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[TIRR] New Options Reports [1976-1978] [1]

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NEW OPTIONS RESEARCH

INTERIM REPORT

January 31, 1978

By Lex Frieden
New Options Research Director
Texas Institute for Rehabilitation and Research
Houston, Texas

NEW OPTIONS RESEARCH

INTERIM REPORT

January 31, 1978

We are trying to learn a number of things from the research at New Options. We want to find out the characteristics of the people who participate in the program. We are interested not only in their physical behavior, but also in their backgrounds and their attitudes. We want to document what they do and what they learn while they are in the program. We want to know what happens to them after they leave the program - whether the program had any signigicant effects on their lives - and if so, what were those effects and what about our program may have caused them. The following is a summary of some of the results of our research to date.

We are presently in the midst of our twelfth six-week program cycle, and sixty-six individuals have been admitted to the project. Fifty-five of these individuals were male and eleven were female. Forty-nine New Options participants were single and seventeen were married, divorced, or separated. Fifty of the sixty-six individuals were spinal cord injured and the others were severely disabled as a result of cerebral palsy, muscular dystrophy, polio, brain damage, spina bifida, rheumatoid arthritis, cerebellar dysfunction, and ataxia. Most of the individuals in the program were

from twenty thru thirty years old. The exact age range was from 17-53 years. Twenty-three percent of the participants were nonwhite.

One variable which may prove to be critical in determining who could benefit most from the New Options program is time since onset of disability. Thirty-one percent of the participants in the program had been disabled less than two years when they entered New Options. The most recent time since onset of disability was five months. Another thirty-one percent of the program participants had been disabled two to five years before they came to New Options. Finally, thirty-eight percent had been disabled more than five years before they participated in the program. The longest period from onset of disability to admission in New Options was twenty-nine years.

Another critical variable which may later be tied to potential to benefit from this program is the individual's pre-admission living arrangement. Approximately half of the participants came from rural communities, and the other half were from metropolitan areas. Perhaps more importantly, eighty-two percent of the New Options participants were living with their family before they came to the program and the remainder came from institutionalized settings such as junior colleges, hospitals, and nursing homes. With respect to transportation, all but two of the sixty-six participants were dependent on someone else to drive them. Seventy-five percent of these individuals depended directly on family members or close friends.

With the exception of three individuals, each of the participants in the program used either an electric or manual wheelchair for mobility. All of the participants had special bowel care needs, and eighty-six percent depended on an assistive urinary device of some sort. Two-thirds of the individuals in the program needed help transferring from their bed to their wheelchair or from their wheelchair to their bed. Most of them needed physical assistance dressing and bathing. Some needed assistance with eating and writing. Most of their physical assistance before they came to New Options was provided by family members or by individuals in the institution where they lived. Only seven of the participants were physically independent from a functional viewpoint.

Another key variable to which much attention has been directed is that of income or economic level. More than two-thirds of the individuals in the program had an income below $200 per month before they came to New Options. Only three of the sixty-six had incomes of more than $500 per month and one of these two supports a family of thirteen.

Fifty percent of the participants had some kind of comprehensive medical rehabilitation before they came to the program. Thirty percent had limited medical or vocational rehabilitation, and twenty percent had no previous rehabilitation. About fifty per cent of the New Options participants had been in school before they were disabled. The remaining fifty percent had been working. Most of these individuals had been doing mechanical labor such

as construction work, mechanics work, and agricultural work.

Since the onset of their disability and before participating in New Options, about half of the individuals had tried to attend school. The other half had tried a variety of activities including reading, painting, mechanical work, stamp collecting, traveling, fishing, and "just getting by".

Several unobstrusive monitoring techniques including the Rest Time Monitor and Wheelchair Odometer are being used to continuously measure gross activity levels of New Options participants. The average daily out of bed time for New Options participants was thirteen hours per day. This compares to a daily best week average of around 8.5 hours per day for paraplegics and quadriplegics who were in comprehensive rehabilitation programs at TIRR. Individual's mileage per week for the entire sample ranged from 1.1 to 35.8 miles. The average weekly mileage per individual across the entire sample was 9.1 miles, or approximately 1.3 miles per day average per individual.

Approximately five hours of each participants time per day is spent doing activities scheduled by the project. As a result, participants are able and encouraged to use most of their time in self initiated and self managed activities. There are approximately ten planned modules each week, an average of three planned field-trips per week and pre-arranged meetings with about six associates-active handicapped individuals from the community.

In an effort to document the individual effects of the program on New Options participants, follow-up is routinely done three to four months after each participant leaves the transitional program. Several significant changes in living arrangements may be noted for those individuals on whom follow-up data are complete. About half of the former participants are now living comparably more independently than they were before their participation in New Options. Many of them have moved from nursing homes or their parents homes into apartments, houses, and dormitories - both individually and in shared group living arrangements. Additionally, nearly two-thirds of the former participants are now in school, or have part time or full time jobs.

Observations made during the transition from protected settings such as nursing homes and parents homes to less well protected or more independent settings such as apartment units and college dormitories may lead to valuable insights regarding the psychological adjustment and adaptation of individual's to severe physical disabilities. The number and variety of references to changing self images or self concepts made by former participants is striking. For example, participants have said: "It is really hard to believe what can and is being done from wheelchairs. There are some very intelligent people in wheelchairs."; "Being in a wheelchair puts you in a minority but it doesn't stop you from living a normal life."; "Most people just don't realize that people in wheelchairs are normal too, they just have some kind of handicap. Everyone has a handicap of some sort, whether

it be large or small. Some people in wheelchairs are better off than some able bodied people."; "It is very hard for some people to adjust to being in a wheelchair. It is easier for some than for others, but it can be done."; "New Options opened my eyes and my mind to what a fulfilling life I could have in spite of my handicap."; "I cannot tell you how much self confidence I acquired in those few weeks - I got over being ashamed that I was in a wheelchair.".

Self reports by former participants are substantiated and validated by follow-up information and feedback received from counselors who sponsored individuals in the program. Most counselors agreed with their clients by saying that they seemed to be more self-sufficient, more self-confident, or more independent after they participated in New Options. Several counselors reported that they noticed a better outlook, a better attitude, or more motivation on the part of their client following participation in the program. Other counselors claimed that their clients were more goal oriented than they were before. Most comments from counselors who sponsored clients in the program were typified by the statement that "my client realized that he is ultimately responsible for meeting his own needs".

Staff members and the project Department of Vocational Rehabilitation courtesy counselor largely agree on the following characteristics as important traits in persons who seem to have benefitted from the project: readiness to face life as a severely disabled indivi-

dual; desire to make changes in lifestyle; willingness to set and work on some goals; willingness to risk experimenting with new ways of doing things and new kinds of behaviors; average intellectual capacity (comprehension of verbal input, no major memory deficits, reasonable attention span); ability to read; ability to speak well enough to be generally understood; ability to hear; no severe emotional pathology; and physical endurance for program (sitting tolerance, bowel control that is predictable, suitable urinary management).

The preceeding summary of research at New Options is intended to answer some questions and to raise others. Efforts are presently under way to determine whether reports of improved motivation are based on observations of verbal assertiveness or behavioral achievement. We want to find out more about how independence is related to learned skills and behaviors and to self-image or motivation. We want to know how the New Options program might be improved, and we want to know how portions of this program might be utilized to benefit more traditional rehabilitation programs. It is hoped that further research at New Options will help answer many of these and other questions.

RESEARCH PROJECT REPORT

PROJECT NO. R-172

1. TITLE: Transitional Living: A Program Fostering Community Integration of Severely Physically Handicapped Persons

2. PROJECT STATUS (Check):

Proposed ☐ New ☐ Continuing ☒ Completed ☐ Discontinued ☐ Transferred ☐ Other ☐

3. BEGINNING: June, 1976 (Mo./Yr.) EXPECTED COMPLETION: December, 1979 (Mo./Yr.) COMPLETED: (Mo./Yr.)

4. PERSONNEL: (List Principal Investigator First)

NAME OF PERSONNEL AND DEGREE	DISCIPLINE	% TIME ON PROJECT (based on 8-hour days/year)
J.A. Cole, Ph.D.	Anthropology	85%
L.M. Frieden, Ph.D.	Psychology	65%
J.C. Sperry, L.P.T.	Physical Therapy	100%
M.A. Board, M.S.W.	Social Work	100%
S. Plotkin, M.A.	Vocational Counseling	40%
V. Sorrells, V.A.	Coordinator Staff Assoc.	100%
D.C. Sharp	Research Asst./Documen.	100%
R.M. Reed	Attendant Manager	100%
several people	Attendant Staff	100% (3)
several people	Handicapped Staff Assoc.	variable

5. FINANCIAL DATA:

ESTIMATED COST FROM BEGINNING TO END OF PROJECT: $ 719,000

ITEM	ANNUAL COST IN DOLLARS			
	RT-FUNDS	UNIV. FUNDS	OTHERS*	TOTAL
Personnel Costs				
Supplies and Other Expenses				
Travel				
Equipment				
Indirect Costs Allowed by HEW				
TOTAL				
PERCENT				

* LIST OTHERS:

STATEMENT OF THE PROBLEM:

Recent developments in rehabilitation have placed an increased emphasis on creating opportunities for special living arrangements, 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 situation to the management and assumption of an independent lifestyle.

With passage of the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978, more and more handicapped individuals will be seeking to make the transition from lives of isolation and dependency toward greater autonomy and more involvement in the community. Present national programming now offers few prototypes that prepare the severely physically handicapped individual to move from a dependent setting into an independent setting and allow him to assume the multiple stresses of independent living and employment in a gradual manner. As funding for independent living in Title VII increases, growing emphasis will be placed on finding workable methods to teach independent living skills.

In June of 1976 TIRR began a model transitional living program called New Options 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. The planning and initial months of operation of New Options were supported in part by RT-4 funds which continue to support a portion of the research to evaluate program effectiveness. In October of 1976 an R&D grant (13-P-57889/6-01) was funded by RSA. This has substantially increased the project capability to conduct service demonstration and evaluation research.

Three years of experience in a previous R&D residential project (SRS R&D 13-P-55487/6-01) (RT-4 Project R-157 and R-158) have provided valuable background information to project personnel on the process of reintegration of severely physically handicapped persons in to the community. Forty

severely disabled young adults lived in the Cooperative Living Project since it opened in January of 1972. This project provided a first opportunity to begin involvement in education, vocational training or employment. 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 September, 1975, mean length of stay in the project was 15 months.)

The New Options transitional project has utilized 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 offers a number of advantages: (a) the acquisitions of important skills can be made in much less time, (b) the new program serves 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 provides more information and experience than residents of Cooperative Living gained in spite of the longer stay in the project because of important added project resources, (d) the project permits 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.

The New Options project is housed in TIRR's Maximum Independence Center, a dormitory-style building located four miles from the main Institute building in the Texas Medical Center. Each project participant has a private room. Meals, transportation, and non-professional attendant assistance are provided on a shared basis. The project staff includes a project director (anthropologist), research director (psychologist), functional skills adviser(physical therapist), social worker, part-time vocational counselor, driver, attendant manager, and attendant staff. A number of active handicapped persons from the community who lead many program activities are called staff associates and their work is organized and supervised by a full-time coordinator of staff associates.

The project is based on a combination of several service delivery methods. The kinds of information and skills learned over time in Cooperative Living were incorporated into a set of eleven training modules for New Options. These cover living arrangements, educational/vocational opportunities, attendant and financial management, functional and social skills, consumer affairs, medical needs, mobility, sexuality, and time management. The concept of field trips is incorporated into most of the modules in order to provide opportunities for observing and practicing new skills in actual community settings.

Because Cooperative Living residents had learned so much from observation of fellow residents who had already achieved various goals, the concept of role models was adopted in New Options in the form of Staff Associates. These are active handicapped persons from the community hired to teach many of the training modules. Individual counseling is also built into the New Options experience to assist persons in self-assessment, evaluation of living alternatives, goal identification, and the development of plans for practicing new responsi-

bilities and reaching goals.

Two primary types of research are conducted in the transitional living project. The first examines the development and evolution of the project from a holistic anthropological perspective. It is intended to provide a description of internal processes of development, to trace the changing relationships of the project to its host rehabilitation hospital and to the state vocational rehabilitation agency, and to provide background information on the program as a context for viewing outcome data. A major goal of this portion of the study is to provide a structured overview of the transitional living program to facilitate replication. The second type of research employs a longitudinal multimeasure design with control groups to evaluate the effects of the program on participants' behavior, attitudes, and information base. The hypothesis being tested in this portion of the study is that the TIRR transitional living program presents certain information, skills, and experiences which facilitate the behavioral adaptation and personal adjustment of individuals to severe physical disabilities. These two portions of the study are discussed separately below.

SUB-STUDY I: AN ANTHROPOLOGICAL STUDY OF PROGRAM DEVELOPMENT

OBJECTIVE(S):

1. To trace internal processes of development in the transitional living program, focusing on changes in goals, methods of planning, program content, and in other areas.

2. To analyze the project as a social system, examing roles, interpersonal relationships, and patterns of interaction among staff members and participants.

3. To examine external relationships between the transitional living project and other organizations with particular emphasis on relationships with the host rehabilitation hospital and the state vocational rehabilitaiton agency.

METHODOLOGY:

Respondents in this portion of the study include project participants, members of the attendant staff, professional staff members, and personnel of other organizations who interact regularly with the project. Participants in the transitional living program include severely physically handicapped persons completing rehabilitation programs at the 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 use wheelchairs as their major means of mobility. Initially project participants were single persons with spinal cord injuries who were between the ages of 18 and 50, though the population has been systematically diversified to include persons with other types of physical disability. The live-in project provides a program of transitional training and experience for 8 persons at a time with the program lasting 6 weeks for each participant. It is expected that a total of apprximately 120 persons will participate in the transitional program during three years of operation.

Previous research that provides an overview of an entire therapeutic en-

vironment can be found in the literature on the concept of the therapeutic community (see for example Caudill, 1958; Cumming & Cumming, 1962; Rapoport, 1960). Literature on the development of community-based programs in the area of emotional or psychiatric disability is relevant to this study also (Fairweather et al., 1969; Rausch & Rausch, 1968; Moos, 1974). Some methods of data collection have been borrowed from these studies.

The major method of data collection is participant observation made by the project director from an anthropological perspective and recorded in the form of field notes (Pelto, 1970). These observations are directed toward the objectives listed above as well as toward other areas that emerge as significant during the evolution of the project. They focus on informal day-to-day interaction, on planned program activities, on organizational activities such as staff meetings, and on interaction between personnel of the project and outside organizations.

Observational data are supplemented by other types of information. A comprehensive record of project activities is maintained using detailed weekly calendars and logs kept by the attendants and driver. Some participants are asked to keep diaries during their stay to record their activities and their feelings and responses to experiences.

Interviews are conducted periodically with participants, staff members, and persons from outside organizations who interact with the project to explore their feelings about various aspects of the program. At the end of each six-week program cycle, participants are asked to complete a questionnaire evaluating the training modules, staff, and other aspects of the program. In the future, additional information on personal perceptions of the transitional program will be gathered. During the project's third year this effort focused primarily on (a) articulating each staff member's views about the effectiveness of various methods for teaching independent living skills, and (b) defining considerations that will affect incorporation of New Options teaching/learning methods into other programmatic contexts. The results of this aspect of the research will be incorporated into a detailed final grant report as a major effort to disseminate the experience of the project to others who wish to establish independent living skills training programs.

Descriptive reports produced in this anthropological study are intended to convey a general view of the evolution of the transitional project over time and to analyze processes of development. This portion of the project research documents the nature of the program itself and thus serves as a measure of the independent variable (program) in the portion of the research dealing with program effects and outcomes.

SUB-STUDY II: A STUDY OF PROGRAM EFFECTS AND OUTCOMES

METHODOLOGY:

Design: A longitudinal multimeasure design with control groups is being employed in this study. A series of indicated measures is systematically being made before, during, and after the subject participates in the program to determine the effect of the independent variable (program) on the subjects' behavior, attitudes, and information base.

Subjects: Each participant in the New Options transitional living program is coincidentally a subject in this study. Other severely disabled individuals may also be asked to participate as control subjects in this study. (See description of participant population in preceding section.)

