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# FOIA MARKER

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**Record Group/Collection:** Donated Historical Materials  
**Collection/Office of Origin:** Frieden, Lex, Collection  
**Series:** Disability Rights Organizations  
**Subseries:**

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**OA/ID Number:** 52064  
**Folder ID Number:** 52064-009

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**Folder Title:**  
[TIRR] New Options Proposal and Correspondence [1974-1977] [2]

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**Stack:**

**Row:**

**Section:**

**Shelf:**

**Position:**

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## TIRR TRANSITIONAL PROJECT

The TIRR transitional project will provide training in social adaptive skills for persons with severe physical disabilities. The live-in program is designed to last approximately nine weeks for each participant. Some persons may need less training and leave the program after a shorter period of residence. Others may profit from additional special services such as drivers' training, a formal vocational evaluation, or time in a practice living situation which may require more time.

During an individual's first week in the project, he or she will be introduced to the various program activities and to the project techniques of self-assessment and goal-setting. The participant will develop an individualized program plan with project staff members which will be formulated in a contract specifying what is expected of each party. Each participant will be assigned a buddy at the beginning of his or her stay. The buddy relationship will serve as a focus for work on social interaction and interpersonal relations throughout a person's stay in the project.

The program will be organized so that all subject areas are covered in an eight-week period. Some on-going activities will be scheduled on a weekly basis. Other program areas will be developed as short-term training modules which are scheduled in an eight-week sequence. The various program elements are described below.

social skills group

3 hours per week

Two sessions of 1½ hours each will be conducted per week by a social worker, to deal with social relationships inside and outside the project, family relationships, feelings about self and the future, and other areas as appropriate.

weekly seminar on educational and vocational opportunities 4 hours per week

Seminar will be conducted by a vocational counselor to include group discussions and numerous field trips to colleges, vocational training programs, and employment locations; active handicapped persons in the community will be involved as resource persons.

weekly seminar on living arrangements

4 hours per week

Seminar will be conducted by core project staff to include group discussions and numerous field trips to nursing homes, residential projects, a college dormitory, and individual living arrangements; active handicapped persons in the community will be involved as resource persons.

weekly buddy counseling

1 hour per week

Individual and joint counseling by project social worker will focus on buddy relationship as a means of developing an understanding of other persons and skill in interpersonal interaction.

weekly consultations with RN, PT, OT

1½ hours per week

These professional staff members will be available one morning a week to serve as consultants to project participants in assessing their needs and devising programs to meet these needs; to include long-term planning as well as dealing with immediate problems.

weekly mobility assessment group

1½ hours per week

A weekly meeting will be conducted by core staff members to examine mobility problems encountered by participants on various field trips and to consider ways of dealing with these problems.

weekly sex and coffee group

1½ hours per week

A weekly group will be conducted by the project social worker to examine attitudes and feelings about sexuality, role expectations, and dating.

weekly evaluation and assessment session

3 hours per week

One morning per week, participants will take part in an evaluation session to be supervised by core project staff. These sessions will fill two purposes. One is to measure the individual's status in various program areas as an aid to self-assessment. This information will be used by the participant in formulating plans for the coming week. The second purpose is to provide information to the staff about the effectiveness of various program elements.

weekly group on problem-solving

1½ hours per week

This group will meet in the afternoon following a morning assessment session to assist persons in considering needs, specifying goals, and formulating plans formulating plans for the coming week. Long-range planning will also be emphasized.

weekly group for significant others

1½ hours per week

A group will be conducted one evening per week as needed for family members, spouses, close friends, or counselors of project participants. The group will consider the transitional experience of the project participant, examine the SO's feelings about these changes, and help the SO in being a supportive influence after the participant has left the transitional project.

### field trips

Field trips into the community will be included in many program activities (visits to vocational training sites and residential projects, for example). In addition, other trips to shopping areas, recreational activities, etc. will be regularly scheduled with participants to be involved in trip planning. After each trip, participants will complete a form concerning their social interaction on the trip and a form on mobility problems they encountered. These experiences will later be discussed in group sessions.

### short-term training modules, cycle I 4½ hours per week

Short-term training programs in self-care and medical needs (two weeks), functional skills (three weeks), and homemaking skills (three weeks) will be conducted by an RN, PT, and OT respectively. These modules will meet three mornings a week (1½ hours per session) for the designated number of weeks. They will be scheduled one at a time in an eight-week cycle.

### short-term training modules, cycle II 4½ hours per week

Short-term training modules will be conducted by core project staff with substantial involvement of active handicapped persons in the community. Subject areas will include attendant management (two weeks), financial management (two weeks), mobility and transportation (two weeks), consumer affairs (one week), and leisure activities (one week). Groups will meet three afternoons a week (1½ hours per session) for designated number of weeks. Modules will be scheduled one at a time in an eight-week cycle.

These activities will be combined in a weekly schedule as indicated below. The scheduling will be varied as the project progresses to test the effectiveness of alternative arrangements.

TENTATIVE WEEKLY SCHEDULE / TIRR TRANSITIONAL PROJECT

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	WEEKENDS
MORNING	module I consultations buddy coun- seling	buddy coun- seling social skills group	module I field trips	module I staff meeting consultations	evaluation & self- assess- ment	field trips
AFTERNOON	buddy coun- seling sex and coffee group module II	seminar on vocational- educational opportuni- ties	mobility assess- ment social skills group module II	seminar on living arrangements	problem- solving group module II	field trips
EVENING		SO group	field trips			field trips

cont'd from p. 2

1 1/2 hr. direct obs. 120g

11-12 hrs. work

1 1/2 hr. from 861. 20g.

3-4 hrs. work

for 50 cycles (2 tanks)

spans (10 and 1/2 hrs)

= 10hr. testing in Dir.

200 hrs. evaluation

interview 1 hr. / obs. / vid.

145, 200

100 hr. interviewing


~~200~~ 250 hr. evaluation

145 / 14, 800, 200  
50 / 20, 20, 200  
200



An analysis and description of the program as a whole will be made from an anthropological perspective. The main objective of this portion of the study is to document the planning of the transitional program and to trace its evolution over time as new participant populations are included, staffing arrangements change, and as the program content is refined. Fairweather's study of the evolution of a community-based program for ex-mental patients is perhaps the best prototype of the type of study that is planned (1969). During the course of the project Fairweather continuously ~~made explicit and~~ documented the expected outcomes of various planning decisions. He then used on-going experience in the project to test the accuracy of these predictions.

Two major types of data will be used in this portion of the study. The first is factual information about how time is spent in the project. This information will be provided by the system measures discussed above, by staff diaries to be completed daily by professional staff members in a simple standardized recording format, and by <sup>minutes</sup> ~~minutes~~ of meetings with staff members and with outside agencies to be maintained <sup>time</sup> by the project director. The second type of data includes perceptions and assessments made by various staff members about the program. An <sup>6</sup> ~~ev~~luation form will be completed monthly by staff members. It will be based on the Community-Oriented Program Evaluation Scale (COPES) developed by Roos et al in their study of psychiatric treatment settings (1974). The evaluation form will focus on individual assessments of the various program elements, on relationships among staff and among participants, on interaction between participants and the active handicapped community resource persons, on managerial and decision making processes, on the social atmosphere, and on areas that are



seen as problems by the staff members. In addition to these types of data, the project director will continuously record observations in the form of anthropological field notes. These observations will be focused on areas such as staff relationships and on roles within the project. They will include explicit statements of expectations expressed by staff members in various planning meetings.

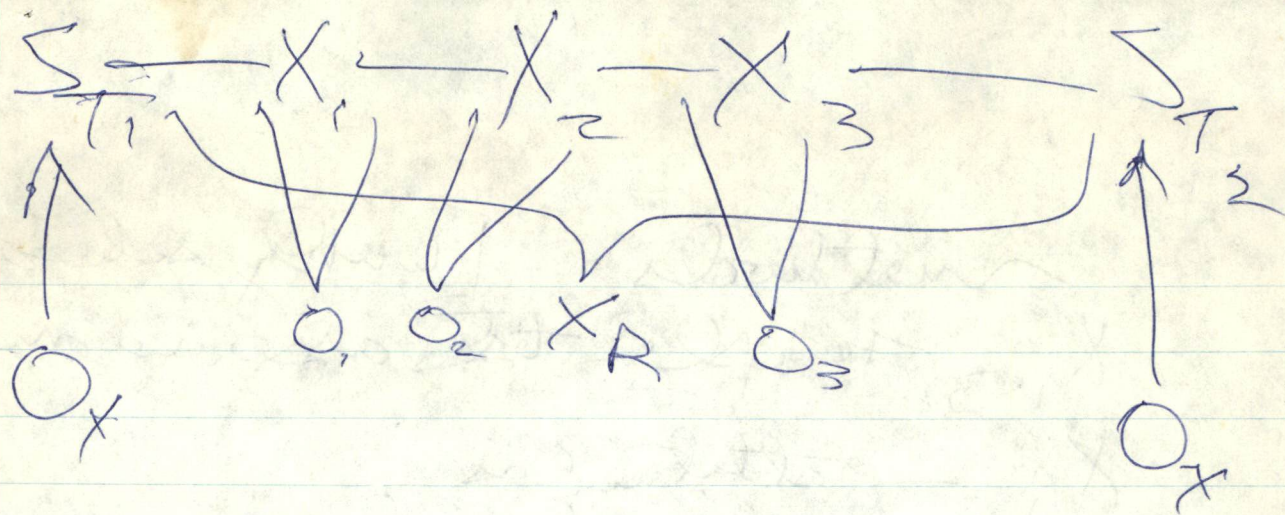
Lex -

The transitional grant has been formally approved. Deirdre thinks it will be funded in Sept.

I talked with Ed about Dick Santo Mon. evening and also told Scott Bigham to invite whomever he thought would be interested.

Jean





known treatments & goals  
 $X_{13}$  teaching  $\rightarrow$  learning  
 $X_R$  "rehab" (whole person)

measures

$X_{1-3}$  specific tests of knowledge  
 and skills

$X_R$  monitor attitudinal and  
 behavioral changes

designs

$X_{13}$  pretest - posttest control  
 groups w counterbalanced  
 treatment presentation

$X_R$  longitudinal multi-trait  
 multi-method measures

methods [weekly schedule]  
X<sub>103</sub> simple test asso. w module

X<sub>R</sub> — attitudes  
semantic differential  
interview S+O  
inventory

— behavior (unobtrusive)  
archives

accretion - odometers  
erosion money spent  
body counts  
counters

observations - sociogram

function v lists  
interview

system mgt. - design  
monitor, organize, file  
transformation  
evaluation  
feedback

[unintended effects / good food  
unknown treatment of objects  
requirements were  
constant and simple -  
robust observation

early interviews  
typical initial exploration  
direct observation  
diaries  
→ Central group → ?  
experience

interviews: design of notes.  
collection of data  
analysis  
feedback

1 1/2 hrs. direct obs. requires  
11-12 hrs. work

1 1/2 hrs. of forum obs. requires  
3 hrs. work

3 primary categories of measurement designed to measure 1-3  
all added to beh. changes caused by

3 unknown treatments  
unintended effects

1 known long term goals  
effects of program (milieu) components  
2 known short term goals  
effects of specific treatment

4 Soc interaction of structure system  
indep. - indep. system  
self concept  
self efficacy  
self confidence  
initiative  
self-reliance  
range of activity

random control group  
evaluate set criteria

BA Interview

▷. Additional form

▷. Stranger form

▷. Beh. etc. diary

systems meas.

always

transp.

workgroup

group

services

class attendance

mobility meas.

class

always

module exams

(BA) programmed learning

BA be general

BA (attitude)  
Rottor  
intend/get scale

BA Siller  
semantic dif.  
ATAP (yepes)

lex-

This is the stuff from  
Israel Goldiamond that  
Barbara wanted to look  
at in formulating a  
proposed resident-kept  
record. I thought you  
might want a copy  
too.

Sean

*Table 2 has 10/1/74*

## I. CONSTRUCTIONAL QUESTIONNAIRE

(The purpose of these questions is to obtain information, hence their wording is to be tailored to the occasion.)

### (INTRODUCTION)

I am going to ask some questions to help us both understand what it is that we should work toward.

The questions have three purposes:

First, we'll need information to help acquaint us with you.

Second, from the questions people ask, you can learn things about them, so this should help you learn about our approach.

Third, to see how we're progressing, we need records, and before and afters. This is a kind of before on how you see things now, and what aims you want now, so please speak up.

### (QUESTION 1: OUTCOMES)

I am going to ask you a group of questions about our goals. You are here because you want certain changes to occur, or want something else.

(a. Presented outcome) The first of these is: Assuming we were successful, what would the outcome be for you?

