by clients. It is possible, however, to observe some trends in the use of such services, by those served by ILCs.

Medical and Health Care

Comparing the clients' current use of medical services with the use patterns of these clients before they came to the center, there is a

decrease of 47% in frequent hospitalization, relatively little difference in frequent use of therapy, doctor's visits, counseling, and a slight increase in the number of individuals stating that they used no medical service frequently. While direct provision of health services is not among the list of regularly provided center services, 31% of clients reported that centers had a positive effect on their self-health care. Both these trends indicate possible savings in medical costs, both private and public.

Attendant Care

Review of attendant utilization patterns before and after contact with the center shows an increase of 24% in the number of clients using an attendant, and a reduction of 28% in those not using an attendant but looking for one. Also, there was a net change in the direction of persons increasing use of attendant hours. Sixty-nine percent of those receiving help with finding attendants reported that the center had a positive effect on the quality of their attendant care, as compared to 23% of the entire client sample, which cited positive effect. Such increased utilization may indicate an increase in costs of attendant care, since both numbers of people using the service, and hours of service, show an increase. This cost may be borne by the individual, or by the public through various support programs.

Financial Support

The one financial support program that shows a substantial change after contact with centers is Homemaker Chore, where there was an overall increase in the number of individuals indicating this as a source of income. In terms of other financial support earnings showing change after contact with the center, job earnings shows a slight increase, as does SSI and SSDI payments. Forty-eight percent of the respondents who reported current job earnings indicated that they did not have job earnings before.

Transportation and Other Aids

Centers appear to have been effective in the impact on clients' abilities to get rides when needed, and to get help from equipment or devices. Of the 86 clients receiving help in getting a ride, 83% indicate

positive effects; for those receiving help in equipment provision, 86% reported positive effect; 88% of equipment repair clients indicated positive effect. Provision of transportation services by centers shows a definite effect on clients' assessments of impact, with almost half of those clients from centers providing transportation reporting positive effect in getting rides, as compared with 29% in centers providing neither transportation nor referral.

It is difficult to assess the possible cost implications of such service use; the improved ability to use already purchased devices and equipment may mean increased cost-effectiveness in these services; increased ability to get rides may mean increased transportation operating costs borne by public systems, but it may also mean increased ability to obtain jobs and pursue independent living goals.

The Impact of the Services on the Disabled Individuals' Participation in Family and Community Activities

Evaluation of the ILC impact on clients' participation in family and community activities is difficult. There is no one ideal level of participation across all clients. The appropriate level of participation, and direction of positive change, depends on the wishes of the individual client and his or her own family and friends.

Most clients in the survey reported no impact on their relationship with family, friends, or the larger community. In the cases where effect was expressed, however, the client reported the change as positive. Of the 57 clients living with parents when first contacting the center, 37% reported positive effect. Twenty-six percent of those living with spouse or other family members reported positive effect on relationship with spouse or children.

Overall, about one-third of the clients responding indicated a positive effect on social relationships with friends and in the community. Response varied by center.

Other Sources of Funding Independent Living Centers

Centers are supported by a variety of funding sources, with the support for the current fiscal year totaling approximately \$5.6 million; about

half of these funds are reported as coming from a variety of programs of the California Department of Rehabilitation, which include funds from the General Fund and from federal programs of the Rehabilitation Services Administration. Public funds account for over 90% of the total.

Dependence on "soft" money presents centers with stability problems, and in the longer run, a more stable funding base is sought. In the short run, funding patterns depend on what is available. Some centers are developing "fee for service" approaches to program support, but report difficulty in setting prices that cover cost, and in obtaining the volume necessary for program support.

The Cost and Savings to the General Fund of Providing the Services

Currently, almost one-third of the budgets in the ILCs are supported by the state General Fund directly, through AB 204. In addition, many of the services clients receive in support of their independence come from the General Fund as state programs or as part of the state match for federal funds. The state-of-the-art in benefit-cost or cost-effectiveness studies does not allow conclusive analysis of whether or not there is a net cost savings in independent living for those with severe disability. However, there are many non-economic benefits that must be considered, in addition to economic savings that might be realized by deinstitutionalization. Areas where public or private savings are indicated, from the results of this study, include decreased hospitalization costs, increase in job earnings, reduction in AFDC, and a slight decrease in institutionalization. Areas where public costs are increased are in use of attendant care, homemaker chore support, increased use of transportation, and some increase in clients' abilities to obtain benefits to which they are entitled.

Client and Community Perceptions

In the study, clients and community members responded to questions on center impact. In BPA's analysis, three centers have strong positive effect in both client and community assessment. A center with lower client scores shows positive community impact; however, the center with the lowest client rating scores low on community assessment. Of the two centers

with the lowest community scores, one had a very strong client rating. Overall, then, three centers appear to be regarded positively by both clients and community, several others have mixed reviews, and one center falls behind the others in overall assessments.

A complete evaluation of the effectiveness of the ILC program requires data collection and analysis beyond the budget and time frame of this study. While findings in these pages indicate positive performance in some areas identified as Independent Living goals -- housing, reduced hospitalization, and attendant care -- more information on the services clients use and the effects on clients' ability to live independently is needed.