Control Groups: Since subjects are rotated through the program on a continuous basis, those individuals who are just coming into the program serve as a control group for those who are leaving (see Campbell & Stanley, 1963, Institutional Cycle Design). In order to insure comparable control groups, the program is kept as stable as possible with planned changes occurring only on even cycles. The institutional-cycle control group aspect of the research on this project has been difficult to implement, primarily because of difficulty in identifying program participants more than six weeks before their entrance in the program. The fact that such matched sample control group data will exist on some but not all program cycles will not interfere with its usefulness, nor will use of this method interfere in any way with the on-going longitudinal data collection that has been taking place since the project began.

MEASURES:

1. Independent Variables: The primary independent variable (program) is being constantly monitored and documented with staff and subject diaries and checklists. The anthropological study of program development is a major source of this information. Subject variables related to objective 4 are discovered by intake documents (medical and personal histories) and referral forms.

2. Dependent Variables: The dependent variable related to objective 1 (behavioral effects) is being measured regularly by several instruments. These instruments include wheelchair odometers and rest time monitors (Halstead, Cooperative Rehabilitation Engineering Center, TIRR, BCM, and TAMU), and functional activity and performance scales (Tufts Long Range Evaluation Summary, RT-7).

The dependent variable related to objective 2 (information effects) will be measured by a series of quizzes. These quizzes which are now being pilot tested relate to the informational content of specific training modules and seminars.

The dependent variable related to objective 3 (attitudinal effects) is being measured by a questionnaire developed by the project staff. Other standardized instruments such as the Siller Semantic Differential, Yuker Attitudes Toward Disabled Persons Test, Tennessee Self Concept Scale, etc., will be introduced periodically in order to validate and supplement the data obtained with this instrument.

The dependent variable related to objective 4 (outcome is being measured by some of the instruments described above as well as others. Follow-up questionnaires are routinely mailed to subjects approximately four months

after they participate in the program. These questionnaires include module ratings, program ratings, application information, follow-up questions, a goal completion survey, and the functional activity and performance scale mentioned above. Follow-up questionnaires are also sent to those counselors who refer clients to the program. Additionally, a comprehensive telephone survey is being conducted in order to obtain detailed, up to date, follow-up information about subjects' present living arrangements and activities. Results of this survey and all other studies conducted during the project will be included in next year's RT report.

PATIENT/CLIENT CHARACTERISTICS:

Age
- 1-6 years : 0
- 16-64 years: 126
- 65 and over: 0

Sex
- Male: 99
- Female: 27

Income Status
- Public Assistance: 123
- Self-support: 1
- Modified self-support: 2

SRS/RSA Priority Target Groups
- Severely disabled: 126
- Drug abusers: 0
- Alcoholics: 0
- Public Offenders: 0
- Other: 0

Clients on Vocational Rehabilitation Rolls: 126

Total Patient/Clients Served with R&T Center Funds: 0

RELEVANCE OF THE PROBLEM TO REHABILITATION:

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 individuals leave this specialized protected environment and return to the larger society. Some persons manage to bridge the gap successfully between the institutional environment and the community, but these are usually persons with exceptional capabilities and resources. Current rehabilitation programs are largely lacking in methods to assist physically impaired persons in making this transition. For many 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. The New Options project is intended to develop and evaluate transitional programming designed to bridge this

serious gap in rehabilitation services. Community integration and an active lifestyle can become feasible goals for many handicapped persons if they are taught and can practice new adaptive skills and if they are allowed to deal with stresses and assume responsibilities in a segmented sequence.

CURRENT YEAR'S ACTIVITY, PROGRESS, AND FINDINGS TO DATE:

During New Option's third year of operation, the program continued to operate as a service delivery system and to refine and evaluate methods for teaching independent living skills. These efforts have been reviewed at length in previous RT reports on the project. In addition to continuing these activities, the project also evolved in several new directions during its third year.

(1) development of audio-visual materials

(2) increased emphasis on interaction within the residential system as an experiential learning tool for participants and attendants

(3) emphasis on follow-up research

(1) Development of audio-visual materials

This effort received a major commitment of staff time and of financial resources during the project's third year. In planning audio-visual developments, consultation was sought to determine the most effective way to make New Options learning methods and tools useful to persons in other settings. The expectation was that medical rehabilitation programs, consumer and voluntary organizations, public agencies and various educational facilities could adapt New Options materials to teach independent living skills to handicapped individuals in their own program settings.

Two major publications have been produced to date. These include a 100-page softbound book and a looseleaf training manual. The book examines the process by which severely physically handicapped persons become independent and describes the New Options project as one means of fostering this process. Learning methods developed in the program are described in detail.

The book also includes a bibliography of suggested resources for a program library and copies of the many operating documents used in the program such as admission forms, sample calendars of activities, goal worksheets, fieldtrip behavior records, and sample counseling reports.

The training manual contains detailed information on each of the eleven training modules developed in the project. An introduction to each module summarizes its purpose, requirements for the group leader, and suggested resources. Specific course outlines are then provided for 5 or 6 sessions within each of the 11 modules.

Production of the book and the training manual required major efforts of the project staff to consolidate and evaluate all of the teaching strategies tested in the project. Distilling a broad array of experiences into concise and usable form and making explicit the rationale for intuitive judgments required careful reflection.

Before completion of New Options, two smaller publications will be produced. These include 2 videotapes and selected printed materials dealing with attendant management issues, and a publication on the use of peer educators in teaching community living skills.

Dissemination of these materials is discussed at length in later sections of this report.

(2) Increased emphasis on interaction within the residential system as an experiential learning tool

During the course of the project's third year, several major problems occurred within the attendant system which had previously been managed primarily by an attendant manager. It was decided to use this as an opportunity to experiment with the concept of a therapeutic community in which all interactions within the system are explicitly shaped to support program goals.

In implementing this change a major portion of the social worker's time was diverted from other responsibilities to management of the residential system. A number of new attendant staff were hired including a new attendant coordinator. Program expectations of attendants were made more explicit in written policies and incorporated into more elaborate staff training procedures.

A major commitment of time was made to on-going meetings of both attendant staff and of program participants. One-to-one supervisory meetings with attendant staff were increased.

After three months of operation in this manner, a decision was made to return to the previous operational structure for the residential system in which an attendant coordinator reported directly to the project director. The major reason for this change was recognition of the unreasonable demands of time, energy, and emotional stamina required of the project social worker to manage the system with this level of intensity. The social worker also experienced role conflict with her other continuing responsibility of individual counseling with program participants. In spite of the decision to return to an earlier structure,the experiment was wxtremely valuable in providing an intensive examination of interaction within this type of residential system. The results of this experiment and the issues it surfaced will be incorporated into a set of audio-visual materials on attendant management that were mentioned previously.

(3) Emphasis on Follow-up research

During the project's third year an intensive effort was made to interview each former New Options participant in depth. This is part of the overall effort to collect and analyze comprehensive data on the project to produce a thorough final grant report evaluating the effectiveness of New Options. Research developments are discussed at length in Section b below.

b. Longitudinal Research on Individual Outcomes: During the past three years, twenty-two New Options cycles have been completed. One hundred twenty-six people have started as participants in the program, and one hundred one persons have finished the course. Of those who were admitted, ninety-nine were male and twenty-seven were female. Eighty-three percent of the program participants were spinal cord injured. The rest were severely disabled as a result of cerebral palsy, muscular dystrophy, polio, brain damage, spina bifida, rheumatoid arthritis, cerebellar dysfunction, and ataxia. Most of the individuals in the program were from twenty to thirty years old. The exact age range was from 17 to 53 years. Thirty-one percent of the participants were non-white.

One variable which may prove to be critical in determining who could benefit most from the New Options program is time since onset of disability. Thirty-one percent of the participants in the program had been disabled less than two years when they entered New Options. The most recent time since onset of disability was five months. Another thirty-one percent of the program participants had been disabled two to five years before they came to New Options. Finally, thirty-eight percent had been disabled more than five years before they participated in the program. The longest period from onset of disability to admission in New Options was twenty-nine years.

Another critical variable which may be tied to potential to benefit from this program is the individual's pre-admission living arrangement. Approximately half of the participants came from rural communities and the other half were from metropolitan areas. Perhaps more importantly, eighty-two percent of the New Options participants were living with their family before they came to the program and the remainder from institutionalized settings such as junior college, hospitals, and nursing homes. With respect to transportation, all but two of the participants were dependent on someone else to drive them. Seventy-five percent of these individuals depended directly on family members or close friends.

With the exception of six individuals, each of the participants in the program used either an electric or manual wheelchair for mobility. All of the participants had special bowel care needs, and eighty-six percent depended on an assistive urinary device of some sort. Two-thirds of the individuals in the program needed help transferring from their bed to their wheelchair or from their wheelchair to their bed. Most of them needed physical assistance with dressing and bathing. Some needed assistance with eating and writing. Most of their physical assistance before they came to New Options. was provided by family members or by individuals in the institution where they lived. Only seven of the participants were physically independent from a functional viewpoint.

Another key variable to which much attention has been directed is that of income or economic level. More than two-thirds of the individuals in the program had an income below $200 per month before they came to New Options. Only three of the participants had incomes of more than $500 per month and one of these two supports a family of thirteen.

Fifty percent of the participants had some kind of comprehensive medical rehabilitation before they came to the program. Thirty percent had limited medical or vocational rehabilitation, and twenty percent had no previous rehabilitation. About fifty percent of the New Options participants had been in school before they were disabled. The remaining fifty percent had been working. Most of these individuals had been doing mechanical labor such as construction work, mechanics work, and agricultural work.

Since the onset of their disability and before participating in New Options, about half of the individuals had tried to attend school. The other half had tried a variety of activities including reading, painting, mechanical work, stamp collecting, traveling, fishing, and "just getting by".

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Approximately five hours of each participants time per day is spent doing activities scheduled by the project. As a result, participants are able and encouraged to use most of their time in self initiated and self managed activities. There are approximately ten planned modules each week, an average of three planned fieldtrip per week and pre-arranged meetings with about six associates active handicapped individuals from the community.

In an effort to document the individual effects of the program on New Options participants, follow-up is routinely done three to four months after each participant leaves the transitional program. Several significant changes in living arrangements may be noted for those individuals on whom follow-up data are complete. About half of the former participants are now living comparably more independently than they were before their participation in New Options. Many of them have moved from nursing homes or their parent's homes into apartments, houses, and dormitories - both individually and in shared group living arrangements. Additionally, nearly two-thirds of the former participants are now in school, or have part time or full time jobs.

Observations made during the transition from protected settings such as nursing homes and parents homes to less well protected or more independent settings such as apartment units and college dormitories may lead to valuable insights regarding the psychological adjustment and adaptation of individuals to severe physical disabilities. The number and variety of references to changing self images or self concepts made by former participants is striking. For example, participants have said: "It is really hard to believe what can and is being done from wheelchairs. There are some very intelligent people in wheelchairs."; "Being in a wheelchair puts you in a minority but it doesn't stop you from living a normal life.";

"Most people just don't realize that people in wheelchairs are normal too, they just have some kind of handicap. Everyone has a handicap of some sort, whether it be large or small. Some people in wheelchairs are better off than some able bodied people."; "It is easier for some than for others, but it can be done."; "New Options opened my eyes and my mind to what a fulfilling life I could have in spite of my handicap."; "I cannot tell you how much self-confidence I acquired in those few weeks - I got over being ashamed that I was in a wheelchair.".

Self reports by former participants are substantiated and validated by follow-up information and feedback received from counselors who sponsored individuals in the program. Most counselors agreed with their clients by saying that they seemed to be more self-sufficient, more self-confident, or more independent after they participated in New Options. Several counselors reported that they noticed a better outlook, a better attitude, or more motivation on the part of their client following participation in the program. Other counselors claimed that their clients were more goal oriented than they were before. Most comments from counselors who sponsored clients in the program were typified by the statement that "my client realized that he is ultimately responsible for meeting his own needs".

Staff members and the project Department of Vocational Rehabilitation courtesy counselor largely agree on the following characteristics as important traits in persons who seem to have benefitted from the project: readiness to face life as a severely disabled individual; desire to make changes in lifestyle; willingness to set and work on some goals; willingness to risk experimenting with new ways of doing things and new kinds of behaviors; average intellectual capacity (comprehension of verbal input, no major memory deficits, reasonable attention span); ability to read; ability to speak well enough to be generally understood; ability to hear; no severe emotional pathology; and physical endurance for program (sitting tolerance, bowel control that is predictable, suitable urinary management).

(c) Planned Future Activities:

During the next few months, research on the first three year phase of New Options will be completed. A comprehensive follow-up telephone survey is presently being conducted. Efforts are being made to contact all former program participants to find out where they are living, what they are doing, and what changes in their lives they may attribute to New Options. Results from this survey and analyses of other data collected during the project will be published in a final project report to be completed by December 1979.

One of the initial goals of the New Options project was to explore ways in which teaching methods developed in this program might be incorporated into other program settings. Two such settings are currently being explored in depth. The first involves incorporation of New Options teaching materials and strategies into medical rehabilitation programs at TIRR. Plans are currently being developed to establish an in-patient program called Rehab III that combines an in-depth assessment of community living skills, upgrading of medical and functional status, and individualized instructional programs using New Options materials. It is expected that New Options

staff will be involved in developing methods for assessing community living skills and in adapting New Options teaching methods from a group-oriented approach toward more individualized learning strategies.

The second application of New Options methods in another setting involves a local organization of consumers called the Coalition For Barrier Free Living (CBFL). Realizing the significance of the New Options program to the disabled community at large, CBFL is making plans to operate an adapted version of the transitional program in a community college setting. The CBFL, with help from New Options staff, is in the process of securing grant funds to support this effort. They intend to integrate New Options modules into the standard community college curriculum. These modules or classes will be taught by disabled people, and participants or students will receive credit for successful completion of the courses. The CBFL also plans to provide peer counseling, outreach, and vocational development programs in conjunction with the training program. It is thought that by eliminating the residential aspects of the New Options program, more people can be served at a lower cost. The major questions remaining in this new approach relate to the comparative effectiveness of the program. The CBFL hopes to work with RT-4 to answer these questions and gain more insight into the process by which severely disabled people become comparatively independent.

DISSEMINATION OF FINDINGS:

The production of audio-visual and written materials on the content of the transitional project has been a major objective during the project's third year. The structure and contents of a 100-page softbound book and looseleaf training manual are described at length in previous sections of this report. Announcements about these materials and often complimentary copies have been sent to state vocational rehabilitation agencies, state commissions for the blind, counselor training programs and RCEPs, RT Centers, RSA model spinal cord programs, VA spinal cord programs, consumer organizations, National Spinal Injury Foundation Chapters, voluntary associations such as Easter Seals and United Cerebral Palsy, university students programs, clearinghouses disseminating information relevant to handicapped individuals, and numerous professional and consumer periodicals. Orders have been received from persons in each of these target audience categories and from almost all states and several territories.

A related project directed jointly by the New Options project director and research director has also been effective in disseminating information about New Options, as well as similar programs in the U.S. Called ILRU for independent living research utilization, this project sponsored five bi-regional conferences on independent living during the past year. Held in Atlanta, Boston, Chicago, Houston, and Seattle, these meetings were attended by nearly 400 rehabilitation professionals and disabled consumers. In addition to sponsoring these meetings, the ILRU project has produced several written and audio-visual materials which have been widely distributed. One of these, a videotape entitled Independent Living: Six Model Programs, includes a segment on New Options. This tape has been shown on public television and to closed circuit audiences all over the U.S. It recently won a Certificate of Merit at the International Rehabilitation Film Review Festival. The ILRU project will continue to function as a clearinghouse for information about independent living. In this way, it will serve as an ongoing vehicle for disseminating information about New Options.

On a state level, training sessions have been conducted for eight groups of counselors from the Texas Rehabilitation Commission. Training has also been offered at three seminars sponsored by the Department of Human Resources in various locations around the state.

On a national level, broad dissemination of the New Options book and training manual has been discussed in the Dissemination section above. This dissemination has been directed toward a broad range of persons who might incorporate independent living skills training into a variety of program settings. In addition, New Options staff provided in-depth consultation to groups of persons from 5 major rehabilitation facilities in the country seriously interested in starting similar programs and to 4 groups of staff from existing independent living programs. The project has also hosted many foreign visitors who are interested in independent living programming in this country.

It is expected that the need for training materials, teaching strategies, and broad experience in independent living will increase dramatically as Title VII of the Rehabilitation Amendments of 1978 is implemented. It also appears likely that there will be a substantial demand for tested research strategies useful in evaluating the effectiveness of independent living programs.