(b. Observable outcome) Now, this may sound silly, but suppose one of these flying saucers is for real. It lands and 2,000 little Martians pour out. One of them is assigned to observe you -- your name was chosen by their computer on some random basis. He lands some time after L-Day -- Liberation Day from your problems -- and follows you around invisibly. He records his observations and these are put on IBM (Interplanetary Business of Mars) cards. Their computer will decide on the basis of the sample of 2,000 Earthlings they have, what their disposition toward Earth should be. What does he observe?

(b. Alternate or added form: What would others observe when the successful outcome was obtained?)

(c. Present state) How does this differ from the present state of affairs?

(d. Example) Can you give me an example?

### (QUESTION 2: AREAS CHANGED, UNCHANGED)

The next group concerns things in your life which are going well, and things which are not.

(a. Areas unchanged) What's going well for you now, and what areas of your life would not be affected by our program?

(b. By-products) What areas other than those we'd directly work on would change?

### (QUESTION 3: CHANGE HISTORY)

This next series concerns your efforts to change things.

(a. Present attempt) Why start now? How come?

(b. First attempt) When did it first occur to you to try to change? What was going on? What did you do? How did it come out?

(c. Intervening attempts) What did you do then? What was going on? How did it come out? (Series continues until present).

### (QUESTION 4: ASSETS)

The next series is concerned with the strengths and skills you have that we can build on. No one starts out from scratch.

(a. Related skills) What skills or strengths do you have which are related to what you'd like to program?

(b. Other skills) What others do you have?

(c. Stimulus control) Are there conditions when the present problem is not a problem?

(d. Relevant problem-solving repertoire) In the past, what related problems did you tackle successfully? What related programs did you succeed in? How?

(e. Other problems solved) What other problems did you tackle successfully? How?

(f. Past control) Did you once have mastery of the present problem area? If so, when, and under what circumstances? Any idea of how?

### (QUESTION 5: CONSEQUENCES)

I am going to ask some questions about effects produced, and effects you'd like to produce.

(a. Symptom reinforcer: positive) You've heard of the proverb, "It is an ill-wind that blows no good." With regard to some advantages that might have "blown your way," has your problem ever produced any special advantages or considerations for you? (Examples: in school, job, at home) please give specific examples.

(b. Symptom reinforcer: negative) As a result of your problem, have you been excused for things -- or from things -- that you might not be otherwise?

(c. Symptom cost) How is your present problem a drag, or how does it jeopardize you? (Note: Omit if answered in 3a. Why start now?)

(d. Possible current reinforcers) What do you really like to do, or would like to do? Is there anything that really sends you?

(e. High probability behaviors) What do you find yourself doing instead? (or getting instead?)

(f. Social reinforcers) Who else is interested in the changes you're after?

(g. Past social reinforcers) What people have been helpful in the past? How did they go about it? How did you obtain this from them?

(QUESTION 6: COMPLETION)

Is there anything we left out or didn't get enough about? Was there something we overlooked - - or made too much of? Are there any impressions you'd like to correct?

(QUESTION 7: TURNABOUT)

Turnabout is fair play. We have asked you a lot of questions. Are there any questions you'd like to ask of us? Any comments? Kicks? Anything you'd like to know about our goals, or approach?

PROGRAM CONTRACT ONE: ASSESSMENT

PART ONE: Purpose

Two program contracts will be signed. The purpose of this statement is to explain the first one.

The first program contract deals with the arrangements necessary for us to find out how we can best help you attain your goals.

We obtain this information in two ways. One way is the initial interview we have been engaged in. The other has yet to be done. It concerns the way things are going now outside the office. This information can only be obtained from direct observation, either by us, or by you. For this purpose records are required.

Professionals collect data in addition to histories and purposes for coming. For example, the physician collects "resting" measures or basal measures. These records include temperature, pulse rate, blood pressure, basal metabolism, X-ray, as well as other tests. If you want to learn something, the educator may require aptitude and achievement scores. The architect may want to know your living requirements.

Very often, the physician does not initiate his treatment immediately. Nor does the educator immediately plunge you into the course. They wait to see what the data will tell them. The physician may also want data on your situation outside the office before treatment starts. The educator may want to see how you do in temporary classes before assigning you to your regular class. The architect may want to visit you in your present home.

In our program, we require at least two weeks, or two assessment sessions before we start the program. These are called baselines. Sometimes, it may take longer, but we hope to start as soon as possible.

After we are satisfied that we know enough to make our assessment and plans, we shall supply you with our analysis and recommendations. Please note the following: these will be recommendations which we shall offer for your approval. If you have other opinions, you can then say so. Whatever comes out will be by mutual agreement. Otherwise, there is no point in either of us agreeing to go ahead. We may, however, agree to continue to explore further possibilities, if this is mutually agreeable. Or either or both of us may decide to go no further.

Whenever we have obtained mutual agreement regarding the outcomes, programs, and requirements, we shall present a second program contract. If for some reason we decide that continuation will not help you or us, we shall terminate.

We need your consent to get the information necessary for assessment. This first program contract is for this assessment period.

PROGRAM CONTRACT ONE: ASSESSMENT - DIAGNOSIS

PART TWO: General Arrangements

IN ORDER FOR US TO ASSESS  
PROGRAM OUTCOMES, PROGRAM PROCEDURES  
AND PROGRAM REQUIREMENTS,

A. On your part you agree that  
with regard to

B. On our part we agree that  
with regard to

1. APPOINTMENTS,

You will attend sessions set up.  
If you find it impossible to  
attend, please notify us on a  
business day not less than  
24 hours in advance. Time and  
place are in Part Three,  
specific arrangements.

We shall keep appointments  
set up. If we can not meet  
them, we shall try to in-  
form you at least three  
days in advance, barring  
emergencies.

2. RECORDS,

You will try to keep the records  
we assign as well as you can,  
and will bring them to sessions.  
Types of baseline records are in  
Part Three.

We shall explain the purpose  
of the records, the entries,  
and analyze and provide feed-  
back on how well you are  
keeping them.

3. OTHER ASSIGNMENTS,

You will try to fulfill various  
other specified assignments, as  
made.

We shall similarly explain  
purpose of assignments and  
provide feedback on your  
performance.

4. OTHER CONSULTATIONS,

You will, if requested, consult  
with other professionals or  
concerned parties. Nature of  
consultation is indicated in  
Part Three.

We shall explain the  
rationale involved, and  
where necessary, make or  
suggest arrangements.

5. OTHER RECORDS,

You consent, if requested, to  
authorize examination of other  
records, to be indicated in  
Part Three.

We shall similarly explain  
the rationale involved.

6. RESEARCH, TRAINING, AND CONFIDENTIALITY,

(Data from your records can be useful for consultation with other staff members, training of staff, and research publications which help other professionals and thereby other clients.) You consent to the use of such data for these purposes, with restrictions noted in Part Three.

We shall preserve the confidentiality of your records and take every precaution to insure that any data disseminated are not identified with you, in accord with prevailing practice with medical and psychiatric records and research. Any other type of dissemination is specified in Part Three.

7. REGULAR AND SPECIAL FEES,

You consent to payment of fees described in Part Three, both for regular sessions and for special purposes described.

We shall provide the conditions and personnel necessary for assessment, and shall explain the special fees involved.

8. STAFFING,

You will work with whatever staff are agreed upon.

We shall try to adhere to staffing arrangements made.

9. DISPOSITION,

You understand that upon evaluation, we can consider the outcomes to be attained, the program procedures and requirements necessary, to be of such a nature as to make it unprofitable for you or for us to continue.

We shall report to you the results of our assessment and the disposition we recommend.

PROGRAM CONTRACT ONE: ASSESSMENT - DIAGNOSIS

PART THREE: Specific Arrangements

1. Appointments:  
Time:  
Place:

2. Baseline records:

3. Other assignments:

4. Initial consultation required:

5. Other records required:

6. Research and training needs:

Dissemination consented to for each:

a. Tapes of sessions

Video: \_\_\_\_\_

Audio: \_\_\_\_\_

b. Other tapes: \_\_\_\_\_

c. Baseline records:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

d. Other assignments:

\_\_\_\_\_

e. Other records:

\_\_\_\_\_

f. Programmer notes:  
Write ups:

\_\_\_\_\_

g. Special agreements:

\_\_\_\_\_

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|-----------------|--|-----------------------------|
| Audience<br>Key | 1. GD General Dissemination            | 5. TR Trainees              |
|                 | 2. GS General Sessions                 | 6. CS Clinic staff          |
|                 | 3. SS Scientific Journals,<br>Sessions | 7. PG Program staff<br>only |
|                 | 4. HS Hospital staff                   | 8. CC Case con-<br>sultants |

7. Fees	Amount:	Per:	Payable to:	When	Other:
Regular	_____	_____	_____	_____	
Special	_____	_____	_____	_____	

8. Staffing agreed upon:

Baseline: \_\_\_\_\_

Thereafter: \_\_\_\_\_

9. Consent does not imply continuation beyond assessment, or before, if terms unmet, or for other reasons.

I agree to the foregoing:

Client(s) \_\_\_\_\_  
\_\_\_\_\_

Date: \_\_\_\_\_

I agree to the foregoing:

Programmer(s) \_\_\_\_\_  
\_\_\_\_\_  
Monitor(s) \_\_\_\_\_  
\_\_\_\_\_

Date: \_\_\_\_\_

## II. CASE PRESENTATION GUIDE

### A. Introduction

#### 1. Identifying information.

Brief description of patient and a few qualifying statements which are relevant to what follows.

#### 2. Background for the program.

Use A3 as the resolution toward which this presentation is directed. Weave in various items from questionnaire and other sources to present a coherent picture of a person functioning highly competently, given his circumstances and implicit or explicit goals, and personal and social history. Infer how symptom may have been shaped and its functional history.

#### 3. Symptom as costly operant.

Infer how, as a result of A2, the patterns shaped and reinforced up to now are now too costly or otherwise jeopardizing the patient. Infer what reinforcers are presently maintaining patterns, sources, and type of jeopardy and its source. This should be brief and simply stated as the logical outgrowth from A2, which presented in somewhat more detail what led up to this.

### B. Tentative program directions.

#### 1. Outcomes which seem reasonable as targets

#### 2. Evidence for each of these

- a. Relation to reinforcers maintaining symptom
- b. Likelihood of producing additional reinforcers.
- c. Feasibility of substitution for jeopardizing symptom
- d. Relation to present repertoires
  - i. Personal
  - ii. Environmental and available.

#### 3. Feasibility (cost, resources)

### C. Current relevant repertoires

#### 1. General, for program-recording requirements:

- a. Analytical, types of relations explained
- b. Recording repertoires

#### 2. For each of targets recommended:

- a. Previous programs
- b. Current relevant repertoires: assay of current resources

- c. Social repertoires
- d. Environmental assets
- e. Maintaining and available consequences; accessibility.  
Symptom as reinforcement indicator.

D. Change procedures: programing guides

1. For program-recording and analysis of each target

- a. Analytic procedures to be used (texts, manual, discussions)
- b. Records to be kept; graphs.

2. For target areas

- a. Programs and repertoires in past to be transfered or modeled.  
How?
- b. Shaping, modeling, or transfer procedures for changing present repertoires
- c. Getting and shaping program cooperation from others; reinforcing such cooperation
- d. Ways current environmental resources might be used. Facilities.  
Possible social models
- e. Social and other possible support. Analysis of symptom as successful operant.

E. Maintenance guides

1. Through program

- a. Records, graphs, other assignments
- b. Other possibilities
- c. Reliability checks
- d. Extraneous consequences

2. Thereafter

F. Specific programs

1. Available specific programs

2. Staffing

3. Other suggestions

*filled out by [unclear]*

Date

I. Statement of Subgoals  
(Past week)

II. Extent to which  
Subgoals were  
reached; Current  
Relevant Repertoire

III. Comments about Subgoals  
and Program Notes;  
Controlling variables

IV. Statement of Subgoals  
(Coming week)

Initials

WEEKLY SELF-CONTROL WORKSHEET

BRAND: Chicago

V. Justification of Subgoals:  
Relation to Goals and control-  
ling variables.

VI. Program Notes: Procedures for  
attaining Subgoals, given the  
Current Relevant Repertoire.

VII. Suggestions for future  
consideration; Feedback  
requested.

INTERACTION TO BE RECORDED:

DATE:

PAGE:	INITIALS:	TRANSACTIONS					COMMENTS
		AUDIENCE, CONDITIONS	ANTECEDENT or INTENT	MY BEHAVIOR	BEHAVIOR OF OTHER[S]	MY BEHAVIOR	
LOG: INTERACTION	NUMBER:						
	TIME: to						
LOG: INTERACTION	NUMBER:						
	TIME: to						
LOG: INTERACTION	NUMBER:						
	TIME: to						
BRAND: Chicago	NUMBER:						
	TIME: to						

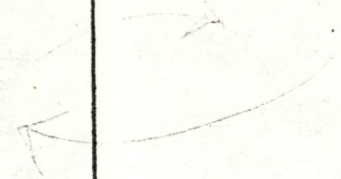
DATE:

CURRENT RELEVANT REPERTOIRE

*done*

SUBGOALS: SUBTERMINAL REPERTOIRE

*To do*



WEEKLY PROGRAM WORKSHEET

PROGRAM NOTES

BRAND: Chicago

EVENT TO BE RECORDED:

DATE:

PAGE	NO.	TIME	PLACE, AUDIENCE, CONDITIONS	CONCURRENT ACTIVITY	DESCRIPTIONS OF BEHAVIOR	WHAT FOLLOWED	COMMENTS
INITIALS		From: to					
		From to					
		From to					
		From to					
		From to					
		From to					
		From to					

LOG: SPECIFIC EVENT

BRAND: Chicago

DATE:

PAGE	NO.	TIME	PLACE, AUDIENCE, CONDITIONS	ACTIVITY INTENDED	ACTIVITY	COMMENTS
INITIAL		From to				
		From to				
		From to				
		From to				
		From to				
		From to				
		From to				
		From to				
		From to				

*How did feel about it -*

LOG: DAILY EVENT

BRAND: Chicago

Exams

evaluate modules  
of groups  
knowledge

TENTATIVE WEEKLY SCHEDULE / TIRR TRANSITIONAL PROJECT

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	WEEKENDS
MORNING	module I consultations buddy counseling	buddy coun- seling social skills group	module I field trips	Module I staff meeting consultations	evaluation & self- assessment <i>interview</i>	field trips
AFTERNOON	buddy coun- seling sex and coffee module II	vocational- educational opportunities	<u>mobility assessment</u> social skills group module II	living arrangements	seminar on planning & problem- solving module II	
EVENING		family group	field trip			

good mobility - ~~admission~~ / ~~transp.~~

TIRR TRANSITIONAL PROJECT

The TIRR transitional project provides training in social adaptive skills for persons with severe physical disabilities. The live-in program is designed to last <sup>approximately</sup> nine weeks for each participant. Some persons may need less training and leave the program after a shorter period of residence. Others may profit from additional special services such as drivers' training, a formal vocational evaluation, or time in a practice living situation which may require more time.

During an individual's first week in the project, he or she will be introduced to the various program activities and to the project techniques of self-assessment and goal-setting. The participant will develop an individualized program plan with project staff members which will be formulated in a contract specifying what is expected of each party. ~~The program is intended to be individualized and flexible.~~ Each participant will be assigned a buddy from the outset. The buddy relationship will serve as a focus for work on social interaction and interpersonal relations throughout a person's stay in the project.

The program of services is summarized below.

- social skills group 3 hours per week  
 Two sessions of 1½ hours per week <sup>will be</sup> conducted by a social worker to deal with social relationships inside and outside the project, with family relationships, feelings about self and the future, and other areas as appropriate.
- weekly seminar on educational and vocational opportunities 4 hours per week  
 Seminar <sup>will</sup> be conducted by a vocational counselor to include group discussions and numerous field trips to colleges, vocational training programs, and employment locations; active handicapped persons in the community <sup>will</sup> be involved as resource persons.
- weekly seminar on living arrangements 4 hours per week  
 Seminar <sup>will</sup> be conducted by core project staff to include group discussions and numerous field trips to nursing homes, residential projects, a college dormitory, and individual living arrangements; active handicapped persons in the community <sup>will</sup> be involved as resource persons.
- weekly buddy counseling 1 hour per week  
 Individual and joint counseling by project social worker <sup>will</sup> focus on buddy relationship as a means of developing an understanding of other persons and skill in interpersonal interaction.
- field trips  
 Field trips into the community will be included in many program activities (visits to vocational training sites, residential projects, etc.). In addition, other trips to shopping areas, recreational activities, and restaurants, etc. will be regularly scheduled by the transportation director with participants to be involved in trip planning. After each trip, participants will complete a form concerning their social interaction on the trip and a form on mobility problems they encountered. These experiences will later be discussed in group sessions.

weekly mobility assessment group \* 1 1/2 hours per week

A weekly meeting, <sup>will be</sup> conducted by core staff members to examine mobility problems encountered by participants on various field trips and to consider ways of dealing with these ~~problems~~.

weekly sex and coffee group 1 1/2 hours per week

A weekly group, <sup>will be</sup> conducted by the project social worker to examine attitudes and feeling about sexuality, role expectations, and dating.

weekly consultations with RN, PT, OT 1 1/2 hours weekly

These professional staff members will be available one morning a week to serve as consultants to project participants in assessing their needs and devising programs to meet these needs; to include long-term planning as well as dealing with immediate problems.

training modules-cycle I 4 1/2 hours per week

Short-term training programs in self-care and meeting medical needs (two weeks), functional skills (three weeks), and homemaking skills (three weeks) ~~will~~ be conducted by an RN, PT, and OT respectively. These modules will meet three mornings a week (1 1/2 hours per session) for the designated number of weeks. They will be scheduled one at a time in an eight-week cycle.

training modules-cycle II 4 1/2 hours per week

Short-term training modules <sup>will</sup> be conducted by core project staff with substantial involvement of active handicapped persons in the community. Modules will include attendant management (two weeks), financial management (two weeks), mobility and transportation (two weeks), consumer affairs (one week), and leisure activities (one week). Groups will meet three afternoons a week (1 1/2 hours per session) for designated number of weeks. Modules will be scheduled one at a time in an eight-week cycle.

group for significant others 1 1/2 hours per week

A group <sup>will</sup> be conducted one evening per week as needed for family members, spouses, close friends, or counselors of project participants. The group will consider the transitional experience of the project participant, examine the SO's feelings about these changes, and help the SO in being a supportive influence after the participant has left the transitional project.

\* It might be useful to formalize some sort of <sup>weekly</sup> review on people's use of attendants throughout the project based on a log kept by attendants - the purpose would be to encourage people to use attendants' time more efficiently. Perhaps this should be combined with the weekly mobility assessment group?

weekly evaluation and assessment session

3 hours per week

Each Friday morning, project participants are expected to take part in an evaluation session. These sessions will fulfill two purposes. One is to measure the individual's status in various program areas as an aid to self-assessment. This information will be used by the participant in formulating plans for the coming week. The second purpose is to provide information to the staff about the effectiveness of various program elements. Since this is an R&D effort, the transitional programming will be continually developed and refined to make it more responsive to ~~assess~~ assessed needs.

A tentative weekly schedule is given below.

IV ← mass. Effects of program (experience) field to modules (information)  $\Delta$  System model effects

level on behavior of

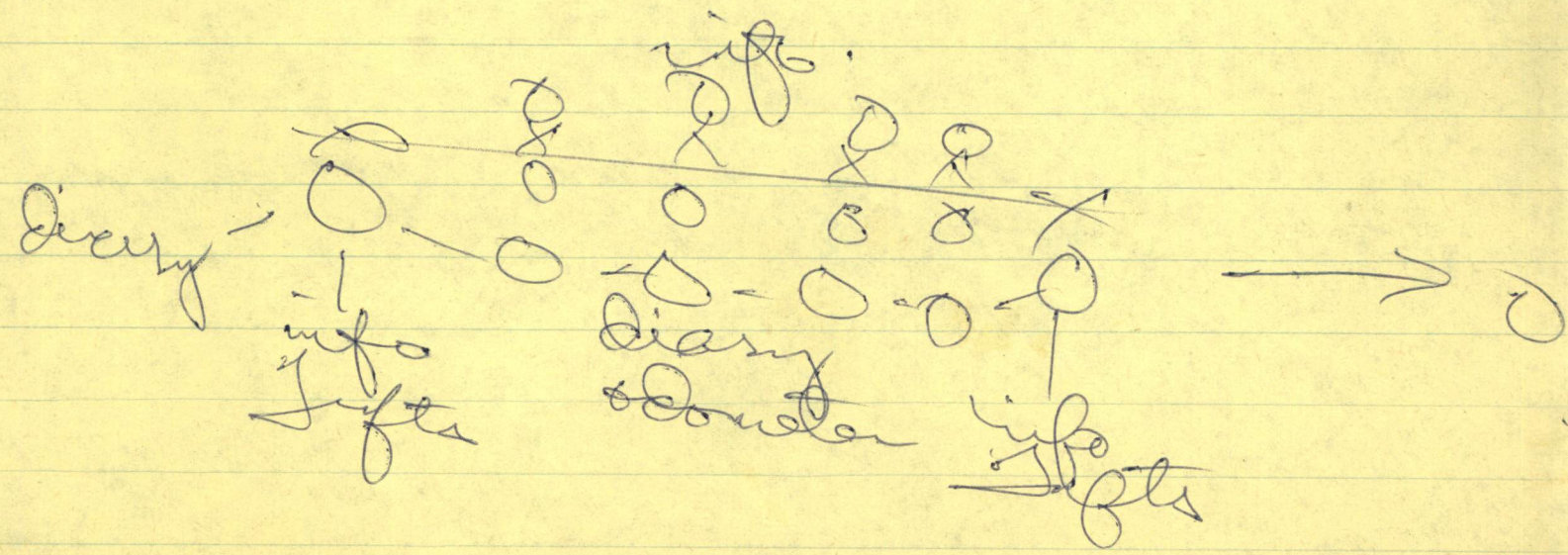
computer diary  $\Delta$   $\Delta$  Battery

on memory  $\Delta$   $\Delta$

on attitudes

$\Delta$   $\Delta$

diary Battery



IV Describe Specific treatment modules

DV pre-post questionnaire [information knowledge]

Control one shot random/matched //

---

IV Describe Program [experience] - system efficiency

DV longit. multimes. behavior <sup>feelings</sup> attitude info <sub>diary</sub> ~~X~~ Questionnaire <sub>Trusts</sub>

Control continuous or shot random/matched

Other 115  
Flowers  
Flowers.

Add:  
~~Phil~~ Phil  
Phil &  
de Tangher

# Objectives of Research

1. Determine effects of program. intended to run short & long term

R	0	X	0	0	0
R	0	0	X	0	0
R		0	0	X	0

(all referrals)

Random assignment of 50 groups

## Assump. II

Program must be well documented. diaries, self subject system records, case files

Effects  $\rightarrow$  place & person  
 diary -  $\rightarrow$  length of t. level  
 observation - mobility  
 tests - attitude, function  
 exams - knowledge, info.

2. Determine what elements of the program are responsible for specific effects.

by systematically ~~varied~~ <sup>varied</sup> aspect of the program.

3. Determine appropriate subject selection criteria.

by systematically <sup>controlling</sup> ~~varying~~ <sup>varying</sup> population

4. Determining the explicit outcomes.

Observating an outcome measure

AGREEMENT TO PARTICIPATE

I, \_\_\_\_\_, agree to participate in a study of the behavior of spinal cord injured people.

I understand that periodically I will be asked to complete an activity check list and that my participation in this project will begin during my hospitalization at TIRR.

*elaborate*

I have been informed that any information obtained in this study will be coded so as to protect my privacy and confidentiality, that it will not be entered in my patient records at the hospital, and that it will not be released to hospital personnel without my approval until after I have completed the study.

Under these conditions, I agree that the information may be used in any way thought best for publication or for feedback to hospital personnel.

I understand that there is no personal risk or discomfort involved and that I am free to withdraw my consent and discontinue participation in the study at any time.

Date: \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Witnessed by: \_\_\_\_\_

Date: \_\_\_\_\_

Witnessed by: \_\_\_\_\_

TRANSITIONAL LIVING: A MODEL FOR THE  
SEVERELY PHYSICALLY HANDICAPPED

17

NARRATIVE DESCRIPTION OF PROPOSAL

A. INTRODUCTION

1. Objective

Recent developments in rehabilitation have placed an increased emphasis on creating opportunities for special housing, education, and employment for severely physically handicapped persons. The Rehabilitation Act of 1973 recognizes the special and unique needs of the severely disabled. The provision of opportunities offered by the Act has permitted some individuals who were formerly isolated in institutions such as nursing homes or in dependent home situations to begin lives of independence and productivity. These efforts, though important, have been slow to evolve, they lack comprehensiveness, and too few persons have been offered maximum options and opportunities. There are countless other individuals who find it overwhelmingly difficult to assume the responsibilities that these new opportunities afford. Many of these persons have the basic untapped capabilities necessary to become independent and develop a lifestyle of personal satisfaction and productivity. However, due to a fragmented approach of limited scope and the absence of a model of transition, many severely physically handicapped persons cannot bridge the gap between a protected institutional existence or an isolated and confining home situation to the management and assumption of an independent life style.