POLICY, PROGRAM, OR PRACTICE CHANGES:

The results of this project and others like it have had profound consequences on the field of rehabilitation generally. By demonstrating that the acquisition of independent living skills and disability related information facilitates adaptation to severe disability, and by proving their effectiveness at helping people acquire needed skills and information, independent living programs have gained credibility and have begun to be looked upon as models of service delivery programs for severely disabled individuals. New Options itself was cited as a model independent living program by the Congressional Committee which recommended broad scale federal support of programs designed to facilitate independence by severely disabled people.

Last November, President Carter signed the Rehabilitation Act Amendments of 1978. Included in these amendments was a new Title VII for the Rehabilitation Act which authorizes substantial federal expenditures to support independent living by disabled people.

With the implementation of these new provisions, one may see a shift of emphasis by public welfare and vocational rehabilitation agencies from treatment, training, and vocational placement to treatment, training, and socio-environmental placement. Specifically, this means that traditionally conservative state departments of public welfare may realize that independent living is ultimately a viable and cost-effective alternative to institutionalization for severely disabled individuals. This shift may emphasize the need to treat chronically disabled individuals as a part of the total environment rather than as patients with problems that require narrowly focused attention.

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The utility of the present research methodology is evidenced by the quality of information yielded to date. Consequently, the expansion of research in New Options has and will continue to be directed toward three general areas. These are: 1) ongoing program evaluation from a process oriented perspective; 2) data acquisition from past and present participants, and detailed analysis relating to program effects or outcome; 3) the refinement of data collection comprehensive instruments and the improvement of methods for capturing individual competencies which may contribute to independent living by severely disabled individuals.

The following is a description of the group of individuals who have participated in the program thus far and a few examples of preliminary results and conclusions taken from the study of program effects.

As of February 15, 1978, twelve six-week cycles of New Options had been completed. Sixty-six individuals had been admitted to the project. Fifty-five of these individuals were male and eleven were female. Forty-nine New Options participants were single and seventeen were married, divorced, or separated. Fifty of the sixty-six individuals were spinal cord injured and the others were severely disabled as a result of cerebral palsy, muscular dystrophy, polio, brain damage, spina bifida, rheumatoid arthritis, cerebellar dysfunction, and ataxia. Most of the individuals in the program were from twenty through thirty years old. The exact age range was from 17-53 years. Twenty three percent of the participants were non-white.

One variable which may prove to be critical in determining who could benefit most from the New Options program is time since onset of disability. Thirty-one percent of the participants in the program had been disabled less than two years when they entered New Options. The most recent time since onset of disability was five months. Another thirty-one percent of the program participants had been disabled two to five years before they came to New Options. Finally, thirty-eight percent had been disabled more than five years before they participated in the program. The longest period from onset of disability to admission in New Options was twenty-nine years.

Another critical variable which may later be tied to potential to benefit from this program is the individual's pre-admission living arrangement. Approximately half of the participants came from rural communities, and the other half were from metropolitan areas. Perhaps more importantly, eighty-two percent of the New Options participants were living with their family before they came to the program and the remainder came from institutionalized settings such as junior colleges, hospitals, and nursing homes. With respect to transportation, all but two of the sixty-six participants were dependent on someone else to drive them. Seventy-five percent of these individuals depended directly on family members or close friends.

With the exception of three individuals, each of the participants in the program used either an electric or manual wheelchair for mobility. All of the participants had special bowel care needs, and eighty-six percent depended on an assistive urinary device of some sort. Two-thirds of the individuals in the program needed help transferring from their bed to their wheelchair or from their wheelchair to their bed. Most of them needed physical assistance dressing and bathing. Some needed assistance with eating and writing. Most of their physical assistance before they came to New Options was provided by family members or by individuals in the institution where they lived. Only seven of the participants were physically independent from a functional viewpoint.

Another key variable to which much attention has been directed is that of income or economic level. More than two-thirds of the individuals in the program had an income below $200 per month before they came to New Options. Only three of the sixty-six had incomes of more than $500 per month and one of these two supports a family of thirteen.

Fifty percent of the participants had some kind of comprehensive medical rehabilitation before they came to the program. Thirty percent had limited medical or vocational rehabilitation, and twenty percent had no previous rehabilitation. About fifty per cent of the New Options participants had been in school before they were disabled. The remaining fifty percent had been working. Most of these individuals had been doing mechanical labor such as construction work, mechanical work, and agricultural work.

Since the onset of their disability and before participating in New Options, about half of the individuals had tried to attend school. The other half had tried a variety of activities including reading, painting, mechanical work, stamp collecting, traveling, fishing, and "just getting by".

Several unobtrusive monitoring techniques including the Rest Time Monitor and Wheelchair Odometer are being used to continuously measure gross activity levels of New Options participants. The average daily out of bed time for New Options participants was thirteen hours per day. This compares to a daily best week average of around 8.5 hours per day for paraplegics and quadriplegics who were in comprehensive rehabilitation programs at TIRR. Individuals' mileage per week for the entire sample ranged from 1.1 to 35.8 miles. The average weekly mileage per individual across the entire sample was 9.1 miles, or approximately 1.3 miles per day average per individual.

Approximately five hours of each participants time per day is spent doing activities scheduled by the project. As a result, participants are able and encouraged to use most of their time in self initiated and self managed activities. There are approximately ten planned modules each week, an average of three planned fieldtrips per week, and pre-arranged meetings with about six associates (active handicapped individuals from the community). Of all the modules, three seem to be consistently best liked by participants. These are sexuality, medical needs, and functional skills.

In an effort to document the individual effects of the program on New Options participants, follow-up is routinely done three to four months after each participant leaves the transitional program. Several significant changes in living arrangements may be noted for those individuals on whom follow-up data are complete. About half of the former participants are now living comparably more independently than they were before their participation in New Options. Many of them have moved from nursing homes or their parent's homes into apartments, houses, and dormitories - both individually and in shared group living arrangements. Additionally, nearly two-thirds of the former participants are now in school, or have part-time or full-time jobs.

Not unexpectedly, the research at New Options indicates that those persons who demonstrate extreme improvement in either physical or psychosocial status while they are in the transitional program are much more likely to become independent in terms of their educational/vocational status or living arragement than those who do not.

Perhaps more interestingly, measures of individual psychosocial characteristics seem to be somewhat better predictors of program outcome than measures of physical ability at New Options. Data thus far collected indicate that psychosocial barriers in the individuals environment or self concept may impede progress towards an independent life style considerably more than physical barriers or functional disability. Other data indicate that females and city dwellers may benefit more from the program than the rest of the sample, at least as far as living arrangement and occupation are concerned. Also persons who are very recently disabled (less than two years) and those who have been disabled for more than five years seem to become more independent as a result of the program than those who are two to five years post onset of disability.

Given these preliminary findings, efforts are currently being made to find out more about the nature of the critical variables involved in the transitional process by conducting extensive follow-up interviews.

Also, an instrument called the Independent Living Skills Evaluation Questionnaire has been developed by the project staff and is presently being pilot tested and validated. This instrument is designed to measure aptitude for independence by asking for solutions to a series of practical questions involving problems which severely disabled persons may encounter in independent living arrangements. The questionnaire may be used to assess changes in individuals knowledge and information bases, or in their approach to solving problems. Meanwhile, the data base at New Options continues to expand so that statistical tests of apparent differences may soon be feasible.

Objective d — to further cooperation with community resources

During the past year, New Options staff worked with a variety of organizations and groups on issues pertaining to the design of transitional and independent living programs for severely handicapped individuals, and on service needs of these individuals. As a result of these communications, several local projects have begun to meet the need for providing supportive services for independent living in the Houston community. For example, Gulf Home Health Services has initiated a community wide attendant service for severely handicapped persons who are not necessarily associated with the cooperative living programs already established in the community. The Texas State Department of Public Welfare has begun operating a major demonstration project designed to facilitate independent living for severely disabled individuals in Houston who before this time have been restricted to nursing homes by an absence of alternatives. The Texas Rehabilitation Commission has purchased a thirty unit complex for an extended rehabilitation facility. Houston Community College has applied for funding to support an attendant training and certification program. New Options staff continues to consult with and advise each of these projects as they develop. Involvement with these projects has provided an opportunity for testing the applicability of independent living designs and methodology to other programs. It has also benefited former participants by giving them more opportunity to practice and to apply skills they learn during the program after they leave the program.

3. Staff Changes

During the past year, New Options created an additional part-time staff position of Resident Advocate which is filled by a former New Options participant. This individual lives on the project premises during the first week of each program cycle. His role is to acquaint the new participants with the attendant system and project rules and policies as well as to promote group cohesiveness through social interaction. A job description for this position can be found in Appendix A.

Another change occurred in February 1978 when a new individual was hired to fill a vacancy in the position of Staff Associate Coordinator. This role was expanded to a full-time position. Responsibilities include coordinating weekly schedules, maintaining a quota of staff associates for each cycle, and monitoring module content and teaching techniques. A biographical sketch of Catherine Rowland, the new Coordinator. can be found in Appendix B.

4. Inventions and Copyrights

No new inventions or products have been developed in this project to date. It is expected that a copyright will be sought on audio-visual materials that will be completed during the project's third year.

5. Cost Benefit Findings

Major benefits of the New Options project include changes in the lives of individuals who participate in the program (personal benefits) as well as contributions of proven teaching methods and written and audio-visual materials to the field of independent living skills training (non-personal benefits). It is expected that the need for program experience and materials in this field will increase substantially in the near future because of recent legislative provisions for independent living services.

Documentation of personal benefits from participation in New Options is discussed at length under Section 2, objective c (page 10). Early follow-up data indicate that more than half of the New Options participants either move from comparatively dependent to independent settings and/or become actively involved in vocational pursuits within three to four months following their participation in the program.

Additionally, nearly all former participants report that they learned new skills, acquired adaptive information, and developed an improved self concept as a result of their New Options experience. This outcome ratio compares favorably with other programs serving severely handicapped populations. Preliminary cost information also indicates that the costs of attaining these outcomes through New Options compare favorably with the per-person costs of other projects serving similar populations such as the Comprehensive Needs Demonstration Projects. Plans are being investigated to compare cost and outcome data with these projects in the future in a more formalized manner.

The development of training materials and packaging of teaching methods have been identified as a major goal of the third grant period. Substantial efforts will also focus on how these methods and materials can be effectively incorporated into comprehensive rehabilitation programs and day or live-in programs that might be operated by a variety of agencies, voluntary organizations, consumer groups, or schools. Successful dissemination of these products of the New Options experience will mean that benefits of the project may become available to a large number of handicapped individuals through a variety of programmatic settings.

RESEARCH PROJECT REPORT

PROJECT NO. R-172

1. TITLE: Transitional Living: A Program Fostering Community Integration of Severely Physically Handicapped Persons

2. PROJECT STATUS (Check):

Proposed ☐ New ☐ Continuing ☒ Completed ☐ Discontinued ☐ Transferred ☐ Other ☐

3. BEGINNING: 6/76 (Mo./Yr.) EXPECTED COMPLETION: 9/79 (Mo./Yr.) COMPLETED: _____ (Mo./Yr.)

4. PERSONNEL: (List Principal Investigator First)

NAME OF PERSONNEL AND DEGREE	DISCIPLINE	% TIME ON PROJECT (based on 8-hour days/year)
Cole, J.A., Ph.D.	anthropology	85%
Frieden, L.M., candidate for Ph.D.	psychology	65%
Sperry, J.C., L.P.T.	physical therapy	100%
Board, M.A., M.S.W.	social work	100%
Wise, J.A., M.A.	voc. counseling	30%
Rowland, C., B.A.	English	100%
research assistant/documentarian		100%
attendant manager		100%
attendant staff		100%
handicapped staff associates		variable

5. FINANCIAL DATA:

ESTIMATED COST FROM BEGINNING TO END OF PROJECT: _____

ITEM	ANNUAL COST IN DOLLARS			
	RT-FUNDS	UNIV. FUNDS	OTHERS*	TOTAL
Personnel Costs				
Supplies and Other Expenses				
Travel				
Equipment				
Indirect Costs Allowed by HEW				
TOTAL				
PERCENT				

If you are uncertain about these figures, leave blank

* LIST OTHERS:

STATEMENT OF THE PROBLEM:

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 lifestyle.

Present national programming offers few prototypes that prepare the severely physically handicapped individual 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. 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.

In June of 1976 TIRR began a model transitional living program called New Options 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. The planning and initial months of operation of New Options were supported in part by RT-4 funds which continue to support a portion of the research to evaluate program effectiveness. In October of 1976 an R&D grant (13-P-57889/6-01) was funded by RSA. This has substantially increased the project capability to conduct service demonstration and evaluation research.

Three years of experience in a previous R&D residential project (SRS R&D 13-P-55487/6-01) (RT-4 Projects R-157 and R-158) 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 have lived in the Cooperative Living Project since it opened in January of 1972. This project provided a first opportunity to begin involvement in education, vocational training, or employment. 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 September, 1975, mean length of stay in the project was 15 months.)

The New Options transitional project has utilized 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 offers a number of advantages: (a) the acquisitions of important skills can be made in much less time, (b) the new program serves 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 provides 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 project permits 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.

The New Options project is housed in TIRR's Maximum Independence Center, a dormitory-style building located four miles from the main Institute building in the Texas Medical Center. Each project participant has a private room. Meals, transportation, and non-professional attendant assistance are provided on a shared basis. The project staff includes a project director (anthropologist), research director (psychologist), functional skills adviser (physical therapist), social worker, part-time vocational counselor, driver, attendant manger, and attendant staff. A number of active handicapped persons from the community who lead many program activities are called staff associates. The structure and content of the program are discussed at length under Current Year's Activity, Progress, and Findings to Date.

Two primary types of research are conducted in the transitional living project. The first examines the development and evolution of the project from a holistic anthropological perspective. It is intended to provide a description of internal processes of development, to trace the changing relationships of the project to its host rehabilitation hospital and to the state vocational rehabilitation agency, and to provide background information on the program as a context for viewing outcome data. A major goal of this portion of the study is to provide a structured overview of the transitional living program to facilitate replication. The second type of research employs a longitudinal multimeasure design with control groups to evaluate the effects of the program on participants' behavior, attitudes, and information base.

The hypothesis being tested in this portion of the study is that the TIRR transitional livng program presents certain information, skills, and experiences which facilitate the behavioral adaptation and personal adjustment of individuals to severe physical disabilities. These two portions of the study are discussed separately below.

Sub-study I: An Anthropological Study of Program Development

OBJECTIVE(S):

1. To trace internal processes of development in the transitional living program, focusing on changes in goals, methods of planning, program content, and in other areas.

2. To analyze the project as a social system, examining roles, interpersonal relationships, and patterns of interaction among staff members and participants.

3. To examine external relationships between the transitional living project and other organizations with particular emphasis on relationships with the host rehabilitation hospital and the state vocational rehabilitation agency.

METHODOLOGY:

Respondents in this portion of the study include project participants, members of the attendant staff, professional staff members, and personnel of other organizations who interact regularly with the project. Participants in the transitional living program 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 use wheelchairs as their major means of mobility. Initially project participants were single persons with spinal cord injuries who were between the ages of 18 and 50, though the population has been systematically diversified to include persons with other types of physical disability. The live-in project provides a program of transitional training and experience for 8 persons at a time with the program lasting 6 weeks for each participant. It is expected that a total of approximately 150 persons will participate in the transitional program during three years of operation.

Previous research that provides an overview of an entire therapeutic environment can be found in the literature on the concept of the therapeutic community (see for example Caudill, 1958; Cumming & Cumming, 1962; Rapoport, 1960). Literature on the development of community-based programs in the area of emotional or psychiatric disability is relevant to this study also (Fairweather et al., 1969; Rausch & Rausch, 1968; Moos, 1974). Some methods of data collection have been borrowed from these studies.

The major method of data collection is participant observation made by the project director from an anthropological perspective and recorded in the form of field notes (Pelto, 1970). These observations are directed toward the objectives listed above as well as toward other areas that emrge as significant during the evolution of the project. They focus on informal day-to-day interaction, on planned program activities, on organizational activities such as staff meetings, and on interaction between personnel of the project and outside organizations.

Observational data are supplemented by other types of information. A comprehensive record of project activities is maintained using detailed weekly calendars and logs kept by the attendants and driver. Some participants are asked to keep diaries during their stay to record their activities and their feelings and responses to experiences.