Present national programming does not offer any evidence of a prototype that prepares the severely physically handicapped to move from a dependent setting into an independent setting. Structured programs which place an emphasis on offering maximum opportunities at cost-effective levels are essentially non-existent. In existing programs, emphasis is not placed on allowing the severely physically handicapped person to assume the multiple stresses of independent living and employment in a gradual manner.

The focus of this project is to develop and evaluate the effectiveness of a transitional model which is designed to foster the integration of severely physically handicapped individuals into their communities. Goals of integration may include the establishment of independent living, involvement in educational and vocational opportunities, active social participation in the mainstream of society, the enhancement of personal skills important in daily problem solving, and the stabilization of goals and objectives required to maintain a satisfying quality of life.

## Justification

The lack of transitional programming is an important gap in services that results in several acute problems to the field of rehabilitation.

### Prolongation of Institutionalization:

There continues to be concern over the inappropriate utilization of bed space in the limited number of rehabilitation facilities that exist in the country. For the most part, poor utilization has been forced upon the facility since a good discharge plan that meets the patient's medical, psycho-social, vocational, mobility, and home care needs often cannot be developed when the earliest point of discharge has arrived. On analyzing the amount of time spent in developing workable discharge plans, particularly for persons with limited economic and personal resources, the results would be surprisingly costly. Frequently only the semblance of a good plan can be developed. Additionally, because of limited rehabilitation bed space, inappropriate utilization deprives other patients of the opportunities to receive rehabilitation services at an early and timely date. This dilemma can be solved, but the solution depends upon establishing a transitional experience which creates a less costly bridge between hospitalization and the return to the community environment. Such a bridge would free bed space, strengthen the cost effectiveness of rehabilitation, and offer a more economically planned means of testing adaptive capabilities and coping skills of the severely physically handicapped individual.

### Cyclic Re-Admissions:

Experience has shown that persons with severe disability are usually required to assume the responsibilities for medical, social, and economic necessities simultaneously. The complexity of these demands can frequently lead to deterioration of their physical well-being. The severely physically handicapped individual is prone to a variety of medical problems--skin breakdown, urological complications, muscle atrophy, and the physiological results of inactivity. Furthermore, when the severely physically handicapped person is reintegrated into the family, many pressures outside of those required to meet the prescribed medical treatment can become paramount concerns to the family. Therefore, even though medical needs should be given a higher priority by the family they often become secondary. Consequently medical complications develop and re-admission to a hospital is imperative. This sets up a vicious cycle.

It has also been documented that in many family situations, the re-integration of the severely physically handicapped individual into the home must be a carefully planned process with maximum emphasis upon education and communication. Once again, a transitional experience is needed for many persons and their families to establish

the necessary physical care, mobility, and emotional supports. A program of preparation that extends beyond the formal institution is the goal of a transitional experience. This experience would have a significant impact on the problems of medical recidivism.

#### Physical and Psycho-Social Isolation:

It is clear that a severely physically handicapped person must totally reorient and reestablish his life pattern after disability. Even with maximum personal capabilities, the process is difficult and includes many obstacles. The exceptional person is usually successful in negotiating a new life style, but the more typical person easily becomes isolated and confined to a closed environment by his disability. The potential for productivity and personal happiness, if such persons were given opportunities, remains unexploited. Our system of rehabilitation services should be able to offer persons an environment where they can extend their basic abilities, build upon new learning experiences, and establish reasonable goals that are supported by carefully segmented planning and individual learning. When an individual possesses potentials for self-direction and vocational productivity, appropriate assistance is crucial in order to avoid stifling his capabilities and motivation.

## 2. Background

Three years of experience in a previous R&D residential project (SRS R&D 13-P-55487/6-01) have provided valuable background information to project personnel on the process of reintegration of severely physically handicapped persons into the community. Forty severely disabled young adults, ~~including the 14 present residents~~ have lived in the Cooperative Living project since it opened in January of 1972. This project provided a first independent living experience for all residents, and for many it offered their first opportunity to begin involvement in education, vocational training, or employment. Twenty-three of the twenty-six persons who have moved away from Cooperative Living have gone on to more independent living situations in apartment clusters or in various individual arrangements. Ten persons have secured full-time employment, and many others have worked part-time. Four persons have married, and three have plans to marry.

Almost all of the Cooperative Living residents made important gains in independence during their stay in the project. The program removed many constraints that existed in residents' former living environments, but contained no elements of structured transitional programming. Gains in independence thus occurred largely as a result of residents' own individual efforts over a relatively long period of time. (As of the end of 1974, mean length of stay in the project was 19 months.) The proposed project will build upon

the valuable background experience of the Cooperative Living project, explicitly incorporating into a planned and structured transitional program many of the features fostering independence that operated implicitly in the earlier program. This structured transition will offer a number of advantages: (a) the acquisition of important skills can be made in much less time (an expected mean of 2 months in contrast to 19 months), (b) the new program will be able to serve a number of persons with marginal potential for independence who would have been unable to benefit from the earlier program that demanded greater personal resources, (c) the new program will provide more information and experience than residents of Cooperative Living gained in spite of their longer stay in the project because of important added project resources, (d) the proposed project will permit the development and careful comparative evaluation of alternative transitional learning experiences. In essence, detailed studies can be made of controlled and directed transitional processes that in the Cooperative Living project were left largely to chance. ~~This will have important implications for replicability.~~

Results of the research on residents of Cooperative Living have been reported in two summary progress reports, and a final grant report is currently in preparation. (This project will end in May of 1975.) In addition to extensive information on residents of Cooperative Living, comparative information has also been gathered on severely physically handicapped young adults living in a dormitory at the University of Houston, in a number of nursing homes, and in three apartment clusters offering shared supportive services. Two of these apartment clusters developed as outgrowths of the Cooperative Living project.

Data on active handicapped persons in Houston is also supplemented by information on residential projects in other parts of the country. As examples of published reports dealing with housing, see Armstrong, 1965; Bartels, 1970; Brattgard, 1972; Fay, 1973; Fenton, 1972; Fishman, 1971; Laurie, 1973; Lillick, 1969; Miller and Gwynne, 1972; Pastalan, 1969; Remmes, 1972; Stock and Cole, 1975. Personnel of the proposed project have had personal contact with representatives of the Center for Independent Living at Berkeley, the Creative Living project in Columbus, Ohio, and the Center for Independent Living in Boston.

Experience in the area of independent housing has provided a valuable awareness of many factors that are important for attaining independence. The experience of personnel from the vocational unit at TIRR has likewise provided valuable insight into the techniques and skills required to support successful educational and vocational involvement (Poor, 1975). A sizeable body of literature exists on factors that contribute to vocational success; see for example Gelfand, 1960; McPhee and Magleby, 1960; Sheltzer, 1959.

Important information on the process of community integration will be gained in a study currently being conducted by the proposed Project

Director and Research Director. This research focuses on critical incidents experienced by catastrophically disabled persons from the time of injury through their reintegration into the community. Examples of such incidents are one's first meal in public or first time to have a bowel or bladder accident away from home. The research is intended to indicate the time frame in which such incidents typically occur and the importance attached to them by respondents. Preliminary interviews based on a checklist of 80 incidents have provided valuable information about the process of adapting to a new social role and about reintegration into the family unit, a network of friends, an employment or educational context, and into the larger society. A copy of the checklist of critical incidents can be found in the appendix. Results of this study will have direct impact on the content of the proposed transitional project.

In addition to its usefulness in providing background information about the process of becoming independent, the three years of experience in the Cooperative Living project will be of further benefit to the proposed transitional program. In the former project a system for providing attendant assistance, meals, and transportation on a shared basis was devised, alternative managerial structures were tested, operating costs were monitored over time, and arrangements for coordinating multi-agency sources of financial support were developed. Comparative information on similar areas is also available from two residential projects in apartment clusters that developed as outgrowths of the Cooperative Living project. Having this background experience will permit project personnel to establish a financially sound residential program with supportive services for the proposed transitional project with a minimum of planning and effort. This will free valuable time and energy for concentration on the main tasks at hand, the development and evaluation of transitional programming.

Because transitional programming is a new area of emphasis in rehabilitation, there is very little background material that directly pertains to the task of devising transitional learning experiences for the physically handicapped. In some respects the proposed project is similar to those halfway houses that provide training to bridge the gap between some form of institutionalization and full integration into the community (Rausch and Rausch, 1968). Some patterns of operation from halfway houses of this type may be relevant to the proposed project such as the program of trial work experiences used by a Houston halfway house for juvenile offenders (Alaya, 1975). It is important to recognize, however, that the proposed transitional project differs in several important respects from halfway houses. It is directed toward the overall development of persons who often have far more comprehensive sets of needs than are found among most halfway house residents. This project will be geared toward active participant responsibility for setting goals and scheduling learning programs, and it will be strongly oriented toward individually-directed growth.

In seeking a model for transitional learning experiences in the proposed project, another pattern seems to be more useful than that of the halfway house. This is the role-learning system used for integrating persons into professional occupational statuses such as those of doctor, architect, or certified public accountant in our society. The role-learning model is based on a transitional sequence beginning with formal learning and passing through a period of internship to full certification of competence. Basic elements of this pattern are (a) formal training, (b) modeling by persons who have already attained the desired status, (c) guided practice in actual work situations, and (d) independent assumption of a role. Discussion of how this pattern of role-learning can be adapted for transitional programming is found in Section C on Methods.

### 3. Rationale

The proposed project is based on several underlying premises. Perhaps the most basic is that transitional programming must be flexible enough to respect and value the individuality of participants. Persons will have the responsibility of setting their own immediate and long-term goals and of selecting program areas they wish to pursue. Work in some fundamental program areas such as financial management, social skills, and educational and vocational opportunities will be expected of everyone who participates in the program. But beyond this the individual can plan his own transitional program, choosing from a range of optional modules such as family groups, leisure time, homemaking skills, or consumer affairs. It will also be possible for participants to develop their own training modules with staff support.

A related premise is that the transitional program should be geared to prepare persons for a wide diversity of long-term outcomes. In the area of housing, participants may decide to enter a nursing home, a family home, one of the three apartment clusters with shared services available in Houston, or an individual apartment or house. The program should also be geared for a wide range of educational, vocational training, and employment options and a diversity of opportunities for socialization. Houston is a particularly appropriate context for a program that urges participants to consider a diversity of options, for it has a wide range of opportunities to offer.

Another basic premise is that the transitional program should be structured to enable participants to deal with stresses gradually in a manageable sequence. It can provide an atmosphere where mistakes or problems in dealing with new responsibilities are not disastrous failures but rather can become important elements in an adaptive process. This pattern of gradually assuming responsibility can segment stresses so that the individual does not have to succeed at everything simultaneously.

The great potential importance of peer modeling is another premise of the project which is based to a large extent on the observed impact of modeling in the Cooperative Living project. By watching other persons, individuals can learn techniques for performing physical tasks, ways of managing various kinds of social interaction, ways to overcome mobility problems, or means of dealing with crisis situations. Modeling is also important as a source of motivation. The transitional project will utilize this tool in many ways with persons both inside and outside the project serving as models.

An additional premise is that an individual's functional status and consequent need for physical assistance can vary immensely in different environments. The analysis and upgrading of physical capabilities within a particular environmental context will be emphasized as an important skill to be learned in the program. The goal will be to prompt individuals to rearrange and alter their own environments in ways that will permit the greatest possible use of remaining physical capabilities.

A final basic premise is that teaching adaptability should be a fundamental goal of the transitional program. In working toward integration into the community it will be easy for project participants to focus too narrowly on the particular set of residential, educational, and vocational opportunities available in Houston. It is important to recognize that a greater degree of independence is possible when the individual learns to seek out and identify opportunities in any community and to deal with unanticipated problems and set backs that he will encounter in any context.