Interviews are conducted periodically with participants, staff members, and persons from outside organizations who interact with the project to explore their feelings about various aspects of the program. At the end of each six-week program cycle, participants are asked to complete a questionnaire evaluating the training modules, staff, and other aspects of the program. In the future, additional information on personal perceptions of the transitional program will be gathered. During the project's third year, this effort will focus primarily on (a) articulating each staff member's views about the effectiveness of various methods for teaching independent living skills, and (b) defining considerations that will affect incorporation of New Options teaching/learning methods into other programmatic contexts. The results of this aspect of the research will be incorporated into a New Options Instructors' Manual as a major effort to disseminate the experience of the project to others who wish to establish independent living skills training programs.

Descriptive reports produced in this anthropological study are intended to convey a general view of the evolution of the transitional project over time and to analyze processes of development. This portion of the project research documents the nature of the program itself and thus serves as a measure of the independent variable (program) in the portion of the research dealing with program effects and outcomes.

Sub-study II: A Study of Program Effects and Outcomes

OBJECTIVE(S)

1. To determine the behavioral effects of the transitional program.

2. To determine the informational effects of the transitional program.

3. To determine the attitudinal effects of the transitional program.

4. To determine what specific effects the program will have on certain types of individuals and to develop a means of predicting relative outcomes.

METHODOLOGY:

Design: A longitudinal multimeasure design with control groups is being employed in this study. A series of indicated measures is systematically being made before, during, and after the subject participates in the program to determine the effect of the independent variable (program) on the subjects' behavior, attitudes, and information base.

Subjects: Each participant in the New Options transitional living program is coincidentally a subject in this study. Other severely disabled individuals may also be asked to participate as control subjects in this study. (See description of participant population in preceding section.)

Control Groups: Since subjects are rotated through the program on a continuous basis, those individuals who are just coming into the program serve as a control group for those who are leaving (see Campbell & Stanley, 1963, Institutional Cycle Design). In order to insure comparable control groups, the program is kept as stable as possible with planned changes occurring only on even cycles. The institutional-cycle control group aspect of the research on this project has been difficult to implement, primarily because of difficulty in identifying program participants more than six weeks before their entrance into the program. It will hopefully be feasible to implement this aspect of the research for at least several cycles in the third year of the project. The fact that such matched sample control group data will exist on some but not all program cycles will not interfere with its usefulness, nor will use of this method interfere in any way with the on-going longitudinal data collection that has been taking place since the project began.

MEASURES:

1. Independent Variables: The primary independent variable (program) is being constantly monitored and documented with staff and subject diaries and checklists. The anthropological study of program development is a major source of this information. Subject variables related to objective 4 are discovered by intake documents. (medical and personal histories) and referral forms.

2. Dependent Variables: The dependent variable related to objective 1 (behavioral effects) is being measured regularly by several instruments. These instruments include wheelchair odometers and rest time monitors (Halstead, Cooperative Rehabilitation Engineering Center, TIRR, BCM, and TAMU), and functional activity and performance scales (Tufts Long Range Evaluation Summary, RT-7). Additional instruments which are presently under development to measure behavioral effects of the program include behavioral logs (Willems, RT-4, Project R-136), a goal oriented behavioral check list, and a survey of critical incidents.

The dependent variable related to objective 2 (information effects) will be measured by a series of quizzes. These quizzes which are now being

pilot tested relate to the informational content of specific training modules and seminars. Data acquired from these instruments will be reported in the project's third year.

The dependent variable related to objective 3 (attitudinal effects) is being measured by a questionnaire developed by the project staff. Other standarized instruments such as the Siller Semantic Differential, Yuker Attitudes Toward Disabled Persons Test, Tennessee Self Concept Scale, etc., will be introduced periodically in order to validate and supplement the data obtained with this instrument.

The dependent variable related to objective 4 (outcome) is being measured by some of the instruments described above as well as others. Follow-up questionnaires are routinely mailed to subjects approximately four months after they participate in the program. These questionnaires include module ratings, program ratings, application information, follow-up questions, a goal completion survey, and the functional activity and performance scale mentioned above. Follow-up questionnaires are also sent to those counselors who refer clients to the program. Plans are being made for a staff person to do follow-up in the field, thus providing an opportunity to do follow-up interviews and direct observations.

PATIENT/CLIENT CHARACTERISTICS:

Age
- 1-16 years: 0
- 16-64 years: 74
- 65 and over: 0

Sex
- Male: 61
- Female: 13

Income Status
- Public Assistance: 71
- Self-support: 1
- Modified self-support: 2

SRS/RSA Priority Target Groups
- Severely disabled: 74
- Drug abusers: 0
- Alcoholics: 0
- Public Offenders: 0
- Other: 0

Clients on Vocational Rehabilitation Rolls: 74

Total Patient/Clients Served with R&T Center Funds: 0

RELEVANCE OF THE PROBLEM TO REHABILITATION:

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 individuals leave this specialized protected environment and return to the larger society. Some persons manage to bridge the gap successfully between the institutional environnment and the community, but these are usually persons with exceptional capabilities and resources. Current rehabilitation programs are largely lacking in methods to assist physically impaired persons in making this transition. For many 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. The New Options project is intended to develop and evaluate transitional programming designed to bridge this serious gap in rehabilitation services. Community integration and an active lifestyle can become feasible goals for many handicapped persons if they are taught and can practive new adaptive skills and if they are allowed to deal with stresses and assume responsibilities in a segmented sequence.

CURRENT YEAR'S ACTIVITY, PROGRESS, AND FINDINGS TO DATE:

a. Program Development: During New Option's second year of operation, the program evolved in several major areas:

(1) refinement of service delivery methods
(2) operation of the project as an organizational system
(3) determination of types of persons with various disabilities who can benefit from the program
(4) research development
(5) preparation for production of audio-visual materials as a substantial program focus

(1) Refinement of Service Delivery Methods

New Options continues to employ a combination of several service delivery methods.

Group Training Modules

The project uses group meetings to explore 11 subject areas important for handicapped individuals who want to become active in the community and independent directing their own lives. The curriculum for training modules in each of these 11 subject areas is based on the previous experiences of many successful handicapped persons. The project expects all participants to attend modules in mobility, functional skills, financial management, social skills, sexuality, time management, medical needs, consumer affairs, living arrangements, vocational-educational opportunities and attendant management.

Some of the modules in the project are conducted as educational courses using traditional didactic teaching methods and group discussion. Others are conducted as therapy groups. Much of the group interaction takes place on fieldtrips in the community to provide firsthand experiences.

The set of training modules developed during the project's first year has remained relatively similar during the second year of program operation. Many refinements have been made in activities used to teach particular information and skills, primarily in a direction of greater involvement in actual community experiences. The project staff has jointly developed a series of questions covering the content of specific module areas which are being combined in an Independent Living Skills Evaluation. Work will continue during the project's third year to test the effectiveness of this instrument in measuring acquisition of information and skills needed for independent living.

Practice Experiences

As a major learning method, the project seeks to structure experiences for participants similar to situations they will encounter if they make major changes in their lifestyles. The purpose of these experiences is to let people practice new responsibilities and skills. Major planning and problem-solving experiences include:

(a) the dormitory style living situation

The project is housed in a dormitory-style setting. Attendant assistance, meals, and transportation are provided on a shared basis. For many persons this is the first time they have had to meet a schedule, rely on a new system of physical assistance with daily routines, manage their money, or learn to trust new sources of emotional support. The project has developed a Residential Behavior Record for participants to rate their own performance in these areas of skill and responsibility.

(b) group fieldtrips

Each fieldtrip made by the project has a specific purpose related to content areas of the 11 training modules. However another major reason for making fieldtrips is to provide situations to test certain skills and responsibilities in actual community situations. The project has developed a Fieldtrip Behavior Record through which group leaders document performance of participants in skills areas such as managing interaction with strangers or dealing with architectural barriers.

(c) individual assignments

Individual assignments are sometimes made to provide practice experience appropriate for one individual. Such assignments may include

telephoning for information from a particular support agency, visiting someone with a job or living situation similar to one the individual is seeking, or practicing interaction with the general public in restaurants or shopping centers. The assignments appropriate for each person are carefully planned, taking into account the individual's array of past experiences as well as the competancies the person will need in order to meet his or her future goals.

During its second year, the project staff has attributed increasing importance to the usefulness of actual community experience as a learning tool. This philosophy was elaborated in a special staff retreat conducted in November (reported in section 2) which led to the documentation of a more experiential program model and to the development of the Fieldtrip Behavior Record as a tool for documenting important experiences.

Modeling

The project hires active handicapped persons on a part-time basis to teach training modules and lead fieldtrips. These staff associates are chosen to teach areas of particular expertise they have acquired and also to represent a variety of different lifestyles and kinds of solutions to the problems typically faced by handicapped persons. During its second year, the project employed 56 associates, 31 of whom are working and 17 of whom are attending college or vocational training. The associates are expected to cover a standardized set of material in various modules they teach. It is also expected that they will convey something of their personal history and course of development to participants so that participants gain an understanding of what it takes to get from point A to point B in setting life goals and planning how to meet them. Modeling by associates lets participants observe specific techniques and problem-solving strategies. Associates also serve as contact brokers for participants, demonstrating how to best get things done and how to find their own contacts in local communities.

In addition to staff associates, another use of modeling in the project is the role of the resident advocate which was developed during the project's second year of operation. This role is filled by a former participant who lives with each set of new participants their first week in the project. He demonstrates how to work the residential system, how to deal with the problems that come up, and whom to ask about various issues. He provides emotional support and serves as a friend at an important time when old supports have left behind. He also provides a model of how to behave in typical project activities and how to structure free time.

Individual Counseling

Individual counseling is scheduled routinely with the project social worker, functional skills adviser, and vocational counselor. Counselors help people assess where they are presently, help them set goals, and help develop sequential plans for how to reach goals. This long-range perspective is important in helping persons realize their own responsibility for directing the course of their lives. Counselors also help people learn to use what they are exposed to in group meetings and plan how to implement new ideas. They provide emotional support and help individuals test the limits of what is acceptable and what will work.

Staff members who work with participants in a counseling relationship have developed written materials to assist the individual in planning and goal setting. These materials include such items as goal-worksheets, contracts for assistance with daily care routines, self-assessments of health status and needs, and behavioral logs. It is expected that these tools developed through experience in working with individuals in New Options will be useful in other settings where counselors seek to assist handicapped persons plan for greater independence.

It is expected that a manual on underlying principles and techniques of these teaching methods will be a major effort of the project in its third year as a contribution to the field of independent living skills training.

(2) Operation of the Project as an Organizational System

During the project's second year, staffing has remained relatively similar to the system developed during the first year. (Major staff members are project director, research director, social worker, functional skills adviser, part-time vocational counselor, part-time coordinator of staff associates, residential manager and staff of attendants.) The roles of social worker and vocational counselor were initially most difficult to fill with persons who complemented the basic program philosophy. These roles are now filled by very appropriate individuals who have been at New Options throughout the project's second year. This stability has greatly facilitated program development.

Major changes in staffing have included the expansion of the coordinator of staff associates role to a full-time position, and inition of a new position of resident advocate. The advocate is a former participant who lives in the project with each new set of participants during their first week of the program cycle. This individual demonstrates how to adapt effectively to the residential system and the program experience. The advocate's role is an expansion of the concept of modeling which is basic to the entire project.

The project's program staff worked creatively as a team on a number of major projects during the past year. These included a shared group experience during October to evaluate the Personal Adjustment Skills program (led by a trainee from RT-13, Arkansas), a major retreat with a research consultant in November which resulted in a more explicit experiential focus in programming, on-going meetings during the winter to plan a film and other audio-visual materials, and a retreat during February to articulate goals more clearly. These major shared planning activities are being complemented at present by an effort to improve the effectiveness with which ideas are actually implemented.

A major focus of joint staff effort during the coming year will be the production of audio-visual materials. This is examined at length in section 5.

(3) Determination of Types of Persons with Various Disabilities Who Can Benefit from the Program

During its second year of operation the project included participants with a wider range of disabilities than previously had been served. Of particular interest to staff was the inclusion of a number of persons who had grown up with their disabilities (persons with cerebral palsy, spina bifida, arthritis or polio residuals). In many cases these individuals had not experienced the childhood activities typical in our society, and the project often provided their first opportunity to be active in community settings or to assume major responsibilities for directing their own lives. The content of the program has proved to be equally appropriate for such individuals, as well as for persons with disabilities acquired in adolescence or adulthood. In many cases, in which individuals grew up with their disabilities, individual counseling and particular individual experiences and assignments have been planned to help persons acquire experiences they "missed out on" while growing up.

In contrast to the general finding that the project is useful to persons with a wide variety of major physical impairments, there is one disability group that has not been effectively served. This group is persons with traumatic head injuries. The project has admitted four such persons to test the effectiveness of the program in meeting their needs, and it is the concensus of the staff that these experiences have not been positive for the participants or the project. Types of functional deficits that seem to interfere most significantly with useful participation include memory impairment, failure to inhibit socially inappropriate behavior, poor judgment about risk-taking, and inability or unwillingness to assume responsibility for cooperating with project policies.

(4) Research Developments

Major research efforts during the second year of operation have included development of a data base on behavior of participants in the program, evaluation of specific modules and program areas through student projects, and evaluation of the overall effectiveness of the program based on information from participants, staff, and referring counselors. The results of these research efforts are discussed at length in section b.

Planning of major research thrusts for the remainder of the project has focused on increased follow-up research based on an interview design using several specific data collection instruments. A second major thrust will be to summarize the projects contribution to the general field of outcome measurement. These future directions are discussed at greater length in section c.

(5) Preparation for Production of Audio-Visual Materials as a Substantial Program Focus

One of the major goals of New Options from the outset has been to package materials and techniques that have proven useful in teaching independent living skills. Such materials and techniques are intended to be useful in other learning settings such as comprehensive medical rehabiltation programs, day programs, or live-in programs operated by a variety of agencies or centers.

During the second project year, major planning has been completed and arrangements have been developed for actual production of materials. This has involved extensive investigation of potential production resources and consultation on types of materials that can best convey the information and experience accumulated through operation of the program as a service delivery system.

Materials that will be produced include

(a) a slide-sound presentation on the overall concepts of the New Options program
(b) an instructors' manual that conveys the project's philosophy and techniques for teaching independent living skills
(c) a participants' looseleaf notebook that contains the content of the training modules including information, exercises, and recommended activities in the community
(d) other participant materials (such as slides, videotapes, and booklets) that supplement the participants' notebook

Production of these materials will be a major focus of the project's third year of operation. Cooperative arrangements have been made for actual production.

b. Longtitudinal Research on Individual Outcomes: As of February 15, 1978, twelve six-week cycles of New Options had been completed. Sixty-six individuals had been admitted to the project. Fifty-five of these individuals were male and elven were female. Forty-nine New Options participants were single and seventeen were married, divorced, or separated. Fifty of the sixty-six individuals were spinal cord injured and the others were severely disabled as a result of cerebral palsy, muscular dystrophy, polio, brain damage, spina bifida, rheumatoid arthritis, cerebellar dysfunction, and ataxia. Most of the individuals in the program were from twenty through thirty years old. The exact age range was from 17-53 years. Twenty-three percent of the participants were non-white.

One variable which may prove to be critical in determining who could benefit most from the New Options program is time since onset of disability. Thirty-one percent of the participants in the program had been disabled less than two years when they entered New Options. The most recent time since onset of disability was five months. Another thirty-one percent of the program participants had been disabled two to five years before they came to New Options. Finally, thirty-eight percent had been disabled more than five years before they participated in the program. The longest period from onset of disability to admission in New Options was twenty-nine years.

Another critical variable which may later be tied to potential to benefit from this program is the individual's pre-admission living arrangement. Approximately half of the participants came from rural communities, and the other half were from metropolitan areas. Perhaps more importantly, eighty-two percent of the New Options participants were living with their family before they came to the program and the remainder from institutionalized settings such as junior colleges, hospitals, and nursing homes. With respect to transportation, all but two of the sixy-six participants were dependent on someone else to drive them. Seventy-five percent of these individuals depended directly on family members or close friends.

With the exception of three individuals, each of the participants in the program used either an electric or manual wheelchair for mobility. All of the participants had special bowel care needs, and eighty-six percent depended on an assistive urinary device of some sort. Two-thirds of the individuals in the program needed help transferring from their bed to their wheelchair or from their wheelchair to their bed. Most of them needed physical assistance dressing and bathing. Some needed assistance with eating and writing. Most of their physical assistance before they came to New Options was provided by family members or by individuals in the institution where they lived. Only seven of the participants were physically independent from a functional viewpoint.

Another key variable to which much attention has been directed is that of income or economic level. More than two-thirds of the individuals in the program had an income below $200 per month before they came to New Options. Only three of the sixty-six had incomes of more than $500 per month and one of these two supports a family of thirteen.

Fifty percent of the participants had some kind of comprehensive medical rehabilitation before they came to the program. Thirty percent had limited medical or vocational rehabilitation, and twenty percent had no previous rehabilitation. About fifty per cent of the New Options participants had been in school before they were disabled. The remaining fifty percent had been working. Most of these individuals had been doing mechanical labor such as construction work, mechanics work, and agricultural work.

Since the onset of their disability and before participating in New Options, about half of the individuals had tried to attend school. The other half had tried a variety of activities including reading, painting, mechanical work, stamp collecting, traveling, fishing, and "just getting by".

Several unobtrusive monitoring techniques including the Rest Time Monitor and Wheelchair Odometer are being used to continuously measure gross activity levels of New Options participants. The average daily out of bed time for New Options participants was thirteen hours per day. This compares to a daily best week average of around 8.5 hours per day for paraplegics and quadriplegics who were in comprehensive rehabilitation programs at TIRR. Individuals's mileage per week for the entire sample ranged from 1.1 to 35.8 miles. The average weekly mileage per individual across the entire saple was 9.1 miles, or approximately 1.3 miles per day average per individual.

Approximately five hours of each participants time per day is spent doing activities scheduled by the project. As a result, participants are able and encouraged to use most of their time in self initiated and self managed activities. There are approximately ten planned modules each week, an average of three planned fieldtrips per week and pre-arranged meetings with about six associates, active handicapped individuals from the community.

In an effort to document the individual effects of the program on New Options participants, follow-up is routinely done three to four months after each participant leaves the transitional program. Several significant changes in living arrangements may be noted for those individuals on whom follow-up data are complete. About half of the former participants are now living comparably more independently than they were before their participation in New Options. Many of them have moved from nursing homes or their parents homes into apartments, houses, and dormitories - both individually and in shared group living arrangements. Additionally, nearly two-thirds of the former participants are now in school, or have part time or full time jobs.

Observations made during the transition from protected settings such as nursing homes and parents homes to less well protected or more independent settings such as apartment units and college dormitories may lead to valuable insights regarding the psychological adjustment and adaptation of individuals to severe physical disabilities. The number and variety of references to changing self images or self concepts made by former participants is striking. For example, participants have said: "It is really hard to believe what can and is being done from wheelchairs. There are some very intelligent people in wheelchairs."; "Being in a wheelchair puts you in a minority but it doesn't stop you from living a normal life."; "Most people just don't realize that people in wheelchairs are normal too, they just have some kind of handicap. Everyone has a handicap of some sort, whether it be large or small. Some people in wheelchairs are better off than some able bodied people."; "It is easier for some than for others, but it can be done."; "New Options opened my eyes and my mind to what a fulfilling life I could have in spite of my handicap."; "I cannot tell you how much self-confidence I acquired in those few weeks - I got over being ashamed that I was in a wheelchair.".

Self reports by former participants are substantiated and validated by follow-up information and feedback received from counselors who sponsored individuals in the program. Most counselors agreed with their clients by saying that they seemed to be more self-sufficient, more self-confident, or more independent after they participated in New Options. Several counselors reported that they noticed a better outlook, a better attitude, or more motivation on the part of their client following participation in the program. Other counselors claimed that their clients were more goal oriented than they were before. Most comments from counselors who sponsored clients in the program were typified by the statement that "my client realized that he is ultimately responsible for meeting his own needs".

Staff members and the project Department of Vocational Rehabilitation courtesy counselor largely agree on the following characteristics as important traits in persons who seem to have benefitted from the project: readiness to face life as a severely disabled individual; desire to make changes in lifestyle; willingness to set and work on some goals; willingness to risk experimenting with new ways of doing things and new kinds of behaviors; average intellectual capacity (comprehension of verbal input, no major memory deficits, reasonable attention span); ability to read; ability to speak well enough to be generally understood; ability to hear; no severe emotional pathology; and physical endurance for program (sitting tolerance, bowel control that is predictable, suitable urinary management).

(c) Planned Future Activities:

There are three primary areas in which new activities will be undertaken during the forthcoming grant period. First, the possibility of adapting New Options methods and materials for use in other settings such as comprehensive medical rehabilitation facilities, extended care facilities, cooperative residential facilities, and so forth will be explored. Program variables such as length of stay in the project, staffing patterns, family involvement, and the degree to which the program provides experiences versus didactic instruction will be studied. Second, a major audio-visual thrust by the project will be completed. Portions of this work currently underway include an informational slide-sound presentation on New Options, an instructors' manual that conveys the project's philosophy and techniques for teaching independent living skills, a participants' notebook containing the content of the 11 training modules, and other participant materials such as slides, videotapes, and booklets that supplement the module materials. Finally, the research focus of the project will shift from a process orientation to concentrate on follow-up. A series of comprehensive interviews will be done with former participants to find out more about the effects of the program and disabled persons' transition to independence. Follow-up research will focus on ways on-going service needs are being met in the community, types of needs not being met, a critical incidents review of the individual's entire course of development from onset of disability to the present, an Independent Living Skills Evaluation currently being developed in the project, and use of other measures currently being explored in the general field of rehabilitation outcome measurement.

DISSEMINATION OF FINDINGS:

The production of audio-visual and written materials on the content of the transitional project has been defined as a major objective since the project began. As the content of various modules has been developed and tested through experience, efforts have begun to present this content using various media. Written information has been developed and is being tested and refined in each of the content areas of the program. The staff has also begun to videotape various modules, starting with medical needs, living arrangements, and functional skills. The production of such materials will increase substantially in the third year of program operation.

Information on the project as a whole has been disseminated through formal presentations as listed below. Staff members have also disseminated information on the project through personal contacts at conventions, meetings of advisory committees, and other visits to various agencies or facilities. During this reporting period, approximately twenty-five rehabilitation professionals from various programs in Texas, the U.S., and overseas visited the project and met with New Options personnel. In addition, the project has received and answered many written requests for information from handicapped individuals and also from representatives of agencies interested in transitional programming.

Papers and Presentations:

Board, M.A. Reactions to disabilities: the individual, the family, and the general public. Presented at North Harris County Junior College, Houston, Texas, February 17, 1978.

Board, M.A. The role of the social worker in a rehabilitation setting. Presented at the University of Houston Graduate School of Social Work, Houston, Texas, April 25, 1978.

Cole, J.A. Anthropological perspectives on bounded environments. Presented at VA/NASA Conference on Habitability in Extended Care Environments, Minneapolis, Minnesota, September 21-22, 1977.

Cole, J.A., Frieden, L.M. and Sperry, J.C. New Options transitional living project: one year's experience. Presented at the annual meeting of the American Congress of Rehabilitation Medicine, Miami, Florida, October 30-November 4, 1977.

Cole, J.A. Developing a transitional living project for a rehabilitation hospital: the anthropologist's role. Presented at the annual meeting of the American Anthropological Association, Houston, Texas, November 29-December 4, 1977.

Cole, J.A. and Frieden, L.M. New Options: report on 18 months' experience. Presented at Spinal Cord Center Core Group Educational Meeting, TIRR, January 19, 1978.

Frieden, L.M. and Cole, J.A. New Options: facilitating the movement towards independence by severely disabled persons. Presented at the annual meeting of the American Psychological Association, San Francisco, California, September 14, 1977.

Frieden, L.M. New Options. In Independent Living by Susan Pflueger, Institute for Research Utilization, Washington, D.C., December, 1977.

Frieden, L.M. The challenge of independence. Presented to the Harris County Easter Seal Society, Houston, Texas. April 25, 1978.

Sperry, J.C. New Options: a transitional living project. Presented at the American Spinal Injury Association Convention, Monterrey, California, April 4, 1978.

In addition to these formal presentations, on-site training visits were made by five groups of state vocational rehabilitation agency counselors. Trainees met with New Options staff to discuss alternatives for independent living by severely handicapped clients.

Examples of written materials and videotapes produced to date by the project are listed below.

Written Materials and Videotapes:

Carter, R.E. and Nelson, J.A. Mechanisms of Spinal Cord Injury. Texas Institute for Rehabilitation and Research, Houston, Texas, March, 1977, (videotape).

Cole, J.A., Sperry, J.C., and Frieden, L.M. New Options Participants' Guide. Texas Institute for Rehabilitation and Research, Houston, Texas, March, 1976.

Frieden, L.M. Choosing a Living Arrangement. Texas Institute for Rehabilitation and Research, Houston, Texas, May, 1977, (videotape).

Frieden, L.M. Programs to Aid Handicapped Individuals. Texas Institute for Rehabilitation and Research, Houston, Texas, September, 1976.

Geyer, R.G. Tips on Attendant Hunting. Texas Institute for Rehabilitation and Research, Houston, Texas, March, 1978, (videotape).

Geyer, R.G. and Brown, D. Techniques for Interviewing Attendants. Texas Institute for Rehabilitation and Research, Houston, Texas, December, 1977, (videotape).

New Options Staff. Assorted Resource Handouts. Texas Institute for Rehabilitation and Research, Houston, Texas, 1977-78.

New Options Staff. Fieldtrip Behavior Record, Residential Behavior Record. Texas Institute for Rehabilitation and Research, Houston, Texas, 1978.

Rogers, J. and Nelson, J.A. Tissue Trauma. Texas Institute for Rehabilitation and Research, Houston, Texas, April, 1977, (videotape).

Spencer, W.A. and Nelson, J.A. Respiratory Complications in Physical Disability. Texas Institute for Rehabilitation and Research, Houston, Texas, May, 1977, (videotape).

Sperry, J.C., Cole, J.A., and Frieden, L.M. New Options Brochure. Texas Institute for Rehabilitation and Research, Houston, Texas, January, 1977.

Veerkamp, J. and Rowland, C. Bank Utilization Questionnaire. Texas Institute for Rehabilitation and Research, Houston, Texas, March, 1978.

UTILIZATION OF FINDINGS:

Many of the products of this project may be utilized by severely disabled individuals and service providers. Research findings and information about sitting tolerances and stamina requirements with respect to functional independence is presently in demand. Many written requests for preliminary findings in this area have already been answered by the project. Representatives from agencies and organizations such as the Paralyzed Veterans of America, National Paraplegia Foundation, Center for Independent Living, United Cerebral Palsy, and Veterans Administration have already inquired about the possibility of making audio-visual training material developed by this project available to their members and clients.

Many materials will be appropriate for incorporation into both comprehensive rehabilitation and re-evaluation and follow-up programs at TIRR where patient education is a high priority and in similar rehabilitation factilities throughout the country. Many of the materials could also be used in day programs where a class or series of classes could be offered to handicapped populations through the sponsorship of various agencies. A workshop for DVR counselors also demonstrated the usefulness of New Options programming for counselor training on opportunities and resources for severely handicapped clients. It is expected that the demand for independent living skills training materials will increase substantially in the near future as rehabilitation legislation is enacted that mandates and funds independent living services.

In addition to use of project materials in other programs, a number of agencies have expressed serious interest in utilizing the project as a direct resource for their own clients. These include the Veterans Administration spinal cord system, state DVR agencies in Montana, Oklahoma, Tennessee, and Illinois, and several workmans compensation insurance carriers.

POLICY, PROGRAM, OR PRACTICE CHANGES:

Many of the functional skills and the psychological and social coping abilities that serve well with in a rehabilitation hospital are inadequate resources as severely phsically 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 implications 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 New Options project is intended to 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 responsibilites in a segmented sequence.

The results of this project may have profound consequences for the field of rehabilitation generally. If New Options is able to demonstrate conclusively that the acquisition of independent living skills and disability related information like that taught in the program is prerequisite to the optimal adaptation to severe disability, educational programs of this sort will almost certainly be demanded by vocational rehabilitation agencies and their clients, and provided by service, training, and treatment facilities across the country. Also, the man-environment approach applied here may be applied throughout rehabilitation - from early treatment through vocational placement and follow-up.

The results of this project may justify a shift of emphasis by public welfare and vocational rehabilitation agencies from treatment, training, and vocational placement to treatment, training, and socio-environmental placement. Specifically, this means that traditionally conservative state departments of public welfare may realize that independent living is ultimately a viable and cost-effective alternative to institutionalization for severely disabled individuals. This project may emphasize the need to treat chronically disbled individuals as a part of the total environment rather than as patients with problems that require narrowly focused attention. This change in emphasis seems likely to occur in the near future in light of provisions in the new rehabilitation legislation.

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PROJECT NARRATIVE

TITLE

Transitional Living: A Model for the Severely Physically Handicapped

PROGRESS REPORT

1. Changes in Plan

None.

2. Progress During Current Grant Period

The New Options transitional living project has remained on schedule during its second year of operation and has made good progress in reaching overall goals and objectives for the entire three-year project. It is expected that all of the goals and objectives set forth in the original grant request will be completed by the end of the project's third year.

The New Options project was site visited by a team from RSA in February of 1978, and their evaluation of overall program development was very positive. All recommendations made by the site visit team in February have been implemented.
In viewing progress during the current grant period, this section of the progress report is organized as follows:

a. Accomplishments, Findings, and Products to Date

- summary of general program development
- review of objectives established for the second grant period
- implementation of site visit recommendations
- time frame of accomplishments

b. Problems Encountered

- summary of problems encountered and steps taken to address these

a. Accomplishments, Findings, and Products to Date

SUMMARY OF GENERAL PROGRAM DEVELOPMENT

During New Option's second year of operation, the program evolved in several major areas:

(1) refinement of service delivery methods

(2) operation of the project as an organizational system
(3) determination of types of persons with various disabilities who can benefit from the program
(4) research development
(5) preparation for production of audio-visual materials as a substantial program focus

(1) Refinement of Service Delivery Methods

New Options continues to employ a combination of several service delivery methods in its effort to evaluate methods for teaching independent living skills.

Group Training Modules

The project uses group meetings to explore 11 subject areas important for handicapped individuals who want to become active in the community and independent in directing their own lives. The curriculum for training modules in each of these 11 subject areas is based on the previous experiences of many successful handicapped persons. The project expects all participants to attend modules in mobility, functional skills, financial management, social skills, sexuality, time management, medical needs, consumer affairs, living arrangements, vocational-educational opportunities and attendant management.

Some of the modules in the project are conducted as educational courses using traditional didactic teaching methods and group discussion. Others are conducted as therapy groups. Much of the group interaction takes place on fieldtrips in the community to provide firsthand experiences.

The set of training modules developed during the project's first year has remained relatively similar during the second year of program operation. Many refinements have been made in activities used to teach particular information and skills, primarily in a direction of greater involvement in actual community experiences. The project staff has jointly developed a series of questions covering the content of specific module areas which are being combined in an Independent Living Skills Evaluation. Work will continue during the project's third year to test the effectiveness of this instrument in measuring acquisition of information and skills needed for independent living.

Practice Experiences

As a major learning method, the project seeks to structure experiences for participants similar to situations they will encounter if they make major changes in their lifestyles. The purpose of these experiences is to let people practice new responsibilities and skills. Major planning and problem-solving experiences include:

(a) the dormitory style living situation

The project is housed in a dormitory-style setting. Attendant assistance, meals, and transportation are provided on a shared basis. For many persons this is the first time they have had to meet a schedule, rely on a new system of physical assistance with daily routines, manage their money, or learn to trust new sources of emotional support. The project has developed a Residential Behavior Record for participants to rate their own performance in these areas of skill and responsibility.

(b) group fieldtrips

Each fieldtrip made by the project has a specific purpose related to content areas of the 11 training modules. However another major reason for making fieldtrips is to provide situations to test certain skills and responsibilities in actual community situations. The project has developed a Fieldtrip Behavior Record through which group leaders document performance of participants in skills areas such as managing interaction with strangers or dealing with architectural barriers.

(c) individual assignments

Individual assignments are sometimes made to provide practice experience appropriate for one individual. Such assignments may include telephoning for information from a particular support agency, visiting someone with a job or living situation similar to one the individual is seeking, or practicing interaction with the general public in restaurants or shopping centers. The assignments appropriate for each person are carefully planned,taking into account the individual's array of past experiences as well as the competancies the person will need in order to meet his or her future goals.