## B. SPECIFIC AIMS

Specific aims of the first grant period are

- (1) to define a unique system of services required to meet the basic needs (physical, psycho-social, vocational, medical) of severely physically handicapped persons engaging in a transitional experience
- (2) to refine criteria for selection of persons entering a transitional program
- (3) to develop basic transitional program content including on-going assessment and consultation and basic training modules

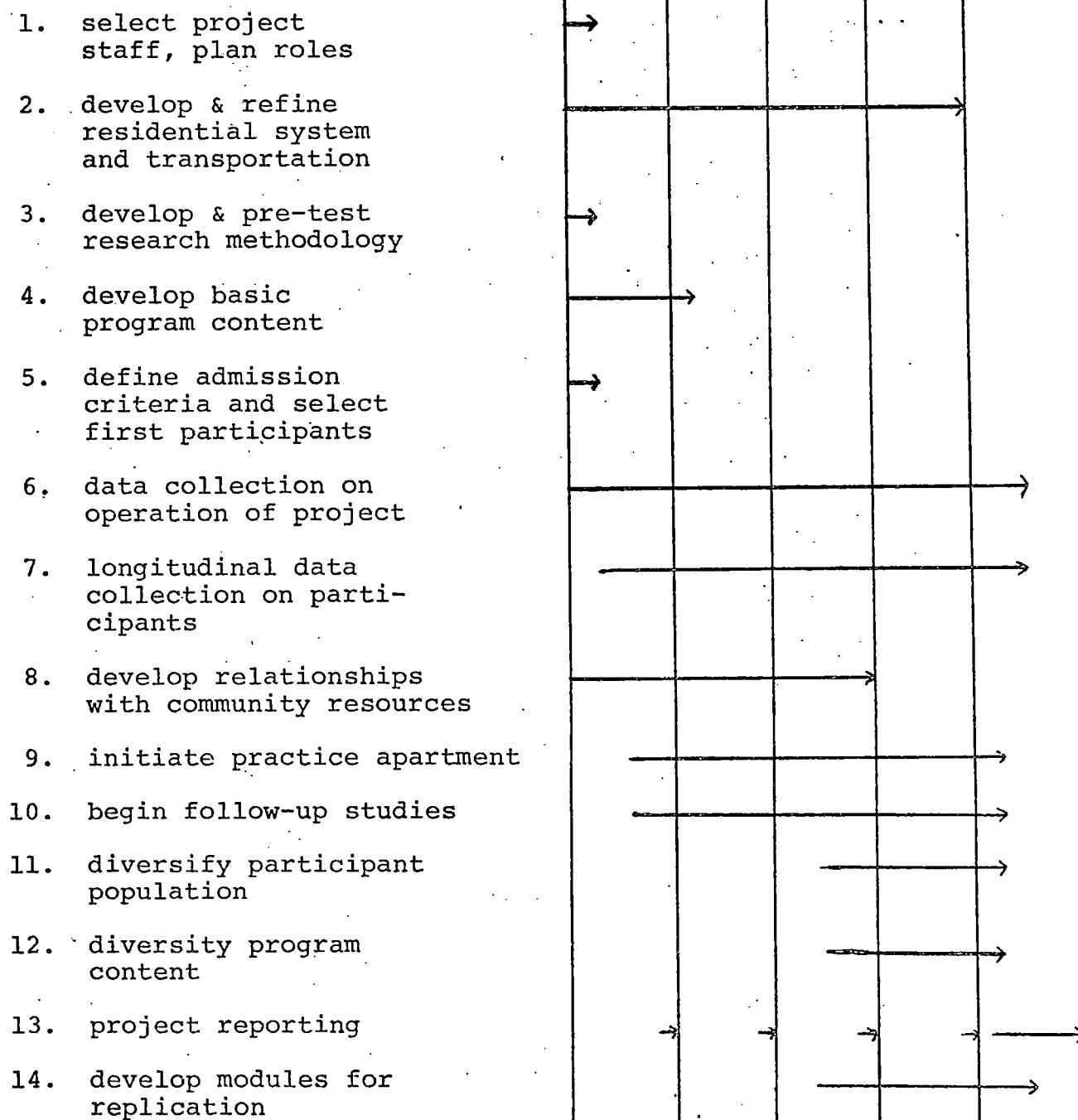
- (5) to develop research design and pre-test research methodology
- (6) to develop a practice apartment that will allow individuals to gain experience in independent living in a protected environment
- (7) to place new emphasis on establishing functional training programs that prepare the individual to upgrade his functional abilities in non-institutional environments

Additional aims to be approached in later grant periods are included in the following Gantt chart.

## PROPOSED SCHEDULE OF PROJECT ACTIVITIES

TIME IN YEARS

## TASKS



## C. METHODS OR PROCEDURES

*Subjects*

The proposed live-in project will provide a program of transitional training and experience for 10 to 12 persons at a time with the program to last an estimated 4 months for each participant. Some persons may feel they are prepared to move on in less time, and others may stay as long as 6 months if circumstances warrant. As individuals enter the program they will formulate agreements with project personnel which specify their individual objectives and identify the program as a means of acquiring skills for moving on at the end of the transitional period to a longer-term living situation. This residence may be one of the three apartment clusters with shared supportive services available in Houston, or it may be an individual support arrangement. Setting goals, formulating contracts, and the assessment of progress will be important individual responsibilities throughout a person's stay in the program. Project personnel will serve as consultants in these areas.

Participants:

Participants in the transitional program will include severely physically handicapped persons completing rehabilitation programs at the Texas Institute for Rehabilitation and Research as well as handicapped individuals living in nursing homes or family homes where integration into the mainstream of society has been hindered. All participants must be medically stable and must meet the criteria defining persons as individuals with most severe handicaps (IMSH). The Institute and the Texas Rehabilitation Commission will be important sources of referrals. Initially the participants will be single persons with spinal cord injuries who are between the ages of 16 and 35, though the population will be systematically diversified as the project progresses. There are several advantages in beginning with a homogeneous group of single young adults. The dormitory-style facility where the project will be initiated is most appropriate for such persons. In addition, key project personnel are most familiar with the characteristics of this group and are therefore better prepared to plan a core transitional program to meet their needs. This core programming will later be expanded and diversified to meet the needs of additional types of participants. Finally, beginning program development with clearly focused goals will permit better organization than a fragmented effort to meet the transitional needs of all disabled persons.

Beginning with the second project year, the population can be expanded to include middle-aged individuals who have pre-disability family relationships and previous vocational experience. In time the population will also include other disability groups such as persons with congenital or progressive handicapping conditions.

It is expected that a total of approximately 100 persons will participate in the transitional program during five years of operation. A similar number of other persons will be involved in comparative research.

↓  
2(two)

### Transitional Programming:

Elements of the transitional program will include

- (1) a basic residential support system that provides room, meals, attendant service, and transportation to participants
- (2) a series of short-term training modules of one to two weeks' duration in areas such as attendant management, financial management, consumer affairs, social skills, family interaction, functional skills, educational opportunities, vocational opportunities, housing arrangements, homemaking skills, self-care and medical management, and sexual experiences with other areas to be identified and developed during the course of the project
- (3) a program of on-going assessment and consultation with the project social worker, nurse, physical-occupational therapist, and vocational counselor in such areas as adjustment to disability, short-term and long-term goals and plans, physical capabilities, and medical status
- (4) structured contacts with selected severely handicapped persons living and working in the community who will guide individual's participation in various community activities and will serve as models of successful reintegration into society
- (5) field trips and recreational activities in the community to provide a variety of socialization and mobility experiences
- (6) living experience in a practice apartment where the individual can try out his acquired skills and identify areas for future work while back-up security is available
- (7) follow-up consultation after the participant has left the project and moved to a new living situation
- (8) supportive and complementary learning techniques to be used on a trial basis in an effort to continually refine and improve the program

Each of these elements is discussed below.

#### (1) Residential Support System

Proven techniques for providing basic residential services have been developed and refined in the previous three year R&D residential project. The transitional project will be housed initially in the Maximum Independence Unit (MIU) of the Texas Institute for Rehabilitation and Research, a modern dormitory-style building where the earlier

Cooperative Living project was housed. It is expected that at the end of the first year the program will be moved to an apartment setting. The Houston Housing Authority has provided rent assistance to residents of the Cooperative Living project for three years, and agency personnel have agreed to provide whatever assistance is possible in the transitional project as well. A letter to this effect is included in the appendix.

Basic supportive services will be provided on a shared basis and will include meals, non-professional attendant assistance 24 hours a day, and transportation. Because a reliable system of supportive services and management has already been developed, project personnel will be able to concentrate their efforts more intensively on transitional programming.

## (2) Training Modules

A series of short-term training modules will be developed to provide information and experience in areas important for independent living, educational and vocational involvement, and social participation. An important goal in developing the training modules will be to construct them as self-contained units that can be disseminated and used individually or in various combinations for other disability groups in various learning settings. These units might take the form of written text materials, slides, tapes, or videotapes, and an instructor's manual suggesting supplementary activities such as group sessions or field trips that have been tested and proven useful in the transitional program. The evaluation and refinement of training modules will be an important aspect of the research design.

Initial modules will be developed in the following areas.

attendant management	how to hire an attendant, how to explain needs, how to manage the intensive social interaction that is often involved in an employer-attendant relationship, authority and diplomacy
financial management	eligibility for sources of income, negotiations with support agencies, budgeting, credit buying, insurance, contracts
consumer affairs	issues of public concern affecting the handicapped such as sources of financial assistance, availability of accessible housing, public transportation, architectural barriers, health insurance, public education
mobility	accessible vehicles, lifts, driving controls, drivers' training, use of public transportation

educational opportunities

types of vocational training available, accessible colleges and universities, applications and interviews, planning an educational program

vocational opportunities

range of employment available to persons with various disabilities, training available, job-seeking skills, applications and interviews

homemaking skills

adaptive techniques of housekeeping, shopping, meal preparation; meal planning, budgeting

self-care and meeting medical needs

self-directed care, resources in the community, routine medical maintenance, emergency care plans, sources of financial sponsorship, medications

housing arrangements

accessible residential structures, architectural modifications, alternative ways of providing supportive services such as attendant assistance, meals, and transportation, financial assistance available

social skills

participation in one interest group in the community, home entertaining, visiting friends, clothes shopping, hair appointments, dental appointments, dining out, requesting assistance with physical needs

leisure time

spectator activities (plays, concerts, sports events), participant activities (hunting, swimming, fishing), hobbies, camping, travel

functional skills

borrowing and inventing new techniques, devising your own assistive tools, rearranging the environment to improve capabilities

family interaction

role expectations, changing relationships, attitudes toward transitional program and increased independence

sexual experience

sexuality in the disabled, dating, role expectations

Additional modules will be devised as their need becomes apparent. Individual participants may also request to develop their own modules in areas of particular interest.

Each module will be planned to last one or two weeks. All participants will be expected to take part in the modules on financial management, self-care management, social skills, and educational or vocational opportunities. Other modules are optional and may be selected and scheduled by participants in conjunction with their on-going assessment goals. Each module will include presentation of some didactic material, group discussions, guided field trips into the community, and where possible an independent practice trip in the community to be made by the individual participant alone.

Modules will be developed by core staff members with reliance on community resource persons such as personnel from the University of Houston or the University Without Walls, staff members of the vocational unit at the Texas Institute for Rehabilitation and Research, representatives of state and federal agencies, and disabled persons who live in the community. In some cases, major portions of a module may be provided by outside resources such as the three-day sexuality workshop regularly sponsored by the Institute, the drivers' education program provided by the vocational unit, or educational programs developed by the University Without Walls.

### (3) On-Going Assessment and Consultation

Before persons enter the project, they will do an initial assessment with the project social worker to review the individual's prior background and assess his current needs and goals. Aspects of the transitional program will be discussed and mutual expectations will be clarified. The participant will be introduced to the responsibility of maintaining his own on-going assessment record as a means of setting goals, planning activities to meet these goals including training modules and various types of consultation, and assessing his progress in various areas. The formulation of contracts will be an important tool for participants to use in setting goals and directing their efforts.

Consultation with the project social worker, nurse, occupational-physical therapist, and vocational counselor will be regularly available. Participants will be expected to take the initiative in requesting help from consultants in meeting goals they have set. Consulting personnel will also be involved in the development of training modules.

#### (4) Contacts with Handicapped Persons in the Community

Structured contacts with active and independent severely handicapped persons in the community will be a major aspect of the transitional program. Three years of experience in the Cooperative Living project have demonstrated clearly that peer modeling is an important factor in motivating handicapped individuals to initiate new activities and in teaching them practical know-how for reaching new goals. Particularly capable individuals who have moved into various independent living arrangements, who have initiated schooling, job training, part-time or full-time employment, and who are active in social and consumer affairs will be paid to let participants visit them at home and to serve as guides in taking participants on field trips. This will allow participants to observe the ways in which successful handicapped persons deal with everyday problems of mobility, meeting their physical needs, and managing social interaction in a variety of environments.

#### (5) Field Trips and Recreational Activities

Field trips will be a part of most training modules, and these will often be guided by handicapped persons who have been asked to serve as models in the transitional program. Specific trip plans will depend on the interests of participants. Visits will be made to agency offices, banks, university campuses, vocational training programs, employment locations, governmental hearings, and a variety of other locations. In addition, the project van will be available to take persons to numerous recreational activities such as ballgames, concerts, movies, shopping, eating out, or trips to the beach. A major purpose of these trips will be to provide opportunities for persons to socialize in a wide variety of situations and to have them negotiate a wide range of obstacles to mobility.