During its second year, the project staff has attributed increasing importance to the usefulness of actual community experience as a learning tool. This philosophy was elaborated in a special staff retreat conducted in November (reported in section 2) which led to the documentation of a more experiential program model and to the development of the Fieldtrip Behavior Record as a tool for documenting important community experiences.

Modeling

The project hires active handicapped persons on a part-time basis to teach training modules and lead fieldtrips. These staff associates are chosen to teach areas of partiular expertise they have acquired and also to represent a variety of different lifestyles and kinds of solutions to the problems typically faced by handicapped persons. During its second year,

the project employed 56 associates, 31 of whom are working and 17 of whom are attending college or vocational training. The associates are expected to cover a standardized set of material in various modules they teach. It is also expected that they will convey something of their personal history and course of development to participants so that participants gain an understanding of what it takes to get from point A to point B in setting life goals and planning how to meet them. Modeling by associates lets participants observe specific techniques and problem-solving strategies. Associates also serve as contact brokers for participants, demonstrating how best to get things done and how to find their own contacts in local communities.

In addition to staff associates, another use of modeling in the project is the role of the resident advocate which was developed during the project's second year of operation. This role is filled by a former participant who demonstrates how to work the residential system, how to deal with the problems that come up, and whom to ask about various issues. He provides emotional support and serves as a friend at an important time when old supports have left behind. He also provides a model of how to behave in typical project activities and how to structure free time.

Individual Counseling

Individual counseling is scheduled routinely with the project social worker, functional skills adviser, and vocational counselor. Counselors help people assess where they are presently, help them set goals, and help develop sequential plans for how to reach goals. This long-range perspective is important in helping persons realize their own responsibility for directing the course of their lives. Counselors also help people learn to use what they are exposed to in group meetings and plan how to implement new ideas. They provide emotional support and help individuals test the limits of what is acceptable and what will work.

Staff members who work with participants in a counseling relationship have developed written materials to assist the individual in planning and goal setting. These materials include such items as goal-worksheets, contracts for assistance with daily care routines, self-assessments of health status and needs, and behavioral logs. It is expected that these tools developed through experience in working with individuals in New Options will be useful in other settings where counselors seek to assist handicapped persons plan for greater independence.

It is expected that a manual on underlying principles and techniques of these teaching methods will be a major effort of the project in its third year as a contribution to the field of independent living skills training.

(2) Operation of the Project as an Organizational System

During the project's second year, staffing has remained relatively similar to the system developed during the first year. (Major staff members are a project director, research director, social worker, functional skills adviser, part-time vocational counselor, coordinator of staff associates, residential manager and staff of attendants.) The roles of social worker and vocational counselor were initially most difficult to fill with persons who complemented the basic program philosophy. These roles are now filled by very appropriate individuals who have been at New Options throughout the project's second year. This stability has greatly facilitated program development.

Major changes in staffing have included the expansion of the coordinator of staff associates role to a full-time position, and initiation of a new position of resident advocate. The advocate is a former participant who lives in the project with each new set of participants during their first week of the program cycle. This individual demonstrates how to adapt effectively to the residential system and the program experience. The advocate's role is an expansion of the concept of modeling which is basic to the entire project.

The project's program staff worked creatively as a team on a number of major projects during the past year. These included a shared group experience during October to evaluate the Personal Adjustment Skills program (led by a trainee from RT-13, Arkansas), a major retreat with a research consultant in November which resulted in a more explicit experiential focus in programming, on-going meetings during the winter to plan a film and other audio-visual materials, and a retreat during February to articulate goals more clearly.

A major focus of joint staff effort during the coming year will be the production of audio-visual materials. This is examined at length in the discussion of objective a. (second year objectives)

(3) Determination of Types of Persons with Various Disabilities Who Can Benefit from the Program

During its second year of operation the project included participants with a wider range a disabilities than previously had been served. Of particular interest to staff was the inclusion of a number of persons who had grown up with their disabilities (persons with cerebral palsy, spina bifida, arthritis or polio residuals). In many cases these individuals had not experienced the childhood activities typical in our society, and the project often provided their first opportunity to be active in community settings or to assume major responsibilities for directing their own lives. The content of the program has proved to be equally appropriate for such individuals, as well as for persons with disabilities acquired in adolescence or adulthood. In many cases in which individuals grew up with their disabilities, individual counseling and particular individual experiences and assignments have been planned to help persons acquire experiences they "missed out on" while growing up.

In contrast to the general finding that the project is useful to persons with a wide variety of major physical impairments, there is one disability group that has not been effectively served. This group is persons with traumatic head injuries. The project has admitted four such persons to test the effectiveness of the program in meeting their needs. It is the concensus of the staff that these experiences have not been positive for the participants or the project. Types of functional deficits that seem to interfere most significantly with useful participation include memory impairment, failure to inhibit socially inappropriate behavior, poor judgment about risk-taking, and inability or unwillingness to assume responsibility for cooperating with project policies.

(4) Research Developments

Major research efforts during the second year of operation have included development of a data base on behavior of participants in the program, evaluation of specific modules and program areas through student projects, and evaluation of the overall effectiveness of the program based on information from participants, staff, and referring counselors. The results of these research efforts are discussed at length under objective c for year two.

Planning of major research thrusts for the remainder of the project has focused on increased follow-up research based on an interview design using several specific data collection instruments. A second major thrust will be to summarize the project's contribution to the general field of outcome measurement. These future directions are discussed at greater length under Work Plan for next grant period.

(5) Preparation for Production of Audio-Visual Materials as a Substantial Program Focus

One of the major goals of New Options from the outset has been to package materials and techniques that have proven useful in teaching independent living skills. Such materials and techniques are intended to be useful in other learning settings such as comprehensive medical rehabilitation programs, day programs, or live-in programs operated by a variety of agencies or centers.

During the second project year, major planning has been completed and arrangements have been developed for actual production of materials. This has involved extensive investigation of potential production resources and consultation on types of materials that can best convey the information and experience accumulated through operation of the program as a service delivery system. Progress in this area is discussed at length under objective a.

REVIEW OF OBJECTIVES FOR SECOND GRANT PERIOD

Objectives set forth for the project's second grant period are as follows:

(a) to produce audio-visual materials so that training resources developed in New Options can be used in other contexts

(b) to strengthen project capability to provide follow-up services to former participants

(c) to expand research efforts

(d) to further cooperation with community resources

(e) to improve transportation capability

(f) to seek additional sources of client referral and sponsorship

Each of these is reviewed at length below.

Objective a — to produce audio-visual materials so that training resources developed in New Options can be used in other contexts

The information offered to New Options' participants through modules has stabilized to the degree that the development of audio-visual material is both appropriate and a priority. Group leaders continue to generate material for use in modules, but to date the effort has been left up to individuals and the quality has been somewhat erratic. Nevertheless, materials in the forms of handouts, written exercises, posters, and videotapes have been made in most of the major subject areas. It is important to note that these materials are utilized as an adjunct to the experienced group leader, and seldom could the media alone in their current form effectively convey the necessary information to participants.

For New Options to make a significant contribution to the field of independent living and community skills for severely disabled individual(s), not only the information conveyed in the group meetings but also the essence of the program must be conveyed in learning materials. This means specifying the philosophy of the program and enumerating the elements that make it both unique and successful.

The development of effective written and audio-visual materials for wide dissemination has been an important goal

since the project began. During the project's first year this objective was deferred until basic program content had been developed and its usefulness evaluated. During the project's second year major efforts were made to devise an overall plan for materials development and to establish relationships with appropriate production resources. These tasks were more difficult than had been anticipated, primarily due to contradictory advice from consultants, the amount and scope of materials that potentially might be produced, and lack of expertise within the staff to critically evaluate potential directions of development. Substantial work has gone into planning efforts, with assistance from both Baylor College of Medicine and the Mississippi Methodist Rehabilitation Center, and the project has now completed a workable master plan and timetable to finish materials production by June of 1979, three months prior to completion of the third grant period.

The initial phase of audio-visual development was to construct an overall plan to meet both our present needs and future goals.

The three major areas of need are listed below:

(1) A marketing tool was needed to identify to sponsoring agencies the merits of a program teaching independent living skills and also increase the number of participant referrals to New Options.

(2) An instructor's manual was needed to assist those who plan to begin a project similar to the transitional program, This should not only present didactic materials such as lesson plans, suggested fieldtrips and discussion topics ,but also should communicate the elements of the program which, together with the informational aspects, combine to make the experience of New Options so worthwhile for severely disabled individuals.

(3) Participant materials which would document and supplement the module content were needed. These should be linked to the Instructor's Manual(#2).

The implementation of these plans was the next focus and one important consideration was the recommendation that the site visit team made on its February visit to New Options , concerning the quality of materials to be produced.
Equally as important a consideration was the total amount of money which could be directed to meeting these needs. Unused audio-visual funds from the first grant year were requested to be carried over to the second grant year. The request for this was made in August of 1977 but the final approval was not obtained until March of 1978. Knowing the amount of money and date of availability was essential in developing the comprehensive plan and potential scope of the audio-visual material.

The following is summary of our efforts and plans to meet these needs.

(1) A ten minute slide-sound series has been developed which effectively communicates an overview of the program to both individuals and large groups. This presentation tool has been effectively utilized in various settings and has served to introduce the program to new sponsoring agencies and thus increase awareness as well as increase number of applicant referrals.

(2) Work started in May of 1978 on the planning for the Instructor's Manual. A company specializing in the development of various learning materials is providing ongoing consultations, guidance, and assistance. It is anticipated that this effort will take five months of work before a finished product is available.

(3) Participant materials to be used in conjunction with the Instructor's Manual (See #2) will be identified and developed as the manual is being completed. It is anticipated that these materials will include loose leaf pages, booklets, audio-cassettes, and video-tapes. The appropriate media will be identified as work on the Instructor's Manual progresses. It is expected that these materials will be completed by June of 1979, three months prior to the end of the third grant period. This will allow time to focus on dissemination activities.

Objective b to strengthen project capability to provide follow-up services to particpants

At the time this objective was written it was estimated that it would require a half-time staff member to investigate and document needs, resources, and referral mechanisms for follow-up services to former participants. A 50% staff position for this purpose was budgeted for the second grant period. However, this item was subsequently deleted by RSA from the second year budget because the overall project funding level for year two had to be maintained at the first year level.

The loss of personnel needed to address this objective has seriously hampered the project's follow-up efforts. Several steps have been taken to compensate for the loss of follow-up capability:

(1) The project has strengthened its basic character as a short-term skills training program rather than a program that can routinely provide actual placement in independent living situations or in jobs. The emphasis is on teaching the individual to be his or her own coordinator of resources and his or her own advocate since the project cannot provide support in these areas on an extended basis.

(2) While persons are in the project, an effort is made to be as specific as possible in formulating future plans and identifying resources in the individual's home community to meet any anticipated follow-up needs.

(3) The project seeks to work as closely as possible with each participant's DVR counselor since this individual usually plays a key role in coordinating resources on a long-term basis with clients.

In many respects the lack of a follow-up staff member has probably caused a positive emphasis within the project on (a) weaning participants away from depending on the project and toward greater self-reliance, and (b) helping the individual use other community resources as effectively as possible.

During the project's third year, follow-up will become a major focus of research efforts. In addition to documenting individual program outcomes, this research will seek to identify the community resources used by former participants to implement the plans they made in the project. It will also document unmet service needs or factors that impeded implementation of plans. This information will help to identify types of services that cannot be obtained in the community and that therefore should be provided by a transitional living program as follow-up service.

Informal interviews with former participants to date suggest that in planning follow-up services, needs for emotional support and assistance in maintaining morale may be as important as coordination of concrete independent living services such as transportation or attendant care.

Objective c to expand research efforts

As described in the original grant proposal, a longitudinal multimeasure design is being employed in this study to document individual outcomes and to evaluate program effectiveness. A series of indicated measures is systematically being made before, during, and after the subject participates in the program to determine the effect of the independent variable (program) on the subject behavior, attitudes, and information base.

The dependent variable related to behavioral effects is being measured regularly by functional activity and performance scales (Tufts Long Range Evaluation Summary, RT-7). The dependent variable related to information effects will be measured by a series of quizzes. These quizzes are presently being used on a pilot basis. The dependent variable related to attitudinal effects is being measured by a questionnaire developed by the project staff.

The dependent variable related to outcome is being measured by some of the instruments described above as well as others. Follow-up questionnaires are routinely mailed to subjects after they participate in the program. These questionnaires include module ratings, program ratings, application information, follow-up questions, a goal completion survey, and the functional activity and performance scale mentioned above. Follow-up questionnaires are also sent to those counselors who refer clients to the program. Plans are being made for a staff person to do follow-up in the field, thus providing an opportunity to do follow-up interviews and direct observations.

It was originally intended that longitudinal data on each participant in New Options might be supplemented by similar information collected from a matched control group of similar persons who did not enter the program. Throughout the project, has become increasingly clear that the population of severely disabled individuals from which New Options participants come is invariably heterogeneous. Also, there appears to be an unpredictable variety of individual human variables which interact in different ways to cause participants to respond to the program. As a result, it is virtually impossible and certainly unfeasible to attempt to match groups of individuals on relevant bases.

This is not to say that a control design is not useful in this research. Nor is it to say that this research will not ultimately yield information about significant individual variables or predictive personal characteristics. In fact the original research design which calls for each participant to serve as his/her own control on a longitudinal basis (Institutional Cycle Design) has proved to be the most effective means of documenting program effects. The wide variety of people who have participated in the program enhances the application of this design.

It should be noted that it has been difficult to implement the institutional cycle control group design in spite of its apparent suitability. This is due to difficulty in identifying program participants more than six weeks prior to their participation in the program. Thus, data related to behavior and attitudes prior to admission into the project is retrospective to varying degrees. It will hopefully be feasible to implement this aspect of the research before participants enter the project for at least several cycles in the third year of the project. The fact that such matched sample control group data will exist on some but not all program cycles will not interfere in any way with the on-going longitudinal data collection that has been taking place since the project began.

The utility of the present research methodology is evidenced by the quality of information yielded to date. Consequently, the expansion of research in New Options has and will continue to be directed toward three general areas. These are: 1) ongoing program evaluation from a process oriented perspective; 2) data acquisition from past and present participants, and detailed analysis relating to program effects or outcome; 3) the refinement of data collection comprehensive instruments and the improvement of methods for capturing individual competencies which may contribute to independent living by severely disabled individuals.

The following is a description of the group of individuals who have participated in the program thus far and a few examples of preliminary results and conclusions taken from the study of program effects.

As of February 15, 1978, twelve six-week cycles of New Options had been completed. Sixty-six individuals had been admitted to the project. Fifty-five of these individuals were male and eleven were female. Forty-nine New Options participants were single and seventeen were married, divorced, or separated. Fifty of the sixty-six individuals were spinal cord injured and the others were severely disabled as a result of cerebral palsy, muscular dystrophy, polio, brain damage, spina bifida, rheumatoid arthritis, cerebellar dysfunction, and ataxia. Most of the individuals in the program were from twenty through thirty years old. The exact age range was from 17-53 years. Twenty three percent of the participants were non-white.

One variable which may prove to be critical in determining who could benefit most from the New Options program is time since onset of disability. Thirty-one percent of the participants in the program had been disabled less than two years when they entered New Options. The most recent time since onset of disability was five months. Another thirty-one percent of the program participants had been disabled two to five years before they came to New Options. Finally, thirty-eight percent had been disabled more than five years before they participated in the program. The longest period from onset of disability to admission in New Options was twenty-nine years.

Another critical variable which may later be tied to potential to benefit from this program is the individual's pre-admission living arrangement. Approximately half of the participants came from rural communities, and the other half were from metropolitan areas. Perhaps more importantly, eighty-two percent of the New Options participants were living with their family before they came to the program and the remainder came from institutionalized settings such as junior colleges, hospitals, and nursing homes. With respect to transportation, all but two of the sixty-six participants were dependent on someone else to drive them. Seventy-five percent of these individuals depended directly on family members or close friends.

With the exception of three individuals, each of the participants in the program used either an electric or manual wheelchair for mobility. All of the participants had special bowel care needs, and eighty-six percent depended on an assistive urinary device of some sort. Two-thirds of the individuals in the program needed help transferring from their bed to their wheelchair or from their wheelchair to their bed. Most of them needed physical assistance dressing and bathing. Some needed assistance with eating and writing. Most of their physical assistance before they came to New Options was provided by family members or by individuals in the institution where they lived. Only seven of the participants were physically independent from a functional viewpoint.