#### (6) Individual Practice Activities

Individual rehearsal of new capabilities will be another basic element of the transitional program. This will occur at several levels. It can begin with role-playing situations within the project such as hiring an attendant or negotiating with a support agency. In addition, many training modules will include practice in the community as an important element.

During the course of the transitional program, participants will leave the project residence for a trial living period in another environment or environments. One such setting will be a practice apartment to be maintained by the project (see Section E on Facilities). Each person will live in the apartment for a period of perhaps two weeks. He will be responsible for making arrangements for attendant care,

housekeeping, shopping, transportation, and for meeting his other needs. During this period he will be encouraged to remain independent of project support, but he will have the assurance that advice and assistance are available if needed.

Experience in the practice apartment may also be supplemented by other rehearsed living situations. For example, one handicapped person living in a house with a private attendant has expressed willingness to exchange residences for a day or two with participants in the transitional program. Practice living situations will enable participants to test their skills and identify areas that need additional work. They can also identify potential problems that may occur when they leave the program and explore solutions to these problems while assistance is available if needed.

In many cases, active involvement in educational or vocational activities will also be initiated during the participant's stay in the transitional program. As with housing, this involvement in the community will also have the advantages of a practice or rehearsal since advice and assistance from project personnel will be available if needed. There are many educational and vocational resources available in the community which individuals can utilize. One of these is the University Without Walls which emphasizes individualized educational programs and involvement in vocational internships to supplement academic learning. The University of Houston has a two-year college which is wheelchair accessible located in downtown Houston, and its main campus has an active program offering special assistance to handicapped students. In the area of vocational involvement, the vocational unit of the Texas Institute for Rehabilitation and Research has operational training programs in microfilming, information processing, and various benchwork skills and offers formal vocational evaluation, counseling, and work adjustment training. In addition, it maintains contact with a number of handicapped persons who have been placed in various types of employment in the community. The transitional project has been discussed with representatives of these resource organizations, and they have expressed willingness to cooperate with the project (see appendix).

The transitional project itself will not be responsible for securing long-term educational involvement or vocational placement for its participants. These services are available through other organizations. However, it will be the function of project personnel to develop working relationships with resource organizations, to assist participants in setting educational and vocational goals, and to assist them in learning to interact and negotiate with appropriate agencies.

### (7) Follow-Up Consultation

Advice and assistance will be provided by members of the project staff to former participants after they have moved from the project into new living situations. An early follow-up assessment will be made as a part of the research activities of the project, and at that time consultation can be made available if requested. This consultation will assist persons in making the transition from the project itself, which may have become a comfortable and secure environment, into a living situation in the community. An important emphasis in this consultation will be to prompt individuals to deal with problems themselves using techniques and experience they have gained in the transitional program.

### (8) Supportive and Complementary Techniques

During the course of the transitional program, various additional learning techniques will be instituted on a trial basis. Their effectiveness will be carefully monitored and those that are useful will be adopted as standard elements of the program. Possible techniques to be used in this manner include a buddy system, a token economy linked to the attendant service system to encourage physical independence, manipulation of the physical environment, and the provision of feedback information from the research to participants as part of their on-going self-assessment. Continuing innovation and evaluation will be important elements of the program.

### Research Objectives and Methods:

Four basic types of research will be conducted on the project.

(1) An analysis and description of the program as a whole will be made from a general anthropological perspective. Areas of emphasis will include the evolution of the project, the role it plays in relationship to other facilities and agencies in the community, its operation as a social system, and its functioning as an agent of change. Studies of cost-effectiveness will also be made. Data for these purposes will include staff diaries, interviews (with staff members, participants, and other persons in the community), observation in the project, and various kinds of operating data such as financial records. This information will be useful in facilitating replication of the project and in tracing its development over time.

A log will be kept to chronicle each person's participation in the project. This record will include the goals set by the individual at various times, his project activities, and his evaluations of

learning experiences. This information will be useful in conjunction with longitudinal measures (section 2) to document the effects of the program on individual participants. Its major purpose will be to provide an on-going assessment of the needs and goal priorities of participants, a record of how project activities are utilized, and participant evaluation of the effectiveness of the project in meeting defined needs. This information will be useful to staff members in altering program content to serve a diverse range of participants.

(2) The effects of the transitional program on participants will be documented using a longitudinal research design. Measures of various aspects of a person's lifestyle will be made before participants enter the project, periodically during their stay, and after they move on to other living environments. Information will be gathered in areas such as medical status, functional status, amount of physical assistance used, housing arrangements, ways of providing supportive services, family relationships, sources of income, expenditures and cost of living, mobility range, social network, leisure activities, educational status, vocational status, and resident attitudes. Various methods of data collection will be used including interviews conducted by staff members, checklists to be completed by participants, diaries, and standardized measures of attitudes. During an individual's stay in the project, these measures will be made at short intervals to detect and monitor subtle changes in behavior and attitudes and to track these changes as precisely as possible.

(3) The effectiveness of the self-contained training modules will be measured using tests given to persons before and after their participation in each module. This information will be used in evaluating and refining the modules and in preparing them for dissemination. It will also contribute to an assessment of the effects of the program as a whole.

(4) Various types of comparative studies will be made contrasting the experience of former Institute patients who participate in the transitional program with that of patients who return directly to family homes, nursing homes, or other living arrangements. These studies will not be a part of the continual data collection in the project but will be conducted from time to time as separate investigations in various subject areas. Current comparative studies that may include samples of the population in the transitional project are a study of critical incidents from onset of disability through community integration (see appendix) and a quality-of-life study to measure satisfaction with lifestyle. Other similar studies will be initiated throughout the course of the transitional program. Such comparative research will help to identify and document the effects of the transitional experience.

The major research goal will be to assess the effects of a model of transitional programming. In addition, research data will also be used during the course of the project in the following ways:

- (a) to assist individual participants in making assessments of their own progress
- (b) to assist staff members in identifying the diverse needs and responses of various types of handicapped persons
- (c) to aid the staff in evaluating and improving the transitional program in general
- (d) to assist the staff in refining and packaging training modules for replication
- (e) to document the development and operation of the project to facilitate replication
- (f) to assess the cost-effectiveness of the project

#### D. SIGNIFICANCE

Many of the functional skills and the psychological and social coping abilities that serve well within a rehabilitation hospital are inadequate resources as severely physically handicapped persons leave this specialized protected environment and return to the larger society. Some persons manage to bridge this gap successfully between the institutional environment and the community, but these are usually persons with exceptional capabilities and resources. Current rehabilitation programs are lacking in methods and in defined approaches that will assist persons in making this transition. This gap in services has far-reaching consequences for the entire field of rehabilitation. For most handicapped persons, the demands of independent living and of educational or vocational productivity are more than can be managed simultaneously. Consequently many potentially productive persons never have a chance to become independent and they either retreat or are pushed into isolated environments. Of those who do try to achieve an active and productive lifestyle, many are unable to meet the demands that it requires.

The proposed project will develop and evaluate transitional programming designed to bridge this serious gap in rehabilitation services. Community integration can become a feasible goal for many persons if they are taught and allowed to practice the skills needed in the real world and if they are allowed to deal with stresses and assume responsibilities in a segmented sequence. This project serves as a prototype for a new rehabilitation method.

## E. FACILITIES AVAILABLE

The proposed transitional project will be initiated in the Maximum Independence Unit of the Texas Institute for Rehabilitation and Research, a modern dormitory-style building located four miles from the medical center near downtown Houston. (A section of this building was used to house the previous Cooperative Living residential project.) Fourteen dormitory-style rooms on a common hallway will be used in this project. Each room has an accessible lavatory with hardware designed for persons with limited use of their hands. Bathrooms with commodes are shared between pairs of rooms, and a large roll-in shower room will be used by all residents. A buzzer and system of call lights are linked to a staff room for attendants. A dining room, recreation area, and atrium will be available to project participants, and laundry facilities and meals are provided in the building. Professional staff members will be provided office space.

As the first set of participants approaches completion of the transitional program, an apartment in the vicinity of the medical center will be rented by the project. Minor physical modifications will be made (widened doorways and ramped changes in level), but the physical facilities will be left largely as an individual would find them in the community. This apartment will be used as a setting where participants can rehearse an independent living situation while the back-up security of the project is still available.

A GMC step-van that was purchased by the Cooperative Living project will be used in the transitional program for taking participants on field trips and to a variety of activities in the community.

## F. CHARACTERISTICS OF APPLICANT AND AFFILIATES

The Texas Institute for Rehabilitation and Research is a private, non-profit rehabilitation hospital. It serves as the Department of Rehabilitation of Baylor College of Medicine and is a federally funded Research and Training Center (RT-4). The Institute is host to a model Regional Spinal Cord Injury Center and serves persons with a variety of other physical handicaps as well.

The host Institute will provide support for the transitional project in a number of ways. These include various administrative services and the provision of meal service, housekeeping, and maintenance in the MIU building where the project will be housed. Various specialized services of the Institute will be used by project participants including clinics, the vocational unit, and the Sexual Attitude Re-assessment Workshops. Part-time professional staff members can be shared with other Institute programs. The hospital will serve as an important source of program referrals and as a source of other patients who will be asked to participate in comparative research.

Cooperative arrangements with resource organizations in the community will be important in the project. In this regard, Houston is a particularly suitable location for a transitional project because of the range of resources and opportunities available to persons who leave the transitional experience. There are three adaptive housing programs in the community that offer shared supportive services in apartment clusters. Various vocational training programs are available including those sponsored by the Institute in microfilming, benchwork, and information processing. Educational opportunities are accessible at the main and downtown campuses of the University of Houston. A cooperative educational arrangement has also been discussed with the University Without Walls, a member of the Union of Experimental Colleges and Universities. This organization has initiated efforts in the area of education for the physically handicapped. A letter is attached that expresses the interest of this organization in cooperating with the transitional project. Cooperative arrangements can also be developed with various schools in the community whereby students of social work, physical therapy, or nursing can gain useful experience by working in the project.

Governmental agencies at the local and state levels have expressed interest in working with the transitional program to provide federally mandated services to the severely handicapped. These include the Houston Housing Authority which has supported the Cooperative Living project with a rent assistance program. The proposed project has been discussed with representatives of the Texas Rehabilitation Commission, and this agency has expressed willingness to refer clients on a statewide basis and to provide financial sponsorship for eligible persons who can benefit from participation in the program. Letters from both of these agencies are attached in the appendix.

#### G. SUPPORT DATA AND OTHER INFORMATION

References, letters of endorsement, and information on a study of critical incidents can be found in the appendix.

#### H. DISSEMINATION OF RESULTS

The proposed project is intended to develop a model transitional living program so that replicability will be a continuing concern. The evolution of the project will be documented with this goal in mind. Specific training modules will be devised as self-contained units using various audio-visual methods and other techniques that can easily be used in a variety of learning contexts.

Information on the program will be disseminated through regular DHEW channels and will be a part of the numerous training activities conducted by RT-4. The Texas Rehabilitation Commission will serve as an important source of dissemination at the state level as it has in the earlier Cooperative Living project. Papers and presentations including a possible exhibit similar to the Cooperative Living exhibit (Cole and Stock, 1974) will also be used to disseminate information on the importance of transitional programming and on the project experience.

## NEW PROGRAM PROPOSAL

Title Transitional Living: A Model for the Severely Physically Handicapped

Program Director Jean A. Cole, Ph.D.

Date 12/31/75

### Synopsis

The proposed project will provide a live-in transitional experience of six to nine weeks' duration designed to foster the integration of severely physically disabled persons into the community. Goals of community integration may include the establishment of independent living, involvement in educational and vocational opportunities, active social participation in the mainstream of society, the enhancement of personal skills important in problem-solving, and the stabilization of goals and objectives to maintain a satisfying quality of life. Transitional programming will include training in the areas of independent living arrangements, educational and vocational opportunities, social skills, problem-solving, sexuality, meeting medical needs, functional skills, homemaking skills, attendant management, financial management, transportation and mobility, consumer affairs, and leisure activities. Structured contacts with active handicapped persons in the community will be a major program element to provide opportunities for modeling. Research will be conducted on the evolution and operation of the program and on changes in the lifestyles of participants. If financial resources permit, the transitional programming materials will be packaged for use in other settings.