Another key variable to which much attention has been directed is that of income or economic level. More than two-thirds of the individuals in the program had an income below $200 per month before they came to New Options. Only three of the sixty-six had incomes of more than $500 per month and one of these two supports a family of thirteen.

Fifty percent of the participants had some kind of comprehensive medical rehabilitation before they came to the program. Thirty percent had limited medical or vocational rehabilitation, and twenty percent had no previous rehabilitation. About fifty per cent of the New Options participants had been in school before they were disabled. The remaining fifty percent had been working. Most of these individuals had been doing mechanical labor such as construction work, mechanical work, and agricultural work.

Since the onset of their disability and before participating in New Options, about half of the individuals had tried to attend school. The other half had tried a variety of activities including reading, painting, mechanical work, stamp collecting, traveling, fishing, and "just getting by".

Several unobtrusive monitoring techniques including the Rest Time Monitor and Wheelchair Odometer are being used to continuously measure gross activity levels of New Options participants. The average daily out of bed time for New Options participants was thirteen hours per day. This compares to a daily best week average of around 8.5 hours per day for paraplegics and quadriplegics who were in comprehensive rehabilitation programs at TIRR. Individuals' mileage per week for the entire sample ranged from 1.1 to 35.8 miles. The average weekly mileage per individual across the entire sample was 9.1 miles, or approximately 1.3 miles per day average per individual.

Approximately five hours of each participants time per day is spent doing activities scheduled by the project. As a result, participants are able and encouraged to use most of their time in self initiated and self managed activities. There are approximately ten planned modules each week, an average of three planned fieldtrips per week and pre-arranged meetings with about six associates (active handicapped individuals from the community). Of all the modules, three seem to be consistently best liked by participants. These are sexuality, medical needs, and functional skills.

In an effort to document the individual effects of the program on New Options participants, follow-up is routinely done three to four months after each participant leaves the transitional program. Several significant changes in living arrangements may be noted for those individuals on whom follow-up data are complete. About half of the former participants are now living comparably more independently than they were before their participation in New Options. Many of them have moved from nursing homes or their parent's homes into apartments, houses, and dormitories - both individually and in shared group living arrangements. Additionally, nearly two-thirds of the former participants are now in school, or have part-time or full-time jobs.

Observations made during the transition from protected settings such as nursing homes and parents homes to less well protected or more independent settings such as apartment units and college dormitories may lead to valuable insights regarding the psychological adjustment and adaptation of individuals to severe physical disabilities. The number and variety of references to changing self images or self concepts made by former participants is striking. For example, participants have said: "It is really hard to believe what can and is being done from wheelchairs. There are some very intelligent people in wheelchairs."; "Being in a wheelchair puts you in a minority but it doesn't stop you from living a normal life."; "Most people just don't realize that people in wheelchairs are normal too, they just have some kind of handicap. Everyone has a handicap of some sort, whether it be large or small. Some people in wheelchairs are better off than some able bodied people."; "New Options opened my eyes and my mind to what a fulfilling life I could have in spite of my handicap."; "I cannot tell you how much self-confidence I acquired in those few weeks - I got over being ashamed that I was in a wheelchair".

Self reports by former participants are substantiated and validated by follow-up information and feedback received from counselors who sponsored individuals in the program. Most counselors agreed with their clients by saying that they seemed to be more self-sufficient, more self-confident, or more independent after they participated in New Options. Several counselors reported that they noticed a better outlook, a better attitude, or more motivation on the part of their client following participation in the program. Other counselors claimed that their clients were more goal oriented than they were before. Most comments from counselors who sponsored clients in the program were typified by the statement that "my client realized that he is ultimately responsible for meeting his own needs".

Staff members and the project Department of Vocational Rehabilitation courtesy counselor largely agree on the following characteristics as important traits in persons who seem to have benefitted from the project: readiness to face life as a severely disabled individual; desire to make changes in lifestyle; willingness to set and work on some goals; willingness to risk experimenting with new ways of doing things and new kinds of behaviors; average intellectual capacity (comprehension of verbal input, no major memory deficits, reasonable attention span); ability to read; ability to speak well enough to be generally understood; ability to hear; no severe emotional pathology; and physical endurance for program (sitting tolerance, bowel control that is predictable, suitable urinary management).

Not unexpectedly, the research at New Options indicates that those persons who demonstrate extreme improvement in either physical or psychosocial status while they are in the transitional program are much more likely to become independent in terms of their educational/vocational status or living arragement than those who do not.

Perhaps more interestingly, measures of individual psychosocial characteristics seem to be somewhat better predictors of program outcome than measures of physical ability at New Options. Data thus far collected indicate that psychosocial barriers in the individuals environment or self concept may impede progress towards an independent life style considerably more than physical barriers or functional disability. Other data indicate that females and city dwellers may benefit more from the program than the rest of the sample, at least as far as living arrangement and occupation are concerned. Also persons who are very recently disabled (less than two years) and those who have been disabled for more than five years seem to become more independent as a result of the program than those who are two to five years post onset of disability.

Given these preliminary findings, efforts are currently being made to find out more about the nature of the critical variables involved in the transitional process by conducting extensive follow-up interviews.

Also, an instrument called the Independent Living Skills Evaluation Questionnaire has been developed by the project staff and is presently being pilot tested and validated. This instrument is designed to measure aptitude for independence by asking for solutions to a series of practical questions involving problems which severely disabled persons may encounter in independent living arrangements. The questionnaire may be used to assess changes in individuals knowledge and information bases, or in their approach to solving problems. Meanwhile, the data base at New Options continues to expand so that statistical tests of apparent differences may soon be feasible.

Objective d — to further cooperation with community resources

During the past year, New Options staff worked with a variety of organizations and groups on issues pertaining to the design of transitional and independent living programs for severely handicapped individuals, and on service needs of these individuals. As a result of these communications, several local projects have begun to meet the need for providing supportive services for independent living in the Houston community. For example, Gulf Home Health Services has initiated a community wide attendant service for severely handicapped persons who are not necessarily associated with the cooperative living programs already established in the community. The Texas State Department of Public Welfare has begun operating a major demonstration project designed to facilitate independent living for severely disabled individuals in Houston who before this time have been restricted to nursing homes by an absence of alternatives. The Texas Rehabilitation Commission has purchased a thirty unit complex for an extended rehabilitation facility. Houston Community College has applied for funding to support an attendant training and certification program. New Options staff continues to consult with and advise each of these projects as they develop. Involvement with these projects has provided an opportunity for testing the applicability of independent living designs and methodology to other programs. It has also benefited former participants by giving them more opportunity to practice and to apply skills they learn during the program after they leave the program.

In addition to these consulting efforts, New Options staff have been more directly involved in the implementation of several community education and technical assistance programs. Meeting with a group of parents of severely disabled individuals at the Harris County Easter Seals Society, New Options staff persons provided information and generated interests necessary to begin a serious search for resources to construct a series of transitional type facilities in the community. These group meetings are continued under the leadership of New Options staff with the cooperation of several other community agencies. New Options personnel helped to plan and organize a five state conference of disabled consumer leaders. This project was carried out in cooperation with a local consumer group, the Coalition for Barrier Free Living. New Options staff periodically provide onsight training for vocational rehabilitation counselors from the Texas Rehabilitation Commission. This training involves meetings, tours, and slide presentations Staff are presently involved in planning a series of educational programs relating to the management of independent living and transitional projects. These programs will be presented several times in Houston, and perhaps in other communities as well.

The anticipated audience includes handicapped individuals, and representatives from cooperating social service and housing agencies.

Individual staff members also served on boards and were actively involved in a number of community organizations including the Houston Area Rehabilitation Association, the Coalition for Barrier Free Living, the Wheelchair Olympics sponsored by the Southwest Wheelchair Athletic Association, and the Houston Task Force on the Handicapped.

Cooperative efforts of the sort described above are beneficial to New Options for several reasons. First, they provide an outlet for the dissemination of information learned by and heretofore available only at New Options. Second, they serve as a testing grounds for techniques and methods of transitional programing developed in the project. Finally, they generate interest in the project and insure good working relationships with other community resources. All of this leads to more project referrals, wider distribution of information gained in the project, and better utilization of the talents and skills of New Options personnel.

Objective e — to improve transportation capability

Transportation is viewed as an extremely important link in the overall project operation, especially with the current leaning towards an experiential program model with an emphasis on fieldtrips. In this model greater effort is placed on preparation and de-briefing sessions for each trip. On these fieldtrips group leaders observe participant behaviors in the areas of dealing with disability in public situations, asking for help, gaining information, handling money and financial responsibility, overcoming mobility barriers, and problem solving. Key fieldtrips include visits to the airport, restaurants, supermarkets, places of employment, banks, and various living arrangements. These fieldtrips are impossible without adequate transportation.

Since the request for supplemental funds for transportation was denied last year, New Options presented its need to the Texas Institute for Rehabilitation and Research and also submitted a request for funds to the Texas Rehabilitation Commission for purchase of a new vehicle. TIRR recently received notification of approval on an UMTA grant request for two additional vehicles for patient use. TIRR and New Options also agreed to share the use of a GMC bus which was initially allocated solely for in-patient recreation. The project continues to maintain its original van but this has been an increasingly unreliable source of transportation.

Objective f — to seek additional sources of client referral and sponsorship

To date majority of referrals to the New Options program have come from the Texas Rehabilitation Commission although we have had one workmen's compensation case in the past year and some families have been able to pay for sponsorship. In some instances the quality of the referrals has been poor, i.e. when the individual obviously has no desire to make changes or when the referring counselor uses the project as a "last ditch effort" for the client after every other alternative has been exhausted.

Several projects have been instigated to improve the referral process:

(a) Meetings with TRC Counselors: A series of meetings with groups of TRC counselors has been implemented in cooperation with the regional training director of TRC. These meetings are organized as half-day visits to the project by groups of five or six counselors and supervisors. During these meetings a short presentation is given on the project, a discussion is held on benefits of the program and on types of persons who seem to benefit most, the referral process is reviewed, and counselors are given a tour of the project by program participants.

(b) Slide-Sound Presentation: New Options, in conjunction with the Baylor College of Medicine, has produced a slide show which can be used with an audio cassette. The presentation it portable and is designed to be taken on visits to potential referral agencies by staff and/or former participants to answer audience questions. Target groups for presentations include TRC counselors, rehabilitation nurses (specifically those working for insurance companies), agency personnel who have regular contact with handicapped adults such as Easter Seals, and other comprehensive rehabilitation-centers and facilities in the state. The project has made a systematic effort in the past several months to identify and prioritize all possible referral agencies and to develop a more systematic plan to visit them on a prioritized basis.

(c) Discharge Planning: An attempt was made to become involved in the Texas Institute for Rehabilitation and Research discharge conferences in order to secure more referrals. However, New Options does not have the necessary staff time to devote to this effort since it would require attending all chart rounds (several per week, at least two hours each). As an alternative, New Options has now made arrangements to receive admissions data on all SCI patients returning to TIRR for a follow-up visit. This usually occurs approximately 6 months after the initial 3 months rehabilitation admission. Persons in this stage of the rehabilitation process are generally receptive to the concept of New Options, and this seems to be an appropriate time to present them with information about the program.

New Options will continue to investigate ways to fit into the discharge system at TIRR. Recommendations from a follow-up committee at TIRR indicate a need for a more formalized discharge planning procedure that New Options might be able to participate in more systematically in the future.

In addition to these formal objectives, two further areas were identified in the project's last grant renewal request as possible areas of exploration. These were (a) exploration of an alternative program location, and (b) exploration of the possibility of varying individual lengths of stay in the project from the standard six-week program cycle.

Project Location

The New Options staff has felt since the program began that the project's location within a building licensed as a hospital may have effects on the atmosphere of the program and on the behavior of participants. (These effects are thought to occur in spite of physical separation of New Options from medical programs, a separate project staff, and residential policies that differ from those of medical programs.) The possibility of relocating the project to an apartment setting in the community has been considered for some time, but this option was not actively pursued during the project's second year. The decision to focus on other priorities was shaped by the general shortage of housing in Houston. It was felt that finding and completing arrangements for an alternative setting, given this general housing situation, would have required an inordinate amount of staff time that was more profitably spent in other priority areas. (The shortage of suitable housing in the city continues to be a problem for New Options graduates who wish to move to Houston to establish independent living arrangements.)

Length of Stay

When New Options was originally planned, it was intended that each participant would spend an individually established length of time in the program up to a maximum stay of six months. However, as the project was actually implemented each person's length of stay was shortened to a standardized six week program cycle for reasons that are discussed at length in the first year progress report. During its second year the project staff wanted to explore the effects of different lengths of stay, and a proposal was submitted to the Texas Rehabilitation Commission for approval of individual extensions of stay under specified conditions. This proposal has not been acted upon. During the project's second year some exploration of this variable occurred as a result of individual circumstances in which persons left the program early or staved more than the usual six weeks. This variation in length of stay has involved only a few individuals and has not occurred on a systematic basis, so it is impossible at this time to draw any general conclusions about the effects of length of stay in the program. Further exploration of this variable may be possible during the project's third year.

IMPLEMENTATION OF SITE VISIT RECOMMENDATIONS

Several recommendations were made by the RSA site visit team that reviewed this project in February of 1978. These recommendations are listed below. Following each item is a summary of steps taken by the project to implement each recommendation.

(1) "An objective rater group should be sought for evaluation of the case record review and client benefit determination."

This recommendation has been incorporated as an important focus for research efforts in the coming grant period as outlined in section C-1, work plan, (page 29).

(2) "Control groups as appropriate should be considered for inclusion in the demonstration project."

Problems in utilizing the planned institutional cycle control group research design and the consequent use of retrospective data are summarized in section B-2 under objective C (page 10). Plans to implement this design for at least a few program cycles in the third grant year to validate the comparisons using retrospective data are also outlined in this section.

(3) "Copies of all questionnaires and data collection instruments for project evaluation should be forwarded to Dr. Harold Vialle and myself(Mr. Paul Thomas)."

Material will be sent as requested.

(4) "Any audio-visual programs developed by the project should be of the highest professional quality and should be disseminated for the widest possible impact on the field of rehabilitation."

Production of audio-visual materials will be a major focus of efforts during the project's third year. A detailed plan and timetable for this work are outlined in section B-2 under objective a (page 7) and in section C-1, (page 32).

(5) "Emphasis should be given to the education of community referral resources as a basic component of the project."

Major efforts have been made to increase the number of project referrals. These are discussed in section B-2 under objective f (page 18).

(6) "The several future goals of the study should be more clearly

and succinctly reflected in the progress report and continuation application for scientific peer review and comment."

It appeared to project staff as though this recommendation was made at the project site visit because the presentation at that visit did not correspond exactly to the outline of objectives for the second grant period as set forth in the latest grant renewal request. (At the site visit the New Options staff sought to convey a view of the project that focused on the program experience of participants and on individual outcomes as documented by research data. This was done with the thought that a formal administrative review of objectives and progress was conducted annually through written reports, and that the project site visit should therefore focus on aspects of the project that cannot be conveyed in formal written reports. This was perhaps an inappropriate use of time during the visit.)