The initial project participants will be young spinal cord injured adults. As the project progresses, the population will be systematically diversified to include persons of different ages and backgrounds and persons with a variety of disabilities including congenital and progressive handicapping conditions. Major sources of referrals will be TIRR and TRC. It is expected that persons will profit most from the program after they have been out of the medical phase of rehabilitation for several months.

### Implementation Plans

Much work has been completed already for implementing the project. Core staff members have been selected (Jean Cole, Barbara Holden, Lex Frieden), the program structure has been planned, much of the program content is currently being developed, a research design has been devised, and financial negotiations have been initiated with TRC and other potential sponsors. The two major tasks remaining are recruiting participants and staffing. Plans have been made in both of these areas, but arrangements cannot be initiated until a commitment to the project is made by the Institute. It is estimated that the project can be operational within four to six weeks from the time such a commitment is made.

### Space Required

Office space for five persons will be needed (project director, social worker, research director, secretary-documentarian, and one shared space for residential manager and driver). One of these offices should be private for interviewing and counseling. Ten beds are requested for participants. One private meeting room that will accommodate up to ten wheelchairs will be needed for group activities. It would seem that minimal remodeling, if any, would be sufficient to provide needed facilities. A copy of a memo to the Annex Utilization Committee outlining specific space requested is attached.

### Resources

This proposal outlines a plan for beginning operation of the program with a minimal commitment of resources from the Institute. Professional staff will be limited to the three core staff members with part-time consultation from an R.N. If the project proves to be beneficial to participants and financially sound, an enrichment process should be initiated to augment the core staff with additional professional assistance from a part-time vocational counselor, PT, and OT, and perhaps other staff members as needs are identified.

### Budget Information

#### INCOME

Income from operation is computed on the basis of ten beds with 95% occupancy at \$55 per diem to be paid by TRC, workman's comp, and other sponsors as program expands. Salaries for project director and social worker are currently being paid from RT-4 funds. RSA R&D grant still pending.

patient service income	\$190,300
RT-4 funds currently paid for salaries	20,900
	<hr/>
total funds available	\$211,200

EXPENSES

<u>Personnel</u>	% time effort	salary level	source of salary
project director	100	12,500	RT-4
social worker	60	8,400	RT-4
research director	100	no cost	fellowship through May
handicapped resource persons	variable	8,000	per diem
R.N. consultant	20	2,300	per diem
resident manager	100	7,200	per diem
secretary-documentarian	100	7,200	per diem
attendant staff	100	36,000	per diem
driver	100	7,200	per diem
total salary costs		\$88,800	
projected fringe benefits		\$17,760	
total salary expense		<u>\$106,560</u>	

Patient Related Expense

meals (\$10 per day)	<u>\$34,600</u>
laundry and light housekeeping to be provided by attendant staff	

<u>Other Expenses</u>	start-up	first year	second year
equipment (office)	3,000	0	0
supplies		600	?
duplicating		800	?
vehicle maintenance and insurance		2,700	?
space rental		49,440	?
travel		2,500	?
total other expenses	<u>\$3,000</u>	<u>\$56,040</u>	

SUMMARY OF EXPENSES

salary expense	\$106,560
patient related	34,600
other expense	59,040
total	<u>\$200,200</u>

SUMMARY OF INCOME

patient services	190,300
RT-4 funds currently paid for salaries	20,900
total funds available	<u>\$211,200</u>

PROJECTED PROGRAM BALANCE \$ 11,000  
AFTER FIRST YEAR

Statistics

beds, inpatient	10
mean LOS	45-60 days
total patients served	50-60 per year
patient days/year	unknown (occupancy est. 95%)
per diem, inpatients	\$55
est. charges from other depts./stay	unknown; will depend on population
total inpatient charges	unknown
total outpatient visits/year	unknown; will depend on population
fee/OPV	unknown
other charges/OPV	unknown
total outpatients served	unknown

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BOB CASEY  
22D DISTRICT, TEXAS

WASHINGTON ADDRESS:  
2353 RAYBURN BUILDING  
WASHINGTON, D. C. 20515  
202-225-5951

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEES:

CHAIRMAN: LEGISLATIVE APPROPRIATIONS  
LABOR-HEALTH, EDUCATION, AND WELFARE  
APPROPRIATIONS  
AGRICULTURE-ENVIRONMENTAL AND  
CONSUMER PROTECTION  
APPROPRIATIONS

Congress of the United States  
House of Representatives  
Washington, D.C. 20515

DISTRICT OFFICE ADDRESS:  
ROOM 12102 FEDERAL BUILDING  
515 RUSK STREET  
HOUSTON, TEXAS 77002  
713-226-4486

D. GAYLE MCNUTT  
ADMINISTRATIVE ASSISTANT

12 November 1975


Lex M. Frieden  
Research Director  
Texas Institute for Rehabilitation and Research  
1333 Moursund  
Houston, Texas 77025

Dear Mr. Frieden:

In an effort to lend every possible support to your application for federal funds from the Department of Health, Education and Welfare, Social and Rehabilitation Service, I have written to the Secretary of HEW, Mr. David Mathews, endorsing your project entitled "Transitional Living: A Model for the Severely Physically Handicapped" and urging early funding. Rest assured, I'll do everything I can to assist, and I'll let you know just as soon as I have any information.

As I'm sure you know, the House Appropriation bill contains the sum of \$20,000,000 for the Rehabilitation Services Administration, while the Senate bill provides \$24,000,000. Final disposition of the matter in Conference is being delayed by the Senate's busing amendments, but I'll keep you posted as this legislation is processed through the necessary channels in Congress.

Sincerely,

  
Bob Casey

BC:dm

BOB CASEY  
22D DISTRICT, TEXAS

COMMITTEE ON APPROPRIATIONS

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D. GAYLE MCNUTT  
ADMINISTRATIVE ASSISTANT

23 December 1975

Mr. Lex M. Frieden  
Research Director  
Texas Institute for Rehabilitation and Research  
1333 Moursund  
Houston, Texas 77025

Dear Mr. Frieden:

Merely for your information I'm enclosing a copy of the response that Congressman Casey received with reference to his efforts to assist the Texas Institute for Rehabilitation and Research. Secretary Mathews' letter is self-explanatory.

As you probably know, Congressman Casey's appointment was confirmed on Friday, and he will be taking his seat on the Federal Maritime Commission, and will not return to the Congress for the second session.

A special election will be held in Texas, probably in February, to elect a new member, but in the meantime, if this office can assist you further, please do not hesitate to let us know.

Sincerely,

  
D. Gayle McNutt  
Administrative Assistant

DGMc/dm

Encl:



THE SECRETARY OF HEALTH, EDUCATION, AND WELFARE  
WASHINGTON, D.C. 20201

DEC 18 1975

The Honorable Bob Casey  
House of Representatives  
Washington, D. C. 20515

Dear Mr. Casey:

Thank you for your inquiry of November 11 regarding the application for project grant titled "Transitional Living: A Model for the Severely Physically Handicapped" from the Texas Institute for Rehabilitation and Research. We certainly agree that Dr. William A. Spencer and his staff have made many outstanding contributions to the rehabilitation of the severely handicapped. Please excuse the delay in responding.

At present, the application is undergoing scientific and technical review in the Office of Rehabilitation Research and Demonstrations, Rehabilitation Services Administration. I have been advised that the staff has very favorable impressions of the proposed project.

We will advise Dr. Spencer as soon as final action on the fiscal year 1976 appropriation for the Rehabilitation Services Administration is completed.

We appreciate your continued interest in the rehabilitation of severely handicapped citizens.

Cordially,

/s/David Mathews

Secretary

## NARRATIVE DESCRIPTION OF PROPOSAL

### A. INTRODUCTION

#### 1. Objective:

In recent years there have been increasing efforts to make opportunities for housing, education, and employment available to physically handicapped persons. The provision of such opportunities has permitted many individuals who were formerly isolated in institutions or dependent home situations to begin lives of independence and productivity. Yet there are countless other individuals, (particularly the catastrophically disabled<sup>?</sup>), who find it overwhelmingly difficult to assume a radically changed role in life and meet all of the demands that the available opportunities entail. Such persons may have the basic capabilities necessary to become independent, but the gulf often seems immense between a protected institutional or home atmosphere ~~with few responsibilities~~ and a lifestyle in which the individual alone must meet the responsibilities of his living situation (including provisions for attendant assistance and transportation) and the demands of employment at a level that will permit financial self-sufficiency. Current programs are not structured to permit gradual assumption of responsibilities which often makes independence an all-or-nothing affair.

The objective of the proposed project is to develop and evaluate the effectiveness of <sup>a</sup> ~~several~~ programs of transitional experience designed to foster the integration of severely physically handicapped individuals into their communities. Goals of community integration include <sup>the</sup> establishment of independent living, involvement in educational or vocational opportunities, and active social participation in the mainstream of society.

Major tasks in meeting this objective will be

- (a) to identify the techniques and skills by which independent and active handicapped persons have achieved integration into their communities
- (b) to devise learning experiences of various types whereby participants in a transitional program can acquire these techniques and skills and can assume responsibilities in a manageable sequence
- (c) to systematically evaluate the effectiveness of transitional ~~learning~~ <sup>programming</sup> ~~experiences~~ for various types of participants
- (d) to structure portions of the transitional program as self-contained units that can be used in flexible combinations in a variety of contexts

Background:

Various kinds of background information and experience are relevant to each of these major tasks.

(a) In identifying the techniques and skills by which active handicapped persons have become integrated into their communities, [three years of experience in a previous R&D residential project, "A Cooperative Self-Support System", have been of great benefit.] (SRS R&D 13-P- ) Forty severely disabled young adults have lived in this Cooperative Living project since it opened in January of 1972. ~~For all~~ residents this project <sup>was a</sup> ~~was their~~ first independent living experience, <sup>for all residents,</sup> and for many it provided their first opportunity to begin involvement in education, vocational training, or employment. Twenty three of twenty six former residents have moved on from Cooperative Living into a more independent living situation in apartment clusters or in various individual arrangements. Ten persons have secured full-time employment, and many others have worked part-time. Four persons have married and three have plans to marry. Results of the research on residents of Cooperative Living have been reported in two summary progress reports, (Dstock, 1973 and Cole, 1974), and a final grant report is currently in preparation. (This project will end May 31, 1975).

In addition to extensive information on changes in lifestyle and increasing independence of Cooperative Living residents, comparative information has also been gathered on severely handicapped young adults living in a dormitory at the University of Houston, in a number of nursing homes, and in three apartment clusters with shared services, two of which developed as outgrowths of the Cooperative Living project.

Extensive information on active handicapped persons in Houston is also supplemented by data from other projects in independent living. In addition to published reports, ( ), personnel of the proposed project have had personal contact with representatives of the Center for Independent Living at Berkeley, the Creative Living project in Columbus, Ohio, and the Center for Independent Living in Boston ( ACRM ).

Experience in the area of independent housing has provided a valuable awareness of many areas important for attaining independence such as the advantages and disadvantages of alternative ways of providing for attendant assistance or transportation. Experience of the vocational unit of TIRR has likewise provided valuable insight into the techniques and skills required to support successful educational and and vocational involvement ( ). Published information is also available on factors that contribute to vocational success.( ).

A study currently being conducted by the proposed Project Director and Research Director focuses specifically on critical incidents experienced by catastrophically disabled respondents from the time of injury through reintegration into the community. Preliminary interviews based on a checklist of 80 possibly important incidents have elicited extensive information about adaptation to a new social role and about experiences of reintegration into an individual's family, social network, employment or educational context, and into the larger society. Results of this study will have direct impact on the content of the proposed transitional project.

(b) Because transitional programming is a new area of emphasis in rehabilitation, there is very little background material that directly pertains to the task of devising transitional learning experiences for the physically handicapped. In some respects the proposed project is analogous to the type of halfway house that is intended as a short term residential experience to bridge the gap between some form of

institutionalization and full integration into the community (ref. Halfway House Movement). Some patterns of operation from such houses may be relevant, such as the program of trial work experiences used by a Houston halfway house for juvenile offenders ( ).

However, the proposed transitional project seems to differ in several important respects from the general category of diverse organizations grouped under the term "halfway houses". The proposed project is directed toward development of the whole person who often has a more comprehensive set of needs than most halfway house residents have. It will be geared toward active participant responsibility for setting goals and scheduling learning experiences. And it will be strongly oriented as a growth experience rather than being a static residential environment as is the case with many halfway houses.

In developing transitional learning experiences for the proposed project, another general learning model seems to be more useful than that of the halfway house. This is the role-learning system used for integrating persons into professional occupational statuses in our society (which is based on a transitional sequence from formal learning through a period of internship to full certification of competence). This pattern is found in the progression from apprenticeship through journeyman status to master craftsman and in the progression from formal education in professional schools through a period of internship to eventual licensure as a physician, lawyer, certified public accountant, architect, or teacher. Common to this pattern of role-learning are the elements of (a) formal training, (b) modeling by persons who have already attained the desired status, (c) guided practice in actual work situations, and (d) independent assumption of a role. Details of how this pattern can be adapted for transitional programming are found in Section C. on Methods.