It is important to point out that all objectives for the second year are clearly stated and reviewed in this report and that objectives for the third year have been established and documented to complete the overall project goals by the end of the third grant period.

b. Problems Encountered

Problems that have occurred in developing the program generally and in implementing objectives of the second grant year have been summarized in the preceding section under specific subject headings. Solutions of these problems or steps taken to minimize their impact are also summarized. These can be found as follows:

	PROBLEMS	SOLUTIONS
(1)	problems in serving individuals with traumatic head injuries	development of a special screening process for head injured applicants to identify persons the project is able to assist

see discussion of general program development, page 5

	PROBLEMS	SOLUTIONS
(2)	problems with a piecemeal approach to audio-visual planning	development of a unified long-range audio-visual plan
	see discussion of objective a, page 7	
(3)	difficulty in developing follow-up service capability within the project after personnel planned for this effort were deleted from the budget	efforts to utilize other follow-up resources to best advantage
	see discussion of objective b, page 9	
(4)	difficulty in implementing an Institutional Cycle Control Group research design	strategies for compensating for this difficulty through retrospective data
	see discussion of objective c, page 10	
(5)	problems caused by an inadequate number of referrals to the project	efforts to attract more referrals
	see discussion of objective f, page 18	

TIME FRAME OF DEVELOPMENTS DURING CURRENT GRANT PERIOD

June 1977
- program cycle 8 (June 6)
- hiring of third social worker and stabilization of this staff role
- student project analyzing financial management module (Russell)

July 1977
- overnight fieldtrip by plane to San Antonio
- student paper containing descriptive analysis of program(Bell)
- program cycle 9 (July 18)

August 1977
- investigation of local audio-visual production resources

September 1977
- program cycle 10 (September 6)
- consultation by Jack Smith (White House Conference), on audio-visual planning
- presentation on New Options at American Psychological Association Meeting (Frieden)
- presentation on New Options at VA conference (Cole)

October 1977
- implementation of new part-time staff position of resident advocate
- staff review of Personal Adjustment Skills training program with trainer from RT-13, Arkansas
- Independent Living Research Utilization project funded by RSA (with two New Options staff as co-principal investigators)
- masters thesis project on changes in behavioral independence (Golsoble), Department of Psychology, University of Houston
- presentation on New Options at American Congress of Rehabilitation Medicine (Cole)
- program cycle 11 (October 24)

November 1977
- staff retreat with research consultant (Stuart) and articulation of more experiential program model, development of Fieldtrip Behavior Record, report clarifying program evaluation strategies and issues (Stuart)
- devlopment of Independent Living Skills Evaluation document

December 1977
- planning of script for proposed film
- student paper,descriptive analysis of project (Sharp)

January 1978
- program cycle 12 (January 3)
- first participant referred and sponsored by workmans compensation
- masters thesis project on locus of control (Forbes) Graduate School of Social Work, University of Houston

February 1978
- expansion of role of staff associate coordinator to full-time position
- site visit by RSA team
- consumer leadership conference
- program cycle 13(February20)

March 1978
- staff-retreat to make goals more explicit
- first of a series of visits by groups of TRC counselors arranged through regional training officer of the state agency

April 1978
- audio-visual consultation from Mississippi Methodist Rehabilitation Center
- presentation on New Options at ASIA meeting (Sperry)
- development of plan to share a reliable vehicle with TIRR recreation department
- program cycle 14(April 18)

May 1978
- retreat to explore potential uses of New Options methods and materials in other programmatic settings
- development of policy on admission of persons with traumatic head injuries
- masters thesis project linking independent living outcomes of project to demographic variables (Clark), Graduate School of Social Work, University of Houston
- agreement for masters level practicum student in social work to spend six weeks in project during coming academic year
- program cycle 15 (May 30)

June 1978
- production of a slide-sound presentation on New Options by Baylor College of Medicine as a tool for developing referrals
- production of a videotape on New Options to be incorporated into videotape series for Independent Living Research Utilization project
- second printing of project brochures
- increased emphasis on follow-up in overall research design

3. Staff Changes

During the past year, New Options created an additional part-time staff position of Resident Advocate which is filled by a former New Options participant. This individual lives on the project premises during the first week of each program cycle. His role is to acquaint the new participants with the attendant system and project rules and policies as well as to promote group cohesiveness through social interaction. A job description for this position can be found in Appendix A.

Another change occurred in February 1978 when a new individual was hired to fill a vacancy in the position of Staff Associate Coordinator. This role was expanded to a full-time position. Responsibilities include coordinating weekly schedules, maintaining a quota of staff associates for each cycle, and monitoring module content and teaching techniques. A biographical sketch of Catherine Rowland, the new Coordinator. can be found in Appendix B.

4. Inventions and Copyrights

No new inventions or products have been developed in this project to date. It is expected that a copyright will be sought on audio-visual materials that will be completed during the project's third year.

5. Cost Benefit Findings

Major benefits of the New Options project include changes in the lives of individuals who participate in the program (personal benefits) as well as contributions of proven teaching methods and written and audio-visual materials to the field of independent living skills training (non-personal benefits). It is expected that the need for program experience and materials in this field will increase substantially in the near future because of recent legislative provisions for independent living services.

Documentation of personal benefits from participation in New Options is discussed at length under Section 2, objective c (page 10). Early follow-up data indicate that more than half of the New Options participants either move from comparatively dependent to independent settings and/or become actively involved in vocational pursuits within three to four months following their participation in the program.

Additionally, nearly all former participants report that they learned new skills,acquired adaptive information, and developed an improved self concept as a result of their New Options experience. This outcome ratio compares favorably with other programs serving severely handicapped populations. Preliminary cost information also indicates that the costs of attaining these outcomes through New Options compare favorably with the per-person costs of other projects serving similar populations such as the Comprehensive Needs Demonstration Projects. Plans are being investigated to compare cost and outcome data with these projects in the future in a more formalized manner.

The development of training materials and packaging of teaching methods have been identified as a major goal of the third grant period. Substantial efforts will also focus on how these methods and materials can be effectively incorporated into comprehensive rehabilitation programs and day or live-in programs that might be operated by a variety of agencies, voluntary organizations, consumer groups, or schools. Successful dissemination of these products of the New Options experience will mean that benefits of the project may become available to a large number of handicapped individuals through a variety of programmatic settings.

C. PROPOSED ACTIVITIES

1. Work Plan for the Third Grant Period

The work plan for the third grant period has been designed so that all of the objectives originally set forth for the project will be completed. During its first two years of operation the project has focused on developing, refining, and evaluating the usefulness of teaching methods and materials that are combined into a transitional living experience. The project's third year will focus on making the findings and experience of New Options available to others so that it can be translated into other programmatic settings.

In completing overall project goals, major efforts during the third grant period will be focused in three primary directions:

(1) completion of data collection and analysis on the project so that its research findings can be summarized as contributions to the literature on program development and evaluation, on individual outcome measurement, and on independent living skills training

(2) exploration of the feasibility of various other programmatic settings as contexts for teaching independent living skills using New Options methods

(3) production and dissemination of printed and audio-visual materials for teaching independent living skills that have been developed and evaluated throughout the operation of New Options as a service delivery system

Specific objectives in each of these areas are listed below:

OBJECTIVES FOR THE THIRD GRANT PERIOD

(1) Research Objectives

to complete collection and analysis of data on individual program outcomes

to complete collection and analysis of data on program development and evaluation

to prepare a final grant report that presents research findings as contributions to the literature on outcome measurement, program evaluation, and independent living

(2) Program Development Objectives

to explore and document programmatic variables

within New Options that will affect transfer of its methods to other program settings (such as costs, staffing, length of stay, types of teaching methods, types of practice experiences, degree of family involvement , and so forth)

to examine in conjunction with other agencies such as rehabilitation facilities, consumer groups, voluntary organizations, service agencies, and others the possibility of utilizing New Options methods for teaching independent living skills

to complete a final grant report that incorporates information on program development in a form usable in fostering the further development of independent living skills training programs

(3) Audio-Visual Objectives

to develop a New Options Instructors Manual that conveys the project's philosophy and techniques for teaching independent living skills

to develop a Participants Notebook that contains the content of the program training modules including information, exercises, and recommended activities in the community

to develop other related participant materials such as videotapes, slide-sound presentations, pamphlets, and others that supplement the Participant Notebook materials

to disseminate these materials for use in other program settings

Plans for developing each of these major areas are outlined below.

(1) Research Plans

In the forthcoming grant period, the research focus of the project will shift from a process orientation to concentrate on follow-up. A series of comprehensive interviews will be done with former participants to find out more about the effects of the program and disabled persons' transition to independence. Follow-up research will focus on ways on-going service needs are being met in the community, types of needs not being met, a critical incidents review of the individual's entire course of development from onset of disability to the present, an Independent Living Skills Evaluation currently being developed in the project, and use of other measures currently being explored in the general field of rehabilitation outcome measurement.

Also, an objective panel of raters will be organized to make judgments about the relative value of different outcomes, and to check the validity of judgments made by staff, referring counselors, and participants themselves. Additionally, present data collection and analysis will continue. Finally, the last portion of the grant period will be spent completing analysis, drawing conclusions, and writing the final report.

(2) Program Development Plans

From its inception New Options has been viewed as an experiment in learning and teaching methods with a specific population who have many unique needs. Several methods have been adopted including group teaching, using audio-visual materials, lectures and presentations, and group discussions and feedback; fieldtrips with group planning before and de-briefing sessions afterwards; peer interaction; individual counseling for goal-setting, planning, problem solving, and self exploration; and modeling techniques particularly through the use of staff associates (active handicapped people in the community) who serve as group leaders in modules and on fieldtrips. It is the combination of these methods and the interactions of the different types of learning that occur which stimulate individual patterns of thinking and ability to take action steps towards reaching goals. Throughout this third grant period we will be exploring how these methods can be used in other settings.

Some feasible settings in which New Options program materials might be incorporated include the following:

- comprehensive rehabilitation programs- Prepackaged program content could appropriately be disseminated after the initial rehabilitation admissions and as a part of a substantial follow-up program. In-house peer counseling ("old patients") might be an effective tool to disseminate information as well as serve as a model for the more recently injured person.
- outreach program of comprehensive rehabilitation centers- Recent legislation has set aside money to build Centers for the Handicapped through the Department of Housing and Urban Development (HUD). Rehabilitation centers could feasibly contract with such Centers for the Handicapped to teach the modules developed by the New Options project. Outreach programs from comprehensive rehabilitation facilities could thus become more formalized and more effective.
- special education programs in regular school systems - New Options module content might be effectively taught in special education classes within the public school system. The modeling concept through inviting guest speakers,"successful" handicapped people living in the community, could be useful even in the early grades. Most of the module content would probably be most effective in the secondary grades since much of the information is geared toward living independently.

- day programs for disabled persons - Several national and state organizations such as the Easter Seals Society for Handicapped Adults and Children and the United Cerebral Palsy Association sponsor day programs for severely disabled persons. New Options program content and teaching methodologies could easily be adapted by such day programs. Program materials could also be modified for handicapped populations with similar disability characteristics such as the blind or the deaf.
- independent living programs run by handicapped consumers - Independent living centers such as the Center for Independent Living in Berkeley, California, could provide New Options module content through programs of Independent Living Skills Training offered to the subscribers of the center's services. This would be run by consumers for consumers and could be a full day program lasting for several weeks or it could be presented in a course format lasting for several months.
- halfway house - New Options could be expanded to a halfway house situation in which a group of disabled persons would share full responsibility for running the household including grocery shopping, preparing meals, paying utility and other bills, and cleaning and maintaining the house. This experiential model could be supplemented with modules, guest speakers from the community, fieldtrips, and group and individual counseling. Placement in a halfway house would be time limited.
- short-term live-in residential program - New Options could continue as a short-term residential program as it is currently operating. It is suggested that such programs should be implemented in geographic locations where community resources are readily available in order to maximize community involvement.

All of these possibilities will be thoroughly investigated during the next grant period to further define how New Options can be expanded to provide the best service possible. We will also be exploring what the prerequisites are for programs implementing New Options teaching methods. Considerations include costs, program materials, staff, transportation, participant characteristics, and populations that can get the most benefit from the New Options program model.

Outreach

To date New Options has provided consultation or presentations to several outside organizations in an effort to investigate other possible settings for the program.

a. Easter Seals Center - Several New Options staff participated in an informal parents' meeting to facilitate discussion about; independent livingoptions for severely disabled adolescents and young adults. Definitions of "independence" and the issue of parental overprotectiveness were explored and the philosophy of New Options was explained.

b. Houston Community College - New Options staff have consulted with TRC and the Houston Community College regarding the need for an attendant training and referral service.

c. North Harris County College - A New Options staff person presented a paper to 2 classes at North Harris County College in an effort to stimulate student interest in the field of rehabilitation and physical disability. New Options emphasis on the rehabilitation of the total person was a major focus.

d. Houston Independent School District (HISD). Although no formal contact has been made with HISD, New Options hopes to explore the possibility of integrating the program into special education classes in the higher level grades.

(3) Audio-Visual Plans

The audio-visual plans for the final grant year center around developing an Instructor's Manual and participant materials which will enable others to offer a program or aspects of a program similar to New Options.

Monthly meetings with consultants who specialize in developing and producing learning materials began in May of 1978. A time table has been established with the goal that by November of 1978 the philosophical and didactic elements of the program will be translated into written form and the New Options Instructors Manual will be ready for publication. Toward the end of this task, participant materials to be used in conjunction with the Instructor's Manual will be identified and developed. These materials might include loose leaf pages, booklets, gaming activities, audio cassettes, videotapes, or perhaps a combination of some of these. By the completion of these materials a plan for distribution will be formulated.

Another task that may be addressed during the next year is the production of a 16mm movie which would illustrate a severely disabled individual taking part in a community skills training program. Planning on this task has included the development of a preliminary script and the initiation of casting. The decision for find scripting and a shooting schedule have been deferred until the priority tasks of the instructor's manual and participant materials are underway.

Additionally, group leaders will continue to produce material which can be utilized by the individuals currently participating in New Options.

2. Proposed Changes

None

3. Research Utilization Plan

The production of audio-visual and written materials on the content of the transitional project has been defined as a major objective since the project began. As the content of

various modules has been developed and tested through experience, efforts have begun to present this content using various media. Written information has been developed and is being tested and refined in each of the content areas of the program. The staff has also begun to videotape various modules, starting with medical needs, living arrangements, and functional skills. The production of such materials will increase substantially in the third year of program operation, and formal plans for dissemination to various potential users are being developed.

Information on the project as a whole has been disseminated through formal presentations during the current grant period as listed below. Staff members have also disseminated information on the project through personal contacts at conventions, meetings of advisory committees, and other visits to various agencies or facilities. During this reporting period, approximately forty-five rehabilitation professionals from various programs in Texas, the U.S., and overseas visited the project and met with New Options personnel. In addition, the project has received and answered many written requests for information from handicapped individuals and also from representatives of agencies interested in transitional programming.

Papers and Presentations:

Board,M.A. Reactions to disabilities: the individual, the family the general public. Presented at North Harris County Junior College, Houston, Texas, February 17, 1978.

Board, M.A. The role of the social worker in a rehabilitatation setting. Presented at the University of Houston Graduate School of Social Work, Houston, Texas, April 25, 1978.

Cole, J.A. Anthropological perspectives on bounded environments. Presented at VA/NASA Conference on Habitability in Extended Care Environments, Minneapolis, Minnesota, September 21-22, 1977.

Cole, J.A., Frieden, L.M. and Sperry, J.C. New Options transitional living project: one year's experience. Presented at the annual meeting of the American Congress of Rehabilitation Medicine, Miami, Florida, October 30-November 4, 1977.

Cole, J.A. Developing a transitional living project for a rehabilitation hospital: the anthropologist's role. Presented at the annual meeting of the American Anthropological Association, Houston, Texas, November 29, December 4, 1977.

Cole, J.A. and Frieden, L.M. New Options: report on 18 months' experience. Presented at Spinal Cord Center Core Group Educational Meeting, TIRR, January 19, 1978.

Frieden, L.M. and Cole, J.A. New Options: facilitating the movement towards independence by severely disabled persons. Presented at the annual meeting of the American Psychological Association, San Francisco, California, September 14, 1977.

Frieden, L.M. New Options. In Independent Living by Susan Pflueger, Institute for Research Utilization, Washington, D.C., December, 1977.

Frieden,L.M. The challenge of independence. Presented to the Harris County Easter Seal Society, Houston, Texas. April 25, 1978.

Sperry, J.C. New Options: a transitional living project. Presented at the American Spinal Injury Association Convention, Monterrey, California, April 4, 1978.

Many of the products of this project may be utilized by severely disabled individuals and service providers. Research findings and information about sitting tolerances and stamina requirements with respect to functional independence is presently in demand. Many written requests for preliminary findings in this area have already been aswered by the project. Representatives from agencies and organizations such as the Paralyzed Veterans of America, National Paraplegia Foundation, Center for Independent Living, United Cerebral Palsy, and Veterans Administration have already inquired about the possibility of making audio-visual training material developed by this project available to their members and clients.

Many materials will be appropriate for incorporation into both comprehensive rehabilitation and re-evaluation and follow-up programs at TIRR where patient education is a high priority and in similar rehabilitation facilities throughout the country. Many of the materials could also be used in day programs where a class or series of classes could be offered to handicapped populations through the sponsorship of various agencies. A workshop for DVR counselors also demonstrated the usefulness of New Options programming for counselor training on opportunities and resources for severely handicapped clients.

It is expected that the demand for independent living skills training materials will increase substantially in the near future as rehabilitation legislation is enacted that mandates and funds independent living services.