(c) Techniques for evaluating the effectiveness of transitional programming and references on research design and methodology are discussed in Section C. At this point, however, it is important to refer to specific background experience of the proposed Research Director. In this project, unobtrusive measures of day-to-day behavior will be of great significance where it is important to know what an individual actually does on a daily basis as well as how well he can perform in a special test situation. The behavioral ecology project at TIRR has developed a highly refined system for making such measures ( ).

The proposed Research Director has had extensive experience on projects in the behavioral ecology program and consequently has expertise in a research methodology that will be of particular value for the proposed project.

(d) Structuring portions of the transitional program as self-contained units for use outside their original context will in some respects be a task without direct precedent. There are some useful parallels in currently-existing programs of TIRR, however. These include the patient education program for in-patients, a program of instruction entitled "Skills for Parents of Handicapped Children" currently being developed as a joint effort of TIRR and and the three-day Sexual Attitude Reassessment Workshops regularly sponsored by TIRR which are patterned on those developed at the University of Minnesota by Ted Cole and his associates. Project personnel have had some relevant experience in this area in working with residents of the Cooperative Living project to produce an audio-visual exhibit on this program in cooperation with a professional medical illustration department. Cooperative arrangements involving student projects can be made with various resource organizations in the community with relevant expertise. These include the University Without Walls and the Communications Department at the University of Houston.

An additional area of prior experience will be of particular benefit in the proposed transitional program. This is the association of project personnel with the Cooperative Living residential program sponsored by TIRR. In the Cooperative Living project a system for providing attendant assistance, meals, and transportation on a shared basis was devised, alternative managerial structures were tested, operating costs were monitored, and arrangements for coordinating multi-agency sources of financial support were developed. Comparative information on similar areas is also available in two residential projects in apartment clusters that developed as outgrowths of the Cooperative Living project. Having this background experience will permit project personnel to establish a financially sound basic residential program with supportive services for the proposed transitional project with a minimum of planning and effort. This will free valuable time and energy for concentration on the main tasks at hand, the development, evaluation, and packaging of a program of transitional experience.

Rationale:

The proposed program is based on several underlying premises. Perhaps the most basic is that the transitional programming must be flexible enough to respect and value the individuality of participants. The general concepts of "independence" and "integration into the community" must be considered in reference to specific individuals. In this framework, a C-2 spinal cord quadriplegic who learned the psychological and interpersonal skills to manage his own environment would have gained a great deal of independence in spite of his total dependence on others in physical functioning.

A program with this emphasis on individuality must be capable of planning for and accepting as "successful" a wide diversity of long-term outcomes. It must be able to suggest to participants and prepare them for entering a continuum of living

situations ranging from returning to a nursing home or family home prepared to exercise greater psychological autonomy to establishing an individual support arrangement in a private apartment or house, possibly with a mate. In this regard, Houston provides a particularly appropriate setting for the transitional project because it has three apartment clusters with systems of shared supportive services available to handicapped persons. The transitional program should also be geared toward a wide range of education, vocational training, and employment options. A diversity of opportunities for socialization is similarly important.

Houston has a large number of resources which are valuable assets to a transitional program. It is important to recognize, however, that the program should not focus too closely on the particular set of options available in this community, but rather should prepare individual to seek out and create opportunities in any context and to learn techniques for adapting to what may be available.

Another basic premise is the notion that participants should gradually assume increasing responsibilities. The process of assuming responsibilities can begin this process can begin on an individual's first day in the program when he sets initial goals for himself and can continue throughout his participation in the program. Such an arrangement stresses to that an individual does not have to succeed at everything simultaneously, and it provides an atmosphere where mistakes or problems are not disastrous failures but rather can be important elements in the adaptive process.

An additional premise is that peer modeling can be an extremely important asset in a transitional experience, conveying both know-how and motivation to participants. A number of active and independent handicapped individuals from the community will be used as resource persons in the project.

Finally, an important goal of the project will be to design elements of the transitional experience so that they can be useful beyond the specific context of the program itself....

## TRANSITIONAL PROGRAM

SOCIAL SKILLS MODULE: Participation in one community group (church, political action, crafts, literary, etc., any interest group of participant's choice), home entertaining, visiting friends (architectural problems encountered such as no ramp, bathroom inaccessible, etc.), clothes shopping, hair appointments (i.e., ways to handle barber chair and equipment), dental appointments, travel and vacations, camping, dining out, plays, concerts, etc.

Techniques will include use of audio-visual material, role-playing, formal instruction, group discussion, field trips, peer consultation, milieu therapy, and varied interactional models.

FAMILY GROUP MODULE: Interaction group for persons significant in a participant's psycho-social environment. The need for participating in this group will be determined by the participant and social worker in the initial assessment and activity plan. The module will include use of audio-visual aids, role-playing, discussion groups, and other educational and sociotherapeutic techniques.

### PERSONAL-SOCIAL ASSESSMENT:

Initial assessment: Upon selection for program, each potential participant will schedule an appointment with the project social worker. This appointment will be arranged in advance of admission for the purpose of clarifying mutual goal expectations, project purpose, as well as the participants' current individual needs and goals as they relate to project activity selection and planning.

The initial assessment will include a joint:

1. Evaluating the participant's response to illness, disability, and rehabilitation;
2. Consideration of his family, friends, and significant other's response to illness, disability, and planning and their potential role and involvement in the project;
3. Assessment of previous level of social functioning (level of social, psychological and physical independence prior to onset of injury.);
4. Assessment of life goals, and expectations prior to onset;
5. Appraisal of level of social, psychological, and functional independence since onset of injury (including reaction to hospitalization, hospital staff, home, or other living situation);
6. Appraisal of participant's assessment of current and future needs;
7. Description of modules for activity program based on current status and projected need evaluation. Written material the modules will be given for the participant's further consideration;
8. Establishment of admission date;
9. Contract in regard to participant's responsibilities upon entering the project.
10. Agreement relating to subsequent on-going assessment of the program.
11. Explanation of assessment forms and continued consultation with the SW, OT, PT, and other project personnel;
12. Introduction to the "buddy system".

Upon admission to the project, the SW, PB, and participant will meet jointly to establish a tailored activity program, review the ongoing assessment form, and clarify individual responsibilities.

Ongoing assessment will be the responsibility of the participant and his PB (project buddy), utilizing assessment forms and project personnel on consultant basis.

4/10/75

Dr. Carlos Ayala

Sir, Horton Ashcroft Place

McClellan Stevens

Dr. Marjorie Jones  
and in housework

community placement

held all existing  
mildly retarded

staff-counselors / Director  
housemother



called Casey (MSM)

11/6/75

no report on H&W conf.

will send copy

also letter to H&W

re: grant

REPORT ON ACTIVITIES IN WASHINGTON, D.C. - Oct. 7, 1975

Persons Contacted: Gail McNutt (Rep. Casey's office)  
Gail Picker (Sen. Bentson's office)  
Henry Neil, staff assistant to House Com. on HEW  
appropriations (Rep. Flood's office)  
Bill Bean, Office of Handicapped Individuals  
Ed Lynch, Office of Civil Rights, HEW  
Martin LaVor, Judy Heumann (Sen. Williams office)

Summary of discussions: McNutt believes that Casey will support a compromise between the House and Senate R&D levels in Conference, which will confer the week of Oct. 20. McNutt offered to have Casey write RSA regarding approval of the Transitional grant, if necessary.

Picker would like to package a new Rehab Act for Bentson to introduce. She needs to be "educated" and wants to learn about rehab, particularly that of the severely disabled. Based on my suggestion, I believe she will attempt to shorten the 24 month waiting period on Medicare for rehab clients.

Neil implied that the Conference Com. would probably compromise on 21 or 22 million for R&D. He also intimated that there was a possibility they would drop I&E. He is unhappy with the RSA bargain - says he "can't get a straight answer from them on anything". He recommended that we get some kind of commitment from them that our grant will be funded first if there is a compromise appropriation. Neil says Congress is down on HEW research, but rehab research is the easiest to defend. He liked the applied nature of the Transitional proposal.

LaVor says there is a 50% chance that President Ford will veto the entire appropriations Bill. He suspects that RSA is influenced by state agencies bias against R&D.

Conclusions: Transitional grant will be funded 1) if House compromises on R&D, 2) if Ford doesn't veto, and 3) if RSA stands committed.

Both state and federal rehab programs may be due for an overhaul.

10/9/75 Lex Frieden

Project # \_\_\_\_\_

Date Approved \_\_\_\_\_

Texas Institute for Rehabilitation and Research

RESEARCH PROJECT PROPOSAL

Date: \_\_\_\_\_

- A. TITLE OF PROJECT:
- B. NAME OF INVESTIGATOR(S): Give name and degree. Include a list of any additional investigators who will join the project at a later date.
- C. STUDENT PARTICIPATION: Give name, university, and class.
- D. STATEMENT OF THE PROBLEM: Include a brief literature review of currently available, relevant knowledge and indicate the knowledge gaps of interests; describe your hypotheses, if any, and indicate the possible significance of the project.
- E. OBJECTIVE(S): Describe specifically what the project proposes to accomplish.
- F. METHODOLOGY: Include a description of the population sample, investigative procedures, experimental design, and the time schedule which is proposed.
- G. ANALYSIS OF DATA: Mention what data will be analyzed and the procedures which will be used.
- H. BIBLIOGRAPHY: Include previous work done by the author(s) of the proposal or related work done by others which has been used for background research.
- I. BIOMEDICAL ENGINEERING REQUIREMENTS: If applicable, consult the Director of Biomedical Engineering; if not applicable, please indicate in your proposal. If applicable, indicate the following:
1. Brief statement of problem
  2. Equipment needs
  3. Services expected from Biomedical Engineering Department
  4. References considered pertinent to Biomedical Engineering problem in this proposal.

add references to all measures 1

Roos

- J. PROTECTION OF PATIENT'S WELFARE: Please use entire outline on page 3 of these instructions.
- K. BUDGET: Please use the form on page 4 of these instructions.
- L. DOCTOR'S ORDER SHEET: Please use the model on page 5 of these instructions and validate with your signature.

J. PROTECTION OF PATIENT'S WELFARE:

1. Describe the requirements for using any special groups in the study sample such as children, the mentally disabled or groups whose ability to give voluntary informed consent may be in question.
2. Describe the discomforts to the subject that are associated with the investigation.
3. Describe and assess any potential risks--physical, psychological, social, legal or other--and assess the likelihood and seriousness of such risks. If methods of research create potential risks, describe other methods, if any, that were considered and why they will not be used.
4. Describe procedures (including confidentiality safeguards) for protecting against or minimizing potential risks and provide an assessment of their likely effectiveness.
5. Describe consent procedures to be followed, including how and where informed consent will be obtained. Attach copy of Informed Consent form.
6. State as fully as possible the potential benefits of the project to rehabilitation, assuming that the research is successful and the results are implemented. "Benefits" may be considered in terms of: a) increasing the individual's functional capabilities, b) reducing dependency, c) increasing the likelihood of employment, d) reducing work days missed, e) containing service costs, f) increasing the efficiency of program operations, g) applicability of the study's methods to other problems, h) implications for the training of rehabilitation professionals, i) revision of governmental policies, j) implications for new or amended legislation, k) contributions to better problem definition, etc.
7. Analyze the risk-benefit ratio.

\_\_\_\_\_  
Principal Investigator

K. BUDGET: (Estimated duration of project \_\_\_\_\_ years).

1. Investigator's time (hours)

2. Personnel

\$ \_\_\_\_\_

3. Equipment

4. Supplies

5. Hospitalization costs

Inpatient \_\_\_\_\_ patients X \_\_\_\_\_ days X \$ \_\_\_\_\_ per day

Outpatient \_\_\_\_\_ patients X \$ \_\_\_\_\_ per patient visit

6. Data processing cost

\$1,500

7. Duplication and publication

8. Photography (include pictures and slides)

\$700

TOTAL

\$ \_\_\_\_\_

Sources of funds

KT  
R.A.  
J.P.R.

L. DOCTOR'S ORDER FOR PROJECT # \_\_\_\_\_

TITLE OF PROJECT:

ORDERS

1.

2.

3.

4.

5.

.....

7. Bob & Lola

3. Julia

2. Joy

5. Laurie

6. Ross

~~Frank~~

10. William

4. Helstead

9. Jeff

1. Campbell

Stanley

8. Duncan